



MISSOURI CANCER REGISTRY

Long-Term Care Facility Cancer Reporting Manual

2002

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*“Not one patient
numbered here has been
forgotten, nor one family.
These are the patients,
sorted this way and that,
correctly and not,
remembering and bidding
to be remembered,
to be counted well,
for their benefit
and for those
who come after.”*

From the Cancer in Illinois Hospital Report 1992-1993

INTRODUCTION

The Missouri Cancer Registry Cancer Reporting Instruction Manual has been written to assist long-term care facilities in reporting cancer cases to the Missouri Cancer Registry (MCR). This is the first edition of the manual (2002).

The Missouri Cancer Registry, established in 1972, serves as a statewide cancer database. Cancer reporting for Missouri hospitals was voluntary from 1977 until 1984, when the Missouri General Assembly passed a bill to require cancer reporting of inpatient cancer cases. Consequently, 1985 represents the first year that Missouri cancer incidence rates can be calculated.

Responding to public health needs, the United States (US) Congress established the National Program of Cancer Registries (NPCR) in 1992. Administered by the Centers for Disease Control and Prevention (CDC), this program provides funds  enhance or establish state central cancer registries. Missouri became a NPCR state in 1995, with 1996 designated as MCR's index (reference) year.

NPCR requires state central registries to:

- Collect incidence data on residents,
- Follow stringent data management procedures,
- Provide training for state personnel, hospital registry and non-hospital reporting facility staff,
- Publish an annual report within 24 months of the end of the diagnostic year,
- Conduct case-finding audits at selected facilities and
- Have legislation in place that mandates reporting of cases by all types of facilities that diagnose and/or treat cancer.

In 1999, the late Governor Mel Carnahan signed an expanded cancer reporting law. This law requires that pathology laboratories, ambulatory surgery centers, freestanding cancer clinics and treatment centers, physicians and long-term care facilities report cancer cases.

The expanded cancer reporting law was necessary not only because it is required by CDC, but also because of the due to the significant change in the patterns of health care. In recent years, this shift to outpatient diagnosis and treatment has resulted in underreporting of certain types of cancer cases (e.g. melanoma of the skin, bladder cancer, prostate cancer, etc.). Without complete data, the Missouri Department of Health and Senior Services (DHSS) cannot conduct accurate epidemiological studies or develop a comprehensive cancer prevention and control strategy.



Missouri Cancer Registry staff are available to provide one-on-one training workshops and educational presentations, as well as analysis of information submitted for special studies. Such studies can be customized based on the requirements of the hospital, physician, or health agency. Refer to Appendix 2 to select the appropriate contact personnel.

I. GENERAL INSTRUCTIONS

The following information provides some basic rules regarding cancer reporting to the state central registry.

The cancer reporting law applies to all types of long-term care facilities. MCR anticipates that the majority of cases will be reported from skilled nursing facilities rather than intermediate or residential care facilities.

All cancer cases diagnosed and/or treated for cancer in your facility, on or after January 1, 2002, must be reported to MCR. This includes:

- Cases initially diagnosed while residing in your facility;
- Cases diagnosed and/or treated for a recurrence while residing in your facility; and
- Cases clinically diagnosed while residing in your facility.

The completed case **should** be submitted to the central registry quarterly. Cases may be submitted more frequently as reporting forms are completed.

The reporting form requests information on a variety of cancer-related items. You may not have enough information to complete all of the items because we know in many cases the information in your medical record will be limited. We just ask that you give as much information as is available, along with the name of the attending physician and the name of hospital in which the patient may have been admitted so that we may contact them if we need more information. **It is preferable to write “unknown” or “information not available” for details you do not have, rather than leaving blanks.**

Long-term care facilities may also submit pertinent portions of a patient’s chart (i.e. history and physical, operative summary, pathology report) for our review.

We do not expect you to call the physician’s office or the patient’s family to gather more information.

In addition to the instructions in this manual, brief directions appear on the reverse of the cancer reporting form. Those directions clarify the kind of information we are seeking.

We do not want this process to be labor intensive. Your comments and suggestions about ways to improve the form, the reporting process, etc., are welcome. This may be as simple as a handwritten note on a separate piece of paper sent along with your completed reporting form. Be sure to include your name, phone number, e-mail address, etc., in case we need to contact you.

A. SUBMISSION GUIDELINES

1. The method of reporting is manual and may be hand-written, using the required cancer reporting forms. If printed text is not legible, MCR staff may contact the facility or return the form for clarification.

2. Changing Information

It is possible that after a cancer case has been submitted to MCR additional information added to the patient's chart will change specific data items. It is permissible to change any data item, including the primary site and histology. Complete the cancer reporting form with the new information and write "**AMENDED**" across the form in red.

EXAMPLE: The patient was originally diagnosed with an unknown primary cancer. After further investigation it is determined that the cancer is a primary of the lung. It is correct to send an *amended form* to MCR and change the primary site.

3. Photocopies

After the information has been recorded and reviewed for completeness and accuracy, please photocopy the cancer reporting form for submission to MCR and retain the original for the facility files. Keeping a copy for your files may assist you in the future to verify that a patient has been reported.

Mark the envelope CONFIDENTIAL and send to:

Non-Hospital Reporting Coordinator
Missouri Cancer Registry
PO Box 718
Columbia, MO 65205

B. REPORTABILITY

1. MANDATORY REPORTING:

a. **Long-term care facilities must report any patient diagnosed with cancer while residing in that institution.**

Actual diagnosis will probably take place in a hospital

Diagnosis might be clinical (X-rays, CT scans, clinical exam, etc.)

Diagnosis might be pathological (biopsy, cytology, etc.)

Treatment may be given outside your institution (surgery, radiation, chemotherapy, etc.)

Treatment may be given inside your institution:

Chemotherapy (5FU, oral etoposide, etc.)

Hormonal (for breast cancer or prostate cancer)

Biotherapy or immunotherapy

There may be no treatment (supportive care or “observation” only)

Includes products like GM-CSF (leukine, neupogen), or products to alleviate pain

b. **Long-term care facilities must report any patient receiving treatment for cancer while residing in that institution.**

Any patient diagnosed with cancer prior to admission in your facility and undergoing cancer-directed treatment

Treatment may be given outside your institution (radiation, chemotherapy, surgery, etc.)

Treatment may be given inside your institution (hormones for breast or prostate cancer)

c. **Long-term care facilities must report any patient diagnosed with a recurrence while residing at that facility.**

Any patient with a history of cancer who has been disease free for several months or several years, who is diagnosed and/or treated for a recurrence of the original cancer

Treatment may be given outside your institution (radiation, chemotherapy, surgery, etc.)

Treatment may be given inside your institution (hormones for breast or prostate cancer)

d. **Long-term care facilities must respond to MCR requests for death information.**

The Bureau of Vital Statistics and DHSS provide MCR with the death certificates of every deceased patient with an immediate or underlying cause of death involving cancer. MCR generally processes this information on an annual basis 12 to 24 months after death certificates are issued. If that patient is not in the MCR database, MCR contacts the facility listed on the death certificate for information [e.g. diagnosis date, treatment, etc.]. The regular reporting form may be used for this information.

The time delay is an inconvenience to many facilities utilizing off-site storage or microfilm records for deceased patients. To reduce this inconvenience, facilities may report deaths as they occur (see voluntary reporting).

What information is required?

Any details related to the **diagnosis, treatment and staging** of this cancer. We need **any** information you have, even if you are unable to complete all data items. By providing us with name of physician or hospital in which the patient may have been treated, we may be able to get more details. This information may be found in the facility or hospital history and physical, discharge summaries, physician consults, operative summaries, pathology reports, etc. Please include the date of death if the patient dies before the case is submitted to MCR.

2. VOLUNTARY REPORTING:

a. Report upon admission:

Any patient previously diagnosed with cancer but receiving no treatment, even though there is active disease. In this case, the cancer may be too advanced for treatment, or the patient's age or other health concerns may preclude treatment. The care for this patient is usually considered supportive, palliative or hospice.

b. Report at time of death:

Complete a form upon a patient's death for a patient with cancer or a history of cancer. The primary cause of death may or may not be related to the cancer diagnosis. Remember, we review these patients based on the information as it is coded on the death certificate. **If you choose to report these deaths as they occur, it will eliminate or substantially decrease the number of requests for death information mentioned under mandatory reporting.**

What kind of information do we want?

Any details related to the diagnosis, treatment and staging of this cancer. We want any information you have, even if you are unable to complete all data items. By providing us with name of physician, or hospital in which patient may have been treated, we will follow up to get more details. Including supporting documents is appropriate. This would include hospital history and physical, discharge summaries, physician consults, operative summaries, pathology reports, etc. There is a form available for completion.

C. CONFIDENTIALITY AND HIPAA

MCR has developed strict policies and procedures as guidelines for the maintenance of confidentiality and the disclosure of data. Non-confidential summary statistics will be released in annual reports or upon request, but the identity of the patient, hospital, physician, health care provider, pathology laboratory, ambulatory surgical center, free-standing cancer clinic or treatment center will **not** be released without written consent from the concerned individual or facility.

Based on the HIPAA privacy regulations, MCR is a “*public health authority* authorized by law to collect and receive such information for the purpose of preventing and controlling disease, injury or disability, including...reporting of disease...and the conduct of public health surveillance....” [C.F.R. 164.512 (b)(1)(i) (2001)] Therefore, a covered entity (i.e., hospital, long-term care facility, etc.) may continue to disclose protected health information without specific individual informed consent.

For further information, see Appendix 6, “Frequently Asked Questions and Answers about HIPAA Regarding Cancer Reporting.”

D. REPORTABLE TERMINOLOGY

Occasionally a diagnosis is not certain. The physician may suspect cancer, but no biopsy is performed to confirm the diagnosis. It may be possible to report those cases, using specific terms as a guide. These are standardized terms used nationally by cancer registries to decide about including cases.

The following terms indicate there **is involvement** of disease and the case should be reported:

- Compatible with
- Consistent with
- Most likely
- Probable
- Suspect
- Suspicious

EXAMPLE: Test results report “CT of the chest, compatible with carcinoma of the left lung.” Although the patient may have refused further work-up or treatment, this case is reportable.

If you are uncertain whether to report a case you may either:

- Complete a form and send it with a note explaining you are uncertain if it should be reported, or
- Call the toll-free telephone (866-240-8809) and ask how to proceed.

E. CASES NOT REQUIRED TO BE REPORTED

- Patients with a history of cancer, and at the time of admission to your facility, have no evidence of disease.
- **Do not report basal and squamous cell skin cancers.**

F. REPORTING DEATHS

Death details are crucial to the completeness of the information in our database. Here are some suggestions for reporting deaths:

- It is possible that a patient may be diagnosed with cancer and die from the disease before your facility has had an opportunity to complete a reporting form for MCR. In this instance, the death information would be reported at the same time the cancer diagnosis is reported.
- You may wish to complete a form upon a patient's death for a patient with cancer or a history of cancer. The primary cause of death may or may not be related to the cancer diagnosis. Remember, we review these patients based on the information as it is coded on the death certificate. **If you choose to report these deaths as they occur, it will eliminate or substantially decrease the number of requests for death information mentioned under mandatory reporting.**
- If you have previously submitted a cancer reporting form on a patient, you do not have to report that patient's death. The information will be matched with the death certificate in the death clearance process.
- Death information may be submitted on the standard cancer reporting form. Complete the form with what information is known, particularly a diagnosis date. If the actual diagnosis date is unknown, it would be appropriate to indicate a "best guess." That is, if you know the cancer was not diagnosed during the current calendar year, it would be permissible to write "prior to 2002."

G. DEATH CERTIFICATE CLEARANCE PROCESS

The death certificate process involves matching patients with death certificates listing cancer as a cause of death to the patient records in the MCR database. The primary cause of death may or may not be related to the cancer diagnosis. MCR follows up on any patient not matched with a record in the MCR database by contacting the facility listed on the death certificate. This process may take place 1-2 years after the patient has been at your facility.

II. CANCER REPORTING FORM

There are brief directions on the back of the cancer reporting form. They may be helpful as a quick reference while you are completing the form. **It is preferable**

to write “unknown” or “information not available “ for details you do not have, rather than leaving blanks.

REPORTING FACILITY IDENTIFICATION

The information entered in this area is used to identify the facility reporting the case. Please record the full name and address of the facility. Record the telephone number, fax number, name and e-mail address of contact person. The contact person is usually the person completing the form or someone familiar with the process

A. PATIENT IDENTIFICATION INFORMATION

1. PATIENT NAME

- Record the patient's last name, then first name, followed by the middle name.
- Middle initial may be used if full middle name is not available.
- Titles, such as MD or Jr., may be recorded after the last name.
- Hyphenated last names are acceptable.
- Record any nicknames in parenthesis.

2. ADDRESS

Please record the patient's address prior to admission to a long-term care facility.

3. BIRTH DATE

Complete the patient's birth date, recording the month in the first two spaces, the day in the next two spaces, and the four-digit birth-year in the last four spaces.

If the month and day of birth are unknown, but year is known, record as: *99/99/1937.

If the year of birth is unknown, estimate the year.

EXAMPLE: The medical record states the patient is 60 years old at the time he is admitted to the hospital, June 15, 1990; there is no birth date documented; record the date of birth as 99/99/1930.

*"9" or "99" is used by cancer registries to indicate unknown information.

4. SOCIAL SECURITY NUMBER

Record the patient's Social Security number, if known. Do not record the spouse's number. Use **9s** if unknown and **0s** if no social security number.

5. RACE

Use the following information to record race:

- ◆ White includes Mexican, Puerto Rican, Cuban, and all other Caucasians.
- ◆ Afro-American includes Negro or Black.
- ◆ A combination of white and Afro American race is coded to Afro American.

6. HISPANIC ORIGIN

Indicate if patient is of Spanish/Hispanic origin. If patient can be identified as one of the following, circle YES:

Mexican (includes Chicano)

Puerto Rican

Cuban

South or Central American (Not Brazil)

Other specified Spanish/Hispanic origin (includes European)

Spanish, Hispanic, Latino, NOS; Evidence other than surname or maiden name that person is Hispanic

Spanish surname only (Only evidence of the person's Hispanic origin is surname or maiden name - no evidence verifying that the person is not Hispanic)

7. SEX

Indicate the patient's sex: Male, Female, Other (hermaphrodite, transsexual)

8. TOBACCO HISTORY – Circle current, former none or unknown. Tobacco history includes the use of cigarettes, cigars and chewing tobacco.

9. ALCOHOL HISTORY - Circle current, former, none, or unknown.

10. VITAL STATUS – Circle alive or deceased.

11. DATE OF LAST CONTACT/DEATH – If the patient is still living, record the date you are completing the form. If the patient has transferred to another facility, record the date of transfer. If the patient died while at your facility, record the death date.

12. DATE ADMITTED TO YOUR FACILITY – Record the date the patient was first admitted to your facility.

13. PATIENT TRANSFERRED FROM/TO – This field is extremely important. This is for you to provide information that will allow us to follow back to another long-term care facility or hospital if further details are needed.

14. PHYSICIAN – Record the primary care physician’s name and telephone number. Again, this allows MCR staff to contact the physician if more information is needed. You may include more than one physician name (i.e. primary care physician and medical oncologist or surgeon, etc.).

a. CANCER IDENTIFICATION

15. NEW VERSUS RECURRENCE

The first item to establish about the patient’s cancer is whether it is a new cancer or one that has been previously diagnosed and treated (a recurrence). Look for clues in the history and physical or admission notes. The physician may make a statement as obvious as “this is a newly-diagnosed cancer” or may state, “This cancer was first diagnosed five years ago.” On the other hand, the physician may offer no information about the diagnosis. If that is the case, just indicate “unknown.”

16. DATE OF DIAGNOSIS

Record the month, day, and year this cancer was **originally** diagnosed by a medical practitioner. If this were a recurrence of a previously diagnosed cancer, the date would still be the date the cancer was **first** diagnosed. Though it may be more difficult to find an exact diagnosis date for a recurrence, just follow the same rules as for a newly diagnosed cancer.

- If the month or year of diagnosis is not documented, estimation of these fields is preferable over recording **unknown**.
- If only the time of year, spring, middle, fall, or winter of the year is documented, use April, July, October, and either December (if end of year) or January (if beginning of year) respectively.
- Record **unknown** if no information is available

17. CANCER DIAGNOSIS

a. PRIMARY SITE

The primary site is defined as the organ or site in which the cancer originated or began. A patient’s disease may spread (metastasize) or be active in several areas of the body, but the **original site** is the one that should be recorded.

Please be as specific as possible. “Ascending colon” would be preferable to “colon.” However, if the only term available to you in the medical record is very general (e.g. throat) that is acceptable. Do not spend a lot of time trying to find a more specific term.

Sometimes, the primary site cannot be determined; in these cases “unknown primary” should be recorded.

The primary site for a lymphoma is generally an area of lymph nodes, although it can be in an organ. If you are unable to determine where the disease began, you may record “Lymphoma, nos.”

Leukemias and other diseases of the blood (myeloproliferative disorders, myelodysplastic syndromes, anemia, etc.) are **systemic** (involving the whole body). You may leave the primary site blank or write “n/a.”

b. LATERALITY

Laterality refers to one side of a paired organ (breast, lung, etc.). If that information is available to you, please record which side of the organ is involved. See list below.

PRIMARY SITES - LATERALITY

This list includes the most frequently diagnosed primary sites. It is not all-inclusive. Please be as specific as possible when recording primary site. A term appearing in bold indicates a site that should be coded for laterality (e.g. right, left).

Adrenal gland	Hypopharynx	Renal pelvis
Anus	Ileum	Retroperitoneum
Appendix	Jejunum	Salivary gland
Ascending colon	Kidney	Sigmoid colon
Bladder	Larynx	Sinus
Bone marrow	Lip	Skin
Bones (specific body area, leg, arm, etc.)	Liver	Small intestine
Brain	Lung	Spinal cord
Breast	Lymph nodes (specific region, axillary, groin etc. or organ)	Spleen
Cecum	Mediastinum	Splenic flexure of colon
Cervix (cervix uteri)	Mouth	Stomach
Colon	Nasal Cavity	Submandibular gland
Connective tissue (specific body area, leg, arm, etc.)	Nasopharynx	Supraglottis
Descending colon	Oropharynx	Testis
Duodenum	Ovary	Thymus
Epiglottis	Palate (soft or hard)	Thyroid gland
Esophagus	Pancreas	Tongue
Eye	Parotid gland	Tonsil
Gallbladder	Penis	Trachea
Glottis	Pharynx	Transverse colon
Gum	Prostate gland	Unknown
Heart	Pyriform sinus	Urethra
Hepatic flexure of colon	Rectosigmoid Junction	Uterus (corpus uteri)
	Rectum	Vagina
		Vulva

18. HISTOLOGIC TYPE and behavior

Histology refers to the study of tissue and cells on the microscopic level. When viewing malignancies, the pathologist sees abnormal growth of the tissue. The pathology or cytology report will include a complete description of the tissue's appearance. Malignancies are grouped according to their appearance.

"Behavior" describes the way the neoplasm will act or behave. Some tumors are considered benign, which means non-cancerous. You do not have to report benign tumors.

Neoplasms that are reportable are either **in situ** or **malignant**. In situ describes cancer at its earliest stage, sometimes considered pre-cancerous. Malignant describes cells that are cancerous and potentially life threatening. You may not see either of these words in your records.

There are hundreds of terms classifying every histology. Here are some major ones.

List of Common Histologies Indicating Malignancy

- Chronic myeloproliferative disease, NOS
- Essential thrombocythemia
- Chronic neutrophilic leukemia
- Hypereosinophilic leukemia
- Adenocarcinoma
- Astrocytoma (brain)
- Carcinoma
- Glioma (brain)
- Hodgkin lymphoma (many more specific terms are used)
- Infiltrating ductal (breast)
- Intraductal carcinoma (breast)
- Large cell carcinoma
- Leukemia (acute, chronic plus other more specific terms)
- Melanoma
- Mucinous cystadenocarcinoma or adenocarcinoma
- Multiple myeloma
- Myelodysplastic syndromes
- Non-Hodgkin lymphoma (many more specific terms are used)
- Non-small cell carcinoma
- Papillary transitional cell carcinoma (urinary organs)
- Polycythemia vera
- Refractory anemia
- Sarcoma (soft tissue)
- Small cell carcinoma
- Squamous cell carcinoma
- Transitional cell carcinoma (urinary organs)

List of Common Terms Synonymous with In Situ Histologies

Bowen's disease
Hutchinson's melanotic freckle, NOS
Intraductal
Intraepithelial, NOS
Lentigo maligna
Non-invasive
Non-infiltrating

19, 20. TREATMENT

Treatment or therapy for cancer should modify, control, remove, or destroy cancer tissue (cancer-directed treatment). Therapy can be used to treat cancer tissue in primary or metastatic site(s).

a. FIRST COURSE THERAPY

The first course of therapy should include all cancer-directed treatments intended in the initial treatment plan and delivered to the patient. Treatment may begin elsewhere (i.e. hospital, physician's office) but continue when the patient returns to your facility.

Sometimes the physician determines the patient would not benefit from treatment. "*No treatment*" is considered a treatment option and may represent the first course of therapy. Write "*no treatment*" in the treatment field. Enter the date "*no treatment*" is decided upon in the treatment date field.

Occasionally for certain cancers discovered very early, the physician chooses a "wait and see" approach. The term for this is "*observation only*." You may see this term in some of the physician's notes. Write "*observation only*" in the treatment field. Enter the date "*observation only*" is decided upon in the treatment field.

b. TREATMENT FOR RECURRENCE

A patient may have a disease-free period of several months or several years. If the cancer returns while residing at your facility, please complete a form. Please indicate clearly this is **NOT** a new cancer. The diagnosis date should be the date of the **ORIGINAL** diagnosis. The rest of the information will apply to the treatment of the recurrence.

c. TYPES OF TUMOR-DIRECTED TREATMENT

Record **all** known cancer-directed therapy administered whether at your facility or at another facility. Documenting all treatments known provides a complete "picture" of

the patient's cancer experience and is meaningful in calculating survival statistics and assessing treatment success.

You may not be able to determine whether a treatment is chemotherapy, hormonal therapy, biological therapy or supportive care. That does not matter. Just record any information you think may be related to the treatment of the patient's cancer. Again, **it is preferable to write "unknown" or "information not available" for details you do not have, rather than leaving blanks.**

We do not expect you to be familiar with the various drug names. Some may be for comfort or pain control rather than to actually treat the cancer. We do not want you to spend a great amount of time trying to determine the nature of the treatment. Just record the information and we'll determine if it is cancer-directed or supportive care.

SURGERY

If you have access to the operative report, it will list the surgical procedure(s). The pathology report may also list the surgical procedure(s).

RADIATION THERAPY

Record the type and date of radiation therapy given. The following categories can be used to identify types of radiation therapy.

- Beam Radiation - includes x-ray, cobalt, linear accelerator, stereotactic radiosurgery, such as gamma knife and proton beam.
- Radioactive implants – often used for prostate cancer.
- Radioisotopes - such as iodine-131 or phosphorous-32, given orally, or by intravenous injection (often used for bone pain)

CHEMOTHERAPY, HORMONAL THERAPY, IMMUNOTHERAPY

Again, we realize you may not be able to determine whether a treatment is chemotherapy, hormonal therapy or biological therapy. That does not matter. Just record any information you think may be related to the treatment of the patient's cancer.

Record any drug given to treat cancer tissue. Some drugs are given alone; others may be given in combinations. You may only see abbreviations for the chemotherapy (e.g. CHOP, ABVD, etc.). You may record these abbreviations. Chemotherapy drugs are used to kill cancer cells and alter the course of the disease.

Hormonal therapies may be drugs such as tamoxifen for breast cancer, or flutamide and Lupron for prostate cancer.

Examples of immunotherapy include bone marrow transplants, interferon, BCG. Most likely, patients in long-term care facilities will not be eligible for these treatments.

OTHER CANCER-DIRECTED THERAPY

Sometimes patients choose therapies that are considered “alternative” or unproven.” The patient may be taking shark cartilage for prostate cancer, or laetrile for other cancers. You may include information about these treatments if available.

Treatment Dates

It may be difficult to find documentation of treatment dates. Use the following guidelines to assist you in completing this field. It is preferable to estimate the date of a treatment than to leave it blank.

- Record the month, day, and four-digit year in which cancer-directed treatment was administered.
- If the exact date that therapy was begun is unknown, it is best to estimate the date, using the information available.
- Record **NONE** when no treatment is given and **UNKNOWN** when it is unknown if any treatment was given.

SUPPORTIVE CARE

For many patients, cancer-directed treatment may not be an option. In these patients, medications may be used to provide relief from symptoms, for pain control, or to limit side effects from other medications.

A few examples include:

G-CSF (Neupogen) – for low white blood counts (neutropenia)

GM-CSF (Leukine) – for low white blood counts (neutropenia)

Epoetin Alfa (Procrit) – to prevent anemia

Pamidronate (Aredia – to treat hypercalcemia (high calcium level)

Pain Medications include Opioids (Examples: [Morphine](#), hydromorphone, [hydrocodone](#), oxycodone, codeine, fentanyl, methadone) and antidepressants (Examples: Amitriptyline, imipramine, doxepin, trazodone)

21. OTHER PHYSICIANS/FACILITIES DIRECTLY INVOLVED IN PATIENT'S CARE

This field may be used to indicate physicians or facilities other than those named in field fourteen.

22. STAGE OF DISEASE AT DIAGNOSIS

Cancer staging systems describe how far the cancer has spread. This information is important because it aids in determining treatment recommendations as well as prognosis.

You may see a cancer described in terms such as "localized," or "advanced." The table below provides a list of those terms as well as their meaning. **YOU DO NOT HAVE TO DETERMINE A STAGE FOR EACH PATIENT.** We only want you to record a stage that may be mentioned by a physician in the patient's medical record. If the physician says localized, record "localized." If no stage is mentioned, state "unknown" or "no information in chart."

DESCRIPTION
In-situ ; pre-cancerous
Localized ; tumor confined to organ of origin; no evidence of spread beyond the primary site
Regional by direct extension ; tumor extends directly beyond the primary site into surrounding (regional) organs or tissues
Regional to lymph nodes ; tumor extends beyond the organ of origin (primary site) into the regional lymph nodes
Regional by direct extension and to lymph nodes ; tumor extends beyond primary site by direct extension, into regional lymph nodes AND adjacent tissues
Distant metastasis ; widely disseminated; tumor has spread from primary site to remote areas of the body, through the blood stream or lymph system
Unstaged; unknown; unspecified - use for unknown primaries and those cases where adequate staging information is NOT available

Another staging system uses the Roman numerals I-IV to describe the extent of disease, with stage I being the earliest and stage IV being the most advanced. A physician may state in a history and physical or admission note that the patient has recently been diagnosed or is being treated for a "Stage I" or "Stage One" ovarian cancer. "Stage I" is the term we'd like you to record in the stage field.

The TNM staging system uses values to describe the tumor (T), the involvement of nodes (N) and the assessment of disease at distant parts of the body (M). The definitions of each are specific to each type of cancer. A physician using this staging

system would state for example the patient has a T1, N0, M0 cancer. That is the information you would record in the stage field. This information may also be found at the end of some pathology reports.

Remember, we do not expect you to determine the stage of a patient's disease.

We want you to be familiar with the various staging systems so you will be able to recognize them and record the information on the cancer reporting form.

APPENDIX 1. MISSOURI REVISED STATUTES

Chapter 192
Department of Health and Senior Services
Section 192.650

August 28, 2001

Cancer information reporting system established--purpose --rulemaking authority.

192.650. 1. The department of health and senior services shall establish and maintain a cancer information reporting system to collect data required for the receipt of federal grant funds pursuant to the Cancer Registries Amendment Act of 1992 (42 U.S.C. 280e, et seq.), as amended.

2. The director of the department shall promulgate rules and regulations specifying the malignant neoplasms which shall be reported and accompanying information to be reported in each case. Such rules and regulations shall provide for collection of the following data:

(1) For inpatient hospital settings, the data items collected by the department of health and senior services as of August 28, 1999, and additional data items required to be collected as a condition of federal funding for state cancer registries pursuant to the Cancer Registries Amendment Act of 1992 (42 U.S.C. 280e, et seq.), as amended; and

(2) For outpatient hospital settings, physician offices, pathology laboratories, ambulatory surgical centers, residential care facilities I and II, intermediate care facilities, skilled nursing facilities, and free- standing cancer clinics and treatment centers, the data items required to be collected as a condition of federal funding for state cancer registries pursuant to the Cancer Registries Amendment Act of 1992 (42 U.S.C. 280e, et seq.), as amended. Reports of malignant neoplasms, exclusive of nonmelanomatous cutaneous malignancies, shall be filed with the director within six months of the diagnosis or treatment. The department director shall prescribe the form and manner in which the information shall be reported.

(L. 1983 S.B. 163 § 1, A.L. 1993 S.B. 52, A.L. 1999 H.B. 454)

Missouri Revised Statutes
Chapter 192
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August 28, 2001

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(1) For inpatient hospital settings, the data items collected by the department of health and senior services as of August 28, 1999, and additional data items required to be collected as a condition of federal funding for state cancer registries pursuant to the Cancer Registries Amendment Act of 1992 (42 U.S.C. 280e, et seq.), as amended; and

(2) For outpatient hospital settings, physician offices, pathology laboratories, ambulatory surgical centers, residential care facilities I and II, intermediate care facilities, skilled nursing facilities, and free- standing cancer clinics and treatment centers, the data items required to be collected as a condition of federal funding for state cancer registries pursuant to the Cancer Registries Amendment Act of 1992 (42 U.S.C. 280e, et seq.), as amended. Reports of malignant neoplasms, exclusive of nonmelanomatous cutaneous malignancies, shall be filed with the director within six months of the diagnosis or treatment. The department director shall prescribe the form and manner in which the information shall be reported.

(L. 1983 S.B. 163 § 1, A.L. 1993 S.B. 52, A.L. 1999 H.B. 454)

Missouri Revised Statutes
Chapter 192
Department of Health and Senior Services
Section 192.653

August 28, 2001

Reports required from certain health care providers, content --exemptions.

- 192.653. 1. The administrator or designated representative of hospitals, pathology laboratories, physician offices, ambulatory surgical centers, residential care facilities I or II, intermediate care facilities or skilled nursing facilities, and free-standing cancer clinics and treatment centers shall report to the department of health and senior services every case of malignant neoplasm as required pursuant to section 192.650. Physicians' offices shall be exempt from reporting cases that are directly referred to or have been previously admitted to any other facility which is required by this subsection to report malignant neoplasms.
2. The attending physician or other health care provider responsible for a patient's diagnosis or treatment for a malignant neoplasm shall provide, in writing, to the administrator or the administrator's designated representative, the information required pursuant to section 192.650.
3. Reports filed with the director may be submitted through a data system designated by the person or organization filing the report.
4. If a facility described in subsection 1 of this section is currently submitting reports of cases to the department of health and senior services through a centralized reporting system, duplicate reporting shall not be required.

(L. 1983 S.B. 163 § 2, A.L. 1999 H.B. 454)

Missouri Revised Statutes
Chapter 192
Department of Health and Senior Services
Section 192.655

August 28, 2001

Confidentiality of reports--release of reports, requirements --publication, when--exchange of data agreements with other registries permitted, when.

192.655. 1. The department of health and senior services shall protect the identity of the patient, physician, health care provider, hospital, pathology laboratory, ambulatory surgical center, residential care facilities I or II, intermediate care facilities or skilled nursing facilities, and free-standing cancer clinic or treatment center which is involved in the reporting required by section 192.653, and such identity shall not be revealed except that the identity of the patient may be released only upon written consent of the patient, the identity of the physician or health care provider may be released only upon written consent of the physician or health care provider, and the identity of the hospital, pathology laboratory, ambulatory surgical center, residential care facilities I or II, intermediate care facilities or skilled nursing facilities, or free-standing cancer clinic or treatment center may be released only upon written consent of the facility.

2. The department shall request consent for release from a patient, physician, health care provider, hospital, pathology laboratory, ambulatory surgical center, residential care facilities I or II, intermediate care facilities or skilled nursing facilities, or free-standing cancer clinic or treatment center only upon a showing by the applicant for such release that obtaining the identities of certain patients, physicians, health care providers, hospitals, pathology laboratories, ambulatory surgical centers, residential care facilities I or II, intermediate care facilities or skilled nursing facilities, or free-standing cancer clinics or treatment centers is necessary for his or her cancer research and that his or her cancer research is worthwhile.

3. The department shall use or publish reports based upon materials reported pursuant to sections 192.650 to 192.657 to advance research, education and treatment. The department shall provide qualified researchers with data from the reported information upon the researcher's compliance with appropriate conditions as provided by rule and upon payment of a fee to cover the cost of processing the data.

4. The department may enter into an exchange of data agreement with other cancer registries maintained by federal, state or local governmental entities. The provisions of subsection 1 of this section shall not apply to such an agreement if the agreement provides that the federal, state or local governmental cancer registry shall protect the identity of the patient, physician, health care provider, hospital, pathology laboratory, ambulatory surgical center, residential care facilities I or II, intermediate care facilities or skilled nursing facilities, and free-standing cancer clinic or treatment center in all data received from the Missouri department of health and senior services.

(L. 1983 S.B. 163 § 3, A.L. 1987 S.B. 164, A.L. 1999 H.B. 454)

Missouri Revised Statutes
Chapter 192
Department of Health and Senior Services
Section 192.657

August 28, 2001

No liability for furnishing or providing access to required information, exception--department examination of individuals not intended--violations, penalty.

192.657. 1. No individual or organization providing information or access to information in accordance with sections 192.650 to 192.657 shall be deemed to be or be held liable, either civilly or criminally, for divulging or permitting access to confidential information unless such individual or organization acted in bad faith or with malicious purpose.

2. Nothing in sections 192.650 to 192.657 shall be construed to compel any individual to submit to medical or health department examination, treatment or supervision of any kind.

3. Violation of any provisions of sections 192.650 to 192.657 shall be an infraction.

(L. 1963 S.B. 163 §§ 4, 5, A.L. 1999 H.B. 454)

APPENDIX 2. RESOURCES/REFERENCES/ADDITIONAL FORMS

MCR STAFF RESOURCES

For information regarding:

- Completing cancer reporting forms
- Forms or reprints of MCR materials

CONTACT:

Nancy Cole, Non-Hospital Reporting Coordinator
866-240-8809 (toll free) or 573-884-2491
colen@health.missouri.edu

For information regarding:

- Studies or reports
- Special data requests
- General administrative issues

CONTACT:

Jeannette Jackson-Thompson, PhD
Chief, Office of Surveillance, Research, and Evaluation
Missouri Department of Health and Senior Services
573-876-3225
jacksj@dhss.state.mo.us

Sue Vest, CTR, Project Manager
866-240-8809 (toll free) or 573-882-7236
vests@health.missouri.edu

GENERAL CANCER RESOURCES

Books:

Altman, R., & Sarg, M. (2000) The cancer dictionary (Revised ed.). New York: Checkmark Books. [\$19.95]

Dollinger, M, Rosenbaum, E. & Cable, G. (1997). Everyone's guide to cancer therapy (3rd ed.). Kansas City: Andrews McMeel Publishing. [\$21.95]

Baggaly, A., Ed. (2001). Human Body. New York: Dorling Kindersley Publishing, Inc. [\$16.95]

Websites:

Steve Dunn's Cancer Guide (<http://cancerguide.org/index.html>) – Informative website created by a cancer survivor dedicated to educating non-medical people about cancer. Includes a simple, yet helpful section about understanding cancer types and staging.

American Cancer Society (<http://www.cancer.org/>) - Select cancer by site for diagnostic and treatment information.

National Cancer Institute's CancerNet (http://www.cancer.gov/cancer_information/) - Select cancer by site for diagnostic and treatment information.

A cancer dictionary from the National Cancer Institute's comprehensive cancer information website - <http://cancer.gov/dictionary>.

RESOURCES FOR COMMON CHEMOTHERAPY DRUGS

Books:

Oncology Nursing Drug Handbook

Websites:

Oncology Tools, U.S. Food and Drug Administration • Center for Drug Evaluation and Research

Product and disease information summaries

<http://www.fda.gov/cder/cancer/>

U.S. Food and Drug Administration

List of Product Approvals by Cancer Indications by Disease Type

<http://www.fda.gov/oashi/cancer/cdrugind.html>

List of product approvals for Cancer Indications In Alphabetical Order

<http://www.fda.gov/oashi/cancer/cdrugalpha.html>

American Cancer Society

http://www.cancer.org/eprise/main/docroot/cri/cri_0

Choose "Cancer Drug Guide" from the menu to the left of the screen.

APPENDIX 3. FREQUENTLY ASKED QUESTIONS (FAQS) REGARDING THE MISSOURI CANCER REGISTRY (MCR)

1. What is a cancer registry? Why is it needed?

A cancer registry is a system for collection, storage, analysis and interpretation of data on cancer patients. Cancer registries may be hospital-based or centralized.

Hospital-based registries use information abstracted from medical records to assess the number of diagnoses per year and frequencies by sites. The information collected consists of demographics, site of cancer, type of cancer, type of treatments, stage of disease at diagnosis and vital status. Hospital registry data are used to evaluate diagnostic and treatment practices; assess quality of patient care and hospital programs; and track outcomes. Registry data are also used to develop standards of care; develop strategic plans and measure progress; and assist hospital administrators and physicians in setting up screening programs.

Central cancer registries depend on the information obtained from hospital-based registries and from other sources (e.g., pathology laboratories, freestanding cancer clinics and treatment centers, physician offices, long-term care facilities, other state central registries, etc.). Data submitted by hospitals and other reporting facilities is edited, and then it is consolidated to remove duplicate cases. Data are then analyzed so that crude, age-adjusted and age-specific annual cancer incidence rates can be produced and trends in incidence for all cancers and for specific types/sites of cancer by age, sex and race can be assessed. These data are necessary to conduct epidemiological studies and evaluate the effectiveness or appropriateness of cancer prevention and control measures.

2. When was the Missouri Cancer Registry (MCR) created?

MCR was originally created in 1972 with approximately twelve hospitals voluntarily reporting cancer cases. The original Statute 192.650 RSMO was enacted in 1984, with 1985 the first full year of implementation. The statute was revised during the 1999 session of the General Assembly when the State Legislature passed House Bill (HB) 454. After having been signed by Governor Mel Carnahan, the new legislation (192.650-192.657 RSMo 1999) became effective on 28 August 1999.

3. What is the goal of the Missouri Cancer Registry?

The ultimate goal is a true population-based cancer registry. In recent years, the patterns of health care have changed, and a shift to outpatient diagnosis and treatment has been recognized. This shift has resulted in underreporting of cancer cases. Sites that are known to be underreported include melanomas of the skin (white females and males); Non-Hodgkin's lymphoma (African-American males; cancers of the oral cavity and pharynx (African-American females) and prostate cancer (all males). Without a complete data set, the Missouri Department of Health cannot conduct accurate epidemiological studies or develop a comprehensive cancer prevention and control strategy.

The Centers for Disease Control and Prevention (CDC) also recognized this trend when they established the National Program of Cancer Registries (NPCR) by enacting The Cancer Registries Amendment Act (Public Law 102-515). This legislation authorizes the CDC to

provide funds to states to improve existing registries or to establish registries where they do not exist. The Missouri Cancer Registry applied for and received a grant from CDC to enhance the state registry. Stipulations of this grant require that at least 95% of new cancer cases will be reported to MCR. This goal can only be accomplished if non-hospital facilities report cancer cases to the Missouri Cancer Registry.

4. What information is required to be submitted by reporting facilities?

Hospitals are required to submit twenty-four (24) NPCR data elements plus 1 Missouri-required data element. The information required for non-hospital facilities is minimal and includes, but is not limited to: patient's name, address, social security number, sex, race, Hispanic origin, date of birth, date of diagnosis, site, histology, stage and treatment.

5. Will the patient's right to confidentiality be breached if this information is reported to the Missouri Cancer Registry?

All cancer cases submitted to MCR will be covered by the regulations within this legislation protecting the identity of the patient, hospital, physician, health care provider, pathology laboratory, ambulatory surgical center, free-standing cancer clinic or treatment center. (See also Chapters 192.067 and 192.655 of the Missouri Revised Statutes)

6. Will physicians and other health care professionals be liable for breach of confidentiality?

Physicians and other health care professionals cannot be liable if state law requires reporting of cancer cases.

7. Are there any federal mandates associated with a state's central cancer registry?

Congress established the National Program of Cancer Registries (NPCR) in 1992 by enacting The Cancer Registries Amendment Act (Public Law 102-515). Public Law 102-515 authorizes The Centers for Disease Control and Prevention (CDC) to provide funds to states to improve existing cancer registries; to plan and implement registries where they do not exist; to develop model legislation and regulations for states to enhance viability of registry operations; to set standards for completeness, timeliness, and quality; and to provide training.

One requirement for retention of federal funding is that "The State has a law authorizing formation of a statewide registry and legislation or regulation in support of all 8 criteria outlined in Public Law 102-515". One criterion is completeness, defined as collection of data on at least 95% of cancer cases diagnosed or treated in the state each year.

When Missouri's existing legislation was enacted in 1984, the completeness criterion could be met with collection of hospital inpatient data. With advances in medical technology and changes in health care delivery, the completeness criterion can no longer be met solely by relying on hospital inpatient data. To maintain a population-based registry, information must also now be gathered from hospital outpatient departments, physicians' offices, freestanding treatment centers, ambulatory surgery centers, long-term care facilities and pathology laboratories.

In addition to meeting federal funding agency requirements, the state health department has the responsibility of maintaining a surveillance system that can produce accurate and complete reports on cancer incidence and trends in incidence. Therefore, the department strives not only to meet the minimum completeness requirement (95%) but also to achieve a 100% population-based central cancer registry.

8. What is the penalty for failure to report a case?

The penalty for failing to report is an infraction (192.657.3 RSMO). An infraction is not a crime as opposed to a felony or misdemeanor but may be punished by a fine. Chapter 556.021 RSMO defines an infraction as:

- An offense defined by this code or by any other statute of this state constitutes an “infraction” if it is so designated or if no other sentence than a fine, or fine and forfeiture or other civil penalty is authorized upon conviction.
- An infraction does not constitute a crime and conviction of an infraction shall not give rise to any disability or legal disadvantage based on conviction of a crime.

9. How often will I be required to report cases?

Reporting frequency will depend on reporting category and number of cases. Hospitals are required to submit at least quarterly with larger hospitals (greater than 500 cases annually) required to report monthly. Larger pathology laboratories may be requested to submit data on a monthly basis; small laboratories on a quarterly basis. Other non-hospital facilities will be required to report at least quarterly. **Physicians are only required to report those cases not reported by another entity, and these cases can be reported quarterly.** Physicians will be contacted on an as needed basis regarding additional data not available from other facilities (i.e., pathology labs will not have treatment information).

10. What patients are required to be reported?

Any patient that is diagnosed and/or treated at your facility for cancer is to be reported. This may include patients that are clinically diagnosed or patients diagnosed or treated for a recurrence as well as newly diagnosed patients. Further information can be obtained by calling the number listed below.

11. Can I request data from the Missouri Cancer Registry?

Yes, aggregate data can be requested by calling the number listed below. No patient, reporting facility, physician or healthcare provider information will be released without permission of the same.

12. Who do I call if I have questions after reading the FAQ Sheet?

For questions regarding hospital reporting, please call 1-800-392-2829.

For questions regarding non-hospital reporting, please call 1-866-240-8809.

rev 3/11/99 (scv) 12/31/99 (scv) 03/16/2000 (scv) 4/26/01 (JJT) 12/11/01 (nfc) 4/19/02 (nfc)

APPENDIX 4. GLOSSARY

Acute

Characterized by sudden, intense onset of symptoms.

Adjuvant chemotherapy/hormone therapy

The use of either chemotherapy or hormone therapy after initial treatment either by surgery or radiotherapy. The aim of adjuvant therapy is to destroy any cancer that has spread.

Alopecia

Hair loss. It is usually partial, although it can be complete. Full recovery usually occurs fairly quickly.

Anemia

A condition in which the number of red blood cells is below normal.

Atypia

Abnormal changes in cells. See also [dysplasia](#).

Axilla

The armpit.

Axillary dissection

Surgery to remove fat and lymph nodes from the armpit. It can be done either at the same time as a mastectomy or as a separate operation. It can be partial or complete.

Benign

Not malignant, not cancer. A benign tumor is not capable of spreading.

Biological Response Modifier (see immunotherapy)

Biopsy

Removal of a sample of tissue or cells from the body to assist in diagnosis of a disease.

Bone scan

A test to see whether the cancer has spread to any bones.

Boost

An extra dose of radiation given to a smaller area, usually the site where the tumor was removed, after the rest of the breast has been irradiated.

Carcinoma

A malignant tumor arising from epithelial cells, which are cells lining the external or internal surfaces of the body. Carcinomas spread to nearby tissues. They may also spread to distant sites such as lung, liver, lymph nodes and bone. See also [metastasis](#)

Carcinoma in situ

A malignant tumor, which has not yet become invasive but is confined to the layer of cells from which it arose. A form of pre-invasive cancer.

Centigray

A measure of radiation. 1 centigray = 1 rad.

Chemotherapy

The use of medications (drugs) that are toxic to cancer cells. These drugs kill the cells, or prevent or slow their growth.

Chronic

A slowly progressing disease or onset of symptoms.

Clinical trial

Research conducted with the patient's permission, which usually involves a comparison of two or more treatments or diagnostic methods. The aim is to gain better understanding of the underlying disease process and/or methods to treat it.

Combined modality treatment

The integration of two or more forms of treatment to combat the cancer. For example: radiation and surgery; radiation and chemotherapy; surgery, radiation and chemotherapy.

Core biopsy

The sampling of tissue with a needle to give a tiny cylinder of tissue for examination by a pathologist.

Cycle

Chemotherapy is usually administered at regular intervals. A cycle is a course of chemotherapy followed by a period in which the body recovers.

Cytology

An examination by a pathologist of the cellular structure of a tissue.

Differentiation

The degree to which a tumor resembles normal tissue. In general, the closer the resemblance, the better the prognosis. Well-differentiated tumors closely resemble normal tissue.

Disease-free survival

The time from the primary treatment of the cancer to the first evidence of cancer recurrence.

Dry desquamation

A reaction to radiotherapy involving the shedding of dry skin.

Dysplasia

An abnormal growth of cells, which look something like cancer cells, but do not have all the features of cancer. See also [atypia](#).

Erythema

Redness of the skin, which is the earliest sign of radiation reaction.

Fine needle aspiration biopsy (FNA or FNAB)

See fine needle biopsy.

Fine needle biopsy (FNB)

The sampling of cells from tissue for examination by a pathologist.

Fraction

Radiotherapy is usually given over several weeks. The dose delivered each day is known as a fraction.

Frozen section

A rapid method of obtaining a pathological examination of tissue during an operation.

G-CSF

Granulocyte cell stimulating factor. A natural substance that promotes the growth of white cells. It can be used after chemotherapy.

Gene

The functional unit of heredity. Each gene sits on a chromosome within the cell nucleus.

Grade

The degree of similarity of the cancer cells to normal cells. A pathologist assesses this. A grade 1 carcinoma is well differentiated and is associated with a good prognosis. A grade 2 carcinoma is moderately differentiated and is associated with an intermediate prognosis. A grade 3 carcinoma is poorly differentiated and is associated with a poor prognosis. A pathologist assesses grade.

Gray

The modern unit of radiation dosage. Doses used in treatment for early breast cancer range from 45 and 65 Gray. See also [rad](#).

Histology

An examination of the structure of a cell by a pathologist.

Hormone receptors

Proteins in a cell that bind to specific hormones. This binding stimulates the cell to act in a certain way.

Hormone replacement therapy

The use of hormones as a substitute for natural hormones in women.

Hormone therapy

The use of drugs, hormones or procedure that affects cancer tissue by changing the hormonal balance of the patient

Hyperplasia

Increased numbers of epithelial cells. If excessive, there is a slightly increased risk of developing subsequent breast carcinoma.

Immunotherapy

Generic term that refers to all chemical or biological agents that alter the immune system or change the patient's defense mechanism toward the cancer.

In situ carcinoma

see [carcinoma in situ](#).

Increment

See [fraction](#).

Jaundice

A condition in which the skin and the whites of the eyes become yellow, urine darkens, and the color of stool becomes lighter than normal. Jaundice occurs when the liver is not working properly or when a bile duct is blocked.

Local recurrence

Return of the cancer in the affected body part.

Linear accelerator

Modern radiation equipment capable of delivering x-rays at very high energies.

Lymphatic system

A system of vessels that drains fluid out of the head, neck and limbs and returns it to the general circulation.

Lymph node

A small collection of tissue along the lymphatic system that acts as a filter. White cells and cancer cells, in particular, collect in lymph nodes. They are found in the neck, the armpit, the groin and many other places. Lymph nodes are also known as glands.

Malignant

a tumor having the capacity to destroy tissue locally, spread and cause death.

Margins of resection

The edge of the tissue removed. See complete local excision.

Medical oncologist

A doctor who specializes in the use of chemotherapy and hormone therapy.

Metastasis

The spread of a cancer from the primary site to somewhere else via the bloodstream or the lymphatic system.

Metastasize

See [metastasis](#).

Metastatic cancer

Cancer that has spread to a site distant from the original site.

Micrometastases

Small undetectable deposits of cancer that grow later.

Moist desquamation

A response to radiotherapy in which skin peels off. It is made worse by friction and sweat.

Nadir

The lowest measured value. In cancer treatments, it usually refers to the lowest white blood cell and platelet count.

Nausea

Feeling sick or wanting to be sick. If it is caused by chemotherapy, it can last for anywhere between a few hours and a week.

Necrosis

The death of an individual cell or groups of cells in living tissue. Sometimes seen in carcinomas.

Neutropenia (febrile)

A decreased number of white cells in the blood, which greatly increases the risk of infection. It usually occurs as a result of chemotherapy.

Occult metastasis

A metastasis that has not yet shown up.

Oncologist

A doctor who specializes in treating cancer.

Oncology

The study of the biology and physical and chemical features of cancers. Also the study of the cause and treatment of cancers.

Open biopsy

Surgery performed under local or general anesthetic in which a sample of tissue is removed so a pathologist can examine it.

Overall survival

The time from the primary treatment of the cancer to death.

Palliation

The alleviation of symptoms due to the underlying cancer, without prospect of cure.

Primary site

Body part or organ where cancer began

Prognosis

An estimate of what is likely to happen in the future.

Prognostic factors

Factors that are associated with a better or worse outcome of the disease. They are not the same as causes.

Progression

The continuing growth of the cancer.

Prosthesis

An artificial part designed and fitted to overcome a defect in the body.

Protocol

A detailed program of treatment.

Rad

An old unit of radiation dose now superseded by the Gray. 1 Gray = 100 rads.

Radiation oncologist

A doctor who specializes in treating cancer with radiation. Also known as a radiotherapist.

Radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill tumor cells.

Relapse

Recurrence of disease after an initial response to treatment.

Remission

A reduction or disappearance of the symptoms of cancer. It can be partial or complete.

Response to therapy - complete response

The disappearance of all detectable cancer for a minimum of one month. Also known as remission.

Response to therapy - disease progression

Continued growth of the cancer.

Response to therapy - partial response (partial remission)

A reduction in size of the cancer of 50% or more.

Response to therapy - stable disease.

No change in the cancer.

Secondary tumor

A deposit of cancer cells way from the original tumor. See metastasis.

Simulator

A machine that allows a radiation oncologist to calculate the correct dose and position of the radiotherapy.

Staging

Refers to the allocation of categories (0, I, II, III, IV) to groupings of tumors defined by internationally-agreed criteria. Staging helps determine treatment and prognosis. Describes extent of disease.

Surgical oncologist

A surgeon who specializes in the care of people with cancer.

Systemic

Disease that affects the whole body.

Telangiectasia

Small dilated blood vessels that appear in areas that have been heavily irradiated.

Toxicity

Side effects that are due to treatment.

Treatment failure

The inability of the treatment to halt the growth or spread of the cancer.

Tumor

An abnormal growth of tissue. It may be localized or invade nearby tissues or distant tissues (metastatic).

Tumor suppressor gene

A gene that usually prevents cancers growing. When it is not functioning normally, tumors can grow. Examples include p53 in breast cancer, RB protein in retinoblastoma and possibly BRCA1 in breast cancer. Also known as an anti- oncogene.

Tumor type

The overall cell pattern of the tumor.

Ultrasound

The use of sound waves to form a picture of internal tissues.

Vascular infiltration

Invasion by cancer cells of lymphatics or veins. It is a sign that the tumor is likely to spread.

SOURCE: National Breast Cancer Centre - 4th floor, NSW Cancer Council, 153 Dowling Street, Woolloomooloo, NSW 1340, Australia.

<http://www.nbcc.org.au/pages/nbabout/contact.htm>

APPENDIX 5: DISEASE PROCESS INFORMATION

Introduction

The information in this section is to assist you when you are reviewing patients' charts and would like to have a better understanding of certain types of cancer, their diagnosis and their treatment. It is not appropriate to use this information for the average person diagnosed with cancer. It was written with long-term care facility patients in mind.

Although there are more than one hundred types of cancer, we have included only some of the more common types of cancer. We do not expect you to become experts on cancer, but hope to familiarize you with some of the basics.

It may be helpful to refer to the cancer reporting manual and the glossary in Appendix 4 while you are reviewing this information.

SPECIFIC TUMOR TYPES

Bladder Cancer

Symptoms/Diagnosis:

Blood or blood clots in the urine and other urinary symptoms.

Urinalysis to check for blood in urine (hematuria).

Washing of the bladder to examine the cells (cytology).

Intravenous pyelogram (IVP), abdominal CT, and chest x-ray may be useful.

Cystoscopy – visual examination of the bladder using a lighted tubular instrument.

Treatment:

Depends on the stage of the disease. For tumors that do not invade muscle, tumors may be removed with surgery (transurethral resection of the bladder or TURB), with lasers (YAG or CO2) or with chemotherapy drugs placed into the bladder.

BCG (a biological therapy) is frequently used. It is given by catheter inside the bladder weekly for six consecutive weeks.

More advanced disease requires more extensive surgery or radiation therapy, depending on the general health of the patient.

Staging:

May be stated using any of the staging systems described in the manual, page 17.

Benign Brain Tumors

Currently there is no requirement to report benign brain tumors. There is a legislative effort underway to amend the Public Health Service Act to provide for the collection of data on benign brain-related tumors. We will update you when (if) this becomes part of the law.

Malignant Brain Tumors

There are several types of brain tumors; distinguished from one another by the way the cancer cells look under the microscope. This section covers brain tumors that start in the brain. (Sometimes cancer in the brain has spread from another part of the body.)

Histologies include:

- Astrocytoma
- Ependymoma
- Glioblastoma Multiforme
- Glioma
- Malignant Meningioma (may be benign or malignant, only report malignant)
- Medulloblastoma
- Oligodendroglioma

Symptoms/Diagnosis: frequent headaches, vomiting, or difficulty walking or speaking.

CT scan, or MRI may be used to visualize a tumor.

A biopsy helps to determine the tumor type and the aggressiveness of the tumor.

Brain tumors may be diagnosed by radiology tests alone.

Treatment:

Surgery is the most common treatment. Depending on the patient's general health, age, etc. this may not be an option. In that case, radiation may be used to shrink the tumor.

Staging:

There is no staging system for this disease.

Breast cancer

Symptoms/Diagnosis:

Occasionally physicians find long-term care facility patients with breast masses or neglected breast cancer (based on the appearance of a lesion with obvious tissue death).

Treatment:

Depending on the patient's general condition, there may be no treatment other than hormones. It is possible this patient will never enter a hospital for diagnosis or treatment of this cancer.

For patients in generally good health, surgery (most likely mastectomy) could be an option.

Staging:

May be stated using any of the staging systems described in the manual, page 17.

Leukemia

Leukemia is a disease of the blood. The classification system for leukemia can be confusing, so for our purposes, we will only discuss the two main forms: Acute and chronic.

Symptoms/Diagnosis:

Patients may have symptoms including: enlarged lymph nodes, swollen gums, bruises or small pinpoint red rash on the skin.

Diagnosis will include blood tests (to look for abnormal white blood cells).

Bone marrow examination may also be performed (usually in a hospital setting).

Treatment:

ACUTE: Chemotherapy for these patients is intensive and almost always completed in a hospital setting. Physicians are often reluctant to offer treatment for elderly patients. In many cases, the patient or family refuses treatment. Without treatment, length of survival averages 3-5 months after diagnosis.

CHRONIC: Treatment for patients with early stage disease may consist of "observation only." Chemotherapy for those with more advanced disease might include: fludarabine, hydroxyurea, busulfan (myelaran). Chronic leukemias sometimes convert to an acute phase. Average survival is measured in years rather than months (for all age groups).

It is possible this patient will never enter a hospital for diagnosis or treatment of this cancer.

Staging:

There is no staging system for this disease.

Liver cancer

Also known as hepatocellular carcinoma or hepatoma. Rare type of cancer. Most cancers in the liver spread there from another organ and are identified by the organ

from which they spread (e.g. colon, breast, etc.) **This section refers only to cancers originating in the liver.**

Symptoms/Diagnosis:

Like pancreatic cancer, this cancer is generally diagnosed at an advanced stage. Symptoms may include bloating, abdominal pain, weight loss, decreased appetite and nausea. Jaundice is frequently present.

Diagnostic work-up may include blood tests, liver function studies, Alpha Feta Protein (AFP)

Imaging tests may be useful to establish the stage of disease (CT, ultrasound, MRI)

Diagnosis almost always includes a liver biopsy. This will help determine if the cancer actually started in the liver.

Treatment:

Treatments generally consist of relieving symptoms of the disease. It is possible this patient will never enter a hospital for diagnosis or treatment of this cancer.

Survival often is measured in months.

Staging:

May be stated using any of the staging systems described in the manual, page 17.

Lung Cancer

Symptoms/Diagnosis:

Cough that won't go away. Coughing up blood. Hoarseness, shortness of breath. Increased amount of sputum. Lung infection that won't clear up. Fatigue.

Lung sounds may indicate the presence of fluid in the lungs.

Sputum (mucus coughed up from the lungs) may be examined for malignant cells.

Chest x-ray or CT scans are helpful.

Treatments:

Surgical removal of the tumor is the best treatment option. This usually is recommended only if the tumor is thought to be contained within the lung.

Radiation is often used for older patients, or patients whose health is compromised due to other conditions (emphysema, etc.).

There may be a role for chemotherapy, probably palliative (oral etoposide, platinum drugs, taxol, taxotere, camptosar or CPT-11, Gemzar or navelbine).

Survival is dependent on extent of disease and the overall health of the patient.

Staging:

May be stated using any of the staging systems described in the manual, page 17.

Lymphomas

Cancers that develop in the lymphatic system are known as lymphomas. Lymphomas are divided into two types: Hodgkin's disease and non-Hodgkin's lymphomas. The treatment varies according to the type diagnosed.

Symptoms/Diagnosis:

One or more enlarged lymph nodes, usually neck, under the arms or in the groin. Sometimes fatigue, fever, chills, night sweats, decreased appetite, weight loss.

Blood tests may show abnormalities.

Imaging studies may show masses, or enlarged areas of lymph nodes.

Biopsies are performed and may include the bone marrow.

Treatment:

HODGKIN'S: Usually depends on extent of disease. Combined chemotherapy and radiation therapy often used. Chemotherapy regimens include: MOPP or ABVD.

NON-HODGKIN'S: Treatment depends on the grade (low, intermediate, high).

Close observation may be the treatment of choice for older patients.

Radiation therapy alone.

Chemotherapy alone (cytoxan, chlorambucil, CVP, CMOPP, CHOP)

Combination chemotherapy and radiation therapy.

Staging:

Uses the Ann Arbor staging system, Stages 1-4. This staging system is not used for any other cancer.

Multiple myeloma

Most often a disease of the bone marrow, also known as plasma cell myeloma. This disease is treatable but rarely curable. **This cancer is underreported in Missouri.**

Symptoms/Diagnosis:

Bone pain is the most common symptom, often accompanied by weakness and fatigue.

Blood tests often reveal anemia.

99% of patients will have an M-protein in the blood or urine.

Bone marrow examination must reveal at least 10 percent abnormal plasma cells.

X-rays show skeletal abnormalities in 75% of patients at diagnosis.

Treatment:

Since the disease is not curable, physicians may choose not to treat patients due to potential side effects, costs, etc.

Possible drugs: melphalan (Alkeran) with or w/o prednisone, BCNU with or without prednisone

Bone pain may be treated with analgesics (aspirin, acetaminophen, and ibuprofen), narcotics or radiation therapy

Staging:

There is no staging system for this disease.

Myeloproliferative Disorders

This is a group of diseases in which too many of certain types of blood cells are made in the bone marrow.

Includes: Polycythemia vera
Chronic myeloproliferative disease, NOS
Essential thrombocythemia
Chronic neutrophilic leukemia
Hypereosinophilic leukemia

Symptoms/Diagnosis:

Usually diagnosed with blood tests.

Bone marrow biopsy

Treatment:

The treatments for these disorders are used to control symptoms. They are usually not curable conditions. If there are no symptoms, no treatment is necessary.

Treatment depends on the type of disorder.

Treatments may lower the amount of blood in the body (phlebotomy).

Treatments may filter platelets from the blood (plateletpheresis).

Chemotherapy (hydroxurea, chlorambucil)

Radiation – external beam radiation or using a radioactive drug, P32

Splenectomy (removal of the spleen)

Staging:

There is no staging system for these diseases.

Myelodysplastic Syndromes

This is a group of diseases in which the bone marrow does not function normally and not enough normal blood cells are made.

Includes: Refractory anemia
Refractory anemia w/sideroblasts
Refractory anemia w/excess blasts
Refractory anemia w/excess blasts in transformation
Myelodysplastic syndromes w/5q deletion (5q-) syndrome
Therapy-related myelodysplastic syndrome, NOS
Myelodysplastic syndrome, NOS

Symptoms/Diagnosis:

Most common sign is anemia. Patient may bleed without any reason, bruise more easily than normal, feel tired all of the time, or have an infection that won't go away. Blood tests may reveal abnormalities. Number white blood cells (WBC) may be too low; platelets may be low. Bone marrow biopsies would be used to determine exact kind of disease.

Treatment:

Main treatment is giving red blood cells or platelets to relieve symptoms of the disease.

Staging:

There is no staging system for these diseases.

Pancreatic cancer

This cancer is underreported by Missouri hospital cancer registries, most likely due to the fact these patients may only be seen for ERCP.

Symptoms/Diagnosis:

Usually there are no symptoms until the cancer is already at an advanced stage. Symptoms may include jaundice, abdominal masses/pain, enlarged liver, abdominal fluid (ascites) and sometimes swollen legs. Several blood tests are helpful in diagnosis this cancer (CA 19-9, CEA, serum bilirubin). Imaging tests may be useful to establish the stage of disease. Endoscopic retrograde cholangiopancreatography (ERCP) is frequently the only procedure used and is not considered cancer-directed treatment. During this procedure a tube is inserted into the opening of the pancreatic duct. If the patient's biliary duct is obstructed by tumor, a stent may be inserted which actually bypasses the obstructed. This procedure is done on an outpatient basis at hospitals or GI clinics.

Treatment:

Even if diagnosed at an early stage, this cancer is rarely curable. Surgery is usually used only for palliation (relief from symptoms). Occasionally patients have surgery to relieve an obstruction, but not sure how often this would be used on patients already in generally poor health. Life expectancy for these patients is generally measured in months. It is possible this patient will never enter a hospital for diagnosis or treatment of this cancer.

Staging:

May be stated using any of the staging systems described in the manual, page 17.

Prostate cancer

This cancer is underreported in Missouri.

Symptoms/Diagnosis:

Patient could be having urinary symptoms (blood in urine, difficulty urinating, etc).
May be diagnosed by elevated prostate-specific antigen (PSA).
Digital rectal exam (DRE) could detect an abnormality of the prostate.
Bone scan might be used to determine extent of disease if PSA extremely high.

Treatment:

If surgery is not possible, treatment could be one of several hormonal therapies (either oral or shots).
Hormonal therapies include:

It is possible this patient will never enter a hospital for diagnosis or treatment of this cancer.

Staging:

May be stated using any of the staging systems described in the manual, page 17.

Unknown primary

Sometimes a patient develops cancer cells that cannot be traced to the site where they first started growing (primary site). When this happens, physicians try to find the most likely source of the cancer because this will determine the best type of treatment, as well as the chances for recovery. Unknown primary cancers account for approximately 3% of all cancer patients.

Symptoms/Diagnosis:

A biopsy is the best way to determine a cancer's beginnings.
If tissue is not available, radiology tests (CT scan, chest x-ray, etc.) may be helpful.

Treatment:

Surgery is a common treatment to remove the cancer, especially if only one area of cancer is detected in the body.
If the cancer is widespread, or found in several areas of the body, treatment options are more limited. Chemotherapy may be an option depending on the overall health and age of the patients.
Hormonal therapies may be used if breast or prostate cancers are suspected.

Staging:

There is no staging system for this disease.

The prognosis for these patients is generally poor. Survival is most frequently measured in months.

Bibliography

Dollinger, M., Rosenbaum, E., & Cable, G. (1997). Everyone's Guide to Cancer Therapy (3rd ed.) Kansas City: Andrews McMeel Publishing.