

CHAPTER XII: CANCER REGISTRY AND REPORTING

Disclaimer: The information contained in this chapter is not intended to be used as legal advice. Please refer to the most current specific state statutes and your own legal counsel when warranted. Some statutes may be referred to throughout this chapter.

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Collection and analysis of health data has proven to be a key resource in patient care. In order to effectively monitor cancer diagnoses and treatment in an institution, a data collection system must be put in place. A Cancer Registry collects demographic, cancer identification, treatment and follow-up data on all eligible cancer patients. This data can then be used for evaluating diagnostic, treatment, and clinical support services, administrative program planning, and outcomes assessment.

This chapter will serve as a resource for obtaining information on standards and procedures for maintaining a cancer registry, Commission on Cancer program standards, and State of Maine regulations as they relate to the Maine Cancer Registry and its Data Review Committee (formerly the Cancer Prevention and Control Advisory Committee).

COMMISSION ON CANCER

When it was recognized that there was a need for specific guidelines in cancer care and treatment, the American Cancer Society urged the American College of Surgeons to undertake this responsibility. Hospital-based cancer programs were identified as being the foundation for building improved outcomes in the care of cancer. Guidelines were first established in the 1930s by the Cancer Program of the American College of Surgeons. Since then, the Cancer Liaison Program, Cancer Registry, and Cancer Program survey process have also been added. In 1965, the program was renamed the Commission on Cancer, and the membership was expanded to include members from other national professional organizations involved in cancer control. The goal of the multidisciplinary Commission on Cancer is to decrease the morbidity and mortality caused by cancer and to improve the quality of patient care. These are pursued by encouraging each institution to improve its cancer control efforts in prevention, early diagnosis, pretreatment evaluation, staging, treatment, rehabilitation, and surveillance for

recurrent and multiple primary cancers, and to enhance the care of the terminally ill patient.

In 2003 and 2004 respectively, the standards for approval of cancer programs were refined to reflect the programs' comprehensive scope. Two publications, Facility Oncology Registry Data Standards (FORDS) and Cancer Program Standards, are available on the American College of Surgeons website (www.facs.org/cancer/index.html)

APPROVAL CATEGORIES

To promote access to quality care for all cancer patients, the American College of Surgeon categories of approval have been expanded to include very small hospital and non-hospital environments, such as free-standing and integrated cancer programs and managed care organizations. In addition, there are now eight areas of evaluation included in the approval process to further encompass the full range of cancer program activities. They include:

- Institutional and Programmatic Resources
- Cancer Committee Leadership
- Cancer Data Management and Cancer Registry Operations
- Clinical Management
- Research
- Community Outreach
- Professional Education and Staff Support
- Quality Improvement

It is beyond the scope of this chapter to discuss each of the specific areas of evaluation in detail; however, the reader is encouraged to review the Cancer Program Standards 2004. In facilities where approval is not sought, the Cancer Registry is encouraged to meet the standards defined in FORDS for the following areas:

- Abstracting
- Accession Register
- Case Eligibility
- Case Finding
- Data Usage/Request Logs
- Master Patient Index
- Follow-up
- Procedure Manual
- Quality Control
- Reference Date
- Suspense List

Cancer programs approved by the Commission must have a cancer data management system in place that meets defined standards. These include:

A Cancer Registry that meets standards as defined in Facility Oncology Registry Data Standards (FORDS) collects and analyzes data on all reportable diagnosis;

The registry is staffed by knowledgeable personnel. Registry staff is encouraged to gain and maintain Certified Tumor Registrar (CTR) credentials;

For each year between ACOS survey, 90 percent of cases are abstracted within six months of the date of first contact;

The registry maintains patient confidentiality;

The registry collects the required data set and utilizes the data definitions and codes in Facility Oncology Registry Data Standards (FORDS);

Follow-up information is systemically obtained for patients in the registry data base, and the required follow-up rates are met;

The registry submits data to the National Cancer Data Base (NCDB);

Data are used for special studies and reported to the medical and administrative staff;

A quality control plan is in place with documentation of procedures to monitor case finding, data collection, accuracy, and timeliness.

MAINE CANCER REGISTRY

In July 1982, the Maine legislature authorized the Department of Human Services, Bureau of Health, to establish a statewide cancer registry (22 MRSA 1401 et seq). The Department was authorized to make investigations concerning cancer, including prevention, treatment, and mortality. In 1995 the legislature amended the Maine Cancer Registry law to mandate the reporting of all cancer cases from hospitals and other health care facilities providing screening, diagnostic or therapeutic services for cancer. The purpose of this amendment was to assure that the Maine Cancer Registry database is complete and continues to be a valuable cancer surveillance and research tool.

If at all possible, patient data is to be submitted to the Maine Cancer Registry via 3.5 diskette in the most recent NAACCR format (currently Version 10). Facilities that do not report electronically can obtain abstracting and reporting forms by contacting the Maine Cancer Registry at the address below:

Maine Cancer Registry
Department of Human Services
Key Bank Plaza – 4th Floor
SHS #11

Augusta, ME 04330-0011
(207) 287-5272

DATA REVIEW COMMITTEE (previously the Advisory Committee)

The Cancer Prevention and Advisory Committee was established in June 1987. The Committee served as an advisory body to the Department of Human Services on the development and maintenance of a statewide approach to cancer prevention and control, as well as on the operation of the Maine Cancer Registry. With the Maine Cancer Registry well established, the Cancer Prevention and Advisory Committee was repealed in 2001 and replaced by the Maine Cancer Registry Data Review Committee. The Committee is appointed and convened by the Bureau of Health to review and advise the administrators of the Maine Cancer Registry on the release of identifiable data as requested by researchers for the purpose of cancer prevention, control, and research. The Committee is composed of not fewer than three members, representing training and experience in the fields of medical or public health research or disease control and prevention.

CONFIDENTIALITY

The Maine Cancer Registry includes measures for assuring patient confidentiality. These measures are described in the Registry's Rules and Regulations, copies of which are available from the Registry at the previously listed address. Requests for data from the Registry must be made in writing and according to Department policy. Requests are reviewed and those not meeting the specific guidelines for release will be denied.

NCRA

The National Cancer Registrars Association (NCRA) was chartered in 1974 and incorporated in 1976 as a nonprofit organization whose purposes include establishing standards of education for cancer registrars, information sharing for its members on the latest methods of cancer diagnosis and treatment, and communications on the current trends in incidence and survival. To date, there are over 4,000 members. For more information, contact:

National Cancer Registrars Association
1340 Braddock Place, Suite 203
Alexandria, VA 22314
(703) 299-6640
<http://www.ncra-usa.org>