



Department of Health and Human Services
Centers for Disease Control and Prevention



National Program of Cancer Registries— Advancing E-cancer Reporting and Registry Operations (NPCR-AERRO)

Glossary

Advancing E-cancer Reporting and Registry Operations (AERRO)
National Program of Cancer Registries (NPCR)
Division of Cancer Prevention and Control (DCPC)
Centers for Disease Control and Prevention (CDC)
Department of Health and Human Services (DHHS)

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Cancer Registry Terms

Note: The NPCR-AERRO glossary uses definitions from established sources in the cancer registry and e-health communities where available. The source is cited for each definition; if no source is cited the definition is provided by NPCR-AERRO.

Abstract

Definition Source: *Cancer Registry Management Principles and Practices*

An abstract is an abbreviated record that identifies the patient, the disease, the cancer-directed treatment, and the disease process from the time of diagnosis until the patient's death. The abstract is usually divided into different sections:

- Patient Identification
- Cancer Identification
- Stage of disease at diagnosis
- First course of treatment
- Recurrence
- Follow-up

The abstract is the basis for the rest of the registry's functions. Without the summary data of a patient's cancer experience, no other registry function can take place.

Accession

Definition Source: *Cancer Registry Management Principles and Practices, 2nd Edition*

It is to enter a case into a registry and assign it a number. The **accession** number is a unique number assigned to the patient by the registrar, indicating the year in which the patient was first seen at the reporting institution and the sequential order in which the patient was identified by the registry or abstracted into the database. The **accession** number is used for all additional primaries the patient may develop, regardless of the year in which the subsequent reportable tumors occur.

Cancer Case

A summary of all event reports submitted by reporting facilities. It contains the final best information regarding a patient and his or her cancer and includes patient demographic, medical, staging, treatment, and service information.

Cancer Information

Cancer Information is facts or data that describe the occurrence, diagnosis, and treatment of cancer.

Case

Definition Source: *Cancer Registry Management Principles and Practice, 2nd Edition*

An occurrence of a primary cancer. A patient with two primary cancers represents two cases. C. consolidation combines data from multiple sources pertaining to the same person or case into a single record containing the most complete information from all sources; also called record linkage; commonly a function of a central registry. C. definition is the process of establishing the criteria for inclusion and exclusion for casefinding reportability.

Case definition

Definition Source: *Health Information Management Concepts, Principles, and Practices*

A method of determining criteria that should be included in a registry.

Case-Finding

Definition Source: *Cancer Registry Management Principles and Practice, 2nd Edition*

The systematic process of identifying all cases of a disease eligible to be included in the registry database for a defined population, such as patients of a hospital or residents of a state. It is also called case ascertainment. Active case is performed by registry personnel who screen the source documents themselves. A case completeness log is a list by year and month in which the number of cases identified each month can be compared. Combination case is the use of active review by the registrar for critical casefinding sources and passive review of other sources as provided by reliable participants in other departments. Passive case is performed by other health care professionals whom the registry relies on to notify the registrar of potentially reportable cases; also called self-reporting.

Central Cancer Registry Registrar

A data management professional who validates event reports; links patients and tumors; performs consolidation, audits, quality assurance, and rapid case ascertainment; links to external data sources to improve data and for research; conducts death clearance, follow-up, and interstate data exchange; responds to calls for data; and provides data for use by others.

Classification System

Definition Source: *Health Information Management Concepts, Principles, and Practices*

A system for grouping similar diseases and procedures and organizing related information for easy retrieval; a system for assigning numeric or alphanumeric code numbers to represent specific diseases and/or procedures.
Example: ICD-9, CPT, ICD-O-3

Confidentiality

TN900 approved by HITSP, Oct, 2007.

Obligation of an entity that receives identifiable information about an individual as part of providing a service to that individual to protect that data or information, including not disclosing the identifiable information to unauthorized persons or through unauthorized processes.

Consolidation

Definition Source: <http://www.naaccr.org/filesystem/pdf/RecConsol1999-1.pdf>

In routine cancer registry operations the process of combining data from two or more linked source records for the same patient and tumor to produce a single “best” value for each patient and tumor variable.

Current Procedural Terminology (CPT)

Definition Source: *Health Information Management Concepts, Principles, and Practices*

A comprehensive list of descriptive terms and codes published by the American Medical Association and used for reporting diagnostic and therapeutic procedures and other medical services performed by physicians.

Data Capture

Definition Source: *Health Information Management Concepts, Principles, and Practices*

The process of recording healthcare-related data in a health record system or database.

Data Dictionary

Definition Source: *Health Information Management Concepts, Principles, and Practices*

A descriptive list of the data elements to be collected in an information system or database; the purpose of the list is to ensure consistency of usage.

Data Element

Definition Source: *Cancer Registry Management Principles and Practices, 2nd Edition*

A fact, category of information, or specific item of information; also called a field. Sex, race, name, and primary site are examples of data elements.

Data Source

An entity that either collects or produces information about a cancer patient. Data may be in printed or electronic format. Examples of data sources: pathology laboratory, mortality report, hospital. Examples of data include demographic – date of birth, census tract, date of death; medical – primary site, histology type of cancer, cause of death, treatment; or administrative – physician, billing/claims, name of hospital/clinic.

Demographic information

Definition Source: *Health Information Management Concepts, Principles, and Practices*

Information used to identify an individual such as name, address, gender, age, and other information specifically linked to a specific patient.

Diagnostic Imaging

Techniques and processes used to create images of structural or functional patterns of human organs or tissues for the purpose of identifying, diagnosing, or monitoring disease. Radiographs (X-rays), fluoroscopy, ultrasound, mammography, computerized tomography (CT scans), positron emission tomography (PET scans), magnetic resonance imaging (MRI scans), and nuclear medicine imaging are included. Information reported from diagnostic imaging includes the type of study, body location, description and evaluation of the image, and diagnosis.

Disease Index

Definition Source: *Health Information Management Concepts, Principles, and Practices*

A listing of diseases and conditions of patients sequenced according to the code numbers of the classification system in use. Diseases and conditions identified in patient medical records are coded by health information professionals using standard classification systems such as ICD-9-CM or CPT (Current Procedural Terminology). The Disease Index, compiled from these codes, is a casefinding source for the cancer registry.

Editing

Definition Source: *Cancer Registry Management Principles and Practices, 2nd Edition*

Reviewing the information on a case for logic, consistency, and possible errors.

Electronic Health Record

Definition Source: *Health Information Management Concepts, Principles, and Practices*

A health record housed in an information system designed to provide users with access to complete and accurate clinical data, practitioner alerts and reminders, clinical decision support systems, and links to medical knowledge; also known as computer-based patient record (CPR) [Note: located in the textbook's glossary under Computer-based patient record.]

Electronic Reporting (e-Reporting)

Definition Source: *e-Reporting A New Priority; Journal of Registry Management; 2004; Vol 31; No. 3; pp 92-100.*

e-Reporting is the automated, unattended (by humans) transmission of data between 2 or more parties.

Encounter

A meeting between a patient and a physician whose services are provided during one visit to a clinic, provider office, or hospital is defined as an encounter.

e-Prescription

e-Prescribing is the process of prescribing medication using a computerized physician order entry system linked with clinical decision support that can send prescriptions or prescription-related information to pharmacies electronically.

Event Report

An electronic transmission of information to a cancer registry.

Abstracted Event Report

An extraction and/or summary of information created by a data source specifically for a cancer registry.

EHR Event Report

A report, document or note within the Electronic Health Record. It includes: radiology report, pathology reports, clinician and nurses notes, discharge summary, admissions form, etc.

Corrected Event Report

An event report that corrects an error in a previously submitted event report is a corrected event report.

Registry Event Report (Abstract)

An abstract is an abbreviated record that identifies the patient, disease, treatment, and disease process from the time of diagnosis until the patient's death. It usually is divided into sections: patient identification, cancer identification, stage of disease at diagnosis, first course of treatment, recurrence, and follow-up. The abstract is the basis for the rest of the registry's functions; without this summary of a patient's cancer experience, no other registry function can take place.

Non-Registry Event Report

Non-Registry Event Report is an electronic submission of data from a data source other than a cancer registry.

Rapid Event Report

A rapid event report is an event report transmitted in real time to notify a central cancer registry of a cancer diagnosis quickly, usually to include a patient in a research study.

Routine Event Report

A report submitted by a data source relating to a patient with cancer, such as a pathology report, discharge summary, insurance claim, or death certificate.

Follow-up

Definition Source: *Cancer Registry Management Principles and Practices, 2nd Edition*

An organized system of long-term surveillance of patients; the activities involved in monitoring patients after discharge; the process of obtaining annually updated information regarding a patient's health status to ensure continued medical surveillance. Active follow-up refers to someone, usually a physician or cancer registrar, initiating direct contact with patients to encourage them to see their physician. Follow-up data in an abstract include those fields useful for tracking the patient after he or she has left the hospital, including the name, address, telephone number, and relationship of a relative, friend, or neighbor who is most likely to know how to locate the patient. Follow-up letters are written requests for information on a patient's health status which can be addressed to a physician, the patient, or a contact. The follow-up rate is a calculation of the percentage of patients who have current information (within fifteen months) on their health status; the target rate is 90 percent successful follow-up. Follow-up staff is the individual(s) in a registry who conduct all patient tracking activities. Passive follow-up refers to methods that do not require contact with hospitals, physicians, or patients, in order to determine the patient's vital status, such as linkage with voter registration records or driver's license lists.

Follow-back

Definition Source: *Cancer Registry Management Principles and Practices, 2nd Edition*

Reviewing a patient's medical history to ascertain if a case reported first by a death certificate ever had that cancer diagnosed at any other source while the patient was alive.

Healthcare Data Source

Definition Source - Original

An entity collecting information for direct medical care (evaluation, diagnosis, treatment, follow-up, prevention, etc). It does not include health insurance data sources.

Health Level 7 (HL7)**Organization**

Definition Source: <http://www.hl7.org>

Health Level Seven is one of several [American National Standards Institute](#) (ANSI) -accredited Standards Developing Organizations (SDOs) operating in the healthcare arena. Most SDOs produce standards (sometimes called specifications or protocols) for a particular healthcare domain such as pharmacy, medical devices, imaging or insurance (claims processing) transactions. Health Level Seven's domain is clinical and administrative data. Our mission is to: "*To provide standards for the exchange, management and integration of data that support clinical patient care and the management, delivery and evaluation of healthcare services. Specifically, to create flexible, cost effective approaches, standards, guidelines, methodologies, and related services for interoperability between healthcare information systems.*"

Standard

Definition Source: *Public Health Information Network Functions and Specifications, Ver. 1.2, December 18, 2002*

HL7 is a formatting standard for structuring, storing, and messaging clinical data. The standard also supplies a basic set of vocabularies to be used for the attributes in the HL7 Reference Model. HL7 v.3.0 specifications describe 6 basic components:

1. The sets of fields or attributes that make up a message
2. The vocabularies that are needed to enforce consistent data entries in the fields
3. The logical database structure for storing the records
4. The messaging or transport method that the records are shared by
5. The structure of the message to be shared, XML
6. The relationships of the various components in an HL7 message that follow a hierarchy.

Health Record

Definition Source: *Health Information Management Concepts, Principles, and Practice*

A paper- or computer-based tool for collecting and storing information about healthcare services provided to a patient; also called patient record, medical record, resident record, or client record, depending on the healthcare setting.

Health Insurance Portability & Accountability Act of 1996 (HIPAA)

Definition Source: www.hipaadvisory.com/regs/HIPAAprimer.htm

HIPAA" is an acronym for the Health Insurance Portability & Accountability Act of 1996 (August 21), Public Law 104-191, which amended the Internal Revenue Service Code of 1986. Also known as the Kennedy-Kassebaum Act, the Act includes a section, Title II, entitled Administrative Simplification, requiring:

1. Improved efficiency in healthcare delivery by standardizing electronic data interchange, and
2. Protection of confidentiality and security of health data through setting and enforcing standards.

More specifically, HIPAA called upon the Department of Health and Human Services (HHS) to publish new rules that will ensure:

1. Standardization of electronic patient health, administrative and financial data
2. Unique health identifiers for individuals, employers, health plans and health care providers
3. Security standards protecting the confidentiality and integrity of "individually identifiable health information," past, present or future.

Hospital Cancer Registry

A hospital cancer registry collects information on all cancer patients who use the services of a hospital. It may be required to report cancer cases to the central registry, to respond to inquiries from the central registry, or to allow central registry access to its records.

Hospital Data Source Employee

He or she interacts with the central cancer registry during the initial phase of the business process when event reports are prepared and transmitted.

Individually Identifiable Health Information (IIHI)

TN900 approved by HITSP, Oct, 2007.

Information that relates to an individual's physical or mental health; the provision of healthcare to an individual; or the payment for healthcare provided to an individual, in which the information identifies the individual or could be used to identify the individual. This is a more encompassing term that includes Protected Health Information and Personal Health Information.

International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM)

Definition Source: *Health Information Management Concepts, Principles, and Practices*

Classification system used in the United States to report morbidity and mortality information.

International Classification of Diseases for Oncology, 3rd Edition (ICD-O-3)

Definition Source: *Health Information Management Concepts, Principles, and Practices*

Classification system for reporting incidences of malignant diseases.

Master Patient Index (MPI)

Definition Source: *Health Information Management Concepts, Principles, and Practices*

A list or database maintained by a healthcare facility that records the names and identifications of every patient who has ever been admitted or treated in the facility. [Note: located in the textbook's glossary under Master population index.]

National Hospital-based Cancer Program

National Hospital-based Cancer Program provides leadership for systematically collecting, disseminating, and interpreting cancer data from hospital cancer registries and a resource for research to address the cancer burden in the United States.

National Population-based Cancer Program

National Population-based Cancer Program provides leadership for collecting, disseminating, and interpreting cancer data from geographically-defined cancer registries (usually regional or state populations). They serve as a resource for research to address the cancer burden in the United States.

Natural Language Processing

Definition Source: *Health Information Management Concepts, Principles, and Practices*

A process by which digital text from online documents stored in the organization's information system is read directly by software and automatically coded.

Nomenclature

Definition Source: *Health Information Management Concepts, Principles, and Practices*

A system of terms that is structured according to pre-established naming rules; also referred to as clinical terminology. Example: SNOMED.

Non-Healthcare Data Source

Definition Source: *Original*

An entity collecting information about a person which can be used to enhance and/or validate medical information. Examples include health insurance providers, National Death Index, Bureau of Vital Records, Department of Motor Vehicles.

Non-Hospital Source of Cancer Data

Non-Hospital Source of Cancer Data is an organization outside a hospital that provides information about the patient.

Pathology Report

Definition Source: *Cancer Registry Management Principles and Practices, 2nd Edition*

The written description of the microscopic examination of a tissue. The *gross description* reports the physical characteristics of the tissue: size, color, and abnormalities visible with the unaided eye. The *microscopic description* reports the cellular characteristics aided by **the use of a microscope**: what cells are involved, the behavior, and the aggressiveness or grade of any abnormality. The *final diagnosis* is a summary of the findings and indicates the pathologist's impression of what was found in concise terms.

Privacy

TN900 approved by HITSP, Oct, 2007.

An individual's or organization's right to determine whether, when and to whom personal or organizational information is released. Also, the right of individuals to control or influence information that is related to them, in terms of who may collect or store it and to whom that information may be disclosed.

Privacy Rights

TN900 approved by HITSP, Oct, 2007.

Specific actions that an individual can take or request to be taken with regard to the uses and disclosures of their information.

Reporting Facility

A reporting facility provides data to the cancer registry. It is responsible for the accuracy of the data and for providing corrections and updates. The two types of reporting facilities in the central cancer registry domain are healthcare facilities and non-healthcare facilities.

Security/Security Measures/Safeguards

TN900 approved by HITSP, Oct, 2007.

Encompass all of the administrative, physical and technical actions used or taken to protect health information regardless of the medium or format.

SNOMED-CT

Definition Source: www.snomed.org

A dynamic, scientifically validated clinical health care terminology and infrastructure that makes health care knowledge more usable and accessible. The SNOMED CT Core terminology provides a common language that enables a consistent way of capturing, sharing and aggregating health data across specialties and sites of care.

Stakeholder

Definition Source: AHIMA

An individual who has an interest in, or is affected by a project or activity is called a stakeholder.

Summarized Follow-Up Record

Summarized Follow-Up Record is a record containing the most appropriate method and data to obtain information about the patient's vital status and cancer status.

Summarized Patient Record

Summarized Patient Record is a record containing the most specific patient demographic information, provided by multiple data sources, to identify the patient uniquely and assist in the follow-up process.

Summarized Treatment Record

Summarized Treatment Record is a record containing the most specific treatment information, provided by multiple data sources, for analysis and research.

Summarized Tumor Record

Summarized Tumor Record is a record containing the most specific medical information about the cancer, provided by multiple data sources, for analysis and research.

Suspense File/Suspense Case

Definition Source: *Cancer Registry Management Principles and Practices, 2nd Edition*

In registry terms, awaiting further action. The s. file or s. list is an inventory or document identifying potentially reportable cases which have not been abstracted; a list of cases which have been ascertained but not yet completed. A case is a reportable disease awaiting completion and entry into the registry database.

Transmission Standard

Definition Source: *Health Information Management Concepts, Principles, and Practice*

Standards that support the uniform format and sequence of data during transmission from one healthcare entity to another; also referred to as communication, messaging, and transaction standards.

Trusted Data Source

An entity that has been identified and validated as having information relating to a cancer patient that meets the standards for inclusion in a cancer registry.

Hospital Function Definitions

Note: The NPCR-AERRO glossary used definitions established by credible sources in the cancer registry and e-health communities where available. The definition was developed by NPCR-AERRO workgroups when no source is given.

Certify a Data Source for Electronic Reporting

The Use Case describes the process for evaluating and subsequently certifying a Data Source as being qualified to perform electronic reporting that meets cancer registry standards.

Prepare and Transmit Event Report

The process whereby a Data Source submits event reports to the hospital cancer registry, using established criteria for record layout format, required event report types, required data items, and transmission standards.

Receive Batch File

The process of verifying a group of event reports meet the standards for record layout format, and that the batch has not been previously submitted.

Validate Event Report

The process of verifying that that information in the event report meets logic, consistency, and data validity standards

Perform Casefinding and Passive Follow-up

The process of verifying that information submitted on an event report represents a reportable case and of updating vital status and other follow-up information for patients with an abstract in the cancer registry.

Perform Abstracting

The process of verifying that information submitted on an event report represents a reportable case and of updating vital status and other follow-up information for patients with an abstract in the cancer registry

Validate and Edit Abstracted Data

The process of verifying that information in the cancer registry abstract meets logic, consistency, and data validity standards.

Conduct Active Follow-up

The process of annually obtaining updated information regarding a patient's health status to ensure continued medical surveillance.

Submit Data to CCR and NCDB

Submit cancer information to various organizations to meet state and accreditation regulations, and assist in research activities.

Perform Quality Assurance/Quality Control

Quality Control: A planned set of activities by which the cancer registrar monitors current quality and take appropriate remedial action to positively affect future quality, maximizing correct reporting and characterizing the reporting process in measurable terms. Quality Assurance: a formalized, retrospective review of patient records to determine quality of case, case completeness and data quality.

Perform Analysis

Analyzing collected cancer data and converting it into information about treatment, survival and other factors affecting cancer patients. Perform statistical analysis on collected data to provide interpreted information on cancer for a particular population.

Handle Security

The process to ensure patient health information is protected by using transmission protocols and implementing secure storage that meets industry standards for health care data; this function is outside the scope of NPCR-AERRO.

Conduct Education and Training

A function of training registry staff; this function is outside the scope of NPCR-AERRO.

Hospital Data Sources Definitions

Note: The NPCR-AERRO glossary used definitions established by credible sources in the cancer registry and e-health communities where available. The definition was developed by NPCR-AERRO workgroups when no source is given.

Admissions

The hospital department that processes patient admissions and generates key patient identification and demographic data, including the patient's name, address, date of birth, race, sex, social security number, and insurance carrier.

Business Office

Department responsible for billing and collecting payment from individuals or third-party payors for health care services rendered by the facility. Business office provides the information on the financial statement submitted for payment.

Diagnostic Imaging

Techniques and processes used to create visual images of structural or functional patterns of human organs or tissues for the purpose of identifying, diagnosing, or monitoring disease. Radiographs (X-rays), fluoroscopy, ultrasound, mammography, computerized tomography (CT scans), positron emission tomography (PET scans), magnetic resonance imaging (MRI scans), and nuclear medicine imaging are included. Information reported from diagnostic imaging includes the type of study, body location, description and evaluation of the image, and diagnosis.

External (Non-Hospital) Cancer Data Source

A data source that operates as a separate entity from the hospital is called an External (Non-Hospital) Cancer Data Source.

Freestanding Chemotherapy Center

A healthcare facility established as a separate entity from traditional hospitals, though it may be affiliated with a hospital. It offers chemotherapy treatments and may provide cancer information to hospital registries for shared patients or establish its own registry database for monitoring patient care and outcomes. It may be required to report cancer cases to the central registry, to respond to inquiries from the central registry, or to allow central registry access to its medical records.

Freestanding Pathology Laboratories

Department responsible for the examination and analysis of all organs, tissues, cells, and bodily fluids removed from patients for the purpose of investigation and diagnosis of disease. The pathology lab is also responsible for the conduct of autopsies to study disease processes and to determine cause of death. Information reported from Pathology includes type of material examined, body location from which the specimen was taken, gross and microscopic description and evaluation of tissues, components of bodily fluids, and diagnosis.

Freestanding Radiation Oncology Center

A healthcare facility established as a separate entity from traditional hospitals, though it may be affiliated with a hospital. It offers radiation treatment and may provide cancer information to hospital registries for shared patients or establish its own registry database for monitoring patient care and outcomes. It may be required to report cancer

cases to the central registry, to respond to inquiries from the central registry, or to allow central registry access to its medical records.

Freestanding Surgical Center

A surgical facility that is independent from an acute care facility is called a freestanding surgical center.

Hospital Disease Index

A complete, numerically sequenced list of coded diseases and conditions diagnosed in patients within a hospital is the Hospital Disease Index. Diseases and conditions identified in patient medical records are coded by Health Information professionals using standard classification systems such as ICD-9-CM or CPT (Current Procedural Terminology). The Disease Index, compiled from these codes, is a casefinding source for the cancer registry.

Pathology Laboratory

The hospital department that examines organs, tissues, cells, and bodily fluids removed from patients for the investigation and diagnosis of disease, and conducts autopsies to study disease processes and to determine cause of death. Pathology reports include the type of material examined, body location from which the specimen was taken, gross and microscopic description and evaluation of tissues, components of bodily fluids, and diagnosis. A pathology laboratory may be required to report cancer cases to the central registry, to respond to inquiries from the central registry, or to allow central registry access to pathology records.

In-Hospital Source of Cancer Data

An area or department within a hospital that provides medical care to the patient and records the results is an In-Hospital Source of Cancer Data.

Medical Record Department

The department that compiles, stores, and retrieves patient medical records is called the medical record department.

Medical Records

Paper-based or computerized information gathered during the patient's encounters with the facility. Patient medical records are the primary source of patient identification, diagnosis and treatment information.

Oncology Clinics

Ambulatory care units responsible for staging, medical treatment, and follow-up of cancer patients within a hospital setting is called oncology clinic. The scope of services provided by oncology clinics is determined by the purpose and goals of individual clinics. For example, a clinic may focus on a particular disease such as breast cancer, or may focus on providing a centralized setting for chemotherapy administration, or may coordinate all services provided to oncology patients throughout the facility. Medical oncology documentation varies according to the services provided and may be separate from the hospital medical record.

Outpatient Services

Ambulatory services provided to patients in hospital-based clinics and departments where the length of stay is less than 24 hours. Documentation of outpatient services, which includes the patient's medical history, physical

examination, diagnostic and therapeutic procedures, consultations, observations and discharge notes, is usually integrated with the patient's inpatient medical record to form a unified hospital medical record.

Pharmacies

Hospital pharmacies maintain the hospital formulary, stock and release drugs for treatment as ordered by physicians, address complex clinical medication management issues, and provide information on available drugs, including generic and brand names, disease-specific prescriptions, and drugs administered to individual patients.

Physician Office/Clinic

A solo or group physician practice usually focused on a specialty area of medical practice such as internal medicine, general surgery, or urology. Its medical records identify cancer patients and provide cancer-specific treatment data and patient follow-up information. A physician practice may be required to report cancer cases to the central registry, to respond to inquiries from the central registry, or to allow central registry access to its medical records.

Radiation Oncology

Department responsible for curative, adjuvant, or palliative treatment of cancer using ionizing radiation to control malignant cells. Radiation may be given as external beam radiotherapy, brachytherapy or implantation of radioactive sources, or injection or ingestion of radioactive materials. Radiation oncology documentation, which may be maintained separate from the hospital medical record, includes pre-treatment consultation summarizing the cancer diagnosis and treatment to date, treatment planning and daily dose delivery, treatment summary, and patient follow-up visits.

Specialty Database

A collection of data on a specific disease, used to describe the hospital's collective diagnostic and treatment experience with the disease. Specialty databases are tools for improving the quality of care and measuring the effectiveness of health care delivery for that disease. One example of a specialty database is the cancer registry database which contains cancer-related information abstracted from patient medical records and patient follow-up data gathered from outside sources.

Treatment Logs

Daily records of treatment rendered or procedures performed within a hospital department such as a surgery unit or an outpatient chemotherapy clinic. Treatment logs, which generally list patient identifiers, procedure performed, diagnosis, and practitioner, are a source of casefinding data.

Central Cancer Registry Function Definitions

Note: The NPCR-AERRO glossary used definitions established by credible sources in the cancer registry and e-health communities where available. The definition was developed by NPCR-AERRO workgroups when no source is given.

Certify a Data Source for Electronic Reporting

The Use Case describes the process for evaluating and subsequently certifying a Data Source as being qualified to perform electronic reporting that meets cancer registry standards.

Prepare & Transmit Event Report

The process whereby a data source submits event reports to the central cancer registry, using established criteria for record layout format, required event report types, required data items, and transmission standards.

Receive Batch File

The process of verifying that a group of event reports meet the standards for record layout format and non-duplicate status.

Validate Event Report

The process of verifying that information submitted on an event report represents a reportable case and meets logic, consistency, and data validity standards.

Perform Patient Linkage

The process of using defined criteria to determine whether source records refer to the same patient, based on the degree of agreement between demographic and other data fields. This process can be automated, manual, or a combination. Synonyms: Record linkage, matching

Perform Tumor Linkage

The process of using defined criteria to determine whether source records for the same patient refer to the same tumor, based on the degree of agreement between cancer data fields. This process can be automated, manual, or a combination.

Perform Consolidation

The process of combining data from two or more linked source records for the same patient and tumor to produce a single "best" value for each patient and tumor variable.

Perform Casefinding Audit

A casefinding audit is a review and evaluation of the ability of a Data Source to identify and transmit eligible, reportable neoplasms to the central cancer registry (CCR). It involves a review of the most likely sources of cases – disease indices, pathology reports (surgical, bone marrow, autopsy, cytology, etc), radiation therapy logs, surgical logs, etc, to identify cases of cancer that should have been reported to the central cancer registry and compare these cases to those that were reported.

Perform Quality Assurance/Quality Improvement

Quality assurance/quality improvement is a planned set of activities by which the central cancer registry monitors quality and takes appropriate remedial action to improve future quality, maximizing correct reporting and characterizing the reporting process in measurable terms.

Perform External Linkage to Improve Data

The process of obtaining and/or validating data items by linking with non-CCR databases to enhance internally held data with externally obtained data. As, for example, when missing vital status and unknown race in a registry are enhanced with death certificate data.

Conduct Death Clearance

Death Clearance consists of two processes. Death Certificate Follow-Back: The process of reviewing a patient's medical history to ascertain if a case reported first by a death certificate ever had that cancer diagnosed at any other source while the patient was alive. Death Certificate Clearance: The process of linking death certificates from a state's vital statistics office with registry records in order to obtain death data for previously registered cancer cases.

Conduct Active Follow-Up

An organized system of long-term surveillance of patients; the activities involved in monitoring patients after discharge; the process of obtaining annually updated information regarding a patient's health status to ensure continued medical surveillance.

Perform Interstate Data Exchange

The process of reporting cases occurring in a non-resident to the appropriate central cancer registry.

Respond to Calls for Data

To submit cancer information to various organizations to meet federal and state regulations and to assist in research activities. (Previously labeled reporting)

Provide Data for Use by Others

To disseminate statistical analyses and data interpretations to researchers for scientific research, policy makers for planning services, hospitals for planning technology purchases and staffing, and NGOs for community cancer prevention and control.

Conduct Linkage for Research

To provide cancer registration data to researchers regarding their study cases.

Perform Research and Analysis

To perform statistical analyses and data interpretations for scientific research, policy planning, cancer prevention and control

Perform Rapid Case Ascertainment

A special case-finding procedure which allows early or preliminary reporting of certain types of cases to notify researchers about eligible study subjects.

Handle Security

The process to ensure patient health information is protected by using transmission protocols and implementing secure storage that meets industry standards for health care data; this function is outside the scope of NPCR-AERRO.

Conduct Education and Training

A function of training registry staff; this function is outside the scope of NPCR-AERRO.

Central Cancer Registry Data Sources Definitions

Note: The NPCR-AERRO glossary used definitions established by credible sources in the cancer registry and e-health communities where available. The definition was developed by NPCR-AERRO workgroups when no source is given.

Healthcare Facility Data Source

An organization that provides medical services to patients, and contributes clinical as well as other information to a cancer registry is a healthcare facility data source.

Hospitals

Healthcare facilities that provide a range of inpatient and outpatient diagnostic, treatment, and palliative care services. Hospitals may serve a community or regional population, or serve as a teaching and referral healthcare center. Hospitals may seek approval for their cancer programs from the American College of Surgeons Commission on Cancer, whose program standards require operation of a hospital cancer registry. Hospital cancer registries may be required to report cancer cases to the central registry, to respond to inquiries from the central registry, or to allow central registry access to hospital records.

Freestanding Pathology Laboratories

Pathology laboratories which operate as separate entities from healthcare facilities, providing services to clients that may include physician and clinic practices as well as hospitals. They are responsible for the examination of all organs, tissues, cells, and bodily fluids removed from patients for the investigation and diagnosis of disease, and for the conduct of autopsies to study disease processes and to determine cause of death. Reported information from pathology laboratories includes the type of material examined, body location from which the specimen was taken, gross and microscopic description and evaluation of tissues, components of bodily fluids, and diagnosis. Pathology laboratories may be required to report cancer cases to the central registry, to respond to inquiries from the central registry, or to allow central registry access to pathology records.

Cancer Treatment Facility

A healthcare facility established as a separate entity from traditional hospitals, though it may be affiliated with a hospital. It offers a range of diagnostic and treatment services to cancer patients, such as radiation and chemotherapy treatments, including overall management of oncologic care. A cancer center maintains patient medical records; it may provide cancer information to hospital registries for shared patients or establish its own registry database for monitoring patient care and outcomes. It may be required to report cancer cases to the central registry, to respond to inquiries from the central registry, or to allow central registry access to its medical records.

Claims Data

Data that describe billing and collecting payment information for healthcare services rendered by the facility is claims data. The data are created and maintained by the Business Office.

Clinical Trial

Clinical trial is a type of research study that tests how well new methods of screening, prevention, diagnosis, or treatment work.

CMS

(Center for Medicare and Medicaid Services) It is a type of health insurance plan.

Freestanding Health Care Practitioners

Individual or group physician practices, usually focused on a specialty area of medical practice such as internal medicine, general surgery, or urology. Their medical records provide identification of cancer patients, cancer-specific treatment data, and patient follow-up information. Physician practices may be required to report cancer cases to the central registry, to respond to inquiries from the central registry, or to allow central registry access to their medical records.

Health Insurance Plans

Medical practice managed by an insurance plan, in which plan subscribers generally receive primary care at clinics owned by the plan, with referral to outside specialists as needed. Plans maintain consolidated medical records for their patients who receive medical care from multiple plan facilities and may provide cancer information on shared patients to hospital registries. They may also establish their own registry databases for monitoring patient care and outcomes. Plans may be required to report cancer cases to the central registry, to respond to inquiries from the central registry, or to allow central registry access to their medical records.

HMO

Health maintenance organization is a type of health insurance plan.

State/Medical Assistance

State/Medical Assistance is a type of health insurance plan.

Hospices/Palliative Care

Patients with terminal disease may receive long-term care and end-of-life care at home or in a specialty hospital unit, nursing facility, or designated hospice facility. A hospice may be required to respond to inquiries from the central registry, or to allow central registry access to its medical records, particularly for case ascertainment on patients who have died with a cancer diagnosis identified only through death certification information.

Bureau of Vital Statistics

An agency within a state government that collects, maintains, and distributes information on births and deaths for state residents. It provides demographic and follow-up data for patients in the central registry database, including race, ethnicity, occupation, date of death, and cause of death.

Census Tract Database

A database maintained by the United States Census Bureau, with demographic and economic data presented by census tract, county, and state divisions. It provides information for generating a measure of socioeconomic status for cancer patients by address at diagnosis.

State Health Departments

Agencies within state governments whose mission is to promote and maintain the health of state residents are the state health departments. They are generally the units within state governments that apply for and manage federal

grants to support federally mandated health-related programs, such as the National Breast and Cervical Cancer Early Detection Program. Central registries are required to link their data with the National Breast and Cervical Cancer database to identify missing cases and to improve data quality in both databases.

IHS/Local Tribe Clinics

The Indian Health Service (IHS) provides comprehensive health services through IHS and tribally contracted hospitals, health centers, school health centers, and health stations. The health services provided include medical, dental, and environmental health programs. Central registries are required to link data with the IHS database to improve the identification and surveillance of American Indian/Alaska Natives diagnosed with cancer.

Medical Examiner

Medical Examiner is a public official who investigates any death not due to natural causes.

National Death Index

A central computerized index of death record information aggregated from state vital statistics offices, beginning with 1979 deaths. Established as a resource to aid epidemiologists and other health and medical investigators with mortality ascertainment activities, the index provides information on the date of death, location of death, and cause of death.

Nursing Homes/Hospices

Long-term care and end-of-life care facilities. Cancer patients may be diagnosed while either permanently or temporarily resident in nursing homes. Patients with terminal disease may receive hospice care at home, in a specialty hospital unit, in a nursing facility, or in a designated hospice facility. Nursing homes and hospices may be required to respond to inquiries from the central registry, or to allow central registry access to their medical records, particularly for case ascertainment on patients who have died with a cancer diagnosis identified only through death certification information.

Freestanding Diagnostic Imaging Centers

Imaging centers which operate as separate entities from healthcare facilities, providing services to clients that may include physician and clinic practices as well as hospitals. They are responsible for the visual imaging of body organs and structures for the purposes of diagnosing disease, evaluating progression of disease, and monitoring the effects of treatment upon imaged disease. Imaging information is generally made available to central cancer registries through reporting procedures established with physician offices and treatment facilities.

State Cancer Registries

Population-based registries whose purpose is to a) identify cancer cases that are not reported by outside entities, (b) abstract cancer information that may be missing from unreported and reported cases, and (c) resolve conflicts and consolidate cancer information from multiple sources into single cancer records. Staff monitor completeness of reporting, maintain relationships with reporting entities, maintain knowledge of coding systems and coding rules, and assist reporting entities in developing casefinding and abstracting practices.

Province

A province is an administrative geographic division of Canada; similar to a state in the United States.

Voter Registration

Rolls of registered voters within a state, maintained by local jurisdictions, containing the voter's name, date of registration, and address at registration. Voter registration provides information for determination and confirmation of address at diagnosis.

Department of Motor Vehicles

A state agency that issues driver licenses and maintains traffic offense data. It provides information for the determination or confirmation of date of birth and address at diagnosis.

Prisons

Medical records of incarcerated persons may document routine care delivered to a general prison population, or individual care received at a designated prison medical center. Cancer diagnostic and treatment information for prisoners is generally available through the hospital which has contracted with the prison facility for non-routine medical services. Follow-up information may be obtained from the care provider.

National Cancer Programs Definitions

Note: The NPCR-AERRO glossary used definitions established by credible sources in the cancer registry and e-health communities where available. The definition was developed by NPCR-AERRO workgroups when no source is given.

National Cancer Programs

National cancer programs provide leadership for collecting, disseminating, and interpreting cancer surveillance data and a resource for research to address the cancer burden in the United States.

NPCR

Established by Congress through the Cancer Registries Amendment Act in 1992, and administered by the Centers for Disease Control and Prevention (CDC), the National Program of Cancer Registries collects data on the occurrence of cancer; the type, extent, and location of the cancer; and the type of initial treatment. These data represent 98 percent of the U.S. population. NPCR is a business actor, external to the organization.

SEER

The Surveillance, Epidemiology and End Results Program of the National Cancer Institute is an authoritative source of information on cancer incidence and survival in the United States. SEER currently collects and publishes cancer incidence and survival data from population-based cancer registries covering approximately 26 percent of the US population. SEER is a business actor, external to the organization.

CoC @ ACoS

The American College of Surgeons (ACoS) Commission on Cancer (CoC) is a consortium of professional organizations dedicated to improving survival and quality of life for cancer patients through standard setting, prevention, research, education, and monitoring quality of care. It analyzes hospital registry data. It is a business actor, external to the organization.

NAACCR

NAACCR is the North American Association of Central Cancer Registries. A collaborative umbrella organization for cancer registries, governmental agencies, professional organizations, and private groups in North America interested in enhancing the quality and use of cancer registry data. NAACCR is a business actor, external to the organization.

NCDB

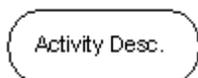
A joint program of the Commission on Cancer (CoC) and the American Cancer Society, the National Cancer Data Base (NCDB) is a nationwide oncology outcomes database for more than 1,400 CoC-approved cancer programs in the United States and Puerto Rico. These data are used to explore trends in cancer care, create regional and state benchmarks for participating hospitals, and form the basis for quality improvement.

Modeling Symbols

This document is a collection of symbols and figures from the Unified Modeling Language used for diagramming in the NPCR-AERRO Project. It is to make reading of the diagrams easier for the non-technical audience attending the SAMS Session. Basic knowledge of the symbols used in the diagrams present in the packet can be obtained from this document. References are given at the end of the document.

Activity

It is represented by a rectangle with rounded oval edges.



Actor

Actors represent system users and are depicted as the "stickman".



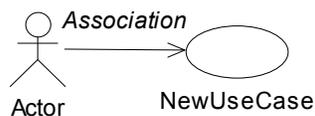
Aggregation

This relationship shows that the aggregate object is constructed from other objects or it logically contains other objects where the diamond points to the aggregate object. This aggregate object has the ownership of the parts.



Association Relationship

It is an orthogonal or straight solid line with an arrow at one end. It provides a pathway for communication.



Association can be of two types.

Unidirectional Association

The end with the arrow indicates who or what is receiving the communication.

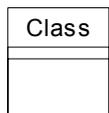


Bidirectional Association

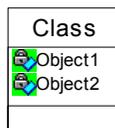


Class

A class is an abstraction of real world items. When these items exist in the real world, they are instances of the class and are referred to as objects.



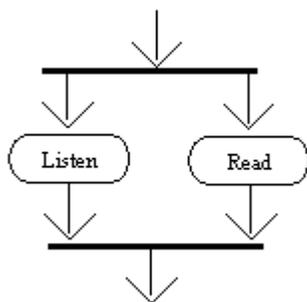
Class without objects



Class with objects

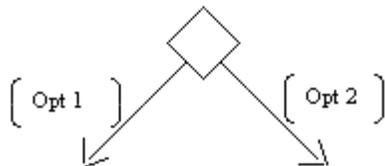
Concurrent Activities

Activities occurring simultaneously or in parallel are called concurrent activities. This is represented by a horizontal split (thick dark line) and the two concurrent activities next to each other, and the horizontal line again to show the end of the parallel activity.



Decisions

This is similar to flowcharts; a logic where a decision is to be made is represented by a diamond with options written on either sides of arrows emerging from the diamond.



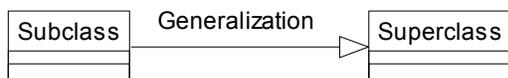
Final Activity

The end of the activity diagram is shown by a bull's eye called final activity.



Generalization

It is a relationship between a more general class/use case and a more specific class/use case where the arrow points to the more specific class/use case



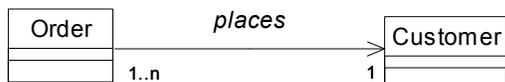
Initial Activity

It shows the starting point or the first activity of the state. It is represented by a solid circle.



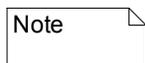
Multiplicity/Cardinality

It specifies the number of expected instances of the class. In the case of relationships, it indicates the number of links between each instance of the client class and the instances of the supplier class.



Note

A note captures the assumptions and decisions applied during analysis and design.

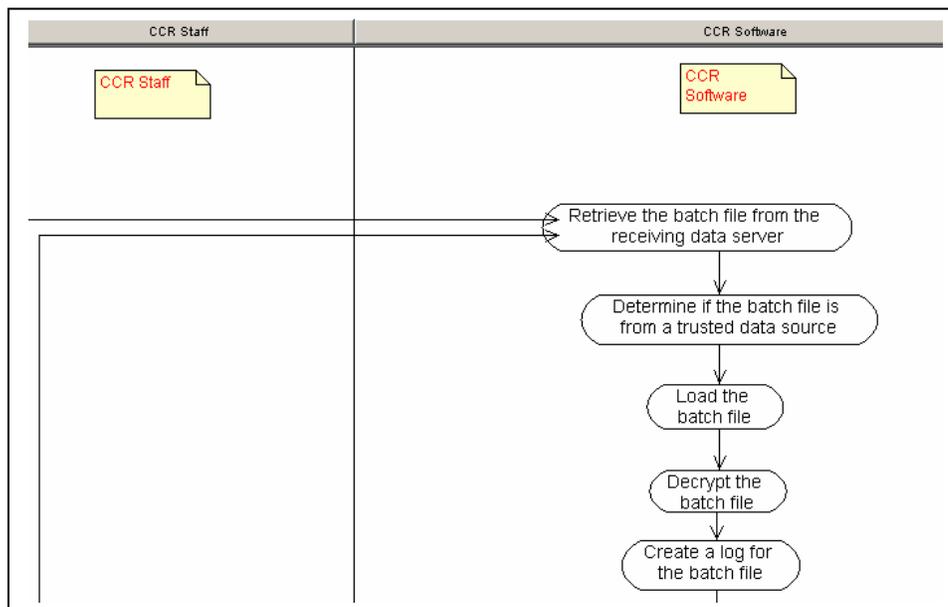


Modeling Definitions & Diagrams

This section of the glossary describes the symbols and diagrams in Unified Modeling Language in detail. References are given in the end of the glossary.

Activity Diagram

A diagram that shows the decomposition of an activity into its constituents is called an activity diagram.



Actor

An **actor** is *something or someone* who participates in a system in order for the system to work. An actor participates in a use case or coherent set of use cases to accomplish an overall purpose. It is an idealization and can be a class of users, roles users can play, or other systems. There can be active or passive actors.

Active: who initiate interaction with a system.

Passive: who are targets of requests or who are activated by the system.

Attribute

An attribute is the description of a named element of a specified type in a class, each object of the class separately holds a value of the type.

Business Processes

A description of a set of related activities that, when correctly performed, will satisfy an explicit business goal.

Business Rules

Statements that constrain, derive, and give conditions of existence are called business rules. Business Rules are used to specify allowed state of affairs, including allowed business object states.

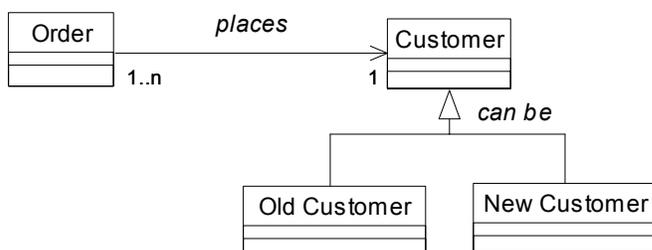
Class

A class represents a concept within the system being modeled. The descriptor for a set of objects that share the same attributes, operations, methods, relationships, and behavior.

A class is depicted on the class diagram as a rectangle with three horizontal sections, as shown. The upper section shows the class's name; the middle section contains the class's attributes; and the lower section contains the class's operations (or "methods").

Class Diagram

A class diagram is used to describe the objects and relationships of a system being modeled. A class diagram is similar to a family tree. The classes and interfaces in the diagram represent the members of a family tree and the relationships between the classes are analogous to relationships between members in a family tree. Interestingly, classes in a class diagram are interconnected in a hierarchical fashion, like a set of parent classes (the grand patriarch or matriarch of the family, as the case may be) and related child classes under the parent classes.



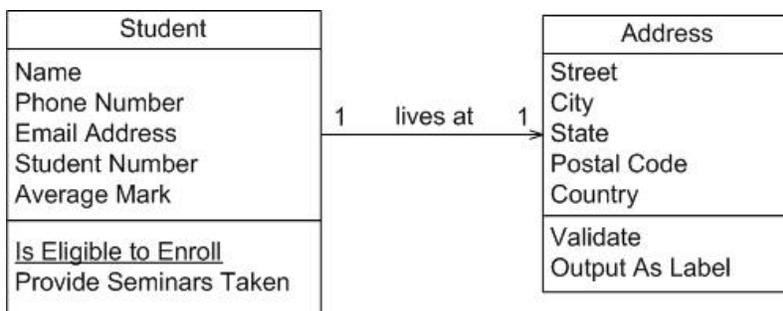
Component Diagram

A component diagram shows the definition, internal structure, and dependencies of component types. A component is a modular part of a systems design that hides its implementation behind a set of external interfaces.

Conceptual Diagram

Conceptual diagram describes the most significant concepts and relations of the problem domain. It's a representation of concepts of the real world instead of components of an object-oriented program. A conceptual diagram is made to help communication, which is to communicate the concepts of the problem domain to others.

Conceptual diagram can include associations and relations of inheritance (generalization) of all the relationships between the concepts or classes.



Context Diagram

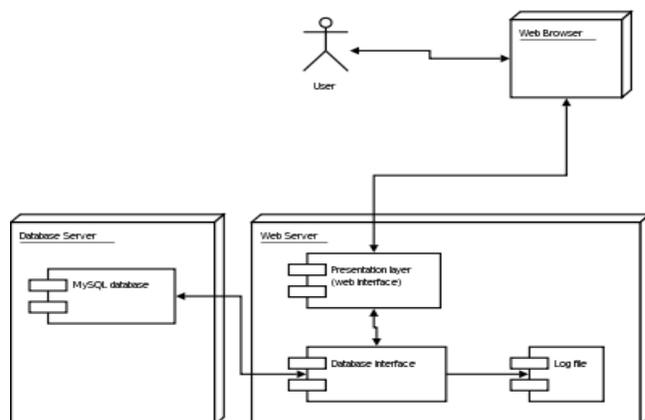
A context diagram is a top level data flow diagram. It only contains one process node that generalizes the function of the entire system in relationship to external entities.

Dependency Relationship

A dependency is a relationship between two diagram elements in which a change to one element affects the other element.

Deployment Diagram

A diagram that shows the configuration of run-time processing nodes and the artifacts that live on them is called a deployment. A deployment diagram may be at the class level or the instance level.



Dynamic View

That aspect of a model dealing with the specification and implementation of behavior over time, as distinguished from static structure found in the static view. It is a grouping term that includes the use case view, state machine view, activity view and interaction view.

Entity

A persistent information component representing a business concept is called an entity.

Functional View

A view dealing with the breakdown of a system into functions or operations that provide its functionality is called a functional view. A functional view is not usually considered object-oriented and can lead to an architecture that is hard to maintain. In traditional development methods, the data flow diagram is the heart of the functional view.

Object Model

A diagram that shows objects and their relationships at a point in time. An object diagrams may be considered a special case of a class diagram in which instance specifications, as well as classes, may be shown.

Relationships

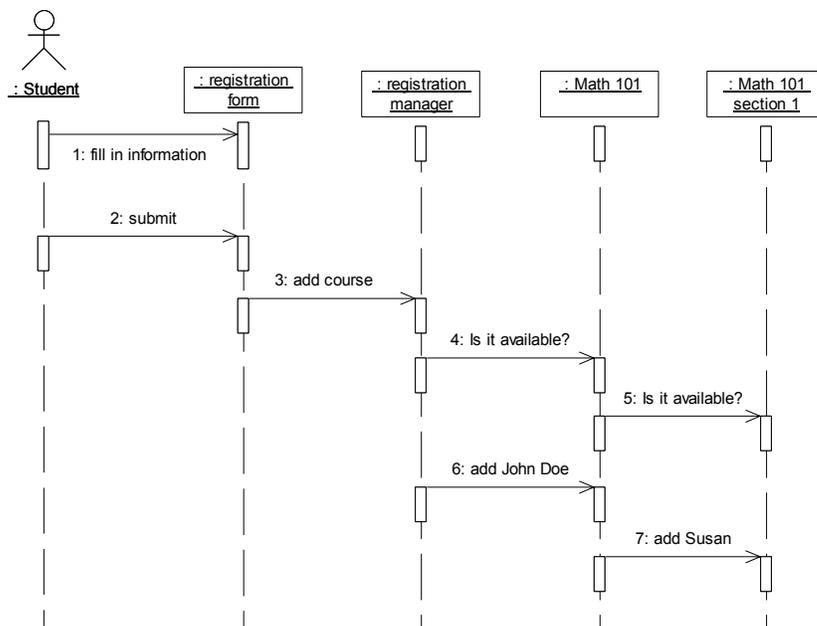
An abstract semantic connection among model elements is called a relationship. This includes association and various kinds of directed binary relationships.

Scenario

A sequence of actions that illustrates behavior is called a scenario. A scenario may be used to illustrate an interaction or execution of a use case instance.

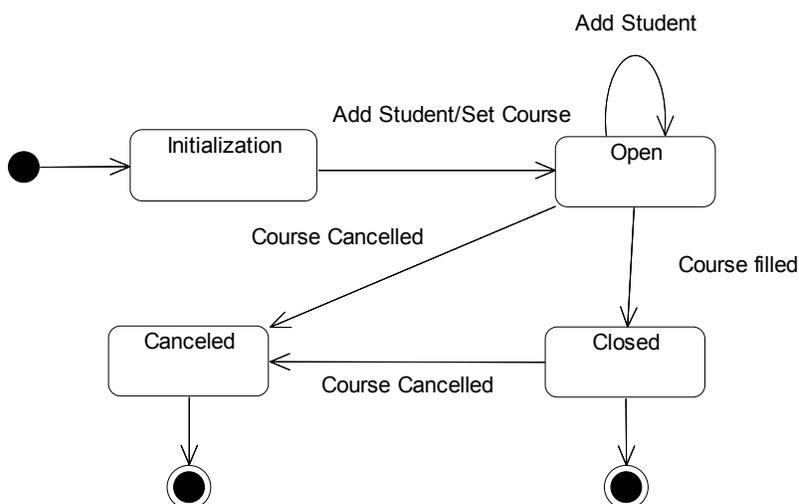
Sequence Diagram

A diagram that shows object interactions arranged in time sequence. In particular, it shows the object participating in an interaction and the sequences of messages exchanged.



Statechart Diagram

A diagram that shows a state machine, including simple states, transitions, and nested composite states is called a statechart diagram.



Strawman

In software development, a plan or document that serves as a starting point in the evolution of a project. The strawman is not expected to be the last word; it is refined until a final model or document is obtained that resolves all issues concerning the scope and nature of the project. In this context, a strawman can take the form of an outline, a set of charts, a presentation, or a paper.

Unified Modeling Language (UML)

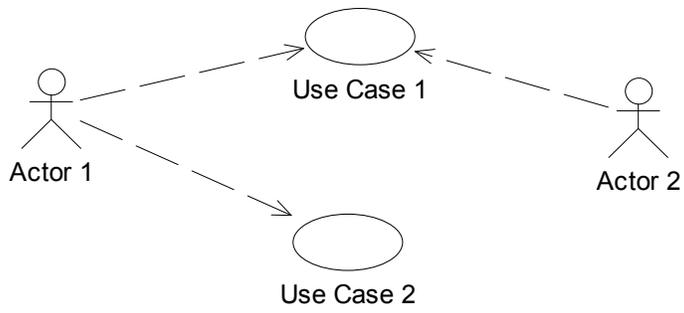
The Unified Modeling Language is a general-purpose visual modeling language that is used to specify, visualize, construct, and document the artifacts of a software system.

Use Case

The specification of sequences of actions, including variant sequences and error sequences, that a system, subsystem, or class can perform by interacting with outside objects to provide a service of value is called a Use Case.

Use-Case Diagram

A use case diagram is one that shows the relationships among actors and use cases within a system.



General Terms

Service Oriented Architecture (SOA)

A building block approach to application development which emphasizes re-use of software components that are built to perform individual functions and which interact with each other through clearly-defined interfaces.

Abbreviations

Code	Definition
ACoS	American College of Surgeons
CAP	College of American Pathologists
CoC	Commission on Cancer
CDC	Center for Disease Control and Prevention
CPT	Current Procedural Terminology
CTR	Certified Tumor Registrar
HL7	Health Level 7
ICD-9 CM	International Classification of Diseases, 9 th Edition – Clinical Modification
ICD-O-3	International Classification of Diseases for Oncology – 3 rd Edition
AERRO	Advancing E-cancer Reporting and Registry Operations
NAACCR	North American Association of Central Cancer Registries
NCDB	National Cancer Database
NEDSS	National Electronic Disease Surveillance System
NCI	National Cancer Institute
NCRA	National Cancer Registrars Association
NIH	National Institutes of Health
NPCR	National Program of Cancer Registries
PHIN	Public Health Information Network
SEER	Surveillance, Epidemiology and End Results
SNOMED	Systematized Nomenclature for Human Medicine

Use Cases

Use Case	Definition	Source ¹
Central Cancer Registry (CCR)	The data system established from collection of all new cancer cases diagnosed in a defined geographical area. The purpose is to process, analyze, disseminate and interpret timely, complete and accurate cancer incidence data for the defined population.	3 draft
Casefinding (Case Ascertainment)	The systematic process of identifying all cases of a disease eligible to be included in the registry database for a defined population, such as patients of a hospital or residents of a state. It is also called case ascertainment.	1
Rapid Case Ascertainment	A special casefinding procedure which allows early or preliminary reporting of certain types of cases in order to get notification of eligible study subjects to researchers.	1
Abstracting	A systematic process of collecting and recording pertinent data from a health record to provide a summary description of the cancer. Collection of pertinent information about the patient, cancer diagnosis, treatment, and patient follow-up. Abstract must be completed for all reportable primaries diagnosed and/or initially treated at the facility since the registry reference date. (Source: COC Revised Standards)	1
Editing	Reviewing the information on a case for logic, consistency, and possible errors. <i>both review and change them to make the source more complete, more accurate, etc. the idea of change ought to be built in to the concept.</i>	1
Patient Linkage	In routine central registry operations, the process of using defined criteria to determine whether source records refer to the same patient, based upon the degree of agreement between demographic and other data fields. This can be automated, manual or a combination. Synonyms: Record Linkage, Matching	2
Tumor Linkage	In routine central registry operations, the process of using defined criteria to determine whether source records for the same patient refer to the same tumor, based on the degree of agreement between cancer data fields. It can be automated, manual or a combination.	2

¹ 1 = Cancer Registry Management Principles and Practice, 2nd Edition

2 = <http://www.naaccr.org/filesystem/pdf/RecConsol1999-1.pdf>

3 = NAACCR Death Clearance WorkGroup

¹ 1 = Cancer Registry Management Principles and Practice, 2nd Edition

2 = <http://www.naaccr.org/filesystem/pdf/RecConsol1999-1.pdf>

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