# SEER Registry Data Management Project

## Business Object Model Text

This document is one part of the business object model. The other part is the diagram.
The development of this model is in progress, so the following text is incomplete. The model was not iterated in Phase 1 as much as the Business Process Model, so there are more fundamental issues which require attention in this model.
This model was converted into the LDM. The LDM was then compared to the BPM and attributes were updated. While an attempt was made to keep the BOM synchronized with the LDM, some attributes were not updated. Therefore, at the extreme detail level, this document is **NOT** completely accurate

**First draft: May 23, 2000**
**Last update: April 17, 2003**
attribute: COC, non-SEER
*attribute:* COC historic (NAACCR ver 10), non-SEER.
**attribute:** NPCR
***attribute:*** NPCR + COC historic

# Entities

## ABSTRACT

**Definition**

A summarized report of the medical information about a cancer/tumor/case as it appears in the patient's medical records at a facility. Usually, this report is compiled by the hospital staff or by a registry staff member sent to the facility specifically for this purpose (an **abstractor**). Ideally, every cancer/tumor/case would have an abstract for every facility at which it was seen/treated. More practically, information gathering is not considered complete until there is at least 1 abstract, although path-only and death certificate only cancer/tumor/cases are released to maintain reporting levels. The data items contained on this report, (which include text summary fields) encompass all SEER and local required fields.
**DESIGN NOTE:** Need to be able to print abstracts. (CT loads abstracts electronically, and then prints them for the codes to review)

**Examples**

**Attributes**

From Judy Boone in CA
Addr at DX—Street Name & number
Addr at DX--City
Addr at DX--State (Canadian Province)
County at DX
Addr at DX-- Postal Code (ZIP)
Marital Status at DX
Race 1
Race 2
Race 3
Race 4
Race 5
Spanish/Hispanic Origin
Sex
Birth Date
Birthplace (city, state/province, county – geocoding)

Religion
Text--Usual Occupation
Text--Usual Industry
Date of Diagnosis (First dx recognized by medical practitioner. May be clinical. Even when histologically confirmed, still the date of first clinical dx)
Age at Diagnosis
Primary Site
Laterality
Histologic Type
Behavior Code
Grade
Diagnostic Confirmation
Type of Reporting Source
Histologic Type ICD-O-3
Behavior Code ICD-O-3
Reporting Hospital

Accession Number--Hosp
Sequence Number--Hospital
Abstracted By
Date of Adm/1st Contact
Date of Inpatient Adm
Date of Inpatient Disch
Class of Case
Year First Seen This CA
Primary Payer at DX
RX Hosp--Radiation
RX Hosp--Chemo
RX Hosp--Hormone
RX Hosp--BRM
RX Hosp--Other
RX Hosp--Non-CA Dir Surg
SEER Summary Stage 2000
Summary Stage 1977
EOD--Tumor Size
EOD-Extension
EOD--Extension Prost Path
EOD--Lymph Node Involv
Regional Nodes Positive
Regional Nodes Examined
TNM Path T
TNM Path N
TNM Path M
TNM Path Stage Group
TNM Path Staged By
TNM Clin T
TNM Clin N
TNM Clin M
TNM Clin Stage Group
TNM Clin Staged By
TNM Edition Number
Pediatric Stage
Pediatric Staging System
Pediatric Staged By

Tumor Marker 1
Tumor Marker 2
Tumor Marker 3
RX Date--CA Dir Surg
RX Date--Radiation
RX Date--Chemo
RX Date--Hormone
RX Date--BRM
RX Date--Other
RX Date--Non-CA Dir Surg
RX Summ--Surg Prim Site
RX Summ--Scope Reg LN Sur
RX Summ--Surg Oth Reg/Dis
RX Summ--Reg LN Examined
RX Summ--Reconstruct 1st
Reason for No CA Dir Surg
RX Summ--Non-CA Dir Surg
RX Summ--Radiation
RX Summ--Surg/Rad Seq
RX Summ--Chemo
RX Summ--Hormone
RX Summ--BRM
RX Summ--Other
Reason for No Radiation
Reason for No Chemo
Reason for No Hormone
Protocol Participation
Date of Last Contact
Vital Status
Cancer Status
Addr Current – Street Name & Number
Addr Current--City
Addr Current--State (Canadian Province)
Addr Current--Postal Code (ZIP)
Follow-Up Contact--Name
Follow-Up Contact--No&St
Follow-Up Contact--City
Follow-Up Contact--State
Follow-Up Contact--Postal
Place of Death
Date Case Completed
Date Case Last Changed
Date Case Report Exported
ICD-O-3 Conversion Flag
Vendor Name
Name--Last
Name--First
Name--Middle
Name--Suffix
Name--Alias
Name--Maiden
Medical Record Number
Social Security Number (SSN)
Telephone
Institution Referred From

Institution Referred To
Last Follow-Up Hospital
Physician--Managing
Physician--Follow-Up
Physician--Primary Surg
Physician 3 (Could be family physician, referral, hospital staff, etc)
Physician 4
Text--DX Proc--PE
Text--DX Proc--X-ray/scan
Text--DX Proc--Scopes
Text--DX Proc--Lab Tests
Text--DX Proc--Op
Text--DX Proc--Path
Text--Primary Site Title
Text--Histology Title
RX Text--Surgery
RX Text--Radiation (Beam)
RX Text--Radiation Other
RX Text--Chemo
RX Text--Hormone
RX Text--BRM
RX Text--Other
Text--Remarks
Place of Diagnosis
+ other registry specific variables
Registry ID number

Time needed (if for Special study)

** There are others, but are listed under health record

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

LA: 50,000/year
HI: 8000-10,000/year

**Local Variations**

## ABSTRACT FACILITY/ORGANIZATION LEAD

**Definition**

Indicates that the Registry expects/hopes to get an abstract from a facility either for a new patient or a new cancer/tumor/case (existing patient).

This handles both the case where the Registry will send an abstractor to do abstracting AND the Registry will request that the facility send an abstract.

**NOTE**: When there is no facility identified for the lead, it isn't an ABSTRACT FACILITY LEAD; instead, the HEALTH RECORD is flagged as needing an abstract but not sure from whom.

Comes from 2.1 Create Abstract; 7.4 Evaluate Active Follow-up Responses; 4.2 Consolidate Registry View Patient Set.

**DESIGN NOTE:** may not know FACILIITY/ORG from which an abstract is needed. Would store a placeholder until more information is obtained (unknown facility code needed).
**DESIGN NOTE:** may need to note if a lead is a physician office only type record as it may not be possible to get an abstract until the patient has been through the hospital system.

**Examples**

**Attributes**

Abstract Facility Lead ID
Registry Patient ID (if known)
Patient ID (facility)
Patient identifiers (Name, SSN, DOB)
CTC ID (Registry, sequence?)
Tumor Seq number (facility)
CTC identifiers (site, hist, behavior, dodx)
Date/time lead created
Staff id (who created lead)
Assigned to (staff ID or facility group)
Date Closed (if blank, then it is still active)
Reason Closed Flag (abstracted, not a CTC, reassigned, not at given facility)
Reason Not Abstracted (required if not abstracted: text)
Facility Staff ID (who provided reason not abstracted)
"Do Not Abstract Before" date (to support aging)
Status {open, closed, purged}

**Uses**

**Policies/Business Rules**

AMD from NM stated that she would like to delete closed leads from the file storing this. She feels that this should be kept simple to cut down on potential problems because this is basically supposed to be a to-do list. NEED to consider ways to keep this 'table' simple and at least allow layers, historic/current.

**Sensitivity**

**Estimated Number of Occurrences**

HI: 200,000 in file since start; 5000-10,000 per year. They have flags
LA: they get paths within 1 month, but no abstract until 6 mths. Therefore, 40,000 paths waiting; about 10,000 paths that they must take action on; 5000 of those resolved by hospital; 2000-2500 by doctors.

**Local Variations**

## ABSTRACT REQUEST

**Definition**

A communication from the SEER registry to the facility (usually a hospital with a cancer registrar) asking for a specific patient/CTC abstract.
**DESIGN NOTE:** Would like to use bar codes on outbound communications that expect responses to facilitate tracking.

**Examples**

Registry discovers that John Smith had a lung cancer/tumor which was diagnosed in facility A. Their 'rolodex' shows that facility A does it's own abstract and has not yet sent one for John Smith's lung cancer/tumor. They request said abstract from the facility.

**Attributes**

Record Request ID
Time/date sent
Patient ID (name, age, hospital accession number if known,… variables to help hospital identify whose record they should be sending)
Tumor site/type
Status {open, closed, purged}

**Uses**

**Policies/Business Rules**

These are filled doing source submissions, but many requests (record, abstract so on) could be filled in the same submission. The 'date fulfilled' variable may not need to be stored here depending on design.

**Sensitivity**

**Estimated Number of Occurrences**

Most abstracts are sent without a request being needed!
LA: about 75 facilities send abstracts (about 2/3), probably 10,000 paths need to have abstracts requested.
HI: about 7500 sent

**Local Variations**

## ACTIVE FOLLOW-UP COMMUNICATION

**Definition**

The action (sending letter, making phone call, etc) that is taken by the SEER registry to attempt to obtain a date of last contact and vital status at that date for a specific person (or group of people) whose last contact date is considered to be 'too old'. ('too old' may vary by registry)
Assumes it could be an ORG REP doing active follow-up or it could be a system generating form letters.
Assumes multiple patients can be referenced in 1 communication. This would be a number of follow-up actions done at the same time, being sent to the same medical practitioners, facilities or organizations including requests for follow-up on multiple patients.
**DESIGN NOTE:** Would like to use bar codes on outbound communications that expect responses to facilitate tracking.

**Examples**

**Attributes**

Status {open, closed, purged}
Date/Time Performed
Copy of communication if applicable

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

LA, ATL do not contact patients or Informants ever.
Some other registries would only contact patients/informants as a last resort.
HI wants to assign a facility who would then be responsible for follow-up on that patient (I assume they would send a batch to each facility).

## ACTIVE FOLLOW-UP NEED

**Definition**

The need for the registry staff to acquire follow-up (vital status) information for a patient by more aggressive means that waiting for records to enter the registry.

**Examples**

**Attributes**

Active follow-up need id
Time/Date stamp
Patient ID
Status {open, closed, purged}
Date closed

**Uses**

A task list for the 7.0 Conduct Active Follow-up tasks.

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

LA: 6000 acted upon, more start in the list
HI; 5200

**Local Variations**

## ACTIVE FOLLOW-UP NEED GROUP

**Definition**

To eliminate M-M cardinality
A random group of needs that are combined for the convenience of the registry staff (6 needs on 1 letter instead of 6 letters, 1 need each)
Are being directed to the same person/facility/organization to get better follow-up

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ACTIVE FOLLOW-UP RESPONSE

**Definition**

A reply (by phone, mail, etc) telling the registry information about each person referenced.
Information ideally includes whether the person is alive or dead as of a particular date. It could also include ‘not my patient, try Dr. xxx’ or ‘We have no knowledge of this patient’.
Comes from an individual or facility. Was specifically requested (Active Follow-up Communications)

**Examples**

**Attributes**

Patient ID (R1)
Date Last Seen (in text of response) (R1)
Vital Status (in text of response) (R1)
Cause of Death (in text of response) (R1)
Follow-Up Response Text (R1)
Date/Time of Response (Received)

**Uses**

**Policies/Business Rules**

Some Registries may track additional information that is outside of "follow-up", for example, additional treatment.
The 3 variable shown as 'in text of response' may not be saved in this entity separate from the text block. They will eventually be stored in the patient set, so they may not need to be here also. This is a design decision.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ADDRESS

**Definition**

A geographic location; a place on the earth

**Examples**

**Attributes**

Side of street
Street Address (name and number)
Apartment number/floor
City
State (Canadian Province)
Postal Code (ZIP)
County (FIPS) *(obsolete COC for Current Address)*
Name of Facility (prison, nursing home, homeless shelter, etc)
Census coding correction? {Y, N} (NJ specific)

**Uses**

**Policies/Business Rules**

Census tract info & latitude/longitude are currently only being tracked for residency at diagnosis.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

NJ: uses a produce from Ascential Software of Boston to obtain CENSUS TRACT data items. (They have a license.) It standardizes ADDRESS information – they would like to store both the address information they originally obtained and the 'corrected' address. Put this on RESIDENCY is established for CTC.

## ADD/CHANGE/DELETE

**Definition**

Could be at the entity level and relationship level as well as the attribute (i.e, data item) level. For example, a new occurrence of CANCER/TUMOR/CASE could be added, or the Vital Status attribute on PATIENT could be updated.

A modification to the information being stored in patient set. Either adding a new occurrence/first value, changing an existing value or deleting an existing occurrence/value entirely.
This would include changes made by people was well as changes made by the computer.

**Examples**

**Attributes**

Old value
New value
Reason
Type of modification (A, C or D – computer provides)
Date/Time stamp (computer provides)

**Uses**

**Policies/Business Rules**

Only authorized Registry staff (who are ORGANIZATION REPRESENTATIONs) are authorized to make updates.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## AUTOPSY REPORT

**Definition**

A specimen analysis, where the specimen is a corpse, created at a coroner's office or pathology lab (where ever autopsy is done). Based on this, the description of the findings in detail and some conclusions. Usually, these are obtained while doing follow-back for a death certificate only case.
It is possible (but very very rare) to obtain an autopsy and not get a corresponding death certificate. This happens when there is misinformation either on the autopsy or the death certificate and the 2 don't match, or they match to the wrong patient and someone needs to be 'resurrected', or when the DC is not filed appropriately. It is assumed that the DC will come in during standard processing, so no specific note is made on a Patient Set that this is an autopsy and a DC is needed.
Can have an Autopsy Only patient set. If you have Autopsy record or if you have autopsy record and death certificate.

**Examples**

**Attributes**

Patient Name
Date
Diagnosis (Text)
Summary of Results (Text)
Autopsy Number
Possibly Medical history of patient (prior diagnoses)
Race (apparent or known)

Age (apparent or known)
Sex
Text – describes what the pathologist saw
Facility Name/ID
Doctor/pathologist/coroner who performed autopsy

May be others as listed under HEALTH RECORD

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## AUXILIARY HISTORY *logical only*

**Definition**

The audit trail for tracking which org rep made what change on what date and why to any of the following: facility, medical practitioner, medical practitioner facility affiliation, organization, organization representative, payer source, person, rule.
**DESIGN NOTE:** version 2 or later
**DESIGN NOTE:** is very important to track password history in ORG REP so registry can prevent reuse of passwords.

**Examples**

**Attributes**

Date of change
Old Value
New Value
Reason (text field, why was this made)

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

HI, IA, NM, LA, AT are interested in this.

## CANCER/TUMOR/CASE

**Definition**

Aka CTC
An instance of the disease of interest. Generally speaking, a Cancer/Tumor/Case is a neoplasm with topology, histology, and behavior codes within the SEER (local or special study) guidelines. This entity stores information for a particular CANCER/TUMOR/CASE that is not stored in the Diagnosis or treatment/procedure entities. The facility/org view just has data from the given facility/org. The registry view has consolidation/summary information over all facility/org views (as well as other information received which does not have a distinct view of its own)

**DESIGN NOTE:** a complete cancer/tumor/case set would be complete for all uses. To check for completeness, would check outstanding follow-back and critical values. Registry may chose to override a failure of these rules if they believe they are not going to get better information. (path only, dc only.)
**Naming Issue:** While this disease is usually a cancer and a tumor, some site, histology and behavior combinations are not truly tumors and others are arguably not cancer. Also, the SEER registries' names include 'Tumor Registry' and 'Cancer Registry'. Case is sometimes used interchangeably with "tumor" or "cancer" but case can also be used to refer to a person in our database. In the documentation, we sometimes use 'Tumor' instead of Cancer/Tumor/Case, usually within a standard data item name. We also use Cancer/Tumor to refer to an instance of a disease that has not yet become a case in our database.
The SMEs from 6/29/00 preferred Tumor as their term, but there are pros and cons for all 3 terms embedded in this name:

- The term Tumor is familiar to the SMEs, but some of them are now Cancer Registries, not Tumor Registries.
- The term Cancer can mean anything (a downside for it).
- The term Case is easily confused with patient set.

**Examples**

**Attributes**

SEER; COC current; *COC historic*; ***COC historic & NPCR***; **NPCR only**
(COC data items typically come from COC approved hospital-created abstracts or not at all. They are not edited or consolidated, but may be used during consolidation.)

**Personal Information at time of Diagnosis:**
Marital Status (at diagnosis)
Age (at diagnosis)

Employer – Name text (local variation on which registries collects employer info)
Employer – Address text (or should this be replaced with employer address?)
Employer – Phone Number text
***Usual/Most relevant Industry – text***, usual industry, longest held
***Usual/Most relevant Occupation – text*** usual occupation, longest held
**Usual/Most relevant Industry (census coding scheme)**
**Usual/Most relevant Industry source**
**Usual/Most relevant Occupation (census coding scheme)**
**Usual/Most relevant Occupation source**
**Occupation/industry coding system**

*Tobacco history*
*Alcohol history*
*Family history (of this cancer: from CT registry)*

**Disease Information:**
Primary Site (R1)
Site coding scheme (R1) {ICD-O-1, ICD-O-2, ICD-8, ICD-9, ICD-10…}
Site source (R1) {original, converted from 1, converted from 2…}
Site conversion reviewed (R1) {Y, N}

Morphology - Histology (R2)
Morphology - Behavior (R2)
Morphology – Grade (R2)
Morphology coding scheme (R2) {ICD-O-1, ICD-O-2, ICD-O-3}
Morphology source (R2) {original, converted from 1, from 2, from 3}
Morphology conversion reviewed (R2) {Y, N}

ICD-O-2 Conversion Flag (D – Morph source & reviewed) {No, converted, converted w/ review}
ICD-O-3 conversion flag (D– Morph source & reviewed)) {No, converted, converted w/ review}

Laterality (at diagnosis)
Class of case (N10-610, Dx, Tx, DxTx)

Coding System for EOD {2NS, 2SS, 13, 4, 10, CS} (currently, each CTC is only coded in 1 system)
CS - Tumor Size
CS – Extension
CS – Tumor Size/Ext Eval
CS – Lymph node Involvement
CS – Regional Lymph Nodes Eval
CS – Mets at Dx
CS – Mets Eval
CS – Site Specific Factor (R9 – currently up to 6)
EOD 10- Tumor Size
EOD 10 - Extension
EOD 10 – Lymph node Involvement
EOD 10 – Regional Lymph Nodes Examined
EOD 10 – Regional Lymph Nodes Positive
EOD 10 – Extension prostate path
EOD 4 digit
EOD 13 digit
EOD 2 digit

Local/reg/dist stage (Historic Stage A) (D from EOD or CS stage)
SEER Summary Stage 2000 (Also required by **NPCR**)
Summary Stage 2000 Derived? {Y, N} (Either assigned directed or D from EOD or CS elements.
SEER Summary Stage 1977
Summary Stage 1977 Derived? {Y, N} (Either assigned directed or D from EOD or CS elements.

TNM Source {path, clinical, *other*, Derived EOD, Derived CS} (R5)
TNM AJCC edition number {3rd, 6th, …} (R5)
TNM T value (Tumor) (R5)
TNM N value (Node) (R5)
TNM M value (Metastases) (R5)
TNM AJCC Stage group (R5)
TNM Modified AJCC Stage Group (R5)
TNM staged by (R5)
(if Source = Clin or Path, can fill in the following 3)
TNM T -Descriptor {Clinical, Path, Autopsy, after Treatment} (R5)
TNM N - Descriptor {Clinical, Path, Autopsy, after Treatment} (R5)
TNM M - Descriptor {Clinical, Path, Autopsy, after Treatment} (R5)

TNM descriptor (N10-980 for example) (R5)

Text Staging
Type of Reporting Source
Recurrence Date 1st
Recurrence Type 1st

Site of Distant Meta (R6 – currently up to 3)
Pain Assessment (N10-3260)
Cancer status
*Other Staging system*
*Protocol Eligibility Status*
*Protocol Participation*
*Presentation at Tumor Board Conference*
*Date of first Tumor Board Conference*
*Year first seen this cancer* (specific to the facility view)
*Pediatric Stage*
*Pediatric Stage system*
*Pediatric Staged by*
*Recurrence Dist site* (R7 – currently up to 3)
*Recurrence Type 1st other*
*Screening Date* (N10-510)
*Screening Result*
*Inpatient/Outpatient Status*

**Treatment Summary Information:**
Date of initial Treatment (D – First date of Course + refused, not recommended type dates)
Treatment Summary Surg/Rad sequence (D)
Treatment Summary Radiation (D: Radiation + Considered Tx/Type of Proc)
Treatment Summary Radiation to CNS (D: Radiation + Considered Tx/Type of Proc)
Treatment Summary Chemo (D: Chemo + Considered Tx/Type of Proc)
Treatment Summary Hormone (D: Horm + Considered Tx/Type of Proc)
Treatment Summary Immuno (BRM) (D: Immuno + Considered Tx/Type of Proc)
Treatment Summary Other Tx (BRM) (D: Other Tx + Considered Tx/Type of Proc)
Treatment Summary Transplant/Endocrine (N10-3250) (D: Transplant/Endocrine + Considered Tx/Type of Proc)

Treatment Summary Regional LN examined
Treatment Summary Surg Primary site
Treatment Summary Scope Regional LN Surgery
Treatment Summary Surg Other Regional/Distant sites
Treatment Summary Reconstruction
Treatment Summary Surg Type

Treatment Summary Surg margins
Treatment Summary DX/Stg/*Pall* proc
Treatment Date Dx/Stg/*Pall* proc
Treatment Summary Palliative Proc
Treatment Date Palliative proc
*Treatment Summary Surg approach*

*Treatment Summary Screen/Bx Procedure* (R8 – currently up to 4)
*Date of 1st positive biopsy* (D)
*Referral to Support Services* {Y, N, Uk}
**Rx Coding System – Current**

**General:**
Text Remarks
Abstracted By (Facility View only) (D: CTC matches to Health Record, type=Abstract; Record created by …)

COC coding system current (Facility View only)
COC coding system original (Facility View only)
Site coding system current (D)
Site coding system original (D)
Morph coding system current (D)
Morph coding system original (D)

**Tracking:**
CTC View Status: {In progress, pending Follow-back, submissible, non-reportable, duplicate}
CTC Info Status: {In progress, pending Follow-back, submissible, non-reportable, duplicate}
(verify against event models. Non-reportable means that this CTC is not reportable to any agency. Non-reportable should be derivable value.)
SEER Non-reportable Reason (Text)
Local Non-reportable Reason (Text)
**Date Case received**
Archived FIN (N10-3100 – who originally sent it in)
**Date Created**
Creator ID (org rep)
**Date Case complete**

**Uses**

**Policies/Business Rules**

Date case received: on facility view, date abstract/health record received or date abstract lead created. On registry view, the earliest date from the facility views. This is just a possible implementation to meet the need of knowing when a particular CTC was discovered by facility.
STAGE: we are interested in stage through first course of treatment surgery. (if they have a Radical Prostatectomy, want stage at time of Radical Prostatectomy, even if diagnosed by TURP 6 mths prior)
Tumor size: if radiation preceded surgery (measurement of size), tumor size is considered not valid because the radiation probably shrank the cancer/tumor. (should be covered by one of the rules)
**DESIGN NOTE**: It would be nice to be able to tell which CTCs had met the bare essential requirements for a given reporting entity (SEER vs NAACCR vs State registry…). This may be done as a flag, but depending on the requirements, it might be determined on the fly. (registry view)

**Sensitivity**

**Estimated Number of Occurrences**

LA: 900,000 in DB; add 42,000 per year
HI: probably around 150,000 in DB (based on patient estimate), add about 5,500 per year

ST: 21,000 per year
NJ: 45,000 per year; about 1.2 million currently. About 400-600 new cases per month.

**Local Variations**

## CENSUS TRACT

**Definition**

The census bureau's view of a geographic location
**DESIGN NOTE:** This table may have to be modified for each registry. See note in Local Procedure re UT.

**Examples**

**Attributes**

Census Tract
Census Tract Coding System {1970, 1980, 1990, 2000}
Census Tract Certainty Code
Census Tract block group

Latitude (not year specific)
Longitude (not year specific)

**Uses**

**Policies/Business Rules**

Census tract info & latitude/longitude are currently only being tracked for residency at diagnosis.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

NJ: uses a produce from Ascential Software of Boston. They have a license. It standardizes ADDRESS information and includes the rest of the information in census tract.
UT: Larry Derrick (who deals with multiple state registries) says he customizes census tract importing for each state. They get different files from their census tract coders and are interested in retaining different subsets of information about it.

## CENSUS TRACT RECORD

**Definition**

The US Census Bureau code for the demographically consistent geographic area where the patient resides
This specifically is the record coming to the registry with an address and the corresponding census tract code.

**Examples**

**Attributes**

Registry Patient ID (sent out by registry to ease integration of census information)
Street address (number, name)
Street side
City
State (Canadian Province)
Postal Code (ZIP)
Census Tract
Census Tract Coding System {1970, 1980, 1990, etc}

Census Tract Certainty Code
Census Tract block group
Latitude
Longitude
Census Year

NJ specific record (See Toshi Abe email 2/26/03):
(From input record: addr at Dx is being tracted, current addr is check)

| | |
|---|---|
| RECPOS | (Unique NJSCR index number) |
| CTRNUM | (Patient ID number) |
| SEQNUM | (NJSCR cancer sequence number) |
| DXADDR1 | (Street address at time of diagnosis) |
| DXADDR2 | (Supplemental street address info) |
| DXCITY | (City of residence at time of diagnosis) |
| DXSTATE | (State of residence at time of diagnosis) |
| DXZIP9 | (ZIP postal code at time of diagnosis) |
| DXCNTY | (FIPS County code at time of diagnosis) |
| ADDR1 | (Current street address) |
| ADDR2 | (Supplemental street address info) |
| CITY | (Current city of residence) |
| STATE | (Current state of residence) |
| ZIP9 | (Current postal ZIP code) |
| CNTY | (Current County of residence) |

(Output record only)

| | |
|---|---|
| LOWADD1 | (Low address of range 1) |
| HIADD1 | (High address of range 1) |
| LOWADD2 | (Low address of range 2) |
| HIADD2 | (High address of range 2) |
| STDSTR | (Geolocator street address at diagnosis) |
| STDCITY | (Geolocator city at diagnosis) |
| STDCNTY | (Geolocator county at diagnosis) |
| STDSTAT | (Geolocator state at diagnosis) |
| STDZIP5 | (Geolocator ZIP-5 at diagnosis) |
| STDLCTY | (Geolocator LEFT county code at diagnosis) |
| STDRCTY | (Geolocator RIGHT county code at diagnosis) |
| GLTRACT | (Geolocator LEFT tract at diagnosis) |
| GRTRACT | (Geolocator RIGHT tract at diagnosis) |
| GEOLBLK | (Geolocator LEFT block at diagnosis) |
| GEORBLK | (Geolocator RIGHT block at diagnosis) |
| GLOLONG | (Geolocator longitude (Low value if Vicinity Record)) |
| GLOLAT | (Geolocator latitude (Low value if Vicinity Record)) |
| GHILONG | (Blank or Geolocator High Vicinity Record longitude) |
| GHILAT | (Blank or Geolocator High Vicinity Record latitude) |
| GMATCD | (Geolocator match type code) |
| GMATWT | (Geolocator match weight) |

**Uses**

Only important for Residence at diagnosis

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

NJ: uses a produce from Ascential Software of Boston. They have a license. It standardizes ADDRESS information and includes the rest of the information in census tract.
UT: Larry Derrick (who deals with multiple state registries) says he customizes census tract importing for each state. They get different files from their census tract coders and are interested in retaining different subsets of information about it.

## CHEMOTHERAPY

**Definition**

Treatment type: use of chemical(s)/drugs to treat Cancer/tumor. Usually performed in many sessions. Many different kinds of chemicals may be used (separately or in combination), there are many different distribution methods.

**Examples**

**Attributes**

Chemo {single agent, multi agent, Unknown number of agents}
*Agent Name* (R1 – currently up to 5)

**Uses**

**Policies/Business Rules**

Information in Chemo must be examined along with 'refused' attributes to also determine refused, recommended unknown if done. No chemotherapy (not done –there was no chemotheraphy or unknown-indications confusing) is summary information (N10-700, N10-1440 - CTC??)

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## CMS (HCFA) RECORD

**Definition**

Organization is sent a file of interest by the registry. A file is returned with the latest date of contact by that organization.
This should include about 95% of the 65 and older population

**Examples**

**Attributes**

Registry Patient ID
Name
Current address (is this only information registry sends out or could they get better information back?
DOB
SSN
Date (Date may be date coverage started or date of last procedure. Just the last contact CMS has had with the person.)

**Uses**

Used for follow-up, may also obtain better information about current address, full name, dob, etc.

**Policies/Business Rules**

LA: this file is created by CMS, who does a linkage of CMS record to a list provided by LA.

DT said this file was free to the registries because SEER has an agreement with CMS

**Sensitivity**

**Estimated Number of Occurrences**

NJ: send out 200,000 and receive 2000-3000 per year for updates

**Local Variations**

## COLLABORATION AGREEMENT

**Definition**

An agreement between the researcher and the seer registry to allow the use of data with promises not to use it incorrectly

Generally these are needed for special studies or information requests and the registry must track for legal reasons,

Collaboration agreements refer to a single Special Study. If a study has multiple information requests, they would be covered under the same agreement. An information request that was distinct from a special study and needed a collaboration agreement would again be the only thing referenced by the related collaboration agreements.

A single special study or distinct information request may require ---multiple collaboration agreements---;---only 1 collaboration agreement.

**Examples**

**Attributes**

Collaboration Agreement ID
Date proposed Collaboration agreement sent
Collaboration agreement document
Date collaboration agreement received
Signed? {Y, N} (replace unsigned copy with signed)

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## COMORBID CONDITION

**Definition**

A disease that a patient has concurrent with the disease of interest (here, a diagnosis of the cancer/tumor)

Required by COC, currently allowing for 6

**Examples**

Steve has a lung cancer/tumor and emphysema. At time of diagnosis, emphysema is a comorbid condition.

**Attributes**

**Uses**

**Policies/Business Rules**

ACoS: COC requests up to 7 comorbid conditions.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## CONSIDERED TREATMENT MODALITY

**Definition**

This replaced Recommended Treatment Modality. This entity would also capture treatments that were considered and not recommended to the patient because of contra-indications
Recommended=Y treatments are part of the medical practitioner's plan of therapy with which he hopes to control or remove the cancer/tumor. This can include surgery, radiation therapy, chemotherapy, hormone therapy, immunotherapy and other therapies such as new protocols being tested, etc. The order in which the different types of therapies are given is important.
Only tracking TREATMENT types of procedures that are ordered.

**Examples**

**Attributes**

Date Considered
Recommended? {Y, N}
Text
Reason Treatment Modality Not Given? {Contra-indicated; Recommended unknown if given; Recommended Refused (D – if Patient refuses Considered Treatment Modality exists); Unknown if Recommended (D - this is the value if the entity doesn't exist), etc} (for Surg, Rad, *Chemo, Horm*)
Treatment Information status flag

**Uses**

May trigger abstract facility lead or follow-back (discovered something was recommended, but unknown if given)

**Policies/Business Rules**

The only TYPE OF PROCEDURE that are valid are ones where Treatment Procedure = Y.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## CORRECTION RECORD

**Definition**

A record sent by a facility or organization to the SEER registry informing them that a correct has been made at the fac/org to the record of the patient/CTC. Sort of a notification, sort of a please adjust your records accordingly.
WARNING: New NAACCR format for correction records may become a standard. It is the entire record again with a C in the key field to indicate correction.
Should eventually be part of the 'health record corrects health record' relationship.

**Examples**

**Attributes**

Date

Patient ID
CTC ID (if needed)
Data Item Name
Old Value
New Value
Reason (text field)

ALTERNATIVELY:
Date
(all variable as seen on original record type, usually abstract, with some different values)
Correction? (Flag {' ', 'C'})

**Uses**

Process should be able to handle corrections with 1 data item corrected or entire new record with modifications.

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

There is a specified format for correction records in CA.]
NJ: paper, processed by hand. Not all facilities send 'correction' records – only cancer-fax hospitals (about 10% of data from these hospitals). Rest don't send records or send new full record. Former is processed via follow-back.

## COURSE

**Definition**

Standard course of treatment as defined by registries.
The medical practitioner's plan of therapy with which he hopes to control or remove the cancer/tumor. This can include surgery, radiation therapy, chemotherapy, hormone therapy, immunotherapy and other therapies such as new protocols being tested, etc. The order in which the different types of therapies are given is important.
Generally a course of treatment is related to a cancer/tumor/case while it is at a particular stage of progression.

**Examples**

1st course: radiation to shrink cancer/tumor, surgery to remove it
2nd course: after discovering that total cancer/tumor has not been removed or that it has spread, chemotherapy to force the cancer/tumor into submission

**Attributes**

Sequence of course {1, *2, 3, etc*} (2nd course and later are obsolete COC fields)
Calculation method (COC, SEER for 1st course)
First Date of course Treatment

**Uses**

**Policies/Business Rules**

Most registries only track 1st course

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

While AcoS may be dropping this, some registries have historical data.
DT says researchers still want this, so they will continue to collect

## CYTOLOGY REPORT

**Definition**

Report on the results of a test at the cellular level, things discovered while examining cells under the microscope

**Examples**

**Attributes**

Contains some subset of the HEALTH RECORD variables
Also text descriptions of doctor's thoughts

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## DATA EXCHANGE AGREEMENT

**Definition**

This is a formal signed agreement between a SEER Registry and one or more parties to share data (CTCs) or accept incoming data.
Similar to Special study: (should be) checking that a CTC is reportable because of a DEA. The difference is frequently just the residency. However, this is not the only difference (ie benign brain tumor) possible.
HI believes these last 'until otherwise stated'

**Examples**

New Mexico has hospital just over Texas border they have agreement with.
DT, LA, NCCC get residents of their area who were diagnosed elsewhere in the state from the state cancer registry.

**Attributes**

DEA ID
DEA Partner ID (Org ID or Fac ID)
Information (types of records/CTCs) that registry expects to receive
Information (types of records/CTCs) that registry has agreed to send
Format for transfer of data (NAACCR96, XML, etc)
Start date of agreement
(end date of agreement or would you just delete it?)
Schedule for data transfer (monthly 1/1, 2/1, 3/1, …; quarterly 1/1, 4/1, 6/1, …)

**Uses**

**Policies/Business Rules**

Sounds like this may currently be just a filed copy of the agreement without a mechanized effort to track whether data has been sent in.
**DESIGN NOTE:** it may be worth investigating the possibility of tracking special study data transfer the same was as a DEA. We send data to them (by way of information request) for both, and we would like data back (by way of source submission) from both. Not sure how much overlap there is or if it's better to keep the 2 separate.

DT, UT, LA, IA, HI: if patient is discovered only via DEA, they are not contacted for any reason (FUP, follow-back, not included in special studies).

**Sensitivity**

**Estimated Number of Occurrences**

HI: 15-25
LA: 7 CA regions, 2 states
IA: 13 neighboring states
AT: will all neighboring states (5)

**Local Variations**

NCCC: LO stated that this excluded hospitals, but usually with the state (California Registry).
California has agreement with other states to exchange data. LA and NCCC get their out of state exchanged through the CA state cancer registry.
IA exchanges complete data with neighboring states, but an abbreviated set of data variables for CTCs occurring in non-neighboring states.

## DATA ITEM

**Definition**

A piece of information of interest for tracking a CTC (first used on incoming records, then stored in the patient set).

**Examples**

Gender: 1=Male, 2=Female, 3=Transsexual, 9=Invalid

**Attributes**

Name
Acceptable values
Format for registry

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## DATA ITEM GROUP

**Definition**

To eliminate M-M cardinality.
A non-random group of data items that are compared against each other during an edit.

**Examples**

Site-hist-beh
Gender-site
Gender-hist
Dob-hist

**Attributes**

**Uses**

To track in one place what data items failed an edit and potentially need follow-back.

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## DEATH CERTIFICATE/STATE DEATH FILE RECORD

**Definition**

A state issued document containing information about a person who has died.

New patients can be discovered via this. It's the entire population, not just a group selected by the registry.

WARNING: while a full Death Certificate could become a patient set by itself, SMEs feel that some death indexes do not have enough information to do anything but create a lead (to go get the DC)

PROCESS notes:

1. Death list/index is obtained by the registry. It is scanned for passive follow-up (patient match is found) and for new CTCs (passes fine filter for Cancer/Tumor/Case). In NM, if either is true then a death certificate is requested from the state. For all other registries, a death certificate is only obtained in it passed the fine filter for CTC and failed to match at the CTC level.
2. The DC is obtained. If follow-up only (NM), it is merged with patient set, processing is complete. If this is a new CTC, the DC is screened to verify that it really is reportable and is then added as an incomplete patient set (or CTC set if patient exists.) In that case, then do
3. Check DC for physician/facility information. If found, contact source and request abstract. (That is, create an abstract facility lead.) If the source is not an abstract source (possibly a coroner's office) or if the source replies that there isn't any info available to do an abstract (for example, person arrived DOA at hospital and the hospital never treated person for cancer/tumor) , try to get a new physician/facility to contact – patient came from hospital, hospice so on. Contact new source… Follow-back from DCs are never done with next of kin.
4. If there is no source or the trail dead-ends and the registry is unable to obtain additional information, they mark this as a DCO (see glossary).

DCs do not need to be matched on facility or treatment as they do not have this information (Although some registries may want a view for the DC). Also, although most health records which fail the broad screen (Determine Potential CTC) are removed from the data store, DC tape/list/index records are retained in the name of passive follow-up. These are public records.

DCs may only be consolidated into the Registry View at the patient and possibly CTC levels.

There is timing involved. Some registries get pre-finalized records from the health department. They may wish to run passive follow-up first and wait several months prior to doing the screen for CTCs. (Information may arrive from hospitals after death file received, final death record may be modified.) Also, would need to re-run passive follow-up at some point because patient records sometimes arrive at registry after DC info received (for non-cancer COD, this is most important).

It is possible to receive 2 death certificates for the same person. For example in NM, an attending physician fills out a DC and then the State Office of Medical Investigators (OMI) fills out one. The OMI is usually more accurate & invariably has a DC number larger than the physician's. Process would be to keep both DCs, combine manual review of cause of death codes and follow-back with Bureau of Vital Statistics to determine which DC to use. In other words, consolidate the 2 DCs. Would probably want to know which was considered the 'primary'.

If DC has cancer/tumor listed and a patient match is found, but a CTC match is not, follow-back must be done to determine why the difference exists. If no site was previously obtained, was site finally determined? Is the DC site metastatic or a new site?

**DESIGN NOTE:** registries need to know that a PATIENT/CTC started as a DCO case but is now a xxx type case (physician's office, facility, etc). We do track that a PAT/CTC is DCO and we could determine from facility view creation dates whether a DC view was created first. However, if the Facility view is not created for the death certificate, we wouldn't be able to do this. We should have a back-up for this need. This would likely be checking to see if there is a ACD for DCO flag turning it off.

**Examples**

**Attributes**

Name
Address (if known)
Physician/facility
DC number
Cause of death (R1)
Date of death
Time of death
Place of death
Primary DC (default=True)

**Uses**

Used to find CTCs that have been missed (either patient has not been to a medical facility or it slipped through the cracks)

Used for passive follow-up to easily obtain information about those who have died.

**Policies/Business Rules**

This is public information and can be released to the facilities if desired.

**Sensitivity**

NM, DT, IA: access and release of DC information is restricted by agreement with the VSB. (Can't give to non-registry staff, since it costs money to acquire it.) NM can release COD to hospitals who have seen the patient only.

IA: contact of physicians listed on DC may be restricted in future, but hasn't happened as of 10/2002

HI: use of SSN by registry is likely to be restricted on DC.

**Estimated Number of Occurrences**

LA: 1400-1500 : DCO only
HI: 2000 : DCO + FUP

**Local Variations**

LA: gets actually Death Certificate from state cancer registry. Gets master death list from VSB.

## DIAGNOSIS

**Definition**

The detection of a cancer/tumor (frequently based on procedure, specimen evaluation or image evaluation) in a person (thereafter known as a patient)

There may be multiple diagnoses per facility

**DESIGN NOTE:** may not know FACILIITY where diagnosis occurred. Would store 'reported' diagnosis that happened in facility not-A in Facility A's view if A knows about them.

**Examples**

**Attributes**

Date of Dx (Month and Year)
Text Primary Site Name
Text Primary Histology Name
Morphology – Grade ICD-O-1 (also in CTC)
Morphology – Grade ICD-O-2 (also in CTC)
Laterality (at diagnosis) (also in CTC)
Diagnostic Confirmation

**Uses**

**Policies/Business Rules**

If there are multiple diagnoses for a single facility, the abstractor may choose to summarize the diagnostic information and it will appear that only 1 diagnosis occurred there. This is current practice (as it is a time saver) and is not completely under registry control (facility created abstracts). However, multiple DX from a facility are allowed for in the model.

SEER is only interested in the 'first' diagnosis. However, when the diagnosis information is consolidated, there are some data items that aren't strictly the data from the earliest date. Consolidation of registry view will probably imply only 1 diagnosis entity in that view.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## DISEASE INDEX

**Definition**

A listing from a hospital of who was admitted (discharged), a date & the diagnosis code for their admission.

Provided to the registry at the registry request.

WARNING: Registries said they frequently get disease index records which are mis-coded as cancer/tumor. They do not want to make patient sets from these alone.

**Examples**

**Attributes**

Discharge Date
Admission Date
Patient identifier
DX (ICD-9) code (presumably, the ICD version may change with time and facility)

Seattle disease index can include the following:

Name
DOB
SSN
Medical Record Number (within facility)
Race (label)
Birth place (text)
Patient Address
Physician
Physician address
Facility ID
Service Codes
Disease code (R1)

**Uses**

Used to find missed Cancer/tumor/cases during case finding

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

ST: 154,000 per year

**Local Variations**

ST: can use this information to update unknown data item values, but it's a last resort. Otherwise, would not 'consolidate' this information into the Patient set, as it is not the most reliable.

## DMV RECORD

**Definition**

Drivers' registration records
Current file is acquired, not based on match.

**Examples**

**Attributes**

Unique Identifier
Name
Address
DOB
Renewal Date/Examination Date (date of last contact with DMV)
(Probably other info available, probably not of interest to registry)

**Uses**

Used as supplemental file to verify name, address, and vital status.

**Policies/Business Rules**

LA: this file is created by DMV, who does a linkage of DMV record to a list provided by LA.
AT: not currently able to access these records.

**Sensitivity**

IA: believes release of DMV information is restricted by federal law. It is at very least restricted in some states.
NM: decides on release of this data to Special study on case by case basis.
NM: drops DWI information from record as it enters the system.

**Estimated Number of Occurrences**

NJ: 800,000 records per year

**Local Variations**

IA & Seattle: get unique ID on these records

## DOCTOR'S OFFICE

**Definition**

A 'private' practice for a physician or group of physicians where patients are seen

**Example**

**Attributes**

See FACILITY attributes

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## EDIT

**Definition**

The entire record or patient set (not a specific field, all views) was edited, that is, checked for completeness, consistency and correctness.
May be visual edits or computer edits. Edits may be codified or just common sense (site/type is coded, Ewdard should be Edward is common sense) Org Rep ID for computer edits needs to allow for Computer code (SYS or similar)

**Examples**

**Attributes**

Date\time stamp

**Uses**

**Policies/Business Rules**

EDIT may be done by a different person than the org rep who does the HEALTH RECORD UPDATE (because of training or over burdened staff). Registries said they would not usually care to track who edited because it would overburden the system (both computer and staff). They NEED to track who did the update.
Edits on Records would probably only be fixing typos. All other edits would be done on the 'red' side, patient sets.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

Some registries make absolutely no changes to records. All edits occur on patient sets. (IA)

## EDIT ISSUE

**Definition**

A problem, inconsistency or error with a data item or with multiple related data items (sex/site).
Issues are within a single record or patient set, but may be caused by either a single variable (field edit) or by the interaction of several variables (inter-field and inter-CTC edits). After/during consolidation of a patient set, inter-CTC edit (aka inter-record) issues may be revealed either when the value of the same variable for the 2 CTCs is inconsistent or when information in 1 CTC is inconsistent with information in another.

**Examples**

Field (mostly prevents typos): Gender=X
Inter Field: Gender=F, Site=Prostate
Inter Record: CTC1 Site=Breast, Laterality=Left, Treatment=Radical Mastectomy. CTC2 Site=Breast, Laterality=Left.
Warning: Site=Childhood leukemia, Age at Dx=60

**Attributes**

Edit issue (description of problem or name of edit failed)
Date discovered
Date resolved
Facility Error? {Y, N}
Status (Resolved Org Rep; Resolved Follow-back; Pending follow-back, Open, Related data set deleted)
Resolution

**Uses**

**Policies/Business Rules**

A single data item on a specific record could have multiple issues.
If editing is inter-field or inter-CTC, a single EDIT ISSUE would involve multiple DATA ITEMS.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ENDOCRINE & TRANSPLANT SURGERY

**Definition**

This is a new category of treatment. Specifically, it is the combination of the endocrine surgery components removed from hormonal therapy and the transplant surgery removed from the BRM other treatment group.

**Examples**

**Attributes**

Type (Endocrine, Transplant, etc)

**Uses**

**Policies/Business Rules**

There probably aren't hospital data items associated with this, just registry items.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ETHNICITY

**Definition**

Aka the Surname file.
A list where each entry is an instance; the ethnicity assigned to a given surname and the likelihood that the assigned ethnicity is correct.

**Examples**

Sanchez Hispanic 85%

**Attributes**

Surname
Probable ethnicity
Certainty score

**Uses**

Used to generate computer assigned ethnicity.

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## EXTERNAL NEED HISTORY *logical only*

**Definition**

The audit trail for tracking which org rep made what change on what date and why to any of the following: data exchange agreement, information request problem, special study.

**DESIGN NOTE:** version 2 or later

**Examples**

**Attributes**

Date of change
Old Value
New Value
Reason (text field, why was this made)

Special Study:
Modification Desired
Date Modification Requested
SS Staff Requesting (would probably be stored in Reason)

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

HI and IA are interested in this.
NM might be interested in this.

## EXTRACT

**Definition**

a file which is sent out to requester. May be identified or de-identified. Amount of protection needed is controlled in Determine if Valid Request process.
File specifications should be in information request.
A recurring information request that requires an extract would have a new extract file created each time the request is due. This is because this is a dynamic database.
Store pertinent info about file
File
Documentation (# records, file layout, lrecl, name/directory)
Programs to create file

Access info: log authorized people/accounts/passwords.

**Examples**

**Attributes**

See Report/Extract
Documentation (# records, file layout, lrecl, directory/name: Need these for extract)

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## FACILITY

**Definition**

This is a specific address where healthcare services are provided. Location subtypes include Hospital Cancer Registry, Other Providers and Hospital Record Dept (although some may be external to the facility). They may also be a Data User Location

**Examples**

Hospital
Hospice
Nursing homes
Path Lab
Treatment center
Radiation therapy Units (free-standing)
Doctor's office
Clinic
Medical examiner's office

**Attributes**

Type of Facility {Lab, Hospital, Treatment Center, Doctor's Office, …}
Facility Name
Mileage from Registry
Cost to visit
Season to visit? (Spring/summer/fall, year round)
FAX Number
E-mail Address
Web Address
Case Finding Department (R2) (could be person or facility/department within facility)
Case Finding Contact (R2)
Case Finding Type (R2) (what type of records are expected)
Case Finding Source Location (R2) (could be location of lab, e.g. basement)
Facility ID
*Facility FAN*
Do not Contact flag (R3) {Y, N}
Disallowed contact type {FUP, FB, SS, Race, } (R3)

Bed size (For hospital, hospice, Nursing home)

Policy (R1) (Facility policies that affect how registry staff completes work)

**Uses**

This is basically a rolodex of information about the facilities a registry deals with.

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

LA: 120 + Dr offices
HI: 20-50

**Local Variations**

## FACILITY GROUP

**Definition**

A group of facilities which participated in a treatment (a series of events which are collected as a single clump of data, such as radiation, chemo, hormone therapy, etc).

**Examples**

**Attributes**

**Uses**

Used to normalize the BOM.

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## FOLLOW-BACK NEED

**Definition**

Registry identification of one problem that could be related to multiple data items.
Problem could also be from 2 data packs (patient set/patient set, patient set/record or record/record) This would occur during matching if the match could not be determined because of the discrepancy in values.
In some cases, once follow-back has been initiated, the record can not be processed further until the follow-back response has been received. May wish to indicate urgency or disposition of response in these cases.
In other cases, processing of the record can continue and the follow-back response applied when received. In these cases, the follow-back response needs to be applied to patient as well as record.
Would be nice implementation to show follow-back tag on record/patient set when it is being edited for those Follow-back needs still unresolved. ('follow-back unresolved' with variables in question highlighted?)
Following back on information in patient set or on a record. Could follow back on any data items. (**NOTE**: patient set would include Patient, Identification, Residency, Cancer/Tumor/Case, Diagnosis, Prescribed Treatment Modality, Refusal, Procedure)
Identified by registry staff or system, a trigger that a given variable(s) are either missing (critical variables) or have conflicting values. May be caused by an edit issue, matching or just general edit (viewing) of data.

**Examples**

Conflict with DOB and diagnosis date (before DOB) for Jimmy Jones. 1 problem, 2 variables.
During match, SSN and address match, but not sure if it's John Smith or Joan Smith and so not sure if it's one person or two. Would have to follow back with the facility/org that told you John Smith and and one who told you Joan Smith. 2 data packs.
Refusal date could be in conflict with prescribed treatment modality for Sally Smith.

**Attributes**

Time/Date stamp
Data value in question (R1, D)
Description of problem
Original Source of information (R2)
Instructions (could include things like who to contact, how to contact them, who gets the answer to the follow-back, etc.)
Status {Open, Pending, Resolved}
Date closed

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## FOLLOW-BACK NEED GROUP

**Definition**

To eliminate M-M cardinality
A random group of needs that are combined for the convenience of the registry staff (6 needs on 1 letter instead of 6 letters, 1 need each)
May not be related to the same patient but are being directed to the same person/facility/organization to get an answer.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## FOLLOW-BACK QUERY

**Definition**

A question from the registry to a specific physician, hospital, etc, about a specific patient in order to clarify or obtain reportable data items.
A single query is to a single recipient, but may potentially have multiple questions to the same recipient about one or more records or patient

sets, and may be about multiple variables within a single data pack (record or patient set).
**DESIGN NOTE:** Would like to use bar codes on outbound communications that expect responses to facilitate tracking.

**Examples**

**Attributes**

Follow back query ID
Status {open, closed, purged}
Facility Patient ID (R1)
Facility CTC ID (R1)
Data item(s) in question for facility (R2 within R1)
Data value(s) received from facility (R2 within R1)
Description of Problem to facility
Date/Time Sent
Method of query (letter, phone call, etc)

**Uses**

To fill in missing information or clarify confusing/inconsistent information.

**Policies/Business Rules**

If five entities are to be queried, there are five queries. This is so the sent dates and resolution dates can be tracked separately for each.
One query has to be about one patient or one record, but it could be about multiple needs within the patient set or record.
Most registries do NOT contact patients or informants for follow-back ever. Others would only do so in extreme circumstances (IA, HI).

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## FOLLOW-BACK RESPONSE

**Definition**

This is the response/answer to a FOLLOW-BACK (COMMUNICATION). A single response may address 0 to many follow-back needs. (response may be 'Received your letter, I don't know the answers to your questions.')

**Examples**

**Attributes**

Patient ID (R1)
Response Text (free-form text that could include codes) (R1)
Date Received

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## FOLLOW-UP ABSTRACT

**Definition**

A FOLLOW-UP Abstract is a subset of a regular abstract (see text in ABSTRACT). The follow-up abstract is to collect additional first-course treatment information OR for combined facilities that will do a complete abstract for a patient from one of their facilities and follow-up abstracts from the other facilities the patient is seen at.
PROCESS NOTES:

If these don't match on CTC, want to create an abstract facility lead. If these don't match on facility, it will depend on the registry/facility what they want to do. If the FUP abstract just contains additional treatment info, they need to create an abstract facility lead. (If the facility in question does not normal submit FUP abstracts to other facilities, definitely create the lead) If the FUP abstract is for the 2nd use (multiple facilities w/in an org), then only create a lead if no other facilities in the org have submitted a regular abstract.

**Examples**

**Attributes**

Contains some subset of the HEALTH RECORD variables

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## FOLLOW-UP RECORD

**Definition**

From California registries: a record received from hospitals which do follow-up for their internal cancer registrar. Contains follow-up information. Sometimes also contains updated information about the patient. (This could really be split into follow-up record and correction record, but registries have no control over what facilities send them.) SMEs said that any information may potentially come in on this record (Really a follow-up record and correction record combined, but that's what they have to deal with)
Could be sent automatically (as created by hospital) or in response to active follow-up request to the hospital.
PROCESS NOTES:

Similar to Correction records in process terms. If the registry receives a follow-up record, they were supposed to get an abstract for the same person from the same facility.

1. Follow-up record is received in 13.0, the file is verified as readable, the records are verified as acceptabled, codes are converted as necessary/possible, the record is checked for duplication within the system. Acceptable records are given an ID and stored.
2. Follow-up record information goes directly to 15.0 Matching since there is not usually information to screen. Search for Patient match. If none is found, the information is saved as an unmatched follow-up record and an abstract facility lead is created.

3. If a patient match is found and there is CTC information on the follow-up record (recurrence or treatment or so on), Search for CTC match. If a CTC match is not found, create an abstract facility lead.
4. If a patient match and a CTC match are found and there is treatment information on the follow-up record, Search for Treatment match. Proceed with Search for Facility match (step 5), add treatment information to the patient set. (May be new treatment, so not a big deal if no match is found.)
5. If a patient match is found, Search for Facility match. If none is found, the information is saved as an unmatched follow-up record, an abstract facility lead is created, consolidation of the follow-up information and the registry view patient information may occur at this point.
6. If a facility match is found, consolidate the facility view, then consolidate the registry view. Unless otherwise determined in step 3, no abstract facility lead should be created.
7. Existing Unmatched follow-up record information is pulled into the matching process when new records arrive so that they may be matched as soon as possible. If they do not match to any of the new records, they remain as unmatched records. If a match is found, it would be nice to remove the abstract facility lead that goes with the follow-up record – probably a maintenance process.

**Examples**

**Attributes**

Contains some subset of the HEALTH RECORD variables
Date of last contact
Type of follow-up
Vital status
Source of follow-up (admission, phone call, so on)
(Recurrence: ignored by registry)
Facility id
Accession number (facility's patient id)
Other id keys (patient name, SSN, DOB, address)
Informant name
Informant address
New follow-up physician name
New patient address information

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

IA can generate these records in-house as well. This allows better data management. (if a mistake has been made, it's easier to remove information found on a 'record' than information just hand entered. It's also easier to then tie the information to the correct record.)
NJ: gets these on paper, think about 40,000 per year.

## FORMAT

**Definition**

This includes the record layouts and the individual field layouts. Both parts are needed. Would include any record format contained in the file (there may be multiple)
Could include a column specified record format or a XML record transmission, etc.
Would need to specify the acceptable values for each field and what each value means (though it could be ICD-O-3 histologies, the values and means of which are found elsewhere.)
**NOTE**: A given source communication may have more than one record type in the file. The most common combinations are Abstracts, Corrections, and Follow-up records. Also possible to get all Abstracts but mixed NAACCR versions. Some abstracting tools create all 3 of these records and can therefore create a file with all 3 record types included.

**Examples**

NAACCR (version is included in record, format includes layout and field formats)
NAACCR abstracts + NAACCR corrections
PC-Dash
HL7
HCFA

**Attributes**

File type (column delimited, XML doc, etc)
Record layout (R1) (which fields are included and where they can be found)
Field Format (R1b) (for each field, the name of a standard format or a list of acceptable values and their meanings.)

**Uses**

**Policies/Business Rules**

Most registries currently expect that a single file has a single record type.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## HEALTH RECORD

**Definition**

A set of information (generally some form of electronic file) that contains medical information (may include vital status)
Some of the 'records' the registries are getting are text or pdf files that they have to parse into useful data fields. While we may be able to define the types of records by variables expected, it would be nearly impossible to define all the formats these arrive in.
Not all health records have enough information to become patient sets.
A burst of data (record, document) would be a single occurrence of health record regardless of the number of times it arrived at the registry.
If an exact duplicate is found, a new 'includes' relationship is added (source sub or FB response…), not another health record.
**DESIGN NOTE:** for non-abstract 'become patient set' record types, if there is a way to assign a temporary ID to a patient set that was formed, it may need to be a design consideration. Concern is that a partial patient set of this type might not match to an existing patient set. When the abstract comes in, the data would obviously match to the partial

patient set, but the match to the existing patient set could then be found because information was more complete. Arguing against this, at submission time, if this is still a partial patient set, the registry would want to make it a 'real' ID and submit it.
**DESIGN NOTE:** need to allow the registry to configure which types of health records they want to consolidate when first received at the registry. For example, Seattle does not consolidation Path reports (autopsy, cytology, hematology, oncology would probably be similar), disease index, or Radiotherapy reports.

**Examples**

BECOME PATIENT SETS:
Abstract
Autopsy Report
Cytology Report
Death Certificate/State Death file record (IA has enough information on short death record to build patient set, other registries must get full DC)
Follow-up Abstract
Hematology Report
Indian Health Services Record
Oncology Report
Path Report
Radiology Report
Radiotherapy Report
Special Study record (must have match)

BECOME LEADS:
Correction Record
Disease Index
Follow-up Record
Hospital Discharge File
National Death Index
Surgery Log

Obituary (follow-up only)
Passive FUP (registry created stripped down version of a health record)

**Attributes**

TRACKING:
Health Record ID
Received multiple times (Either Y/N or Count of times received)
Patient ID
CTC ID (if needed)
Hospital Medical Record Number
Military Medical Record Suffix
Hospital Assigned Accession Number
Correction record? {Y, N}
Special Study ID (for special study records only)
Document ID
Reporting source
Pathology Number
Autopsy Number
Death Certificate Number
Name of Paper for Obituary
Date of Paper for Obituary
Page Obituary is on
Potentially Reportable to SEER and/or Local? {Y, N} (Gross filter)

Potentially Reportable for Special Study(s)? {Y, N} (R1 Gross filter)
Possibly Reportable to SEER and/or Local {Y, N} (Fine filter)
SEER Non-reportable Reason (Text)
Local Non-reportable Reason (Text)
Status (see Event Model – need to add status "pending case finding")
Follow-back pending? {Y, N}

PATIENT SET:
Patient Name (full: first, middle, last, maiden, salutation, suffixes (Jr, Sr, MD, DDS))
Soundex of last name
AKA type {First, Last} (R1)
AKA name (R1)
SSN
Current Address/residency (number, street, city, county, state/province, postal code)
Telephone number
Gender
Birth date (month, day year)
Place of Birth (city, state/province, country - geocoding)
Race/Ethnic group (R2)
Spanish origin
Quantum (fraction native American - ½, ¼, 1/8, etc)
Amer Indian Community
Nearest relative/friend (relationship, full name, address, telephone. For follow-up)

Family Physician (name, address, telephone)
Referral Physician (name, address, telephone)
Hospital Staff Physician (name, department, telephone)
Doctor/pathologist/coroner who performed analysis
Primary surgeon
Following physician

Facility referred from
Facility referred to

Age at contact (at Dx is most important contact)
Marital status at diagnosis
Address/residency at Diagnosis (number, street, city, county, state/province, postal code)
Primary payer at diagnosis
Employer (name, address, department, supervisor, telephone)
Occupational history (major, secondary)
Social history (use of/contact with carcinogenic agents: smoking, drugs, drinking, birth control pills)
Previous Dx (name of referring physician, name of facility, date, site, type) (R3)
Previous Treatment (y/n, planned date, type (R4), planned (R4))
Other previous neoplasms (y/n, count?)
Possibly Medical history of patient (prior diagnoses)
Admission date (month, day, year of first admission/outpatient treatment
Diagnosis date (month, day, year: FIRST dx by recognized medical practitioner may be clinical. Even when histologically confirmed, still the date of first clinical dx)

Discharge date (month, day, year discharge date for first hospital admission. Blank for outpatient only cases)
ICD-O primary site
ICD-O histology
ICD-O behavior
ICD-O version used
Laterality
Grade
Type of EOD coded {13 digit, 2 digit, 4 digit, 10 digit}
EOD
Summary stage (registry)
Class of case
Diagnostic confirmation?
Comorid conditions (R5 – other conditions at diagnosis, text field)
ICD diagnosis code (R5)
ICD Version used (R5)
Surgery code (R6)
Marker Name (R7)
Marker level (R7)

Pre-op diagnosis
Microscopic exam
Date sample taken
Date sample analysis performed
Procedure done to obtain sample (code)
Diagnosis (Text)
Summary of Results (Text)
Text – describes what the pathologist saw
Summary of Specimen (Text), including procedure

Treatment type {Radiation, chemo, hormone, immuno, other} (R8)
Treatment planned (R8)
Reason no Treatment (R8)
Date of Treatment (R8)
Treatment Sub-type (R8 – treatment specific: surgery {bcs, mrm, rad prost,…}, radiation {beam, seed, etc}, etc)
Radiation to Surgery sequence {R < S, S < R, R=S, Unknown}
Surgery to Lymph nodes?
Number lymph nodes examined
Reconstructive surgery

Vital Status
Date of last contact
Cause of death (R9)
Date of death
Time of death
Place of death (geocoding)
Primary DC (default=True)

Date of last service (IHS)

Data item value (R10 – special study record)
How information obtained {interview, from physician, etc.} (R10– Special study record, text?)

**Uses**

**Policies/Business Rules**

If a health record fails the broad screen (isn't even remotely of interest to the registry) it must be deleted. Prior to deletion, it may be used for passive follow-up. If it is of interest for follow-up, would only retain person id, date of contact and source. All other information is HIPAA protected.

Death Certificates are the sole exception to this rule, since they are a matter of public record.

For each record, the 'original' black part has recodes/conversions which are not subject to change and are exact (one to one value change, no human intervention, not subject to modified interpretations) as well as original values that did not need to be modified. This recoding is almost immediate. The 'converted' blue part contains data items which repeat due to the need for multiple coding schemes with human intervention (i.e. site, hist, beh, grade, treatment, eod).

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

NJ: 70,000-80,000 electronic (not including path rpts on paper, correction, follow-up or special study records). Probably 110,000-120,000 records w/out correction or follow-up.

## HEALTH RECORD UPDATE

**Definition**

A change to a single data item in a health record, caused by an edit issue based on rules or by a follow-back response. An implementation might be an 'e-post-it' attached to the record in question.

**DESIGN NOTE:** Normally, this should be separate from the original values obtained, so that history can be preserved. However, if information is incorrectly keyed into the registry system (the data on the stored record is different from the data originally sent), the 'original' value should be corrected to reflect what the facility told you.

This would include changes made by people was well as changes made by the computer.

**Examples**

**Attributes**

Date/Time (when changed)
Old Value
Updated Value (to what)
Reason Code (Categorical: Converted to standards, Converted Up version, Converted Down version, Correcting mistake, applying follow-back, etc)
Facility Counted Error? {Y, N}
Comments/Reason for Update (text: Why changed, i.e. common sense/follow back response #123)

**Uses**

**Policies/Business Rules**

Only authorized Registry staff (as ORGANIZATION REPRESENTATIONS) are authorized to make updates.

Only HEALTH RECORD will get updated – SUPPLEMENTAL RECORD will never get updated.

HEALTH RECORD UPDATE may be done by a different person than the org rep who does the EDIT (because of training or over burdened staff).
Registries NEED to track who did the HEALTH RECORD UPDATE, but would not usually care to track who edited.
Track all changes so that need for intervention or new training can be determined.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## HEMATOLOGY REPORT

**Definition**

Report on the results of a test of the blood, things discovered while examining blood cells under the microscope: blood work

**Examples**

**Attributes**

Contains some subset of the HEALTH RECORD variables
Includes text field for doctor's comments

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## HORMONE THERAPY

**Definition**

Treatment type: use of hormone(s) to treat Cancer/tumor/case. Usually performed in many sessions. Many different kinds of hormones may be used (separately or in combination), there are many different distribution methods.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules**

Information in type of hormone must be examined along with 'refused' attributes to also determine refused, recommended unknown if done. No hormone therapy (not done –there was no hormone therapy or unknown-indications confusing) is summary information (N10-710, N110-1450 - CTC??)

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## HOSPITAL

**Definition**

A type of facility, generally can provide care for multiple patients where patients frequently spend the night (inpatient admissions), although outpatient care occurs here too.

**Examples**

**Attributes**

See FACILITY attributes (the 3 above may be hospital only)
Reporting/non-reporting
Tumor Registrar? {Y, N}
Submission schedule (1/1, 3/1, 5/1, etc)
Teaching hospital {Y, N}
approval status
Reference date (if Cancer registry hospital, the diagnosis date after which a facility follows-up with their patients. Patients diagnosed prior to that date are not followed by the hospital.)

**Uses**

**Policies/Business Rules**

In California, Hospitals must report occurrences of cancer to the registry by law.
DT: contract hospitals are those that Detroit is running the hospital registry for. They have to collect COC vars for these hospitals. (DT would need a local flag 'Contract? {Y, N}'
NM: law states all cancers must be reported. They have to negotiate separately for non-cancer diseases they wish to collect.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## HOSPITAL DISCHARGE RECORD

**Definition**

Obtained through state health department. No personal identifier, but more information about morbidity and insurance.

**Examples**

**Attributes**

Date of discharge
Patient ID (Name, SSN,…)
Possibly others, SMALL subset of health record attributes

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## IDENTIFICATION

**Definition**

This is view specific.

A facility/organization/SEER registry's method of distinguishing one patient from another and different CTCs within a patient
Would include Death Certificate number
Could also include DMV identification number, etc.
**DESIGN NOTE**: registries are very worried about unexpected gaps or duplication of the registry patient ID (CTR #, Region #, CR #, etc). HI, IA don't care how it's assigned as long as these problems can be found. There is no embedded information other than the last digit is a check digit.

CTC record number (D: i.e. part 1 of 4; static – assigned as CTC is discovered) - computer generated number for transferring data to others. Does not imply order of CTC.

Types include
- CTC: Sequence number, record number
- Patient: facility medical record number, accession number (facility), Registry ID, organization identifying number, Military record number suffix

**Examples**

**Attributes**

ID Number
Type (Person ID, Accession #, Medical Record #, CTC Sequence #, CTC record #, Military suffix)

**Uses**

Needed to follow-up or follow-back with a source.

**Policies/Business Rules**

May have the same number across facilities/organizations meaning different things, must known whose identification it is to get a unique number.
American College of Surgeons assigns the rules for the hospital accession number
Only refers to this View's ID
Registry ID may also be called CTR Number, rather than accession.
These numbers may be 'deleted' (if dups are found and so on); they are never reused.
DT: Accession number is the year of diagnosis + the sequence of CTC for the year, tied to facility. So 19980120 would be the 120$^{th}$ CTC discovered at that facility in the diagnosis year 1998. It's assigned by the facility.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ID PROBLEMS

**Definition**

Problematic IDs for a specific facility or organization that the registry has discovered.
They need to track these so they don't was future time trying to resolve them.

**Examples**

Fac A accession # 123 was skipped because it was discovered to be non-reportable prior to submission to the registry

**Attributes**

ID (the actual string)
Facility ID or Org ID (that it's tied to)
Type {accession, medical record, etc} (we believe accession is only one truly of interest)
Comment (text: skipped because…, duplicate – refers to registry patient 123 and 345)

**Uses**

This prevents the registry from having to duplicate effort because they have the information stored and accessible to the reporting tool.

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## IMAGE

**Definition**

Any image on any media that is taken of a patient/CTC (X-ray, etc.)
Registry probably just gets evaluation.

**Examples**

**Attributes**

Type (X-ray, CT-scan, etc)
Image ID (for tracking into system)

**Uses**

**Policies/Business Rules**

**Warning**: Date taken is important, but is being tracked via the date of procedure during which this image was taken.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## IMAGE EVALUATION

**Definition**

The evaluation of an image at a facility
This evaluation may contain information about a diagnosis or about a CTC (or both)
Current specific text fields include: Physical exam, X-ray/Scan, Scopes, Lab tests, Op, Path
Medical Practitioner is out of scope

**Examples**

**Attributes**

Text: evaluation, potentially related to diagnosis or extent of disease.

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## IMMUNOTHERAPY (BRM)

**Definition**

Treatment type: trying to use the body's immune system to attack the cancer/tumor cells. The material given to the patient acts as a tag for the immune system (attack here) and attaches itself to the cancer/tumor cells.

**Examples**

Interferon given to Jane Doe

**Attributes**

Type of immunotherapy (what exactly was given)

**Uses**

**Policies/Business Rules**

Information in type of immunotherapy must be examined along with 'refused' attributes to also determine refused, recommended unknown if done. No immunotherapy (not done –there was no immunotherapy or unknown- indications confusing) is summary information (N10-720 - CTC??)

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## INDIAN HEALTH SERVICES RECORD

**Definition**

HIS patient master file
Record of health encounters by American Indians through the Indian health services.
Helps with follow-up and casefinding for Indians.
Contains no treatment or free text, not enough for an abstract. Similar in nature to a discharge list or disease index.

**Examples**

**Attributes**

Name
SSN
DOB
Gender
Quantum (fraction native American - ½, ¼, 1/8, etc)
ICD-9 diagnosis code (R1 – 9 codes total)
Address
Community
Vital Status
Date of last service

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**
Only received by New Mexico

## INFORMANT FOR PATIENT

**Definition**
This would not be a PHYSICIAN of the PATIENT or the PATIENT him/herself, but another person.
Someone with knowledge of the patient, usually parent, husband or wife

**Examples**
Jane Jones is an informant for Judy Jones (her sister)

**Attributes**
Nature of Relationship {spouse, parent, sibling, neighbor, etc}

**Uses**
Contact for follow-up
For special studies interviews if patient has died

**Policies/Business Rules**
Would be interested in an informant is also a patient (hence, how relationship is constructed.)

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**
LA does not contact Patients or Informants.
Registries may not be seeking this information, just noting it down if it comes in.

## INFO REQUEST PROBLEM RESOLUTION

**Definition**
Given that there was an information request and that the receiver had a problem with the fulfillment, this is the means by which a registry fixed the problem. It may generate a new request or just a modification of the output from the original request.
This would include corrected data, modified formats, a new/expanded request.

**Examples**

**Attributes**
Outcome {regenerate report/extract, don't do anything, new/expanded request, …}
Description of Resolution (text)
Instructions to Reproduce Report/Extract
Time/Date (when was it resolved)

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

Most registries would modify the original request if necessary rather than creating a new request to track.

## INFORMATION REQUEST

**Definition**

The desire to obtain knowledge contained in the registry. Includes requests for CTC information by people outside the registry as well as internal reporting relating to the collection of data (abstracts received from facility, outstanding follow-back queries)
This could be an ad Hoc request, a request for a standard report, etc. This includes "standard" submission requests.
Includes requests in support of a special study (not a request for individual records, but for some kind of generalized information such as incidence rates)
**DESIGN NOTE:** to use this mechanism to release records to a special study.
Could be Registry sets up a request (to itself) for information to send to HCFA, for example.
A request can be recurring. For example, data gets submitted to SEER every six months. This would be one request (not a new one every six months), that gets fulfilled a bunch of times.
May not always choose to track requests for standard reports. May do minimal tracking (Staff id xyz sent out Annual report 1/1/01.) Otherwise, information is tracked pretty consistently. They have to know where the data is going and show that the data is being used (public is getting benefit from its tax dollars)
1 request may lead to multiple fulfillments based on whether or not the data is found in or can be combined in a single report (partial fulfillment). The decision as to how many fulfillments are needed is based on the org rep's experience.
When a Medical Practitioner makes a specific patient request, they can only receive patients where the MPs name is on the patient set and they can only receive data they are supposed to know about. Medical Practitioner may make a general request, but this could be covered as PERSON makes request with a priority flag.
Requesters usually don't ask for a specific media

**Examples**

CDC Submission
SEER Submission
"Break down by site by county"
Number of abstracts received by facility for year
John Q Public asks to see survival rates of prostate cancer
Suzie Patient asks to see all health records received by the registry about her and to see the patient set constructed from that data.

**Attributes**

Information Request ID
Date Received
Description (what was requested)
Purpose {dissertation, news report, …}
Project (if any)
On-going/Ad Hoc (ad-hoc means those reports/extracts that are not expected or that we do not normally produce. On-going is a recurring event like the release of data to SEER, ACoS, special study, data exchange.)
Schedule (if an on-going request)
Registry internal review board status {pending, approved, denied}

Registry internal review board Org Rep ID (who reviewed)
Registry internal review board Date Reviewed
Why Invalid (text: inappropriate use, inappropriate data items, etc)
Why Can't Fulfill (such as data not available, media not available, …)
Status {received, potentially fillable, invalid, fillable, cannot fulfill}
Who should be billed (if anyone)
Priority Flag (for doctors, facilities etc who provide data or patient with a cancer/tumor. Those we wish to be nice to.)

**Uses**

Would like to be able to connect many requests for one requester
Would like to be able to find requests for similar information (so that work isn't duplicated
Would like to know if the same group has already requested/received the information.
Would like to know how many requests a person has made (and if they are duplicating a request.)
Among other things, it sounds like this should be used to track if the registry matches a file to registry data for an outside group (such as a special study). They wanted to know the same sort of information as is listed above (specifically description should include what file/database is being linked to). If matching is done in batch mode, tracking the same information here might be redundant. We assume they would be returning the record being matched and the additional variables requested from the matching records/patient sets back to the recipient.

**Policies/Business Rules**

If request comes in and is deemed invalid, for a reason such as confidentiality, it is not necessarily logged as an INFORMATION REQUEST. Some registries may choose to log only 'valid' requests, others may choose to log some 'invalid' requests (for example, only log those which needed IRB approval and failed)

**Sensitivity**

In California, a new law has been passed SB683(?) which restricts the release of data that can be used to identify individuals. The original goal was to prevent the data from being subpoenaed. However, the end result is still unclear. NCS believes this will mostly affect which information requests are approved, and not the actual mechanics. Talk with Dennis Deapen from LA if further questions occur.

**Estimated Number of Occurrences**

HI: about 10 standing requests; 100ish total
LA: 1 person has about 150 standing requests; 500 total. (½ research, ¼ health concerns such as cancer clusters, ¼ hospitals)

**Local Variations**

Registry internal review board varies by registry. NM is Dr. Key. It's not formalized in IA, although they have 1 person who vets all requests, and can ask Dr. Lynch & K. McKeen if the unexpected comes up, and larger groups have been know to meet. DT sounded very formalized. They probably meet first, because they may be the ones deciding if IRBs are needed.
HI, DT require written requests.

## INFORMATION REQUEST FULFILLMENT

**Definition**

The act of sending the information requested to the recipient, may need to generate a file/report or merely locate it.

Multiple fulfillments may need to be attached to the same request based on whether or not the data is found in or can be combined in a single report (partial fulfillment)
The method of fulfilling an information request needs to be tracked in case of problems. The exact Report/Extract that was sent to the recipient is noted.
If request is fulfilled using an registry-controlled file, Need to track whether the recipient has been trained in the use of the file.

**Examples**

**Attributes**

Start Date
Completion Date (sent)
Effort (hours worked)
Status {open, closed, purged}

**Uses**

**Policies/Business Rules**

Only authorized Registry staff (as ORGANIZATION REPRESENTATIONS) are authorized to fulfill a request.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## INFORMATION REQUEST PROBLEM

**Definition**

Given that the info request was filled, the requester/recipient desire to somehow modify what was received. Sometimes this starts a new info request.
For an expanded request based on a request which required IRB approval: If the request is for data items were in the first request and it is within valid dates, this would not require a new IRB. If the data items were NOT in the original request, but it's within valid dates, it would require a modification to the existing IRB approval. If the IRB approval has expired, new IRB approval is needed.

**Examples**

Error in data, what was received was not what was requested, format not acceptable.

**Attributes**

Information request problem ID
Time/date problem received
Type of Problem {data, format, expanded report/extract, …}
Status {possible problem, confirmed problem, resolved}
Description of Problem

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

HI: 70ish, 50-75% expanded or incorrectly stated requests.

**Local Variations**

## INSURANCE DEMOGRAPHIC INFORMATION (HMO)

**Definition**

Information obtained from various insurance groups on the cancer/tumor patients.

Organization is sent a file of interest by the registry. A file is returned with the latest date of contact by that organization.

**Examples**

**Attributes**

Registry Patient ID
Name
Current address (are these just the information the registry has sent out or would you get corrections?)
DOB
SSN
Date (Date may be date coverage started or date of last procedure. Just the last contact HMO has had with the person.)
(other variables, probably not of interest to the registry)

**Uses**

Used for follow-up, may also obtain better information about current address, full name, dob, etc.

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## IRB DOCUMENTATION

**Definition**

Documentation from an Institutional Review Board.

Generally these are approvals/disapprovals for special studies or information requests that the registry must track for legal reasons, Please note, this would also include an internal review board performed by the SEER registry.

IRBs refer to a single Special Study. If a study has multiple information requests, they would be covered under the same IRB. An information request that was distinct from a special study and needed an IRB would again be the only thing referenced by the related IRBs.

A single special study or distinct information request may require --- multiple IRBs ---;---only 1 IRBs.

**Examples**

**Attributes**

IRB documentation ID
Date IRB approval requested
Status {pending, approved, denied}
Org Rep ID (at facility or org, who reviewed IRB request) (R1?)
Date Reviewed
Comments

**Uses**

**Policies/Business Rules**

IRB approval is required for ALL special studies: IA, LA, HI, UT, DT, NM, AT

**Sensitivity**

**Estimated Number of Occurrences**

HI: not usually for info requests, more likely for special studies

**Local Variations**

## IRS RECORD

**Definition**

Needed to follow people who leave the state (under 65). Used to get current addresses of registry cohort.

Still investigating use

**Examples**

**Attributes**

Name (need to link)
SSN (need to link)
Address information
Last filing date
Vital status at last filing date
(other variables, probably not of interest to the registry)

**Uses**

As a better passive follow-up source than DMV for the under 65

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## LAB

**Definition**

A facility were a sample/specimen is evaluated (path reports are created). Patient wouldn't normally come here.

**Examples**

**Attributes**

See FACILITY attributes

**Uses**

**Policies/Business Rules**

In California, Path Labs must make information accessible to cancer registry by law.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## LOOK-UP HISTORY *logical only*

**Definition**

The audit trail for tracking which org rep made what change on what date and why to any of the following: type of active follow-up, type of cancer, type of marker, type of media, type of non-cancer disease, type of procedure, type of record.
**DESIGN NOTE:** version 2 or later

**Examples**

**Attributes**
Date of change
Old Value
New Value
Reason (text field, why was this made)

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**
HI and IA are interested in this.
LA and NM might be interested in this if they see it as auxiliary file.

## MARKER

**Definition**
A biological state at the time of diagnosis
This is a very fuzzy name. In some cases, the marker wouldn't change over time. In others, this represents an elevated level of something (i.e. antigens in the blood) believed to be related to an occurrence of a cancer/tumor.
Also called tumor marker
NAACCR 10 allows for 3 tumor markers.

**Examples**
PSA levels
PR and ER measures

**Attributes**
Measurement (if available)
Tumor Marker Code (See N10-1150 to 1170)

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## <MATCH>

**Definition**
**CURRENTLY, ALL MATCHES ARE DESCRIBED BELOW. PROBABLY NEED TO BREAK THESE APART AS THE LINKING VARIABLES ARE LIKELY TO BE DIFFERENT.**
The (possible) association between two data groups based on several variables.

The link between a health record and a patient set (1 type for patient, 1 type for CTC, 1 type for treatment) and the link btwn a supplemental record and a patient are persistent to allow for tracking back to original records.
The link between records might become record/patient set links, so you wouldn't always need to retain that record/record link (would be replaced by 2 record/patient set links). However, it is also possible that 2 records which link are still un-reportable and would wish to retain the link under those circumstances.
The link between patient sets become 1 patient set (no need to retain link). Same for link between CTCs and link between treatment. If the patients (CTCs or treatment) are rejected, retain the MATCH entity with the MATCH UPDATE = rejected for future use.
**DESIGN NOTE:** Need to consider what to match against: entire patient set, Registry view, Facility view. Most matching could occur at registry view, however for some records (especially corrections), they would like to match facility view first.
This entity aids in decomposition of patient set if it is discovered that 1 patient set contains information for 2 people. However, after true matches are determined, the records will have to be consolidated again.

**Examples**

**Attributes**

*(The data item level information is only needed when someone is trying to improve the matching algorithm. It is not actually used when doing matching.)*
Data item match probability level (R1, D: how likely is this that these 2 things are the same, Smith=Smith 100%; Smith=Smyth 95%)
Data item score (R1, D: given that these match, how important is it, Smith match – 5 out of 100 points; Hufflepuff match – 90 out of 100 points)

Overall weighted score (only score used by person trying to match)
Alias/maiden name used? {Y, N} (Patient level match only)
Last Reviewed Date (implementation)
Current Status (Possible, Accepted, Rejected)

**Uses**

**Policies/Business Rules**

If matching is done in batch mode, SMEs would like to be able to access for each batch submitted: who requested link, which files/databases are being linked, why link is needed, who gets the results, who should be billed (if anyone), when was batch completed, is it a recurring event, what is the timing of recurrence (weekly, monthly, etc).
Currently, if a match is rejected and no linking variable information has changed, the registries would prefer NOT to see a rejected link on the list of possibles.
If a link has been rejected but information stored in a linking variable has changed (post last reviewed date), the SMEs would like to see the link in the list of possibles with a warning that this link has been rejected and the reason for the rejection so they can determine if the reason is still valid. It seems that if the link is again rejected, there ought to be some place to store the new date to check against for future links. (if nothing changes post continued rejection, they probably don't want to keep seeing it). Last reviewed date is a possible implementation of this. It

might also be a nice feature if they could turn off this screening mechanism of possible links if they are trying to do quality control.
**DESIGN NOTE:** SMEs would like to consider all names the patient is known by during link (aliases, maiden names, names at different facilities). Also, they desire the use of name frequency when assigning a weight to the name match. (John Smith==John Smith is good, but not very reassuring compared to Xavier Whosiewhastset == Xavier Whosiewhastet. The relative frequency of finding the name needs to be factored into the weight)

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## MATCH UPDATE *(logical only)*

**Definition**

Changes to a MATCH's status as entered by an org rep.
Retained to prevent re-investigating the same match, either in patient set to patient set matching or record to patient set matching
Match updates from possible to rejected are likely not of interest.
Used for auditing.

**Examples**

**Attributes**

Date
Status {possible, accepted, rejected}
Comments (ie rejected reason)

**Uses**

**Policies/Business Rules**

Current policy is that all match events but exact matches becoming accepted will be decided by people.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## MEDICAL PRACTITIONER

**Definition**

Could be a doctor, physician's assistant, nurse practitioner, medical examiner (not coroners), potentially personnel administering treatment such as chemo or radiation …
Anyone who practices medicine and would potentially be of interest to the registry
Information may have been obtained from a Medical Board physician file

**Examples**

Doctor John J. Smith

**Attributes**

Medical Practitioner ID
Last Name
First Name
Suffix Name (Sr, Jr, III)
Title (R1) (MD, DO, DDS etc)

Do Not Contact? {Y, N}
Physician Code (Frequently Medical License Number, but other number may be assigned)
Specialty (R2)
Phone Number (R3)
FAX Number
E-mail Address
Web Address
Preferred Mode of contact? (probably text. i.e., don't use phone, only use email are 2 possible notes)
Preferred Time of contact? (Text)

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

UT: as physicians join the UT system, the registry asks if they wish to be notified if their patient is going to be involved in a study. If the physician says no, they consider this to be blanket passive approval for all that physician's patients for special study.
**DESIGN NOTE:** UT would thus need an additional data item connected to this table: Blanket consent? {Y, N}

## MEDICAL PRACTITIONER FACILITY AFFILIATION

**Definition**

A physician or staff member who practices at/performs medical activities at a given address
Multiple M.P. work at a single facility, a single M.P. may work at multiple facilities (doctor has his own office and works in a hospital).

**Examples**

**Attributes**

Primary affiliation? {Y, N}
Email address
Phone number

**Uses**

Indicate what facilities where a physician practices.

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## NAME LIST FOR RACE/ETHNICITY RECORD

**Definition**

Record in a list where, for a given Race or Ethnicity, the surnames that are probably of this type
Like census tract these are not really about a particular person, but are linked to them.
Feeds into Surname file.

**Examples**

**Attributes**
Last Name
Probability
Race/Ethnicity group

**Uses**
Feeds into Surname file
Used for determining race/ethnicity (go figure)

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## NATIONAL DEATH INDEX

**Definition**
A summarized record of the information contained in a death certificate.
For follow-up only, can only send for people that the registry knows about (can find new CTC, but not new patient)
SEE death certificate for more details
Contains Cause of Death, so is considered a health record.

**Examples**

**Attributes**
Name
DC number
Cause of death (R1)
Date of death

**Uses**
To find final follow-up information for patients in registry database
Occasionally discover new CTCs in registry patients.

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## NON-SURGICAL DIAGNOSTIC PROCEDURE

**Definition**
Non-surgical, diagnostic procedures the patient undergoes. Aka everything else ☺
These would include MRI, CT Scans (which generate images), blood draws, as well as Doctors visits with no specific ICD procedure code (palpate area, examine skin discoloration for melanoma, physical exams)
**DESIGN NOTE:** not really trying to track this in great detail separately. May be best implemented as comment fields

**Examples**
Bone scan
X-Ray

Sonogram
MRI
Liver scan
Blood Draw

**Attributes**

Type of non-surgical diagnostic procedure
Text

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## OBITUARY

**Definition**

From the newspaper, the write up of someone's death. They are used for follow-up purposes only. The information would be overwritten when a death certificate arrives. They can not be used to code cause of death. Costly for the few acquired; outdated.
PROCESS NOTES:

UTAH & ATLANTA:
Screen for COD=cancer/tumor (1.1 – gross filter). If found,
Match on Patient (4.1.1 - name, year of birth?) If patient match found,
Consolidate Registry view Patient Information (4.2.3)
Edit (17.0)
Finalize Patient Set (5.0)
IF 1.1 or 4.1.1 fail, obituary is ignored.

DETROIT:
Match all on Patient 4.1.1, If patient match found
Consolidate Registry view patient information (4.2.3)
Edit (17.0)
Finalize patient set (5.0)
AND
Screen for COD=cancer/tumor (1.1 – gross filter). If found,
Match on Patient (4.1.1). If not found,
Add abstract facility lead: depending on obit, facility may be blank
During management of leads (10.1), if a record comes in for this patient, close the lead.

**Examples**

**Attributes**

Name
Date of Death
(Vital status=dead)
(Source=obit)
Name of paper
Date of paper
Page obit on
Org Rep who found.

**Uses**
For people who die out of state and are only captured by NDI.
**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**
few
**Local Variations**
LA and HI do not use these
IA only gets them as part of an active follow-up response, they scan the obit and save it, like any other health record
UT and ATL use the process noted above to process records. UT noted that while this process is time consuming and should be obsolete, people keep doing it. ATL noted they are trying to avoid calling grieving relatives for active follow-up when the person died out of state. Registry only finds this out using NDI and ATL doesn't get NDI every year.

## ONCOLOGY REPORT

**Definition**
Report from oncology dept about treatment and/or diagnosis
Usually the medical oncologist
**Examples**

**Attributes**
Contains some subset of the HEALTH RECORD variables
May also contain text fields for doctor's comments
**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION

**Definition**
This entity could include a variety of types of ORGANIZATIONS: State Health Departments, SEER Registries, Software Vendors, State Registries, Hospital Registries, Other Registries, Department of Motor Vehicles, etc.
**Examples**
Minnesota State Health Department
Atlanta SEER Registry
CMS (HCFA)
IMPAC
ACTUR
…
**Attributes**
Organization Name
Phone number
Fax number
E-mail
Web address

Organization Type {SEER registry, other}

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION GROUP

**Definition**

To remove M:M cardinality on who is conducting a special study.
A random grouping of organizations who have decided to work together on the same project.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION REPRESENTATION

**Definition**

A person who is doing something on behalf of the organization, a staff member or employee
**DESIGN NOTE:** this is mostly being used for tracking purposes. Bear in mind that the tracking must be easy to use, or it won't be done.
Location subtypes of SEER org reps are Mobile Abstractor Laptop, Central Registry Office (listed under SEER Registry) and Registry Staff Home (listed under residency)

**Examples**

**Attributes**

Name
Org Rep ID
Phone number
Comments
Contact person? {Y, N}

SEER only
Training completion date
Role
Account
Password
Remote Access Allowed? {Y, N}
Allowed Log-In Time (9-5, all, etc)

Confidentiality Agreement
Status {Open, Closed} (would be closed if employee leaves)
Process ID (R1)
Process Access? (R1) {Yes, No}
Data Table ID (R2)
Data Item ID (R2)
Data Access? (R2) {None, Read only, Read/write}
Schedule day (R3)
Schedule times (R3)

**Uses**

Can track individuals who represent a SEER Registry, a Hospital, a Cancer Registry.

**Policies/Business Rules**

At one point in time, a PERSON can represent many ORGANIZATIONS. For example you could be an abstractor for one ORGANIZATION and moonlight for another.

**Sensitivity**

**Estimated Number of Occurrences**

NJ: 40-60 users (they believe they are a large registry)

**Local Variations**

## OTHER EXTRACT

**Definition**

SEE EXTRACT
Additional massaging of data is not required after the extraction. (ie. SEER submission)

**Examples**

**Attributes**

Same as extract

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## OTHER ORGANIZATION

**Definition**

Any organization within the area of focus that is not a SEER Registry Location subtypes include Intra-State Registry, Other State Registry, Supplemental Data Source, SEER Office and some Hospital Record Dept (those external to the facility). They may also be a Data User Location.

**Examples**

**Attributes**

See ORGANIZATION attributes

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## OTHER RECORDS

**Definition**

Records received by registry used in constructing patient set which aren't really about a particular person.

**Examples**

Census tract record
(May need to split out GIS records separate from Census tract)
Name list for race/ethnicity

**Attributes**

**Uses**

Used for filling in data items for patients which are based on other data items (census tract based on abstract, race/ethnicity based on name)

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## OTHER/UNSPECIFIED TREATMENT

**Definition**

Treated under protocol in double blind study and exact treatment may be unknown
Alternative treatments (without widespread acceptance)
Treatments for newly reportable cancer/tumors which don't fit well in the other categories.
'Other Treatment' is a SEER data item name

**Examples**

Newly reportable: for polycythemia vera – patient producing too much blood – the accepted treatment is blood-letting. ATL stored this in other treatment as it didn't fit any other category. SEER confirmed this placement.

**Attributes**

Type of Treatment

**Uses**

**Policies/Business Rules**

Information in type of other treatment must be examined along with 'refused' attributes to also determine refused, recommended unknown if done. No other treatment (not done –there was no other treatment or unknown- indications confusing) is summary information (N10-730 - CTC??)

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## OVERRIDE

**Definition**

An edit issue that is determined to be caused by correct, if unusually, information. It is noted so that the computer will allow the patient to 'pass edits' and so others who work on the patient set do not have to continue to investigate the edit issue.
**DESIGN NOTE:** Need to allow registries to be able to create new Overrides. If they find a problem with an edit, they would want to override the edit warning until a change to the edit is agreed upon.
**DESIGN NOTE:** This may mean some overrides would have to be deleted when a related edit is changed. How to implement???
**DESIGN NOTE:** would be nice to know if override has been set while waiting for follow-back. This is probably in the bells & whistles category. Best option may be to have FB ID as an attribute?

**Examples**

**The current required override flags are as follows:** (these were in CTC)
Override Flag Age/Site/Morph
Override Flag Seq No/Dx Conf
Override Flag Site/Lat/Seq No
Override Flag Site/Type
Override Flag Hist
Override Flag Ill defined site
Override Flag Leuk/lymph
Override Flag Site/Beh
Override Flag Site/EOD/Dx Dt
Override Flag Site/Lat/EOD
Override Flag Site/Lat/Morph
Override Flag Surg/Dx Conf (***diagnosis and treatment)
Override Rpt Source
Override Flag Site/Type (COC)
Override Flag Site/TNM Stg Group
Override Hosp Seq/Dx Confirmation
Override Accession/Class/Seq
Override Hosp Seq/Site

**Attributes**

Patient ID
CTC ID
EDIT ID (which type of problem - 'site/type', 'site/sex', etc)
Date
Comment (why overridden, text field)

**Uses**

This replaces the 'override flags'

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## PASSIVE FUP RECORD

**Definition**

A stripped down version of a health record created by the registry
These are created when a non-reportable record that has failed the broad screen are used in passive follow-up.
This record retains the health record number and the record type of the original incoming record that contained the information.

**Examples**

**Attributes**

Patient ID
may also include data items used in link:
Patient name
SSN
DOB
Hospital assigned accession number

Facility ID/Org ID
Original Health record type {Disease index, abstract, path report, etc}
Health Record ID
Date of Contact
Follow-Up Status

**Uses**

Used for data integrity – keeps like to patient set going to an actual record. Allows last date of contact to be traced to a source. However, protects registry by stripping away information it is not legal to have (such as the reason for the contact).

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## PATH REPORT

**Definition**

A specimen analysis created at a pathology lab. Based on a specimen, the description of the findings in detail and maybe some conclusions.
PROCESS notes: paper or electronic does not matter, goes through following process path:
13.0 receive record, 1.0 screen record (path), 15.0 match record.
If no facility match or match but no abstract: 2.0 generate abstract, 1.0 screen record (abstract), 15.0 match record
If match, 4.0 consolidate record (path) and if needed, after 2,1,15 above, 4.0 consolidate record (abstract)

**Examples**

**Attributes** *(Most of these attributes were extracted from the May 2000 BOM TAD*)

Patient Name
Physician Name
Specimen Date
Diagnosis
Summary of Specimen (Text), including procedure
Pathology Number
Date of Birth/Age

Sex
Pre-op diagnosis
Coding: HL7, Diagnosis, SNOMED, …???
Microscopic exam
Text – describes what the pathologist saw
Facility Name
Pathologist
Consulting Physician
Dates (filed, specimen, …)
May contain other variables, see HEALTH RECORD attributes

**Uses**

Will use "non-cancer" path reports for follow-up

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

LA: 20,000 kept in DB
ST: 51,000 per year
NJ: 30,000-40,000 paper per year – moving toward AIM

**Local Variations**

NJ: when these come in as paper, they keep them even after they key them in. This might change if the scanning of such records was easy to do. (they would still have old records, but wouldn't continue to store new records as paper). These paper records are archived on and off site.

## (VIEW OF) PATIENT

**Definition**

A facility or organizations view of an individual who has developed a cancer/tumor and is therefore of interest to a SEER registry

**Examples**

**Attributes**

Patient View Status: {In progress, consolidated, submissible, non-reportable, duplicate} (verify against event models. Non-rpt means that no CTC under this patient is reportable to any agency. Non-reportable should be derivable value.))
Patient Info Status {In progress, consolidated, submissible}
(**DESIGN NOTE**: Status flags could also include needs to be edited, matched, pending follow-back (send or don't send) complete (pre-consolidated status). Or these may be better as separate flags)
Restricted View? {Yes, No} (Is information available for registry use only or can it be distributed to facilities? Set by registry by view. For example, in IA, the DMV view is restricted)

*(Name data items are collected over time as they are subject to change. However, they are stored with patient in the form of an alias list.)*
*Salutation* (name prefix) (Mr, Mrs, Ms, Dr, etc)
Last Name
First Name
Middle name
Name Suffix (Jr, Sr)

Maiden Name (last name only)
Last Name alias (R1 Person is also known in the real world as… )

First Name alias (R2 Person is also known in the real world as… )
Middle Name alias (R3 Person is also known in the real world as… )
*(**NOTE**: in NM, they have a separate file that has the following data items: Patient ID, Soundex of Last name, Name (first or last), Flag (indicates whether name is maiden name, other last name, first name), User ID (who updated this record), Update date.*

SSN
SSN alias (R4 Insurance may show up under… Spouses may share SSN)

Gender
Place of Birth (SEER Geocodes)
Date of birth
Race (R5) (Currently there are up to 5 in the NAACCR file layout. Race codes are as of 2000 census)
Race coding scheme - current {4-values; pre 1988; 1988; 1991; 1994; 2000; Other} (N10–170. All races should be in the same scheme.)
Race coding scheme - original collection method
Spanish/Hispanic Origin
Computed Ethnicity (registry view only)
Computed Ethnicity Source (registry view only)
Month of Last Contact (date of death or date last known alive)
Day of Last Contact (date of death or date last known alive)
Year of Last Contact (date of death or date last known alive)
Phone Number (R6)
Phone Number Type (R6) {home, work, cell, …}
Email Address
Do not contact (ever) flag *(Registry view only)*
Do not contact reason {DEA only, minor, mentally disabled, requested no contact, physician denied (unaware of cancer or otherwise), Other (elderly Japanese, American Indian, VA)} (minor is based on DOB and today's date.) *(Registry view only)*
Received from DEA only (Do not contact) {Y, N}
Vital Status
Underlying Cause of Death (R7)
ICD Code Revision used for cause of death
**Place of death** (SEER Geocodes)
**DC state file number**
Occupation/industry from DC
SEER Type of Follow-up expected (FUP or Not? why not FUP? Cervix in situ, SF code, etc. NAACCR layout ver. 9 p221)
Follow-up Facility (The facility who is assigned to do this or the facility from which information can be obtained. This may be blank if registry is to do follow-up and there isn't a pre-determined source facility.)
Follow-Up Source (N10-1790)
Next Follow-Up Source
*Unusual follow-up Method* (N10-1850)
*Autopsy?* {Y, N}
*Quality of Survival* (N10-1780) {normal, symptomatic, ambulatory…}

**For Tracking:**
Date Created
Staff ID (who created)
Date Last Modified

Last Modified Staff ID
Comment

**Uses**

**Policies/Business Rules**

**DESIGN NOTE**: it would be nice to be able to tell whether the patient as a whole still needed work. This flag is probably more complex than yes/no as you might want to know why the patient still needed work. Since the introduction of a new CTC might affect other CTCs, it seems the most appropriate place for this flag is on the patient set. (Registry view)

Name alias(es) and SSN alias(es) should be appropriate to a view. For example, a facility can only have SSNs that they are aware of. This may mean that a facility view is storing an incorrect SSN (which would be a SSN alias on the registry view).

**DESIGN NOTE:** need to allow IT staff to disable data items in the facility view (not the registry view). Since HIPAA does not require facility view, some registries (specifically NM, ST) will choose not to fully implement the facility view. It would be best if the org rep who creates the CTC set could specify whether it was a full viewed set (non-reportable such as a special study where privacy concerns would need to be more strictly enforced) or a partially viewed set (reportable, therefore registry view data can be used, facility view enabled as specified by registry IT.)

**DESIGN NOTE:** would be a practical idea (in response to upcoming privacy concerns and the desire to not duplicate effort in the registries) to design a full facility view for database and 4.0 and to 'shut off' the Patient and CTC information. How much gets shut off would be determined by registry at time of implementation. We would leave active (as default) the treatment, admission and identification for the facility within the facility view. The registry IT could then decide if they needed to add more. The more automated the creation of a facility view is and the more automated the consolidation of a facility view is, the more likely the registries will be to accept the facility view. May need to consolidate registry information first and facility information 2nd. (If you accept the data into the registry view it would automatically be put into the facility view.)

**DESIGN NOTE:** since we need to allow the registries to determine what records (facilities or organizations) get separate views, it would be nice to allow them to specify for each one what items are included. For example, NM wants partial views of health information by facility. IA wants DMV view – only needs some of the patient information.

Patients who were discovered via data exchange agreements (DEA) and through no other method are not contacted for any reason. (FUP, FB, Special studies)

**DESIGN NOTE:** make sure that patient id can't be changed – miskeys are easy. (currently a problem in NJ when they associate a record to a different patient set).

**Sensitivity**

**Estimated Number of Occurrences**

HI: 124,000; add about 5000 per year
LA: 800,000; add 38000 per year, ~37K from LA

**Local Variations**

## PAYER SOURCE

**Definition**

Where the money for treatment or medical encounters is coming from. Usually an insurance company/group. Policies of the payer source may affect treatment selected for/by the patient.
Includes self-pay, write-off, military, Medicaid, private.
Wish to know if delays in transmission are based on primary payer. (delays in bills getting paid) Implies primary payer covers Cancer/tumor/case

**Examples**

Blue Cross
Military
Kaiser HMO
IHS
PPO
Self pay
Write-off

**Attributes**

Type {HMO, Self, Military, Private …} (N10-630)
Payer (Text - Kaiser, BCBS, …)

**Uses**

Influences when & how we get the data from the Facility
Could also influence where the tissue gets sent
Used to determine quality of care by Payer Source

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

Most registries are only tracking primary payer
California is tracking 2 payers.

## PERSON

**Definition**

An individual (cancer/tumor/case status unimportant- in focus as org reps or informants) This info should not be duplicated for all patients or medical practitioners, (unless that person is both a patient and an org rep or informant or information requestor, …)

**Examples**

**Attributes**

Salutation (Mr, Mrs, Ms, Dr, etc)
Last Name
First Name
Middle Name
Phone Number
FAX Number
E-Mail
Web address

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

# PROCEDURE

**Definition**

A medical encounter at which CTC is treated or diagnosed, during which SPECIMENs or IMAGEs may be taken
The same procedures may be used for diagnosis and treatment (A wide excisional biopsy, if it has clean margins, serves as a lumpectomy in addition to being the biopsy; the biopsy results in a specimen probably used in diagnosis, but the lumpectomy is the treatment.)
May be on the whole patient (not just the cancer/tumor), e.g. a systemic evaluation to determine the extent of disease.
If the patient has more than one surgery for a CTC, the registry will wish to track them all. Generally, they don't track chemo, radiation and other treatment series separately, although CT registry says that they do.
**DESIGN NOTE**: it should be easy to extend the subtypes of procedure. Collection requirements may change and more procedures may be needed. This would be a centralized change.
**DESIGN NOTE**: may not know FACILIITY where treatment occurred. Would store 'reported' treatments that happened in facility not-A in Facility A's view if A knows about them.
**DESIGN NOTE**: SMEs need to know when particular treatments (surg, rad, chemo,…) aren't given. While this may be derivable, it must be seamless to the org rep. Also, the method of linking treatment to facility view or registry was problematic when LA tried to do this, so care should be taken that any procedure table has smooth interactions with other tables.
**DESIGN NOTE**: may only receive a report of the procedure results at the registry. Full information may not be available. Would either be inferred or left blank. I.E. May not know facility where it was done. Possible to have a 'guess' at the actual procedure type, but would at least have that.

**Examples**

Bone scan for Joe Smith on 1/7/2001
X-Ray for Judy Jones on 3/20/2000
Sonogram for Sally Smith on 6/29/2001
MRI on Joe Smith on 1/15/2001
Liver scan on Billy Dee Williams on 5/5/1999

**Attributes**

Date (start date) (obsolete for *Chemo, Horm, Immuno*)
Systemic? {Y, N}
Text (description of what happened and, if applicable, results)

**Uses**

**Policies/Business Rules**

May not always know the FACILITY where the procedure occurred (when a Registry learns it from another facility).
Some registries would store all information about a certain treatment type as 1 event regardless of actual timing. (i.e., 2 surgeries, 1 bcs, 4 nodes examined on 4/15 and 1 mrm, 3 nodes on 6/15 would potentially be stored as 1 mrm, 7 nodes, on 4/15)
If this procedure is being retained because it was used for diagnosis only, only these two attributes are needed.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

LA has kept individual treatment information before and didn't like it. If designed like this, they would prefer to be able to keep summary info only and not having 'treatment match'.
Some registries keep more than 1st course treatments (DT, CT, UT). That is, after the initial prescribed treatment course (which may include multiple treatment types, multiple events of a treatment type) has been completed, a 2nd course of treatments may be prescribed.

## RADIATION FOR TREATMENT

**Definition**

Treatment type: use of radiation(s) to treat Cancer/tumor. Usually performed in many sessions. Different levels of radiation may be used, there are many different distribution methods.
This includes Gamma knife surgery; see NAACCR ver 10 #3200(Rad-Boost tx modality), value 43.

**Examples**

**Attributes**

Type of radiation {beam, seed, etc,} (N10-690: D from N10-1570?)
Sequence with surgery? {before, during, after, unknown}
Radiation regional rx modality (N10-1570)

End Date
Rad- Regional Dose cGy (N10-1510)
Rad – Num of Treatment (of this) Volume (N10-1520)
Rad- Boost Dose cGy (N10-3210)
Rad- Boost tx modality (N10-3200)
Rad- Location of Rx (N10-1550)
Rad – Treatment Volume (N10-1540)
*Rad – Elapsed Rx Days* (N10-1530)
*Rad – Intent of Treatment* (N10-1560) {Curative, Palliative, etc}
*Rad – Rx Completion Status* (N10-1580)
*Rad – Local Control Status* (N10-1590)

**Uses**

**Policies/Business Rules**

Information in Type of radiation must be examined along with 'refused' attributes to also determine refused, recommended unknown if done. No radiation (not done –there was no radiation or unknown- indications confusing) is summary information (N10-690, N10-1430 - CTC??)

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## RADIOLOGY REPORT

**Definition**

Imaging report (diagnostic)

**Examples**

**Attributes**

Contains some subset of the HEALTH RECORD variables
Also contains text fields with physicians comments

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## RADIOTHERAPY REPORT

**Definition**

Report coming from the radiation procedure

**Examples**

**Attributes**

Contains some subset of the HEALTH RECORD variables
Also contains text fields for physician's comments

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

ST: 77,000 Radiation/Chemo logs.

**Local Variations**

## RECORD

**Definition**

A collection of related data items, frequently an electronic grouping, but also paper reports
For "list" documents, each person listed would be considered a separate record (e.g. DMV file contains many records).
The facility or organization that submits a record might not be the one for whom record was created, i.e. significant for case finding.
Some of the 'records' the registries are getting are text or PDF files that they have to parse into useful data fields. While we may be able to define the types of records by variables expected, it would be nearly impossible to define all the formats these arrive in.

**Examples**

Joe Smith's record in a disease index.
Sally Smith's path report for her breast cancer/tumor
Jimmy Jones's voter registration record

Health
Supplemental
Other

**Attributes**

Date Created
Unique Document ID

**Uses**

Some information in the RECORD is not reportable (i.e. not SEER data), but may be used for follow-up.

**Policies/Business Rules**

In most instances, we don't care who the person (ORGANIZATION REPRESENTATION) was who created the RECORD. We only care about who creates abstracts and we may only know who created registry-created abstracts.

HEALTH records include health status information other than vital status. For example, the SSA death file DOES NOT contain cause of death, hence this is supplemental, not health.

**DESIGN NOTE**: for each variable that arrives on the record, we would like to have the following structure appended multiple times: (value, coding scheme, source {registry/facility}). This allows for the original facility value (or multiples if they send to us in multiple coding schemes) and the registry value and potential other registry coded values if the registry moves to a new coding scheme (without losing the prior values.) This applies to all record types.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## RECORDS REQUEST

**Definition**

Requesting a list or for "all" pertinent records (i.e. not a request for a specific record for a specific patient/person)

**DESIGN NOTE**: Would like to use bar codes on outbound communications that expect responses to facilitate tracking.

**Examples**

Request for DMV file from the DMV
Request for all abstracts from Metro Hospital

**Attributes**

Record Request ID
Date requested
Status {open, closed, purged}
Comments
Payment amt
From Date
Through Date
Date closed

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

LA: 10-20 most of their people send automatically
HI: reminders every 30 days, about 20-30 phone calls, 20 hospital disease index requests.

**Local Variations**

## REGISTRY-C0NTROLLED FILE

**Definition**

A file which is kept under registry control and not released to public.
May require more data manipulation than just data dump. Could be identified or de-identified file.
File specifications should be in information request.
Store pertinent info about file.
File
Documentation (# records, file layout, lrecl, name/directory)
Programs to create file
Access info: log authorized people/accounts/passwords.

**Examples**

**Attributes**

Registry Controlled File ID (so that access log can be reviewed to determine who is authorized user and what their password/account information is)
File name
Type {Standard, Ad Hoc}
Location (or copy of file, implementation decision)
Programs Used to create (R1)
Staff ID (who created, who to direct questions to)
Date created
Cohort specifications
Data items included
Identified? {Y, N}
Number of records
File layout doc
Comments (text field to hold other considerations, is permission needed from another researcher? Is special training needed to use the file? So on)
Training needed? {Y,N}

**Uses**

**Policies/Business Rules**

LA & HI: do not have these

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## REPORT

**Definition**

A summarized 'parcel' of data collected by a SEER registry (i.e. incidence rates for cancer/tumor x for the last N years) or about the operations of a SEER registry (internal reports, i.e. number of abstracts done by facility). This includes SEER*Stat output, Cancer Statistics Review, web sites with statistics, annual reports, ad hoc information requests and so on. Operation type reports would NOT include payroll reports, just reports about CTC information gathered (entities on the BOM). They can be produced either periodically (annually, monthly, etc.) or by request (SEER*Stat outputs, etc)

**Examples**

Number of abstracts done by facility for given time window
Number of prostate cancer/tumors by race and county
Number of unresolved follow-back requests

Relative Survival of Lung cancer/tumor patients by age group
List of patients

**Attributes**

See Report/Extract
Would want directory/name of report (2001 Annual report)

**Uses**

**Policies/Business Rules**

**Sensitivity**

If a report by cell (age x sex x county) has fewer than a given number, the cell must be masked. (* where *=X or fewer) This number seems to vary by registry. HI: 4 or fewer. LA: 3 or fewer. IA: 5 or fewer

**Estimated Number of Occurrences**

**Local Variations**

## REPORT/EXTRACT

**Definition**

Any report/extract a SEER Registry has or creates. This is the report with data (i.e. not just the structure).
Could be available in any format the registry can use: paper, electronic, etc.
File/report specifications should be in information request.
There are 'standard' report/extract: those that have occurred often or have high demand. There is a set shell structure/content for such reports. Could include standard cancer/tumor incidence, mortality reports, administrative reports on outstanding requests (info, follow-back, follow-up), so on.

**Examples**

Survival Counts from 1st Quarter 2001
Frequency Counts for 2000
Survival Counts
Frequency Counts
Case Completeness
Annual Cancer Report

**Attributes**

Copy of Extract/report
Documentation (# records, file layout, lrecl, directory/name). Not all of this would be needed for reports
Programs to create extract/report (R1)
Type {Standard, Ad Hoc}

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## RESIDENCY

**Definition**

An address that is associated with a patient.

Care about current residency and residency at time of diagnosis for each cancer/tumor/case

Location subtype may be Patient Residence (patient only), Registry Staff Home (registry representatives only) or Data User Location

**Examples**

Joe Smith lives at 123 Main Street, Atlanta
Sandra Jones lived at 456 Oak Street, Los Angeles at the time of her diagnosis.

**Attributes**

Valid for Time of year (ie April – Oct; for people who have multiple permanent addresses)
Current? {Y, N}
At time of Death? {Y, N}

**Uses**

**Policies/Business Rules**

For homeless people, the residency is the place (shelter, etc) they sleep at most often.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## RULE

**Definition**

A standard, law or some other statement governing how a process is done or how data is treated. Tests for problems, ability to retain/exchange data
NCI sets SEER rules. Registry 'rules' are local rules (policy, implementation, local mandates). Other organizations set local rules (although some rules like NAACCR may be followed by all registries). Some rules are facts of life (can't be diagnosed before being born) and others are policy (male breast cancer/tumor causes a 'flag' in editing, valid values for any given field)
**DESIGN NOTE**: Edit rules (17.0) The registries wish to have different levels of edits. That is, weekly edits which contain a specified subset of the edit rules, versus monthly edits which contain a larger subset, versus pre-submission edits which would contain all edit rules. The number of levels and exact subset within the levels should be configurable by registry and will probably change over time so it should be easy to modify at the registry.

**Examples**

Surname List
Site/sex, site/type edits
Date comparisons (born, dx, die)
Valid field values (1=male, 2=female, 3-8 are invalid, 9=unknown)
Local rule: AT: if surname is Hispanic and race code is non-hispanic, notify user.

**Attributes**

Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)

Source of Rule (SEER, NAACCR, State,…)
Effective (start) date
End Date
Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …)
Severity tables

**Uses**

**Policies/Business Rules**

Edit criteria type rules are used in EDIT, are what is violated in EDIT ISSUE, is how the HEALTH RECORD UPDATE values are selected. There are other types of used which are used but not stored. (how a org rep knows to select 816.3 vs 816.9)

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

Many registries need ACoS edit rules
Registries may have state specific edit rules: NM, CA, DT, CA

## SAME CTC

**Definition**

A match that has been found between 2 cancer/tumor/cases within a patient.
This is most likely to occur when patient set to patient set matching has occurred

**Examples**

**Attributes**

Data item match probability level (R1, D: how likely is this that these 2 things are the same, Smith=Smith 100%; Smith=Smyth 95%)
Data item score (R1, D: given that these match, how important is it, Smith match – 5 out of 100 points; Hufflepuff match – 90 out of 100 points)

Overall weighted score (only score used by person trying to match)
Last Reviewed Date (implementation)
Current Status (Possible, Accepted, Rejected)

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SAME PATIENT

**Definition**

A match that has been found between 2 patient sets in the registry's database.
This is the result of patient set to patient set matching

**Examples**

**Attributes**

Data item match probability level (R1, D: how likely is this that these 2 things are the same, Smith=Smith 100%; Smith=Smyth 95%)
Data item score (R1, D: given that these match, how important is it, Smith match – 5 out of 100 points; Hufflepuff match – 90 out of 100 points)

Overall weighted score (only score used by person trying to match)
Alias/maiden name used? {Y, N} (Patient match only)
Last Reviewed Date (implementation)
Current Status (Possible, Accepted, Rejected)

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SAME PROCEDURE

**Definition**

A match that has been found between treatment information within the same patient and same CTC.
This is most likely to occur when patient set to patient set matching has occurred

**Examples**

**Attributes**

Overall weighted score (only score used by person trying to match)
Last Reviewed Date (implementation)
Current Status (Possible, Accepted, Rejected)

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SCANNED IMAGE

**Definition**

For paper records of interest to the registry, the image that the registry staff has scanned so that it can be stored.

**Examples**

**Attributes**

Scanned image

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SEER REGISTRY

**Definition**

Surveillance, Epidemiology & End Results: Organization which collects, stores and disseminates CTC data.
Location subtype is Central Registry Office.

**Examples**

**Attributes**

See ORGANIZATION attributes
SEER registry number (01, 02, 20, …)

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SOURCE COMMUNICATION

**Definition**

The transmission of information from outside into SEER registry; can be a file download, a postcard or so on.
May include multiple source submissions, for example, if multiple record types are included, they would be split into separate submissions.

**Examples**

Electronic burst of data
Act of mailing

**Attributes**

Transmission ID (Sender defined, some registries track & some don't)
Sent Date
Received Date
Registry Org Rep ID who received (may be system)
Sender-specified Record type (R1)
Sender-specified Number of record of this type (R1)
Problem (R2)

**Uses**

**Policies/Business Rules**

Currently and possibly in the future, this entity might be used for when the Registry ORG REPs communicate remotely from the field. However, depending upon technology. May not have to do this; ORG REP may be about to communicate directly to the registry SYSTEM.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SOURCE SUBMISSION

**Definition**

Typically, this is information that needs to be batched or queued up for loading to the system. However, it could simply be a postcard indicating that there are no records to report.

The data being transmitted to the registry; usually a file (can be a file of 1 or a note that there are 0 records)

Actual file (clump of data) being transmitted

A file may have more than one record type. The format would have to note all types so that they can be processed as the correct record type.

**DESIGN NOTE**: make sure these aren't overwritten by accident. In NJ, the submitters sometimes use the same name and have the first file overwritten when they don't want it to be.

**Examples**

Electronic file

Stack of documents

**Attributes**

Submission ID (registry defined)

Received Data File identification (What the source called it, if anything)

Type of record received

Number of Records (D)

Received multiple times (Either Y/N or Count of times received)

Copy of File [**DESIGN NOTE**: would like to store "Image of the Accepted Submission" (exact bit-by-bit image kept for historical purposes) for electronic submissions.]

Date/Time Processed

Registry Org Rep ID (Who processed)

Problem (R1)

**Uses**

**Policies/Business Rules**

The source submission is archived – totally untouched records.

For legal reasons, may have to strip records which fail the broad screen from the archived file (re. AT and LA). These records would be replaced with a check number (or some other mechanism) to allow for duplicate submission checking. (BPM 9.0)

**Sensitivity**

**Estimated Number of Occurrences**

LA: about 300 a year

**Local Variations**

## SPECIAL STUDY

**Definition**

Synonym: Research Project

Researcher provides criteria for and synopsis of study they would like to perform. Needs to get approval from SEER and funding from somewhere.

**DESIGN NOTE**: The desired special study specific variables shown below will have to be added into the data collection tools by the registry for the time window noted. This must be easy to do.

Researcher may change criteria to refine or expand scope (with approval from the registry). This would be stored within the special study concept.

**NOTE**: If a request comes in for an older study and data items were in first proposal and it is within valid dates, this would not require a new IRB. If the data items were NOT in the original request, but it's within

valid dates, it would require a modification to the existing IRB approval (an expanded study). If the IRB approval has expired, new IRB approval is needed. Unless patients will be re-contacted, no new patient consent is needed.
Location subtype would be Data User Location
If local laws change, study would continue, these have approval from the hospitals.
HI believes longitudinal studies should be periodically reviewed. (yearly?)

**Examples**

**Attributes**

Study Name/ID
Contact (Researcher) name
Source of funding
Date approval letter sent
Effective Begin Date
Effective End Date
Description
Special Study Reportability Criteria (Text?)
Number of patients needed (probably not for all studies, some would want ALL patients of a given type)
Special study specific variable name (R1)
Special study specific variable format (R1)
Rapid Case Ascertainment? {Y, N}
Location check needed? {Y, N} (for billing, finding address is more expensive than just reviewing the path report)
Interview? {Y, N}
Registry to obtain consent? {Y, N}
Registry to do random selection? {Y, N}
Cost to Special Study
SS returned Data item (R2)

**Uses**

May need to input data from a special study back into the database (i.e. patient set info).
Want to be able to track staff effort for a study (internal SEER staff, not additional hired specifically or external staff). We decided that the release of data is a 'info request fulfillment', we are tracking staff id/hours there. We may also wish to track hours here if it is determined that it is inconvenient/contrived to track all special study hours within the data transfer mechanism.
Want to be able to track if data is going out as it's supposed to (via information request) and if data has come back (the way we'd like it to.) This may be done within a source submission. **DESIGN NOTE**: it may be worth comparing the similarities of tracking data transfer for a special study to tracking data transfer for a DATA EXCHANGE AGREEMENT.

**Policies/Business Rules**

Criteria may have to include which hospital if IRB approval is only obtained for some.
IRB approval is required for ALL special studies: IA, LA, HI, UT, DT, NM, AT

**Sensitivity**

**Estimated Number of Occurrences**

LA: 20 new per year; about 30 total ongoing; probably ¼ - ½ use existing data. Increasing numbers
HI: more than 20 per year. About ½ use existing data only. Increasing numbers
NJ: about 15 going on at any given time.

**Local Variations**

NJ: all special studies are supposed to return information. They do accept the information. The special study staff and regular registry staff are mingled, and special study staff has full access to their system.

## SPECIAL STUDY INCLUSION

**Definition**

**VIEW**: usually registry view of patient will be used to send info to a special study. However, could be a study based on a specific hospital or could be IRB approval has only been obtained from specific hospitals so data may need to be filtered.
Indicates who has been targeted for a SPECIAL STUDY before anyone has been contacted.
If no contact is required for the SPECIAL STUDY, this relationship identifies which patients or CTCs or records will be included.
Cardinality is given as 1—M for Patient is included in…, however, patient can only participate in 1 special study where the patient is contacted per given time window. While this is a business rule, we believe it is unlikely to change since the point it to not harass the patients. Even if a patient expressed willingness to be in multiple studies, they should be limited to one in an attempt to keep from skewing the results.
Will wish to note who has been released to special study. Since not all studies require patient contact, will potentially be multiple special studies.
**NOTE**: billing to special study is based on the total number of these relationships.

**Examples**

**Attributes**

Date provided to study
Used in Study? {Y, N} (won't know this if special study does not return info to us, would have to have default yes setting) (**NOTE**: this & xxx possibly reportable to SS may in physical be replaced by flag with values {possibly rpt, non-rpt (would need non-rpt reason), sent, used, not used})
Date of Last contact by Spec Study
Outcome of Spec study contact (includes Deceased, Do not contact, Valid response, so on. Judy Boone LA has this item currently; Joanne Harris DT is developing something similar.)
Patient interviewed {Y, N}
Interviewed Date

**Uses**

**NOTE**: Some records are included for case/control studies

**Policies/Business Rules/Cardinality Constraints**

If patient is interviewed in the course of a special study, they are supposed to be unavailable for a given time window for future special studies with interviews. The time window seems to vary by registry, so will need to be set by user. (California is only 1 year, other are ever)
This information should be updated when patient is sent to study and if the study mentions who was interviewed.
If 100 records (for example) are sent for use in a Special Study, this relationship would capture each of those. If there is no indication from the Special Study which were actually used, the 100 would remain

"flagged" so they wouldn't be used in another Study for a given time period (which varies by registry). If the Special Study let the Registry know which ones were used (ex: 60), then the relationships for the 40 that weren't used would be deleted so they be considered "available" again.

**Sensitivity**

**Estimated Number of Occurrences**

NJ: 500 patients in SEER POC; probably 2000-7000 for other studies. They have large numbers.

**Local Variations**

## SPECIAL STUDY RECORD

**Definition**

A record received from a special study containing information about a patient that a special study has gathered (during interviews, etc) and wishes to pass on to the registry.

There is no defined record type yet. This is currently fairly rare, although the registries would like to increase the amount of data returned by special studies. Therefore, almost any information may be included on this.

**Examples**

**Attributes**

Special study id
Patient ID
CTC ID (if applicable)
Data item name (R1)
Data item value (R1)
How information obtained (interview, from physician, etc. text field?)

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

Some registies do not wish to include such data (and probably wouldn't ask for it) because they feel it unfairly skews the quality of data towards those who have been included in studies.

Registries may choose to ignore a study record because they do not trust the source (the study) involved.

Registries may hold all data until study has been completed and apply it then.

NJ: processes this information by hand – probably 10.10 type processing.

## SPECIFIC RECORD REQUEST

**Definition**

Asking for a record.

ABSTRACT REQUEST handles requests for abstracts to fulfill an ABSTRACT FACILITY/ORG LEAD. This entity handles requests of all other record types for a patient (i.e. non-abstract ones where there is no lead).

Follow-back asks for specific pieces of information where this asks for a complete record. Records may be sent to the registry as a result of Follow-back even though the registry did not specifically ask for a record. Given that SEER has some information about a cancer/tumor/case (anything from a lead to an established CTC with referring hospital), they ask a specific facility/org for specific records. (Could be medical records which will be reviewed at the facility when constructing an abstract or could be the abstract itself.)
**DESIGN NOTE**: Would like to use bar codes on outbound communications that expect responses to facilitate tracking.

**Examples**

Requesting from a hospital a path report for Joe Smith
Requesting a death certificate when Jane Jones appears on a death list
Request for X-ray report for John Whosit

**Attributes**

Record Request ID
Date Requested
Facility Patient id (who you are requesting about)
Registry Patient ID (if available)
Status {open, closed, purged}
Comments (Text)
Date closed

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

LA: 5-10 requests per year

**Local Variations**

HI and DT consider this to be follow-back.

## SPECIMEN

**Definition**

A biological sample taken from a person (may be from a specific cancer/tumor site)
For our purposes, if this sample is further divided later (sliced), this would still be the same specimen.
Want a reference number and location so they can get a sample for special study to do further analysis on the specimen.

**Examples**

Blood drawn from Jane Doe
Tissue sample from George Smith

**Attributes**

Type {blood, tissue}
Specimen ID (for tracking into system: **DESIGN NOTE**: If this information isn't coming in on a health record, must add process to obtain it.)
Slide number
Block number
Amount (text - Scant, small, medium and large)

**Uses**

**Policies/Business Rules**

**Warning**: Date taken is important, but is being tracked via the date of procedure during which this specimen was taken.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SPECIMEN EVALUATION

**Definition**

The evaluation of a specimen at a facility
This evaluation may contain information about a diagnosis or about a CTC (or both)
Current specific text fields include: Physical exam, X-ray/Scan, Scopes, Lab tests, Op, Path
Medical Practitioner is out of scope

**Examples**

**Attributes**

Text: evaluation, potentially related to diagnosis or extent of disease.

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SSA DEATH RECORD

**Definition**

Death for the social security administration, a national list
DOES NOT contain cause of death, hence this is supplemental, not health.

**Examples**

**Attributes**

Name
Date of death
Possibly city or state where death occurred, but not necessarily

**Uses**

Follow-Up only

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## STANDARD REPORT/EXTRACT

**Definition**

A report/extract that is produced regularly and hence has a set method of production. Programs to create are saved with easy access and so on. These may have standing due dates.

**DESIGN NOTE**: need to all for easy creation of new standard report/extracts

**DESIGN NOTE**: Need to include NAACCR and XML dumps.

**Examples**

SEER submission (feb & aug)
Annual report on cancer
Monthly production reports to registry manager
SEER*Stat generated reports (incidence, mortality, survival)
NAACCR file formats for DEA exchange
XML extract for California data exchange (LA and NCCC will have to send nightly files to CA state cancer registry in near future)
Easy exchange format to hospitals/facilities
Easy exchange format to other registries (XML of patient set)
LA: send errors in abstracting back to the facility who generated the abstract so they can maintain quality. Send number of errors as well as Abstract and data item where error occurred (and what error was) (Facility must maintain 3% or less error rate)
Error Reports to facilities: problems with a health record submitted to the registry caught by the registry. **DESIGN NOTE**: ought to be able to run this off of HREC UPDATE. Only concern is if a correction record for same problem comes in before facility is notified of update, they need a way to remove it from the count.
Edit Reports to staff: problems with registry created abstracts (HREC UPDATE) or with edits make to record or patient sets (HREC UPDATE review, EDIT review, ACD review). (more QC)
List of Missing/Duplicate facility Accession numbers: could be run off abstracts received or FAC identifies PAT (type=accession).
Daily report listing CTCs where the data items used to determine stage have been modified, but the stage variables have not. (Need PAT and CTC IDs, probably would help to list the item(s) that changed and the old and new values. Basically, a task list for restaging. Probably run nightly and provided to the editor manager.
HI: data quality profiles. Weekly rpts showing levels of data quality issues (lost to FUP, DCOs, etc) to allow early detection of problems
Listing of those CTCs to be included in a reabstracting study. (The inclusion should be tracked).
Report listing missing Accession numbers (Registry tracks ID problems, used in 10.2.1.6)
Report for follow-up: would list all sources on one report. FUP can come from Supplement record matching, active follow-up (brute force by registry staff), follow-back, incidental with other matching (hrecs), from special studies contacts with patients. NJ and ST both expressed interest in having all FUP combined; likely other managers would use something similar. Likely called in 10.2.3, 10.6 or 10.8.4
NJ: Patient records report: Patient can walk into SEER registry and request a copy of all the records received by the registry and they have to comply. Would be nice if this was a standard push-button report.
ATL: report to list 'matches to be resolved/consolidated' in a priority order. Priority would be specified at time of report generation. Examples of priorities would be breast cancer cases; most recent dx date; HRECs from certain facilities; other specified primary sites. This would allow staff to focus attention within a large 'to do' list. This report would have to access MATCH and values of data items within a HREC or it's matching patient set.

Staff productivity report: by staff member, by task type, counts of the number of items completed in a given time span. Should probably be able to look at multiple times spans in one report (monthly, look at past year).
ST: for 10.2.3, would like to get a report by facility counting total records received, number of reportable records received and number of CTCs received (if received 3 records about the same CTC, would be counted 3 times in first and second report, but only 1 time in the last report)
NJ: keeps static copy of DB created every 6 months for research purposes. About 9% of network traffic is against the replicated data.
NJ: after passive follow-up has been processed, they would like an automatically generated report which notes how many records were updated and how many resurrection attempts were made.
NJ: Management reports for follow-up shouldn't have to look in 2 places. Would like a report that gives sources of follow-up including supplemental files and active follow-up methods.

**Attributes**

Format identifier (name, SEER submission, SEER*Stat, etc. see below)
Appropriate for what kind of Requested Information (text?)
Data items available (R1)
File format, report presentation.
How to access format (program name, application location, so on)
Identified file? (Flag {ID, De-ID})

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## STATE BIRTH RECORD

**Definition**

Bureau of Vital Statistics record on births in the state.
Current file is acquired, not based on match.

**Examples**

**Attributes**

Mother's Name
Father's Name (if available)
Date of Birth (of child, used as date of follow-up for mother)
Number of pregnancies
Mother's current address

(other variables, of interest to special studies)

**Uses**

For finding the race of the patient – childhood cancer/tumors (HI)
For finding people who had childhood cancer/tumors who have now given birth: follow-up (ATL)
For fertility information for special studies
For improving knowledge of patients with childhood cancer/tumors

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SUBMISSION NOTIFICATION

**Definition**

The registry's message to the Source of a record or submission telling them information about a transmission. Could be a problem with the entire submission file or with a single record. It also include 'transmission received, 500 records, no problems'

Generally messages about widespread problems, failed transmissions, corrupted file, corrupted record, duplicate submission or record, okay submission, so on.

**DESIGN NOTE**: HI would really like this to be automated – data received, # of records. Could add errors as bell/whistle.

**DESIGN NOTE**: Would like to use bar codes on outbound communications that expect responses to facilitate tracking.

**Examples**

**Attributes**

Status {sent back/error, confirmation/got it, query (need more info), }

Text field (may be description of problem or question, would include # of records received if a 'good' submission, suggested fix to problem, would also include reason for rejecting a correction. If only select records need to be resent, a list would need to be included.)

Date sent

Registry Staff ID

Closed Date (if okay or duplicate, this is date notification sent. If replacement submission is expected, it is date replacement arrives)

Resubmission requested? {Y, N} (would include an entire file resubmission requested or specific records resubmission request.)

**Uses**

Confirmation of receipt of incoming records

Management system for transmission problems

**Policies/Business Rules**

In some registries, a problem with a single record will result in the entire file being rejected.

Would like to use electronic notification as much as possible (driven by anthrax scare as well as reliability of email vs post office)

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

There are local variations about the information being sent back. That is, there are differences in the information that is sent back in the notification about any updates to data items in the RECORD.

## SUPPLEMENTAL RECORD

**Definition**

A collection of related data with no health information, used to verify personal data and update follow-up information.

Information in Supplemental records does not get follow-back. If it conflicts with information in some health record, follow-back may be

initiated, but it is the health record information that is 'corrected'. (Org which produces supplemental record doesn't care what the registry thinks)
DMV, Voters are data dumps. HMO, CMS are sent patient lists for matching.
**PROCESS NOTE**: Information from supplemental records is consolidated at the registry view, patient level. The only possible exception is if a correction to an address appears to be relevant to the address at diagnosis.
**DESIGN NOTE**: some information obtained from supplemental records (such as the DMV records) is restricted. It can not be release by the registry unless it has been received from a non-restricted source. There must be some way to tell on the registry view that a particular data value is restricted. This would be information at the PATIENT level (including RESIDENCY)

**Examples**

DMV record
Voter's registration.
Insurance Demographic information
(HMO)
CMS (HCFA) File
IRS records
State birth record
SSA Death records

**Attributes**

Sent to Special Study? {Y, N}

**Uses**

**Policies/Business Rules**

**Sensitivity**

IA, HI: some/all supplemental files must be deleted after use per agreements with the agency who furnished the data.

**Estimated Number of Occurrences**

HI: 1 million
LA: does not currently keep these online. US pops show 33 million people living in CA.
NJ: 800,000 DMV; also get state tax records – 130,000 per year – matching is done externally. CMS – send out 200,000 and receive 2000-3000 per year for updates

**Local Variations**

Some registries for some sources generate a list of patients they are interested in, send the list to the source and the source does the matching for them and returns matching source records (LA for DMV, CMS). Other registries or other sources receive an entire file and do their own matching.

## SURGERY

**Definition**

An invasive medical procedure
May be used as treatment (i.e. the attempt to physically remove the cancer/tumor)
Purely diagnostic surgeries (such as biopsies) may also be included here.
Site Specific value domains
Surgery summary is stored in CTC

If the patient has more than one surgery, the registry will wish to track them all.

**Examples**

Excisional biopsy
Modified Radical Mastectomy
TURP
Colonoscopy (?)
Lumpectomy, taken out sentinel lymph node
Lymph Node dissection
Distant site surgery (distant to primary cancer/tumor site)

**Attributes**

Surgery Primary Site (specific type of surgery, values vary by primary site)
Reconstruction (1st course recon is required by SEER, subsequent by COC)
Location of regional lymph nodes examined {None, Aspiration, Sentinel, Combination Sentinel/Regional} (aka Scope N10-672)
Regional Lymph Nodes Examined/Removed (count)
Surgery of Other Site {distant LN, regional site, distant site} (N10-674)
DX/Staging/*Palliative* proc (if surgery of dx/stg/pall, what type is it? N10-740. Palliative split to form N10-3280, N10-3270)
Palliative proc? {Y, N}
Most Definitive Surgery of Primary Site? {Y, N}
Surgical Discharge Date
Re-admission to same Hosp w/in 30 Days (N10-3190)

**Uses**

**Policies/Business Rules**

One surgery may involve multiple sites, and may result in multiple specimens.
SEER collects Reconstruction for breast only
Surgery Primary Site includes reconstruction information

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SURGERY LOG

**Definition**

A listing of surgical procedures done in a facility for a given time period. Very stripped down information is included.
WARNING: Registries do not feel there is enough information on this type of record to create a patient set with it alone. They would create an abstract facility lead only.
Searching for surgery types that are usually done to treat cancer/tumors.

**Examples**

MRM
BCS
TURP

**Attributes**

Patient id
Date of procedure
Surgery code
may contain others, see HEALTH RECORD

**Uses**
To verify that no cancer/tumors have been missed, another QA device.
**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## (SYSTEM) *physical only*

**Definition**
A computer system within the registry
Should only be 1 system per registry.
**Examples**

**Attributes**

**Uses**

**Policies/Business Rules**
While there are some things that the system can be programmed to do (calculate match scores) there are others that the registries are unwilling to cede the responsibility for (actually selecting the valid match & consolidating)
**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## TASK HISTORY *logical only*

**Definition**
The audit trail for tracking which org rep made what change on what date and why to any of the following: active follow-up need, follow back need, abstract facility lead, edit issue.
**DESIGN NOTE**: version 2 or later
**Examples**

**Attributes**
Date of change
Old Value
New Value
Reason (text field, why was this made)
**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**
HI and IA are interested in this.

## TREATMENT CENTER

**Definition**

Address where treatment is provided to a patient.

**Examples**

**Attributes**

See FACILITY attributes
Type of treatment provided (radiation center, etc) (R1)

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## TYPE OF ACTIVE FOLLOW-UP

**Definition**

Method by which a registry can attempt to gather information about the vital status of a patient.

**Examples**

Visit to facility (to look up info in medical records, probably done by field abstractor)
Letter
Phone calls
Post cards

**Attributes**

Media of contact (phone, letter, visit, etc)
Type of person/group contacted (patient, physician, informant, hospital)
Acceptable response time (immediate, 2 weeks, etc)

**Uses**

**Policies/Business Rules**

Person contacted=PATIENT: not done at all in some registries, last resort in others.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## TYPE OF CANCER

**Definition**

Primary site, histology and behavior combination

**Examples**

Prostate, Carcinoma, In Situ
Lung, small cell, Malignant
Bone Marrow, Leukemia, Malignant
…

**Attributes**

Primary Site
Histology
Behavior

Coding Scheme {ICD-O-1, ICD-O-2, ICD-O-3}

**Uses**

Look-up lists – probably in ICD-O coding schemes.

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## TYPE OF MARKER

**Definition**

A measurable biological state, (antigen levels, positive receptors) sometimes genetically predetermined, sometimes affected by presence of cancer/tumor.

**Examples**

**Attributes**

Name
Unit of Measure {yes/no, positive/negative, abnormal, numeric value}
Start collection date

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## TYPE OF MEDIA

**Definition**

Physical thing the data was written on/to

**Examples**

Paper
Transmission protocol (FTP, HTTP, etc)
Tape
Diskette
Post Card
CD
Email attachment

**Attributes**

Type
Method of entry (into system, data entry or just read rec)
Method of storage (save in filing cabinet, backup onto tape, scan in, etc)

**Uses**

**Policies/Business Rules**

Some facilities and some registries are unwilling to send data over the internet.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## TYPE OF NON-CANCER DISEASE

**Definition**

The state of being unwell which can be tracked by the International Classification of Disease (ICD), specifically the Clinical Modification schemes.

Specifically, those diseases which aren't classified as cancer/tumors by the registry.

**Examples**

Emphysema
Heart attack
ESRD

**Attributes**

Disease Text
ICD coding scheme {ICD-9-CM, ICD-10-CM}
ICD code

**Uses**

Used for comorbid conditions.

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## TYPE OF PROCEDURE

**Definition**

Any procedures performed within our interest, includes treatment modalities and testing for cancer/tumors. Surgery may result in specimen, other procedures may result in images (X-ray, CT, MRI) or specimen (Blood draw)

Broad categories

**Examples**

Surgery
Radiation Therapy
Chemotherapy
Hormone
Immunotherapy
Endocrine & Transplant Surgery
Other treatment
Other non-surgical diagnostic procedure

**Attributes**

Could this be a Treatment Procedure? {Y, N}
Could result in specimen {Y, N}
Could result in image {Y, N}

**Uses**

**Policies/Business Rules**

Wouldn't need to track all procedures of these types, just the ones related to cancer/tumor (diagnosis or treatment)

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## TYPE OF RECORD

**Definition**

Various categories of records which distinguishes how the data is related. Abstracts contain CTC related info vs DMV which contain driver license related info.

**Examples**

HEALTH: BECOME PATIENT SETS
Abstract (Registry-created, hospital-created)
Autopsy Report
Cytology Report
Death Certificate/State Death file record (IA has enough information on short death record to build patient set, other registries must get full DC)
Follow-up Abstract
Hematology Report
Indian Health Services Record
Oncology Report
Path Report
Radiology Report
Radiotherapy Report
Special Study record (must have match)

HEALTH: BECOME LEADS
Correction Record
Disease Index
Follow-up Record
Hospital Discharge File
National Death Index
Surgery Log

HEALTH:
Obituary (follow-up only)
Passive FUP (registry created stripped down version of a health record)

SUPPLEMENTAL:
DMV record
Voters registration.
Insurance Demographic information
(HMO)
CMS (HCFA) File
SSA Death records (aka SSDI – Social Security Death Index)
IRS records
State birth record

OTHER:
Census tract record - takes person's address & assoc. with geo-code (from a Vendor)
Name list for race/ethnicity

**Attributes**

Major subtype {Health, Supplemental, Other}

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

ATL: very small hospitals (under 100 beds) send medical records of the CTC patients to the registry. These are processed as other health records (13.0 received, 1.0 screen, 2.0 abstracted) but the original medical records are shredded after the abstract is in the database and edited (6 month holding period to hopefully catch any questions that arise).

## UPDATE NOTIFICATION

**Definition**

The registry's message to the source of a record telling them about corrections to the record made by the SEER registry (HEALTH RECORD UPDATE) OR
The registry's message to the source of a view telling them about corrections to the view made by the SEER registry (ADD/CHANGE/DELETE)
This would also track the 'better information notifications' that occur during the process Update Data Source. (not strictly speaking an update to a particular record, but a change to the best information the source could have.) The registries need to retain the differences the registry have notified the facility/org about separate from the facility view until they get confirmation that the facility/org accepted the change. Especially important if record source is a cancer registrar.
**NOTE**: edit issues which could not be corrected within the registry would go to follow-back.
**DESIGN NOTE**: Would like to use bar codes on outbound communications that expect responses to facilitate tracking.

**Examples**

**Attributes**

Record ID
Accession Number (Facility's Patient ID)
Date of Update
Description of Update (list of variables changed, old and new values and why variable was modified)
Date of Notification

**Uses**

**Policies/Business Rules**

Some registries do not do updates. They reject the entire record and request a corrected record from the source. This would be listed as a SUBMISSION NOTIFICATION.
Most registries would only do this for facilities that had their own registries (ie hospital registry) that needed to collect this same information. Otherwise, they wouldn't bother.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

KY would like to track that the facility/org has accepted a change.

## VOTER'S REGISTRATION

**Definition**

A state's record of who has registered to vote.
Current file is acquired, not based on match.

**Examples**

**Attributes**

Name
Address
SSN
Last Date voted
Date Registered
(other variables, probably not of interest to the registry)

**Uses**

Used for follow-up information; may get more complete address/name info, but that would affect matching.

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## *LOCAL or SPECIAL STUDY SPECIFIC VARIABLES

**Definition**

IMS will allow for the construction of data structures (probably tables) to hold local registry variables or special study specific variables.
These tables will be tied to standard tables (given above) by PAT id, CTC id, FAC id, admission date (PAT is admitted to FAC regarding CTC) and possibly Treatment ID/Type (whichever identifies). These should be enough to tie the local and SS vars.
Registries will be responsible for added meta data to the system to tell how each item is connect. The fact that the data structures are separate should be seamless to the user as well as to ACD.

See Logical Consideration list, Miscellaneous, # 6 and 7.

**Examples**

IA: 3rd party payer source (probably the same as PAYER SOURCE)
IA: Family history of cancer (currently included in CTC)
DT: HIV at DX (possibly the same as COMORBID CONDITION)
DT: Registration number (tied to PAT or PAT/CTC?)
DT: Hospital history number (tied to PAT at FAC view or PAT/CTC at FAC view)
DT: Abstractor ID (tied to PAT, CTC, FAC view)
DT: Editor ID (?? Not sure if this is last editor? Probably tied to PAT)
DT: Path report number (for Special studies, tied to PAT, CTC, FAC)
UT: Random Number (tied to PAT, CTC – only if current DB and processes are not sufficient to their minds. See logical consideration list, misc #5) (AT stores random numbers now, but probably won't have to in the new system.)

**Attributes**

Local or Special study flag {L, S}
Data item name

Date start collection
Data item format (R1 Acceptable values and meaning)
Date format instituted (R1)
How tied to Database (Pat? CTC? Etc)
Text: notes about reasoning behind var related decisions

If SS:
Date end collection
Special study ID

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

### <blank>

**Definition**

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

# Relationships

### ABSTRACT FACILITY LEAD is assigned to ORGANIZATION REPRESENTATIVE

**Definition**

The registry staff member who is responsible for going to the facility/org, reviewing the medical records and creating an abstract for SEER
Cardinality: 1-M… usual case will be 1-1 (lead only assigned 1 time), but if the org rep quits and lead is incomplete, it will be reassigned.

**Examples**

**Attributes**

Date assigned (Start)

**Uses**

When a Registry assigns an abstract lead to one of its abstractors.

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ACTIVE FOLLOW-UP COMMUNICATION is to fulfill ACTIVE FOLLOW-UP NEED or ACTIVE FOLLOW-UP NEED GROUP

**Definition**

The relationship that shows which need(s) a particular communication is addressing

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ACTIVE FOLLOW-UP NEED or FOLLOW-BACK NEED is assigned to ORGANIZATION REPRESENTATIVE

**Definition**

Specifically REGISTRY STAFF
This will definitely handle the tracking of the assignment of these needs to field staff. May also be used to handle tracking who within the central registry office is assigned to a task if a time delay is likely.

**Examples**

**Attributes**

Date assigned

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

It is unlikely that the registries will wish to track this information in the cases where an immediate response is obtained.

## ACTIVE FOLLOW-UP NEED GROUP includes ACTIVE FOLLOW-UP NEED

**Definition**

To eliminate M-M cardinality
A random group of needs that are combined for the convenience of the registry staff (6 needs on 1 letter instead of 6 letters, 1 need each)

Are being directed to the same person/facility/organization to get better follow-up information.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ACTIVE FOLLOW-UP RESPONSE includes HEALTH RECORD

**Definition**

Sometimes, in response to active follow-up, the registry receives a record for the patient, probably a health record.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ACTIVE FOLLOW-UP RESPONSE or FOLLOW-BACK RESPONSE or HEALTH RECORD identifies need for abstract from FACILITY or ORGANIZATION

See associative entity ABSTRACT FACILITY LEAD for more information
May not know FACILITY/ORG from which abstract is needed. Need to allow for a place holder.

## ADD/CHANGE/DELETE or FOLLOW-BACK NEED is caused by <MATCH> or EDIT ISSUE

**Definition**

When a modification occurs to a data item within patient set because information contained in a new record which matched to an existing patient set OR is made in order to resolve an edit issue found within the patient set.

Follow-back needs are found when some piece of data is missing or conflicting with other data (edit issue, which would include visual editing) or when a match is being performed and more information is needed to determine if the match should be accepted or rejected.
While follow-back shows up in many processes, the only way that it is known to be a problem is when an ORGANIZATION REPRESENTATIVE

actually looks at the data item and decides there is a problem, which the registries call visual editing.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ADD/CHANGE/DELETE is based on ACTIVE FOLLOW-UP RESPONSE or FOLLOW-BACK RESPONSE

**Definition**

When a modification occurs to a data item within patient set because information obtained through active follow-up or follow-back.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ADDRESS is located within CENSUS TRACT

**Definition**

The census tract for a specific census year that is associated with an address

**Examples**

**Attributes**

**Uses**

Used for address at diagnosis only

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## CANCER/TUMOR/CASE appears to match to CANCER/TUMOR/ CASE

**Definition**

A CTC in a patient set appears to match to a different CTC within the same patient set. If this is determined to be a true match, the 2 CTCs will be consolidated and the match entity will 'disappear'. Record matches will have to be adjusted so that all records match to the resulting consolidated CTC.

This is most likely to happen when a patient to patient match has been found.

If match is rejected, the relationship should probably remain with a rejected status. Usually, an occurrence of this relationship kicks off a lot of work for the registry staff, so they would want to remember the final decision.

Must have a successful patient match prior to matching CTC to CTC. That is to say, this match happens within a patient set.

SEE ALSO associative entity <MATCH> (SAME CANCER/TUMOR/ CASE) for more information

## CANCER/TUMOR/CASE is diagnosed at FACILITY as TYPE OF CANCER

See associative entity DIAGNOSIS for more information.

May not know FACILITY where CTC was diagnosed, have to allow for that.

## CANCER/TUMOR/CASE or PATIENT is possibly reportable to SPECIAL STUDY

**Definition**

The "fine filter" (not the "gross filter")

This includes CTCs or PATIENTs that are not reportable to SEER.

**Examples**

**Attributes**

Reason not reportable

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## COLLABORATION AGREEMENT applies to INFORMATION REQUEST or SPECIAL STUDY

**Definition**

The information request or special study must be tied to the supporting documentation that makes it valid. Not all information requests require such documentation.

One Special Study may be supported by multiple Collaboration Agreements.

One Information Request may be supported by multiple Collaboration Agreements. Many Information Requests could be supported by the same set of Collaboration Agreements. In some cases, this would be because the Information Requests is in support of a single Special Study.

In Seattle, collaboration agreements are basically confidentiality agreements. There is one signed per year, it may cover multiple requests for data to the registry.
In future it is possible, that these agreements would only cover 1 distinct information request or 1 Special study and it's supporting requests.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

In some registries, there is only one Collaboration Agreement per Special Study. Also, it varies by registry whether a collaboration agreement can cover only 1 special study (seems to be most popular) or if a collaboration agreement covers a time window (like Seattle)

## COURSE includes CONSIDERED TREATMENT MODALITY

**Definition**

This is probably a minor relationship, as most registries will only be tracking 1st course. It would allow you to differentiate between treatment considered (including those not recommended or refused) as 1st course, 2nd course so on.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

DT will continue to track this even though COC is dropping 2nd+ courses
Historic data also exists

## DATA ITEM GROUP includes DATA ITEM

**Definition**

To eliminate M-M cardinality. A non-random group of data items that are compared against each other during an edit.

**Examples**

Site-hist-beh
Gender-site
Gender-hist
Dob-hist

**Attributes**

**Uses**

To track in one place what data items failed an edit and potentially need follow-back.

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## EDIT reveals that DATA ITEM or DATA ITEM GROUP violates RULE

See associative entity EDIT ISSUE for more information.

## ETHNICITY is assigned to name of PATIENT

**Definition**

Computer assigned ethnicity – comparing a patient's last name to the surname file and getting the resulting code.
Since this is 1-1 relationship, computer derived ethnicity is stored in patient.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## FACILITY is affiliated with FACILITY

**Definition**

2 patient treatment addresses have strong ties with each other – includes lab within a hospital or lab that all hospital testing is sent to. A facility may be affiliated with multiple facilities.
Moving up food chain: lab is affiliated with hospital
Not the same as sibling facilities within an organization.

**Examples**

**Attributes**

**Uses**

Can be used to indicate that a Lab is at a Hospital, or a Treatment center is at a Hospital, or a Doctor's Office is in a partnership with a Hospital, …
New Mexico: wants to know which sibling facilities within an organization have sent in abstracts (have views). See data flow 'Consolidated Facility View Patient Set' (possible implementation would be a standard search: given patient set, list facilities with view grouped by affiliations.

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## FACILITY refers PATIENT to FACILITY regarding CTC

**Definition**

When one facility refers a patient to another facility, both facilities are supposed to notify the registry.
This is used to verify that all records for the patient are coming into the registry.
This is required by COC

**Examples**

Physician office xyz refers patient Jane Doe to Hospital Q. This should show up on XYZ (referred to Q) and on Q (referred from XYZ)

**Attributes**

**Uses**

Used to indicate 'referred from' and 'referred to' facilities.

**Policies/Business Rules/Cardinality Constraints**

BR: At least 1 of the facilities has to be the facility whose view this is.
You would need to track these on the registry view.
The facility 'referred to' may never see the patient and hence never have a view.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## FACILITY or INFORMANT FOR PATIENT or MEDICAL PRACTITIONER or MEDICAL PRACTITIONER AFFILIATION or ORGANIZATION or PATIENT responds to SEER REGISTRY regarding FOLLOW-BACK QUERY

See associative entity FOLLOW-BACK RESPONSE for more info.
**PERSON** responded

## FACILITY or INFORMANT FOR PATIENT or MEDICAL PRACTITIONER or MEDICAL PRACTITIONER AFFILIATION or ORGANIZATION or PATIENT responds to SEER REGISTRY regarding ACTIVE FOLLOW-UP COMMUNICATION

See associative entity ACTIVE FOLLOW-UP RESPONSE for more info
**PERSON** responded

## FACILITY or MEDICAL PRACTITIONER or ORGANIZATION or ORGANIZATION REPRESENTATIVE or PATIENT or PERSON has problem with INFORMATION REQUEST FULFILLMENT

See associative entity INFORMATION REQUEST PROBLEM for more info.
**PERSON** has problem

## FACILITY or ORGANIZATION has understanding of PERSON (aka 'VIEW')

**Definition**

**VIEW**: this is a definition of how a view differs from the person.

This is how a view can be established of the patient set. The view can be based on how a facility or org presents the data (facility view) or based upon how a Registry consolidates it (Registry view).
A facility view should be what the facility has told the registry. Not just what happened at that particular facility, not what the registry has told the facility until they confirm that the facility accepted the information.
Some things may appear on the registry view that do not appear in any facility view. This may be caused by consolidation of 2+ values leading to a distinct value or by the registry obtaining data from another source (such as the DMV) that it is not allowed to share with the facilities.
**DESIGN NOTE**: One possible implementation to resolve NM concerns about consolidating twice while allowing for the most stringent interpretation of HIPAA is to design the facility view with all the same data items as the registry view, but to allow the IT staff at a registry to disable the Patient Information data items and the Cancer/Tumor/Case Information data items. This will allow efficient work, prevent garbage from being entered into the facility view, and facilitate a quick implementation of the stringent HIPAA rules if it becomes legally necessary.
Benefits of a Fully implemented facility view include: being able to see the consolidated, visually edited facility view easily without having to reconstruct it from the records; allows a registry to restore data at a hospital registry, easily establish a new registry and aid doctors offices obtain ACoS certification; allow for more complete QC of information from the entry into registry as a record through consolidation and editing; allows more accurate distribution of data to special studies with hospital specific studies or partial IRB approval; being secure that best effort has been made to follow HIPAA.
Benefits of Treatment only facility view include: more efficient use of staff time; more complete dissemination of knowledge.
Registry determines what qualifies as a facility view – many seemed interested in maintaining a facility view for Death certificates, NM is interested in maintaining organization views for associated facilities.
See associative entity PATIENT for more information

**Local Variations**

NM seems to be the only registry interested in treatment only facility view at this time.
NM: collects ORG views: where 5 hospitals are part of same organization, they store the data for those 5 together.

## FACILITY or ORGANIZATION identifies PATIENT or CANCER/TUMOR/CASE

See associative entity IDENTIFICATION for more information
The **VIEW** (how the facility notes their view of the person within their own data)

## FACILITY or ORGANIZATION sends IRB results to SEER REGISTRY

See associative entity IRB DOCUMENTATION for more information.

## FACILITY or ORGANIZATION or ORGANIZATION REPRESENTATIVE accepts UPDATE NOTIFICATION

**Definition**

The entity notified about a registry update (health record update or ACD) accepts the update and lets the Registry know. This gives the registry a more accurate idea of what is in the source's files.

**Examples**

**Attributes**
Date Accepted
**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## FACILITY or ORGANIZATION or ORGANIZATION REPRESENTATIVE communicates with SEER REGISTRY on TYPE OF MEDIA

See associative entity SOURCE COMMUNICATION for further information.

## FACILITY GROUP includes FACILITY.

**Definition**
To remove the M-M cardinality on procedure.
**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## FOLLOW-BACK NEED GROUP includes FOLLOW-BACK NEED

**Definition**
To eliminate M-M cardinality
A random group of needs that are combined for the convenience of the registry staff (6 needs on 1 letter instead of 6 letters, 1 need each)
May not be related to the same patient but are being directed to the same person/facility/organization to get an answer.
**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## FOLLOW-BACK QUERY is sent with ACTIVE FOLLOW-UP COMMUNICATION

**Definition**

For efficiency purposes, follow back needs are reviewed when active follow-up is being done and all questions are sent together. This allows tracking of which needs should be reviewed when the response is received.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## FOLLOW-BACK RESPONSE addresses FOLLOW-BACK NEED

**Definition**

A portion of the follow-back response which resolves an outstanding follow-back need. A given response may address multiple needs.
If it fully addresses a need, the need status should be changed to closed.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## FOLLOW-BACK RESPONSE includes HEALTH RECORD

**Definition**

Sometimes, in response to follow back, the registry receives a record for the patient, probably a health record,

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## HEALTH RECORD fulfills ABSTRACT REQUEST or SPECIFIC RECORD REQUEST

**Definition**

A health record could be in response to the Registry's request for a specific record or an abstract. We want to know this has been received so that request can be closed.

**Examples**

**Attributes**

Date fulfilled
Record Request ID (Specific or Abstract)

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## HEALTH RECORD is correction to HEALTH RECORD

**Definition**

Relates a correction record to the record that it corrects.
The correction record could come in before or after the data is written to Patient Set.
**DESIGN NOTE**: this may be best implemented as a electronic staple of the 2 health records or append the new value to the end of the original record (yuck, loses that it came in separately) or some sort of note between the 'matches' to patient set' that shows the 2 records are related, need to decide best approach
Note that while all correction records should eventually be part of this relationship, not all instances of this relationship would include a 'correction record' type. Sometimes the facility would resend a corrected version of the record (may or may not be marked as 'correction').

**Examples**

A path report #1 comes in with incorrect information. Later, a path report #2 comes in with corrected information. Both represent the same facility/patient/CTC. The second one is considered a correction record.

**Attributes**

**Uses**

If you receive a correction record that does not match anything in working or master data, then you know you are missing a record.

**Policies/Business Rules/Cardinality Constraints**

The record that is the "correction" must either be of type CORRECTION RECORD (used for facilities that generate this type of record) or be the same type as the HEALTH RECORD it is correcting, e.g. ABSTRACT corrects ABSTRACT. In either case, this relationship would be used to flag what is a correction to what.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## HEALTH RECORD is possibly reportable to SPECIAL STUDY

**Definition**

The “fine filter” (not the “gross filter”)
Generally in the name of rapid case ascertainment (need to verify and collect CTC quickly) a health record is determined to be a potential candidate for a special study.
This includes health records that are not reportable to SEER.

**Examples**

**Attributes**

Reason not reportable

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## HEALTH RECORD matches to CANCER/TUMOR/CASE

**Definition**

The record at the CTC level matches an occurrence of CANCER/TUMOR/CASE in a patient set.
When a health record causes a new CTC set to be added or causes new info to be consolidated into an existing CTC set, this relationship will remain for traceability (to know what records made up the CTC set).
Only accepted or rejected (w/ reason) matches need to be stored long term. If current status=possible and last reviewed date is older than time window, match should be released and redone if needed. Once one match of many has been accepted, the user should be able to release all others easily.
Check corresponding match events for history.
SEE ALSO associative entity <MATCH> for more information

## HEALTH RECORD matches to HEALTH RECORD

**Definition**

Matching new health records (reportable or not) with other non-reportable records at any level.
Only accepted or rejected (w/ reason) matches need to be stored long term. If current status=possible and last reviewed date is older than time window, match should be released and redone if needed. Once one match of many has been accepted, the user should be able to release all others easily.
If a match is found between 2 non-reportable records, Process-wise they would have to re-screen it to determine if it were still non-reportable or if enough information has been collected/has changed that these records would contribute to a reportable patient set.
Check corresponding match events for history.
SEE ALSO associative entity <MATCH> for more information

**Uses**

Would need to retain these matches if a record was a correction to it's matching record (trying to track errors from facilities, both counts and kinds).

Would need to retain these matches if both records were non-reportable. It has happened that multiple matching non-reportable records provide enough information to determine that the cancer/tumor/case is actually reportable. If 2 non-reportables make a reportable, links can be moved to the patient set. If 2 non-reportables are still not reportable you want to retain the link so that additional records have all information available when reportability is rechecked.

## HEALTH RECORD matches to PATIENT

**Definition**

**SET**: may match to one VIEW better than another, but overall matches to the patient SET.

The record at the patient level matches an occurrence of PATIENT in patient set.

When a health record causes a new patient set to be added or causes new info to be consolidated into an existing patient set, this relationship will remain for traceability (to know what records made up the patient set).

Only accepted or rejected (w/ reason) matches need to be stored long term. If current status=possible and last reviewed date is older than time window, match should be released and redone if needed. Once one match of many has been accepted, the user should be able to release all others easily.

Check corresponding match events for history.

SEE ALSO associative entity <MATCH> for more information

## HEALTH RECORD matches to PROCEDURE

**Definition**

The record at the treatment level matches an occurrence of PROCEDURE (treatment types) for a cancer/tumor/case in patient set.

When a health record causes a new treatment to be added or causes new info to be consolidated into existing treatment within a patient set, this relationship will remain for traceability (to know what records made up the patient set).

Only accepted or rejected (w/ reason) matches need to be stored long term. If current status=possible and last reviewed date is older than time window, match should be released and redone if needed. Once one match of many has been accepted, the user should be able to release all others easily.

Check corresponding match events for history.

SEE ALSO associative entity <MATCH> for more information

## HEALTH RECORD matches to SUPPLEMENTAL RECORD

**Definition**

Matching non-reportable health record to Supplemental records.

This is done to see if a non-reportable record will become reportable because of new information. (This probably just applies to health records that are not reportable because of residency)

If health record is or becomes reportable, this relationship would be changed into record to patient set type matches.

SEE ALSO associative entity <MATCH> for more information

## HEALTH RECORD UPDATE addresses FOLLOW-BACK RESPONSE or EDIT ISSUE

**Definition**

The reason why the update was made

Having discovered a problem with item(s) on the health record, the item is changed to correct the problem. The change may be to set an override flag if its determined that the original values are fine, just unusual.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## IDENTIFICATION cross-references IDENTIFICATION

**Definition**

Person may be determined to have multiple entries in the system and be collapsed into one. (Joined)

Sometimes, the facility changes ID schemes and changes some IDs to comply. Also, sometimes facilities change ownership/management and wind up with 2 IDs for the same person. They would likely pick one at that point. (Replace)

It may be determined that what is being viewed as a single patient is really multiple patients. The patient set information needs to be split appropriately; the matches to records need to be correctly assigned and outstanding follow-up/follow-back need to be reviewed. (Split)

Not meant for correcting data entry errors.

**Examples**

**Attributes**

Org Rep who changed ID
Date
Type {Replace, Split, Joined}
Reason

**Uses**

**Policies/Business Rules/Cardinality Constraints**

Only refers to this View's ID

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## IMAGE is evaluated by MEDICAL PRACTITIONER

See associative entity IMAGE EVALUATION for more information.

## IMAGE or SPECIMEN is taken during PROCEDURE

**Definition**

As the result of a procedure, there may be an image (such as an X-ray, CT scan, MRI) or a specimen (such as a smear, blood sample, tissue sample).

**Examples**

Jane Doe has 4 mammogram images taken during her mammogram session.

Harry Smith has blood drawn for a PSA during his routine physical.

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## IMAGE EVALUATION or SPECIMEN EVALUATION or PROCEDURE is used to make or confirm DIAGNOSIS

**Definition**

This is diagnostic confirmation level.

A given evaluation or procedure may not be enough to generate a diagnosis, multiple ones may be needed. A given evaluation or procedure may lead to multiple diagnoses. These multiple diagnoses may be the same or different CTCs.
Sometimes a diagnosis is based on a procedure that does not result in either a specimen or image. Therefore, procedure is included for completeness. For example, doctor palpates area and discovers lump, but does not take sample. Or doctor examines skin discoloration and determines melanoma.

**CONVERSION NOTE**: Diagnostic Procedures (Y/N for different procedures, these varied by cancer/tumor site) would have to be dummied in. This was recorded from 1973-1987, but is now obsolete.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## IMAGE EVALUATION or SPECIMEN EVALUATION or PROCEDURE is used to determine stage for CANCER/TUMOR/CASE

**Definition**

Text on the evaluation or about the procedures is used to help determine the stage of a CTC. This staging could be the EOD stage, Collaborative stage, etc.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## INFO REQUEST PROBLEM RESOLUTION modifies INFORMATION REQUEST

**Definition**

The resolution to a problem would modify the information request. In some instances, it would necessitate adding a new request. If the wrong data was selected or the requester wishes to expand their request are the 2 most likely instances.

Modifications needed should be shown in info request or resolution.

**Examples**

**Attributes**

New request ID (if needed)

Date modified

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## INFORMATION REQUEST is fulfilled by ORGANIZATION REPRESENTATIVE by using/accessing REPORT/EXTRACT

See associative entity INFORMATION REQUEST FULFILLMENT for more information.

## INFORMATION REQUEST is to fulfill DATA EXCHANGE AGREEMENT

**Definition**

A report/extract/registry-controlled file is sent to the other partner of the data exchange agreement by the SEER registry (probably an extract) in order to transfer the appropriate knowledge as agreed.

The concept of selecting what is reportable to the DEA is handled during the process of extraction. Generally, CTCs residing in given area.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

NM: Dr. Key needs to approve outgoing data before it's sent.

## INFORMATION REQUEST supports SPECIAL STUDY

**Definition**

A researcher who is running a special study needs additional information (not additional participants) which he attempts to gain via an information request.

We have expanded this to include the standing request that the registry releases the data it collects to the special study on a regular schedule. This may be a one time release of data (for example, if it is all coming from established patient sets) or recurring releases of data (if it involves rapid case ascertainment and health records are released as received – may happen on weekly basis)

**DESIGN NOTE**: if it is problematic to have the supporting info needs and the transfer of data mechanism tracked the same way, 2 relationships may be used. Differences weren't obvious during model development, but might show up later.

**Examples**

X years down the line, researcher contacts registry and asks for updated information (ie follow-up for prospective study)

Prostate QOL study asks for incidence and mortality rates for prostate cancer/tumor.

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## IRB DOCUMENTATION applies to INFORMATION REQUEST

**Definition**

The information request must be tied to the supporting documentation that makes it valid. Not all information requests require such documentation.

One Information Request may be supported by multiple IRBs. Many Information Requests could be supported by the same set of IRBs, but

the Information Requests would be in support of a single Special Study. A Info Request that was distinct from any Special Study and needed these supporting documentation would need it's own separate IRBs.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## IRB DOCUMENTATION applies to SPECIAL STUDY

**Definition**

The special study must be tied to the supporting documentation that makes it valid.
One Special Study may be supported by multiple IRBs. Only one Special Study would be supported by the same set of IRBs.
One IRB is from the Registry: all registries track this IRB. There may be 0-M IRBs from other facilities/organizations. Some registries may not track this. In these registries, there is only 1 IRB per Special Study.
If a special study is modified, the IRB document would be modified and sent back to be reviewed. This is counted as the same IRB. A single IRB could have multiple modified versions.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

IRB approval is required for ALL special studies: IA, LA, HI, UT, DT, NM, AT

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## MEDICAL PRACTITIONER cares for CANCER/TUMOR/CASE

**Definition**

Different medical practitioners associated with the cancer/tumor/case
Mostly physicians.

**Examples**

**Attributes**

Attending? {Y, N}
Referring? {Y, N}
Primary Surgeon? {Y, N}
Radiation Oncologist? {Y, N}

Medical Oncologist? {Y, N}
*Managing* Physician? {Y, N}
Follow-up Physician? {Y, N} (NAACCR #2470)

**Uses**

Possible follow-up contact

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## MEDICAL PRACTITIONER is affiliated with FACILITY

See associative entity MEDICAL PRACTITIONER FACILITY AFFILITIATION for more information.

## MEDICAL PRACTITIONER plans treatment for CANCER/TUMOR/CASE

See associative entity COURSE for more information

## MEDICAL PRACTITIONER or ORGANIZATION REPRESENTATIVE or PATIENT or PERSON requests information from SEER REGISTRY on TYPE OF MEDIA for FACILITY or MEDICAL PRACTITIONER or ORGANIZATION or ORGANIZATION REPRESENTATIVE or PATIENT or PERSON

See associative entity INFORMATION REQUEST for more information.

**PERSON** requests information for **PERSON**

## MEDICAL PRACTITIONER or ORGANIZATION or PERSON or SPECIAL STUDY receives mail at ADDRESS

**Definition**

Mailing address for medical practitioner OTHER THAN facility addresses
Mailing address for an organization OTHER THAN facility addresses. (May be a non-facility type organization, or just a separate address)
Mailing address given to registry by person (for example, someone who makes an information request, an informant, etc).
Mailing address for a special study. The contact address.

**Examples**

**Attributes**

Preferred address {Y, N}

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION or ORGANIZATION GROUP conducts SPECIAL STUDY

**Definition**

Both SEER REGISTRIES and OTHER ORGANIZATIONS conduct Special Studies. SEER must approve special study and typically gets special study to 'selected based on criteria & approved by physician/patient' point before releasing the information to the researcher.
The one in charge of the special study, setting up criteria, analyzing study results, etc. The actual researcher may be part of SEER staff or just affiliated with the registry. The organization who is paying for the study.

**Examples**

**Attributes**
Start Date
End Date

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**
ATL: most special studies are within the university.

## ORGANIZATION GROUP includes ORGANIZATION

**Definition**
To remove M:M on who is conducting a special study.
The random grouping of organizations who are funding the same study.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION provides healthcare services at ADDRESS

See associative entity FACILITY for more information
A health care organization can own/manage many hospitals, labs, etc…
In New Mexico, if a Facility is part of an organization, they would like to store the names/ids of the other facilities within the org that have seen a patient within the facility view.

## ORGANIZATION sets RULE

**Definition**
Some one of authority (may be within staff, state/federal legistlation, NCI) who determines a new rule/procedure/data standards.

**Examples**

**Attributes**
Effective Start Date
Effective End Date
**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION stores SPECIMEN

**Definition**
The organization that is responsible for this particular specimen's banking.
**DESIGN NOTE**: If this information isn't coming in on a health record, must add process to obtain it.
**Examples**

**Attributes**

**Uses**
When specimen is needed for a special study.
**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION or ORGANIZATION REPRESENTATIVE contacts MEDICAL PRACTITIONER or MEDICAL PRACTITIONER AFFILIATION to get permission to contact PATIENT or HEALTH RECORD (person) to participate in SPECIAL STUDY

**Definition**
**PERSON** is going to be contacted
Someone must contact the physician to get consent for a patient to be contacted in the name of a special study (PRIOR TO PATIENT CONTACT). This may be SEER registry staff or staff employee by the special study.
This only needs to be done if the patient will be contacted during the course of the special study.
**DESIGN NOTE**: This could include patients who eventually become patient sets (if timing dictates that they are contacted prior to becoming a patient set) as well as health record patients used as controls.
**Examples**

**Attributes**
Date
Consent obtained? {Y, N}
**Uses**

**Policies/Business Rules/Cardinality Constraints**

This is done after the patient has been selected to be in the study based on criteria.

They include passive consent: if they send a letter to the physician 'we want to use your patient' and the physician doesn't complain, they assume he agrees.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION or ORGANIZATION REPRESENTATIVE contacts PATIENT or HEALTH RECORD (person) about participating in SPECIAL STUDY

**Definition**

**PERSON** is contacted

Some studies revolve around patient quality of life and other information that only the patient knows, so the patient must be interviewed (or sent a survey). This occurs after the physician ok and prior to releasing the patient information to the researcher. It is the act of asking a patient if they wish to participate in the study (not the interview, tho for efficiency, interview may be done after okay received, but that's not in scope). The patient may refuse to participate at this time.

Cardinality on contacts PATIENT is 1-1, this is policy, patient should only be contacted once about special studies.

This would include patients that eventually are tracking in patient sets as well as health record patients used as controls.

**Examples**

**Attributes**

Date

Consent obtained{Y,N}

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION REPRESENTATIVE agrees to collaborate with SEER REGISTRY

See associative entity COLLABORATION AGREEMENT for more information.

## ORGANIZATION REPRESENTATIVE or PERSON attempts to access operations of SEER REGISTRY

**Definition**

The attempt (successful or un) to log in to the SEER registry's system.

**Examples**

**Attributes**

Date of attempt
Time attempt made
Account
Password
IP address
Access Status {Success, Failure}

**Uses**

Want to be able to see how many failed hit there are.

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION REPRESENTATIVE changes status of HEALTH RECORD-PATIENT MATCH or HEALTH RECORD-CTC MATCH or HEALTH RECORD-PROCEDURE MATCH or HEALTH RECORD-HEALTH RECORD MATCH or HEALTH RECORD-SUPPLEMENTAL RECORD MATCH or SUPPLEMENTAL RECORD-PATIENT MATCH or SAME PATIENT or SAME CTC or SAME PROCEDURE

See associative entity MATCH UPDATE for more information

## ORGANIZATION REPRESENTATIVE creates TYPE OF RECORD on behalf of FACILITY or ORGANIZATION

See associative entity RECORD for further information.
When this is a registry-created abstract or a record for a special study, the registries wish to track time needed to create.
Usually won't know which org rep if this is created by non-registry staff, however, are interested in who created health records if can be easily obtainable, especially abstracts (for quality control and training purposes)

## ORGANIZATION REPRESENTATIVE deletes inappropriate data via ACD or HEALTH RECORD UPDATE

**Definition**

This org rep would be a manager – see BPM 10.12.2
If a deletion of this type occurs it would need to be tracked as specified in 10.12, it would need to be referenced by BPM 16.0 to verify that no additional corrections need to be made once field data is synchronized.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION REPRESENTATIVE edits HEALTH RECORD or PATIENT (SET)

See associative entity EDIT for more information.
**SET** is edited
Only data validity rules are used in this relationship

## ORGANIZATION REPRESENTATIVE evaluates ACTIVE FOLLOW-UP RESPONSE with respect to PATIENT

**Definition**

SEER staff reviews the answer received for the active follow up action to determine if it provides vital status information later than what the registry currently knows and what other information was received (if any). If acceptable follow up was not received, a new action must be generated.

**Examples**

**Attributes**

Is date later than registry date of last contact? {Y, N}
Is patient Alive? {Y, N}
Action Taken {Patient Set is Updated, No New Information, Change doesn't make sense, Follow-Back is Needed}

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION REPRESENTATIVE evaluates FOLLOW-BACK RESPONSE

**Definition**

SEER staff reviews the answer received for the follow back query to determine if it answers the question, what other information was received (if any) and what process needs the information. If the query wasn't answered, a new query must be generated.
1-m-m-1 cardinality because evaluation may be complex and hence there is room for error or multiple evaluations. Therefore, it is likely that these are periodically re-evaluated in the name of quality control.

**Examples**

**Attributes**

Disposition (see process model text for domain)
Does it Answer the Query? {Y, N}
Resolution decision (text – accepting their answer, making change, whatever)
New data value (R1)

**NOTE**: if it doesn't answer the query, disposition is Follow-Back because more is needed.

**Uses**

**Policies/Business Rules/Cardinality Constraints**

Must be an Authorized Registry Staff Person that evaluates

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION REPRESENTATIVE follows up with FACILITY or INFORMANT FOR PATIENT or MEDICAL PRACTITIONER or MEDICAL PRACTITIONER AFFILIATION or ORGANIZATION or PATIENT to fulfill ACTIVE FOLLOW-UP NEED or ACTIVE FOLLOW-UP NEED GROUP

See associative entity ACTIVE FOLLOW-UP COMMUNICATION for more info

**PERSON** is followed up with about status of PERSON

## ORGANIZATION REPRESENTATIVE identifies need for follow back on DATA ITEM or DATA ITEM GROUP within RECORD or PATIENT (SET) or PATIENT VIEW/RECORD GROUP

See associative entity FOLLOW-BACK NEED for more info.

**SET**: problem could be in any view within the set.

## ORGANIZATION REPRESENTATIVE is asked to fill ABSTRACT REQUEST or SPECIFIC RECORD REQUEST

**Definition**

From 10.2.2, when a SEER org rep must be sent in search of health records that have been request from a facility but not received.

In some registries, a fine may be charged to the facility by the registry for providing the man-power to track down a record. This relationship (if date filled had been completed) would allow the registry to calculate such a fee.

**Examples**

**Attributes**

Date assigned

Date closed

Reason {filled, cancelled record received; cancelled no record could be found}

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

CA & UT can fine, but haven't.

ST has fined

NJ would fine

## ORGANIZATION REPRESENTATIVE makes change to DATA ITEM within HEALTH RECORD

See associative entity HEALTH RECORD UPDATE for further information.

## ORGANIZATION REPRESENTATIVE makes change to DATA ITEM within PATIENT

**SET** – could be within any view. Most likely 1 facility and possibly the registry view.

See associative entity ADD/CHANGE/DELETE for further information.

### ORGANIZATION REPRESENTATIVE makes change to ABSTRACT FACILITY LEAD or ACTIVE FOLLOW-UP NEED or FOLLOW-BACK NEED

See associative entity TASK HISTORY for more info.

### ORGANIZATION REPRESENTATIVE makes change to DATA EXCHANGE AGREEMENT or INFORMATION REQUEST PROBLEM or SPECIAL STUDY

See associative entity EXTERNAL NEED HISTORY for more info.

### ORGANIZATION REPRESENTATIVE makes change to FACILITY or MEDICAL PRACTITIONER or MEDICAL PRACTITIONER FACILITY AFFILIATION or ORGANIZATION or ORGANIZATION REPRESENTATIVE or PAYER SOURCE or PERSON or RULE

See associative entity AUXILIARY HISTORY for more info.

### ORGANIZATION REPRESENTATIVE makes change to TYPE OF ACTIVE FOLLOW-UP or TYPE OF CANCER or TYPE OF MARKER or TYPE OF MEDIA or TYPE OF NON-CANCER DISEASE or TYPE OF PROCEDURE or TYPE OF RECORD

See associative entity LOOK-UP HISTORY for more info.

### ORGANIZATION REPRESENTATIVE overrides RULE with respect to PATIENT

See associative entity OVERRIDE for more info.

### ORGANIZATION REPRESENTATIVE queries FACILITY or INFORMANT FOR PATIENT or MEDICAL PRACTITIONER or MEDICAL PRACTITIONER AFFILIATION or ORGANIZATION or PATIENT to fulfill FOLLOW-BACK NEED or FOLLOW-BACK NEED GROUP

See associative entity FOLLOW-BACK QUERY for more info.

**PERSON** is queried

### ORGANIZATION REPRESENTATIVE requests access to medical records from FACILITY or ORGANIZATION to resolve ABSTRACT FACILITY LEAD

**Definition**

In order for a SEER org rep to create an abstract, they have to go to the facility in question and review the medical records for the patient. Since these records are secure and no one wants to waste time waited for them to be unearthed, the org rep requests the medical records for the leads they wish to resolve prior to going to the hospital.
This is the org rep and not SEER because it is done by the person (on behalf of SEER) at timing convenient to themselves.

**Examples**

**Attributes**

Staff Name who will arrive
Date/Time coming
Reason denied

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION REPRESENTATIVE resolves INFORMATION REQUEST PROBLEM

See associative entity INFO REQUEST PROBLEM RESOLUTION for more info.

## ORGANIZATION REPRESENTATIVE reviews HEALTH RECORD UPDATE or ADD/CHANGE/DELETE or EDIT

**Definition**

An experienced registry staff member periodically examines at least a random sample of the data received by the registries and modification made to it. This is done for quality control, they are looking for problems not caught, problems incorrectly modified and non-problems labeled as problems (and modified).

**Examples**

**Attributes**

Review Date
Problems found (R1 – text)
Type of problem (R1) {Correction missed, Incorrect value used, Correct value modified}
(who did it and when would be found in the update or ACD)

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION REPRESENTATIVE scans RECORD

See associative entity SCANNED IMAGE for further information.

## ORGANIZATION REPRESENTATIVE sends notice about INFORMATION REQUEST

**Definition**

Notices may sent by the org rep in the registry to the requester about the information request: most likely to say the date they expect to send the fulfillment or any problems that exist that make the request invalid or unfulfillable. The reasons are saved in the info request, and the projected date does not need to be saved.
**DESIGN NOTE**: the registry may wish to save a copy of the communication.

**Examples**

**Attributes**

Date of notice

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION REPRESENTATIVE synchronizes field and central version of ANY

**Definition**

The Field staff uses process 16.0 to synchronize data on the field machine to data in the central registry office. This would include any info in the model that goes to field L computer

**Examples**

**Attributes**

Date of synchronization

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION REPRESENTATIVE tracks INFORMATION REQUEST

**Definition**

The staff member who is responsible for receiving an information request and making sure that it is fulfilled

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION REPRESENTATIVE views PATIENT (SET)

**Definition**

For HIPAA, need to track who (external to registry) accessed this patient set, the organization they are associated with and when it was accessed. Really don't care which view, important point is that the patient's information was accessed and they have to be able to tell the patient who has seen their information.

**Examples**

**Attributes**
Date viewed
**Uses**

**Policies/Business Rules/Cardinality Constraints**
External access only
They are interested in this for privacy concerns. If a patient calls and wants to know who saw their information, the registries want to be able to tell them. (same reason for ORG REP views PATIENT)
**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION REPRESENTATIVE visits FACILITY or ORGANIZATION

**Definition**
When the SEER org rep goes to a facility or organization, usually to do abstracting or sometimes case finding.
Place they travel to is based on where records are stored.
**Examples**

**Attributes**
Date
Reason for Visit (abstracting, case finding, probably a text field or a series of flags)
**Uses**
Tracking registry field staff visiting facilities
**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## ORGANIZATION REPRESENTATIVE works on SPECIAL STUDY

**Definition**
The SEER registry staff who work on the special study
Tracking of effort for billing purposes
**Examples**

**Attributes**
Hours for Org Rep
**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## (FACILITY VIEW OF) PATIENT contributes to (REGISTRY VIEW OF) PATIENT

**Definition**

Registry view is considered to be 'parent'; it is built from the facility/org views and supplemental records which may not be included in any other views.

**Examples**

**Attributes**

**Uses**

To associate views within a patient set.

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## PATIENT appears to match to PATIENT

**Definition**

**SET** appears to match to SET, while a VIEW within the set may match more closely, the end result is a SET match.
A PATIENT in patient set appears to match to another occurrence of PATIENT in separate patient set.
If match is accepted, these to entities will be combined into one, so the relationship will disappear.
If match is accepted, all the matches from both patients to various records need to be assigned to the final patient.
If match is rejected, the relationship should probably remain with a rejected status. Usually, an occurrence of this relationship kicks off a lot of work for the registry staff, so they would want to remember the final decision.
SEE ALSO associative entity <MATCH> (SAME PATIENT) for more information
Very Rare

## PATIENT has TYPE OF CANCER

See associative entity CANCER/TUMOR/CASE for more information
While PERSON has type of cancer, this is actually the **VIEW** (understanding) of the patient having the CTC.

## PATIENT has TYPE OF NON-CANCER DISEASE comorbid with CANCER/TUMOR/CASE

See associative entity COMORBID CONDITION for further information.
While PERSON has type of disease, this is actually the **VIEW** (understanding) of the patient having a disease.
Required by COC, currently allowing for 6.

## PATIENT is admitted to FACILITY regarding CANCER/TUMOR/CASE

**Definition**

While a PERSON is admitted, this is actually the **VIEW** (understanding) that the patient has done so.
Patient goes to a facility for diagnosis of or treatment of CTC. The actual date of admission is not always the same as the diagnosis or treatment date.

**Examples**

**Attributes**

***Date of admission***
*Date of discharge*
**First admission for CTC?** {Y, N} (Date of 1st admission **NPCR** required)

**Uses**

**Policies/Business Rules/Cardinality Constraints**

Only 1 admission is tracked for each patient, CTC, facility.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## PATIENT refuses CONSIDERED TREATMENT MODALITY

**Definition**

While a PERSON refuses treatment, this is actually the **VIEW** (understanding) that the patient has done so.
This only applies to RECOMMENDED treatment modalities.
Patient decides (for whatever reason) not to undergo a therapy suggested by the physician. If multiple therapies are suggested (surgery/radiation), the patient may refuse only one piece (multiple refusals are multiple occurrences of this relationship)

**Examples**

**Attributes**

Date of Refusal (may not know or may be derived)

**Uses**

**Policies/Business Rules/Cardinality Constraints**

All or some of the CONSIDERED TREATMENT MODALITIES can be refused.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## PATIENT resides at ADDRESS

See associative entity RESIDENCY for more info
While a PERSON resides somewhere, this is actually the **VIEW** (understanding) of where that is.

## PATIENT or CANCER/TUMOR/CASE or HEALTH RECORD is included in SPECIAL STUDY

See associative entity SPECIAL STUDY INCLUSION for more information
VIEW of patient – usually the registry view.

## PATIENT or CANCER/TUMOR/CASE is possibly reportable to SPECIAL STUDY

**Definition**

In other words they are eligible, but have not yet been sent

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## PAYER SOURCE covers CANCER/TUMOR/CASE

**Definition**

The primary payer for the services provided for a Cancer/Tumor/Case. This is usually an insurance company who has agreed to provide payment for services received by an individual for a given time window (or disease episode). Person may have multiple carriers who pay for different procedures.

Other examples of payers are self-pay, write off, Medicaid, military.

**Examples**

Payer examples include: HMO, Blue Cross

**Attributes**

Date coverage started
Date coverage ended
Primary? {Y, N}

**Uses**

To report on possible differences in quality of care by payer/source

**Policies/Business Rules/Cardinality Constraints**

At one point in time, one CANCER/TUMOR/CASE could be covered by multiple payer sources.

Currently, interested in the primary payer only

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## PERSON represents ORGANIZATION

See associative entity ORGANIZATION REPRESENTATIVE for further information.

## PERSON or PATIENT has knowledge of PATIENT

See associative entity INFORMANT FOR PATIENT for more information.

While a PERSON has knowledge of **PERSON**, this is the **VIEW** (understanding, belief) that this is so.

## PROCEDURE fulfills CONSIDERED TREATMENT MODALITY

**Definition**

Given that a doctor/group of doctors has prescribed or recommended some method of treating a given cancer/tumor in the patient, this particular procedure is one part of providing the treatment.
Recommended = Y

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

If two procedures are required to fulfill the treatment recommended/ prescribed, may only be informed about the second procedure.
Example: breast cancer/tumor. Start with a lumpectomy and entire cancer/tumor not removed. Then a second surgery is done to remove the rest (mastectomy). May get a pre-consolidated clump of information.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

Most registries handle the treatment records/information in different ways.
NCCC - Does not have treatment records, but does carry treatment information about facilities.

## PROCEDURE is directed at CANCER/TUMOR/CASE

**Definition**

A procedure is attempting to diagnose, treat or otherwise interact with a cancer/tumor/case. In some cases, more than 1 CTC will be affected (radiation directed a multiple cancer/tumors in patient)

**Examples**

**Attributes**

**Uses**

Wish to check every facility that interacted with CTC and how they interacted. This relationship handles both treatments and diagnostic procedures.

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## PROCEDURE (TREATMENT) appears to match to PROCEDURE (TREATMENT)

**Definition**

A PROCEDURE (of treatment type) for a CTC in a patient set matches to an occurrence of PROCEDURE (of treatment type) for a CTC in a patient set – that could be a separate patient set, within the same patient set, within the same CTC or within the same view.

If 2 separate patient sets and this is a true match, the patient sets need to be consolidated, if 2 separate CTCs, the CTC sets need to be consolidated, if 2 separate treatments, the treatment information needs to be consolidated.
If this is determined to be a true match, the 2 items (as noted above) will be consolidated and the match entity will 'disappear'. Record matches may have to be adjusted so that all records match to the resulting consolidated patient set.
If match is rejected, the relationship should probably remain with a rejected status. Usually, an occurrence of this relationship kicks off a lot of work for the registry staff, so they would want to remember the final decision.
Must have a successful patient match and CTC match prior to matching Facility view to Facility view. That is to say, this match happens within a patient set for a particular CTC.
SEE ALSO associative entity <MATCH> (SAME PROCEDURE) for more information

## REPORT/EXTRACT includes (any information in the model)

**Definition**

Could include patient set information as well as record information as well as "internal" information for internal Registry reports.
**DESIGN NOTE**: this is marked in the LDM as including PATIENT and CTC, because we believe that these are the inclusions that the registries care about.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

Only truly interested in external reports/extracts where the patient or CTC is identified. For aggregate reports (incidences rates, etc), they probably don't care specifically if they can reproduce the report.
They are interested in this for privacy concerns. If a patient calls and wants to know who saw their information, the registries want to be able to tell them. (same reason for ORG REP views PATIENT)

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## REPORT/EXTRACT is occurrence of STANDARD REPORT/EXTRACT

**Definition**

When a report/extract is used frequently, it becomes known as a standard report/extract. The methods for creating standard reports/extracts are saved for easy recreation.

**Examples**

**Attributes**

Times used

**Uses**

**Policies/Business Rules/Cardinality Constraints**

The use of 'standard' is a policy to speed up the processing time of information requests by keeping frequently needed reports/extracts easy to access and to recreate.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## RESIDENCY is established for CANCER/TUMOR/CASE

**Definition**

Address at diagnosis.

County/State are the most important part of this particular address. It establishes residency in a registry catchment area.

**Examples**

**Attributes**

(from address, but only collected for address at dx)

Rural/Urban Continuum (based on county, only needed for Dx)

Rural/Urban Continuum Format {1993, 2000}

**Uses**

**Policies/Business Rules/Cardinality Constraints**

1 and only 1 residency for each cancer/tumor/case

'Snowbirds' must be assigned a single residency for the CTC

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SEER REGISTRY agrees to exchange data with FACILITY or ORGANIZATION

See associative entity DATA EXCHANGE AGREEMENT for more information.

## SEER REGISTRY desires better last contact date for PATIENT

See associative entity ACTIVE FOLLOW-UP NEED for more information

This patient is the registry VIEW. The person is alive or dead regardless of the registry's knowledge of that event.

This is probably a temporary entity. After the need has been resolved, there shouldn't be a reason to retain this. It can be recreated at will whenever active follow-up is scheduled.

## SEER REGISTRY notifies FACILITY or ORGANIZATION or ORGANIZATION REPRESENTATIVE about status of HEALTH RECORD UPDATE or ADD/CHANGE/DELETE

See Associative Entity UPDATE NOTIFICATION for more information.

## SEER REGISTRY notifies FACILITY or ORGANIZATION or ORGANIZATION REPRESENTATIVE about status of SOURCE SUBMISSION or RECORD

See Associative Entity SUBMISSION NOTIFICATION for more information.

## SEER REGISTRY requests abstract from FACILITY or ORGANIZATON to resolve ABSTRACT FACILITY LEAD

See associative entity ABSTRACT REQUEST for more information.

## SEER REGISTRY requests TYPE OF RECORD from FACILITY or ORGANIZATION

See Associative Entity RECORDS REQUEST for more information

## SEER REGISTRY requests TYPE OF RECORD from FACILITY or ORGANIZATION to get information about HEALTH RECORD

See associative entity SPECIFIC RECORD REQUEST for more information

## SEER REGISTRY sends proposed COLLABORATION AGREEMENT to ORGANIZATION or ORGANIZATION GROUP

**Definition**

When a special study or information request involves restricted information, the SEER registry sends a proposed collaboration agreement document to the requester or special study sponsor
Information request or special study is not considered valid until a signed version of a collaboration agreement is returned.
This agreement is retained for legal reasons.

**Examples**

**Attributes**

Date sent

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SEER REGISTRY or ORGANIZATION or ORGANIZATION GROUP requests IRB DOCUMENTATION from FACILITY or ORGANIZATION

**Definition**

When a special study or information request involves restricted information, the SEER registry or the requester or special study sponsor may have to obtain Institution Review Board approval.
Information request or special study is not considered valid until IRB documentation specifying approval has been received.
This documentation is retained for legal reasons.

**Examples**

**Attributes**

Date requested

**Uses**

**Policies/Business Rules/Cardinality Constraints**

Some registries may choose to make this request. Others require the requester or special study sponsor to do so. In the cases where it is requested by someone else, the actual request is out of scope, although a copy of the documentation should be provided to the registry.
IRB approval is required for ALL special studies: IA, LA, HI, UT, DT, NM, AT

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SEER REGISTRY tracks ID PROBLEM at FACILITY or ORGANIZATION

**Definition**

The registry's knowledge of a problem with a facility's or organization's ID. The registry would contact the facility/org to find out what caused the problem

2 current problems of interest:

Accession number missing from registry data

Accession number assigned to multiple people

**Examples**

**Attributes**

Date discovered

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SOURCE COMMUNICATION is in response to SUBMISSION NOTIFICATION

**Definition**

Wish to know that a failed/corrupted/problematic submission has been resubmitted so you can consider the notification 'closed'.

**Examples**

**Attributes**

Date received

Submission notification tag

Staff ID who received

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SOURCE COMMUNICATION is transmission of SOURCE SUBMISSION

**Definition**

The act of transferring the data from a source to the SEER registry

May be via US mail delivery, FTP, etc.

A particular communication may contain multiple submissions. For example, an email with 4 attachments; a diskette with 3 files.

**Examples**

**Attributes**

Date
Status (Okay trans, Corrupted trans)

**Uses**

**Policies/Business Rules/Cardinality Constraints**

One communication could include multiple submissions (or files) in today's implementation for some Registries. If multiple record types are included in 1 source communications, they would be broken into multiple source submissions.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SOURCE SUBMISSION fulfills DATA EXCHANGE AGREEMENT

**Definition**

The data received by SEER from the other partner in the data exchange agreement.

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

NM: Dr Key needs to approve the use of this data for FUP

## SOURCE SUBMISSION fulfills RECORDS REQUEST

**Definition**

A source submission could be in response to the Registry's request for some kind of records. (abstracts, disease index, records for John Doe) want to know this has been received so that request can be closed.

**Examples**

**Attributes**

Date fulfilled

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SOURCE SUBMISSION includes RECORD

**Definition**

A group of data provided by a source (facility/org), may contain any number of records (1..M, also 0 – that there are no records).

**Examples**

**Attributes**

Location of Record

**Uses**

**Policies/Business Rules/Cardinality Constraints**

Current policy/implementation is that a SUBMISSION contains multiple RECORDs, but of one record type. This may or may not be required/desired in the new system; reconsider during implementation. The absence of this relationship would indicate a submission that contains zero records (i.e. a report that a facility or org or org rep has nothing to submit).

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SOURCE SUBMISSION is described by FORMAT

**Definition**

Each source submission is sent in 1 and only 1 format. The format describes the type of file (XML, text column delimited, text comma delimited, etc), the fields included and where they are located for each record, and the valid values and meaning of the values for each field.

**Examples**

This submission is sent in NAACCR: flat, column delimited, fields and values described in NAACCR data standards guides.

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SOURCE SUBMISSION is result of SPECIAL STUDY

**Definition**

A source submission should be received from each special study providing the registry with information gathered by the special study which may be of interest to the registry.

Things of interest include Date of last contact (if interview done), better information on treatment, prior CTCs, so on. Some special studies may

submit a notice that no information of interest to the registry was collected.

**Examples**

**Attributes**

Date

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SPECIAL STUDY INCLUSION includes same person as SPECIAL STUDY INCLUSION

**Definition**

To connect a person being included in special study A (whether that is via a patient set or health record) to the same person being included in special study B.

For those registries where a patient may be included in multiple special studies at a time, under the constraint that the studies must coordinate contact with the patient.

Whether coordination is needed may be determined by date of studies and whether patient contact is desired.

**Examples**

**Attributes**

Coordination needed? {Y, N}

Controlling Special Study ID

**Uses**

Allows multiple studies to use the same patient for highly desired cancer types without overburdening the patient in question.

**Policies/Business Rules/Cardinality Constraints**

Some registries would not allow a person to be used in multiple studies at the same time.

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## SPECIMEN is evaluated by LAB

See associative entity SPECIMEN EVALUATION for more information.

## SUPPLEMENTAL RECORD matches to PATIENT

**Definition**

**SET**: may match better to one VIEW than another, but end result is SET match.

A supplemental record matches an occurrence of PATIENT in the patient set (i.e. this is just a patient level match). This is also a deterministic match. They don't really need store scores and weights for these.

When a supplemental record causes an updated to info in an existing patient set, this relationship will remain for traceability (to know what records contributed to the patient set).
Only accepted or rejected (w/ reason) matches need to be stored long term. If current status=possible and last reviewed date is older than time window, match should be released and redone if needed. Once one match of many has been accepted, the user should be able to release all others easily.
Check corresponding match events for history.
Used for follow-up
SEE ALSO associative entity <MATCH> for more information

## TYPE OF MARKER is associated with CANCER/TUMOR/CASE or PATIENT

See associative entity MARKER for further information
While PERSON has type of marker, this is actually the **VIEW** (understanding) of the patient having a marker.

## TYPE OF MARKER is collected for TYPE OF CANCER

**Definition**

If marker is only relevant to specific cancer types

**Examples**

Estrogen Receptor is only collected for breast cancer/tumors
CA-125 done for ovarian, etc
CEA done for most digestive sites, breast

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

## TYPE OF PROCEDURE is considered for CANCER/TUMOR/CASE

Only tracking types of procedures where Is this a Treatment Procedure? = Y.
See associative entity CONSIDERED TREATMENT MODALITY for more information.

## TYPE OF PROCEDURE is performed at FACILITY or FACILITY GROUP on PATIENT

While procedure is performed on PERSON, this is the **VIEW** (understanding) of what has occurred.
FACILITY or one member of the FACILITY GROUP may not be known, would have to allow this. Type of Procedure may be a 'guess' instead of exact knowledge if facility is unknown.
See associative entity PROCEDURE for further information.

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**Definition**

**Examples**

**Attributes**

**Uses**

**Policies/Business Rules/Cardinality Constraints**

**Sensitivity**

**Estimated Number of Occurrences**

**Local Variations**

# Attributes

## Attribute1

**Entity/Relationship:**
**Definition**

**Examples**

**Interested Registries**
Interested:
Not Interested:
**Policies/Business Rules**

**Edit Criteria/Domain**

**Sensitivity**

## Attribute2

**Entity/Relationship:**
**Definition**

**Examples**

**Interested Registries**
Interested:
Not Interested:
**Policies/Business Rules**

**Edit Criteria/Domain**

**Sensitivity**

## Attribute3

**Entity/Relationship:**
**Definition**

**Examples**

**Interested Registries**
Interested:
Not Interested:
**Policies/Business Rules**

**Edit Criteria/Domain**

**Sensitivity**

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**Entity/Relationship:**
**Definition**

**Examples**

**Interested Registries**
Interested:
Not Interested:
**Policies/Business Rules**

**Edit Criteria/Domain**

**Sensitivity**

# Other Definitions

## Abstract

**Definition**
All abstracts are partial patent sets, but not all partial patient sets are abstracts.
A patient set is a structured thing. An abstract is a single thing.

A summarized report of the medical information about a cancer/tumor/case as it appears in the patient's medical records at a facility. Mostly, this report is compiled by the hospital staff or by a registry staff member sent to the facility specifically for this purpose (an **abstractor**). Ideally, every cancer/tumor/case would have an abstract for every facility at which it was seen/treated. More practically, information gathering is not considered complete until there is at least 1 abstract, although path-only and death certificate only cancer/tumor/cases are released to maintain reporting levels. The data items contained on this report (which include text summary fields) encompass all SEER and NAACCR requested information.
**Local Variations**

## Accession Number

**Definition**
Facility assigned number identifying a patient and possibly CTC
**Local Variations**
UT, HI, IA: patient only
DT, LA: Pat and CTC

## Admission

**Definition**
Some registries refer to facility information as admission information (since all patients used to be admitted to facilities).
**Local Variations**

## Correction

**Definition**
See process "Correct/Update Master Data"

A notice from the creater of the record that a mistake has been made, which variable changed and the new value. Usually coming from the facility to registry (there is a specific record type, although not everyone uses it). Sometimes the registry will send a correction (along with reasoning) back to the facility.

**Local Variations**

## CTC Set

**Definition**

Residency, Cancer/Tumor/Case, Diagnosis, Prescribed Treatement Modality, Refusal, Procedure

Information about the CTC, selected patient information at time of diagnosis (age, address…) and how the CTC was treated.

**Local Variations**

## Facility View

**Definition**

A facility view is all the information known by the facility about a patient. This would include all CTCs the facility is aware of (and no others), and all diagnosis and treatment information for those CTCs that the facility is aware of, whether or not the procedures involved occurred at the facility.

**Local Variations**

NM will use this as an organization view because they typically combine the information from all facilities within an organization into 1 composite view.

## Incidental Update

**Definition**

**Local Variations**

ATL – They are treated as “complete abstracts”

## Morphology

**Definition**

a.k.a. Histology –type of cancer cell.

Component that help determines which CTC this is: same or different?

More detail about the CTC and where it is.

Values include 8150 (adenocarcinoma)

**Local Variations**

## Patient Set

**Definition**

Patient information, along with CTC and facility information, is considered patient set. All information about the patient, the cancer/tumor/case, its diagnosis and its treatment.

The registry view of a patient set is the combination of known information across all facilities. An abstract is a single report.

**Local Variations**

## Primary (Tumor, Primary Site)

**Definition**

This might be a synonym for cancer/tumor/case, but it was deemed a poor option by the 6/27/00 SMEs although SEER is concerned only with these.

Values include 500 (breast)

The initial outbreak of a particular type of cancer cell. (secondary outbreak is metastatic)

**Local Variations**

### Sequence (Number)

**Definition**

Used to know whether a CTC is first, second or… CTC occurring in a patient.

This might be a synonym for cancer/tumor/case, but it was deemed a poor option by the 6/27/00 SMEs.

**Local Variations**

### Suggested Change Document

**Definition**

Correction record. This name acknowledges that the receiver doesn't have to accept the change.

**Local Variations**

NM – See process "Correct/Update Master Data"

# Abbreviations and Acronyms

### General terms:

| | |
|---|---|
| ACD: | Adds/Changes/Deletes |
| ACoS: | American College of Surgeons |
| AJCC: | American Joint Commission on Cancer |
| BRM: | Biological Response Modifiers (immunotherapy) |
| BSI: | Biological Specimen Inventory |
| CM: | Clinical Modification |
| COC: | Commission on Cancer |
| CS: | Collaborative Staging |
| CSN: | Central Nervous System |
| CTC: | Cancer/Tumor/Case |
| CTR: | Certified Tumor Registrar (aka abstractor) |
| CTR: | Central Tumor Registry |
| DC/DCO: | Death Certificate/ Death Certificate Only case (only source document) |
| Dx: | Diagnosis |
| EOD: | Extent of Disease |
| ER: | Estrogen Receptor |
| FB: | Follow-Back |
| FUP: | Follow-Up |
| ICD: | International Classification of Diseases |
| ICDO: | International Classification of Diseases Oncology |
| Info: | Information |
| IRB: | Institution Review Board |
| LN: | Lymph node |
| NAACCR: | North American Association for Central Cancer Registries |
| Org: | Organization |
| Org Rep: | Organization Representative |
| Path: | Pathology |
| PE: | Physical Exam |
| PR: | Progesterone Receptor |
| TNM: | Tumor/Node/Metastases staging, tumor collaborative stage elements. |
| Tx: | Treatment |
| UDSC: | Uniform Data Standards Committee (within NAACCR) |

## The SEER Registries

| | |
|---|---|
| ATL | Atlanta |
| CT | Connecticut |
| DT | Detroit |
| HI | Hawaii |
| IA | Iowa |
| LA | Los Angeles |
| NCCC | Northern California Cancer Center |
| NM | New Mexico |
| SEA | Seattle |
| UT | Utah |