SEER Registry Data Management Project

Process Model Text – Data Flows, Data Stores

The text is one part of the process model. The other part is the diagram.
The development of this model is in progress, so the following text is incomplete.

First draft: July 12, 2002
Last update: April 17, 2003

Stage: New Physiological (NP)

This model is being developed using a staged approach. This represents the new world of registry operations accounting for facts of life, facts of policy and some facts of implementation only.

Notes to SEER Team:

Data Flows

Abstract Facility Lead(s)

Description

The note (however implemented) that a particular facility should have provided an abstract for a particular patient with a particular cancer/tumor/case

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

DESIGN NOTE: these are currently being stored directly after 1.0 Conduct Screening. They don't flow directly from 1.0 to 4.0 Match and Consolidate Patient Set Info (to see if lead is totally new information or partially known) to 2.0 Conduct Abstracting (to determine based on how much is known whether an abstract is needed and to then get the abstract) merely because of timing issues. The data is following that pass somewhat rapidly, but there may be pauses to facility workflow and people's schedules.

DESIGN NOTE: Abstract Facility Leads that result from unmatched correction records or special study communications will need enough info to set policies on when to go asking for the abstract.

Sensitivity

Data Items (if a group data flow)

Abstract Facility Lead ID (for tracking)
Patient ID (Assigned by registry)
CTC ID (Registry, sequence?)
Health Record ID
Facility ID
Source (text, disease index, referred from re hosp xyz)
Date lead created
Staff ID (entering)
Abstract to be done by? {Registry, Facility}
"Do Not Abstract Before" date (if lead arrives within month of diagnosis, registry may wish to wait to pursue obtaining the abstract.)
Status {On hold, Requested/Assigned, Received/Closed, Closed/Other, Purged}

Metrics

Frequency:
Volume:

Duration:
Quality/Error rate:

Abstract Facility Lead History

Description

Audit trail for changes made to an abstract facility lead.
This also includes the addition of a new lead, but you wouldn't really need a reason for that.

Interested Registries

Interested:
Not Interested:

Local Procedures

IA, HI are interested in this.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Abstract Facility Lead ID
Org Rep ID
Date of change
Old Value
New Value
Reason (text field, why was this made)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Abstract Facility Lead(s) to be Closed

Description

See Abstract Facility Lead
If an abstract has been received or the determination has been made that no abstract will be received, the corresponding abstract facility lead needs to be closed.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Abstract Facility Lead
Note: to be closed (temporary – after status changed this goes away)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Abstract Facility Lead(s) to be Commented

Description

See Abstract Facility Lead
After reviewing the lead, comments may be added to facilitate in tracking the lead.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Abstract Facility Lead
Note: to be commented (temporary – after comment added this goes away)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Abstract Facility Lead(s) to be Purged

Description
See Abstract Facility Lead
A lead that needs to be purged from the tracking system. Usually a lead that has been closed for a registry specified time. Is possible a manager would want to clear a lead prior to that.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
DESIGN NOTE: depending on registry desires, this could be an actual removal from the database. Alternatively, it could remain but not be shown to standard searches.

Sensitivity

Data Items (if a group data flow)
See Abstract Facility Lead
Note: to be purged (temporary – after status changed this goes away)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Abstract Facility Lead Tracking Information

Description
Information about abstract facility leads which allows the registry to verify that the abstracts needed actually arrive in the registry.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
If registry puts a hold on pursuing a lead, probably a good idea to recheck the existing data when the lead comes 'due'. An abstract may be received by the registry in the intervening time.

Sensitivity

Data Items (if a group data flow)

Abstract Facility Lead ID (some tag to show what the tracking info goes with)
Date lead created
Staff ID (entering)
Abstract to be done by? {Registry, Facility}
"Do Not Abstract Before" date (if lead arrives within month of diagnosis, registry may wish to wait to pursue obtaining the abstract.)
Date lead closed (date abstracted, abstract received or reason not abstracted provided – date attempted)
Reason lead closed {Abstract received, not abstractable)
Reason not abstracted (text)
Facility Staff ID (who provided reason not abstracted)
Status {On hold, Requested/Assigned, Received/Closed, Closed/Other, Purged}
Comments

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Acceptable Census Tract Record

Description

It has been determined that the census tract record is valid: readable, all expected fields filled in with acceptable codes.
Would probably only be getting the census tract information for 1 census year. Would have to build the multiple years of information.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Street address (number, name)
Street side
City
State (Canadian Province)
Postal Code (ZIP)
Census Tract
Census Tract Coding System {1970, 1980, 1990, 2000}
Census Tract Certainty Code
Census Tract block group
Latitude
Longitude
Status: acceptable (not stored)

(May be returned if originally provided to the census data source)
Name of Facility (prison, nursing home, homeless shelter, etc)
Apartment number/floor
County

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Acceptable Correction Info

Description

Variables from Acceptable Correction Record (see this data flow)
Don't need to retain the physical implementation of 'record' at this point.
It has been determined that the valid correction record is not a duplicate and all the codes and text have been converted.
When searching for match for correction information, would search health records – subset records on facilities, then search for facility record id (accession number from facility etc), then verify that information on correction record really refers to the same patient/CTC.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Would go directly to matching. In a perfect scenario, the original record has already arrived and the screening and lead finding would have been done on that record.

Sensitivity

Data Items (if a group data flow)

Status: acceptable (== valid converted non-duplicate)
(actual converted codes & keywords need to be tied with this data group)

See correction record
Patient ID
CTC ID (seq? Hist/site?)
Facility ID
(May not really have above 3 identifiers. Could use a Record ID instead match to record, find patient set record goes with, link correction record)
Field to change (Data item name)
Old value
New value
Reason (text field)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Acceptable Correction Record

Description

It has been determined that the valid correction record is not a duplicate and all the codes have been converted.
See correction record

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Would go directly to matching. In a perfect scenario, the original record has already arrived and the screening and lead finding would have been done on that record.

Sensitivity

Data Items (if a group data flow)

Status: acceptable (== valid converted non-duplicate)
(actual converted codes & keywords need to be tied with this data group)
Submission ID
Type of record (=correction)

See correction record
Patient ID
CTC ID (seq? Hist/site?)
Facility ID
(May not really have above 3 identifiers. Could use a Record ID instead match to record, find patient set record goes with, link correction record)
Field to change (Data item name)
Old value
New value
Reason (text field)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Acceptable Follow-Up Info

Description

Variables from Acceptable Follow-up Record (see this data flow)
Don't need to retain the physical implementation of 'record' at this point.
It has been determined that the valid follow-up record is not a duplicate and all the codes and text have been converted.
See BOM Follow-up record for more information

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Would go directly to matching. In a perfect scenario, the original record for the patient from this facility has already arrived.

Sensitivity

Data Items (if a group data flow)

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
Status: acceptable (== valid converted non-duplicate)
(Actual converted codes & keywords need to be tied with this data group)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Acceptable Follow-Up Record

Description

It has been determined that the valid follow-up record is not a duplicate and all the codes have been converted.
See BOM follow-up record

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Would go directly to matching. In a perfect scenario, the original record for the patient from this facility has already arrived.

Sensitivity

Data Items (if a group data flow)

Submission ID
Type of record (=follow-up)
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
Status: acceptable (== valid converted non-duplicate)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Acceptable Health Info *(for expedited Passive Follow-up) (Electronic)*

Description

Variables from Acceptable Health Record (see this data flow and Health Record)
Don't need to retain the physical implementation of 'record' at this point.
It has been determined that the valid health record is not a duplicate and all the codes and text have been converted.

In 4.0, this data flow has bypassed '1.0 Conduct Screening' to expedite the update of follow-up information and has gone directly to match and consolidate patient set information.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See health record
Status: acceptable (== valid converted non-duplicate)
(actual converted codes & keywords are separate flows)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Acceptable Health Record(s)

Description

It has been determined that the valid health record is not a duplicate and all the codes and text have been converted.
Really the variables on the record, not the actual physical construct 'record'.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

To expedite the update of follow-up information, can bypass '1.0 Conduct Screening' and '2.0 Conduct Abstracting' and go directly to 4.0 Match and Consolidate Patient Set (see Acceptable Health Record (for expedited passive follow-up.))

Sensitivity

Data Items (if a group data flow)

See health record
Status: acceptable (== valid converted non-duplicate)
(actual converted codes & keywords are separate flows)
Submission ID
Type of record (=abstract, path report, oncology rpt, etc)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Acceptable Special Study Updated Patient Set Information

Description

See "Special Study Updated Patient Set Information"
Information that the registry is interested in added to their database and is clean, readable and converted to registry standards.
This would have come in as some kind of record.

Interested Registries

Interested:

Not Interested:

Local Procedures

Some registries note the information but do not add it to the database because they feel it would skew the quality of the data – not every patient set has been involved in a special study, so they don't have an equal chance at getting this kind of information.

Some registries will only accept certain data items, only accept information from certain research groups, only accept data in certain circumstances (patient interview occurred) to protect against incorrect corrections.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See "Special Study Updated Patient Set Information"

Status = acceptable (probably on some type of record, so this is a record status)

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Acceptable Supplemental Info (Person Info)

Description

Variables from Acceptable Supplemental Record (see this data flow)

Don't need to retain the physical implementation of 'record' at this point.

It has been determined that the valid supplemental record is not a duplicate (although this part may be bypassed in some registries) and all codes and text have been converted. (Probably a limited number of things to convert)

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sometimes this information is used to resolve possible patient matches. This would include death notices from the newspaper which registries are using for passive follow-up.

Sensitivity

Data Items (if a group data flow)

See Supplemental Record

Status: acceptable (== valid converted non-duplicate)

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Acceptable Supplemental Record

Description

It has been determined that the valid supplemental record is not a duplicate (although this part may be bypassed in some registries) and all

codes and text have been converted. (Probably a limited number of things to convert)
This includes death notices within newspapers – used in course of follow-up.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Supplemental Record
Submission ID
Type of record (=DMV, voters registration, DC, etc)
Status: acceptable (== valid converted non-duplicate)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Accepted Follow-Back Resolution

Description
An answer to the follow-back query which has been determined to be consistent with existing data
Within 3.0 (special study), its the answer the registry returns to the special study in response to 'Special Study Follow-Back Request'. The disposition would have to include the special study id.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Patient ID
(part of resulting ACD or HRec Update)
Data item name (R1)
New value (R1)
Reason (text field, if provided)
Staff ID (who resolved? not sure if they'd send this to special study, maybe as a reference?)
Date/Time (resolution occurred)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Accepted Special Study Modification

Description

A change to the special study contract – most likely criteria or time window – requested by the special study that has been accepted by the registry.
The change is tracked and the special study is notified about those changes the registry has agreed to implement.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Special Study ID
Modification Desired
Org Rep ID (Registry staff making change)
Date of Change

(part of reason)
Date Requested
Org Rep Requesting (SS org rep)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Access History

Description
Information about when a user logged on, logged off and what processes they accessed during that time.
In 11.5.4, this is used to determine if a person should be logged-off for inactivity.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity
Appropriateness

Data Items
Account
IP address
Date of log-in (successful only)
Time of log-in
Date of log-off (successful only)
Time of log-off
Log-off type {Normal, Inactive, System}
(not sure if these will meet need)
Process ID
Date initiated
Time initiated

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Access Info for Registry-Controlled File

Description

For each individual who has been granted access to a registry-controlled file, the account, password, file, etc.
This allows the registry to track who has access to the different files and to terminate access if they feel the information is being misused.
These files may be identified files or de-identified files.

Interested Registries

Interested:
Not Interested:

Local Procedures

NM: Requires training before access is granted.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Name
Phone number
Comments
Registry Controlled File ID
Training completion date
Account
Password
Status {Open, Closed} (would be closed if employee leaves)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Access Information

Description

For any particular org rep, the access they are allowed; which processes can they initiate, what data can they view, what data can they change.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Process ID (R1)
Process Access? (R1) {Yes, No}

Data Table ID (R2)
Data Item ID (R2)
Data Access? (R2) {None, Read only, Read/write}

Metrics

Frequency:

Volume:
Duration:
Quality/Error rate:

Access Request

Description

The request to access the system, to initiate a process, or to access data.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Date of attempt
Time of attempt

Account
Password
IP address

Org Rep ID
Process ID

Data table
Data item name

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Access Status

Description

The result of an attempted access, provided to person attempted to log in, initiate a process, or access data. It is also provided to the system or the process as appropriate.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Access Status {Success, Failure} (data access is {success read, success read/write, failure}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Account(s)

Description

The information that identifies an account on the registry system to the security processes.
(Also the list of accounts)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Account
Status {Closed, Open}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Active Follow-Up Chosen

Description

The type of active follow-up action that has been selected for this patient for this particular attempt
For example: letter to physician, phone call to patient; letter to informant, visit to facility.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Type of active follow up (e.g. Letter, Listing, Visit, …)
Who is being contacted (medical practitioner id, facility id, organization id, patient name, informant name)
Who is to contact (may not need for all action types, would include the registry field staff who is assigned to this need)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Active Follow-Up Need

Description

The discovered need that a particular patient's follow-up information is out of date and better information needs to be aggressively pursued
The existence of this information in the tracking database implies that active follow-up is needed without the presence of a flag.
May wish to allow leeway in the criteria for creating this need (if 2 years is when follow-up expires, than at 18 months, turn this flag on.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Patient ID
Date discovered

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Active Follow-Up Query

Description
The action being taken (e.g., sending a query, making a phone call, making a visit)

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
The registries do not keep a copy of what was actually sent; just note what type of letter was sent.

Sensitivity

Data Items (if a group data flow)
Patient ID
Staff ID who sent
Date follow-up action
Type follow-up action
Copy of communication
Status: query sent

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Active Follow-Up Query to be Closed

Description
See Active Follow-Up Query
If the active follow-up query has been responded to or the determination has been made that no response will ever be received, the corresponding active follow-up query needs to be closed.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Active Follow-up Query
Note: to be closed (temporary – after status changed this goes away)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Active Follow-Up Query to be Purged

Description
See Active Follow-Up Query
A follow-up Query that needs to be purged from the tracking system. Usually a query that has been closed for a registry specified time. Is possible a manager would want to clear a query prior to that.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
DESIGN NOTE: depending on registry desires, this could be an actual removal from the database. Alternatively, it could remain but not be shown to standard searches.

Sensitivity

Data Items (if a group data flow)
See Active Follow-up Query
Note: to be purged (temporary – after status changed this goes away)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Active Follow-Up Query to be Redirected

Description
See Active Follow-Up Query
If the response to an active follow-up query was not received or the response did not fulfill the follow-up need, the query may need to be re-directed to another facility or org.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Active Follow-up Query
Note: to be redirected (temporary – after status changed this goes away)
Must track (Follow-up history):
Staff ID who determines
Date determination made (Date of change)
New recipient (New data item value, data item=recipient)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Active Follow-Up Response

Description

The response to the Active Follow-up Query that was made
Could be a letter back, a return phone call, etc.
Could receive a follow-up record or follow-up abstract in response.
These would be follow-up to an initial health record from the same facility (org)
Could be in a specific form or could be an abbreviated abstract.
For example: FURS, answer to telephone call, letter in mail (patient is alive)
Might contain more treatment, recurrences, etc. Can have an admission with no treatment.

Interested Registries

Interested:
Not Interested:

Local Procedures

NM – May keep a copy of the response (via scanning)

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Follow-up Need ID
Original response (if applicable – not stored, just the letter coming in)
Date/time response received
Vital Status (alive, dead)
Date of last contact
Cause of Death
Source of information {org ID, Facility ID, other} (to know which views to update)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Ad Hoc Registry-Controlled File

Description

A registry-controlled file created specifically for a particular information request. It is not expected to be a standard (repeatedly needed) file. See glossary for definition of registry-controlled file. 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.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

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 {=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
Identified? {Y, N}
Data items included
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}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Ad Hoc Report/Extract

Description

A Report or Extract created specifically for this request. It is not expected to be standard (repeatedly needed).
See glossary for definition of extract and report. Short version:

Extract: 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.
Report: summary of information contained in the registry. Can be CTC data (incidence rates, etc) or registry operation data (monthly abstracts generated by abstractor). Would potentially include task lists (what still needs to be done).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Report/extract identifier (name)
Type {=Ad hoc}
Location (or copy, implementation decision)
Programs Used to create (R1)
Staff ID (who created, who to direct questions to)
Date created
Specifications (Text)
Data items included (R2)
Identified? {Yes, No}

Comments (text field for other considerations, quirks in ad hoc reports or extracts that may make it inappropriate for other requests)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Add(s)/Change(s)/Delete(s)

Description

Previously called “History of Values for Data Item”
The logged modifications that a data item has undergone. Would want to track the actual values, why the value was changed and who changed it. This allows quality control reviews of past decisions as well as a complete picture of the data item during consolidation.
This information is mainly logged during consolidation.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(identifies which particular place within patient set data)
Patient Set ID
CTC ID
Facility ID
Treatment Type(?)

Data item name
Old value
New value
Reason changed (text)
Date/time changed
Who changed (staff id)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Add(s)/Change(s)/Delete(s) to be Deleted

Description

Previously called “History of Values for Data Item”
When the consolidation of 2 data groups (patient set with health record, etc) is rejected, all ACDs caused by that consolidation must be removed from the tracking system
DESIGN NOTE: It may make more sense to have a temporary storage place for all ACDs generated during 4.0 that is saved only at 4.5.3

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
(identifies which particular place within patient set data)
Patient Set ID
CTC ID
Facility ID
Treatment Type(?)

Data item name
Old value
New value
Reason changed (text)
Date/time changed
Who changed (staff id)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Additional Disease Codes and Keywords (Death Certificate, Autopsy)

Description
This would only come from death certificates or autopsy reports. Coded values and keywords for diseases other than the cancer (Most health records are only dealing with one cancer/tumor. A death certificate potentially has many diseases mentioned.)

Interested Registries
Interested:
Not Interested:

Local Procedures
Would like to track coding scheme converted to as well as coding scheme it arrived in. Registries may go to new revisions (especially ICD and ICD-O)

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Data item name (R1)
Converted Data item value (R1)
Data Item Coding Scheme (R1)
Keywords (R2)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Additional Fields

Description
In 5.1.2, fields that are needed to assign ethnicity. These are in addition to name. Again, necessary because of name changes due to marriage, ethnic groupings by geographic area, and so on.
See Patient Demographic Information

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Marital Status
Race
Gender
State (Canadian Province)
County?

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Additionally Required Special Study Information

Description
Those pieces of data that are required by a special study that did not arrive on the potentially reportable record first received by the registry
The registry staff must go to the source facility to obtain this information.
Most often these fields are required to complete screening (i.e. residency for a limited area study), but may also be that the registry has agreed to collect the fields for the study prior to sending the data.
This is most often needed for Rapid Case Ascertainment studies.
These fields are incorporated into special study reportable incomplete patient sets.

Interested Registries
Interested:
Not Interested:

Local Procedures
Some registries only collect data needed to complete the screening.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Varies by study

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Address(es)

Description
Residence location (street number, city, state/Canadian province, postal code)
When address is updated by supplemental record, it is worth checking if the same address correction needs to be made to the address at diagnosis.
When sending list of addresses to get census tract, might need to note side of street as well. Would retain these addresses with census tract in a data store for future use.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Name of Facility (prison, nursing home, homeless shelter, etc)
Street Number
Street Name
Street Side
Apartment number/floor
City
County
State (Canadian Province)
Postal Code (ZIP)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Address at Diagnosis

Description
The main residence of the patient at the time they were diagnosed. 'Main' implies that the patient spends more than ½ the year at the given location.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
Registries sometimes have to make a choice if the person effectively resides 6 months in 2 different locations.

Sensitivity

Data Items (if a group data flow)
Name of Facility (prison, nursing home, homeless shelter, etc)
Street name and number
Apartment number/floor
City
State (Canadian Province)
Postal Code (ZIP)
County

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

All Incomplete Patient Set Info

Description
All information gathered by the registry that they would like to incorporate into a patient set or use to create a new patient set.

In 4.1 processes, this is technically any patient set information from health and supplemental record data that is being processed, regardless of the original data flow (incomplete patient set, acceptable supplemental information, acceptable correction, etc)
The data groups could be incomplete patient set, existing patient set or health record (including correction record, reportable or non-reportable). This information will be used in 'consolidation'. Both data groups will be sent along this flow.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(All data items on the health record and corresponding converted values)
See health record (these variables would potentially include the same as Patient Matched Info, CTC Matched Info, Facility Matched Info and Treatment Matched Info data flows. Or Patient Set data flow. Some data items may have missing values. This is most likely a single facility's view of the patient.)
See BOM entities: PATIENT, INFORMANT FOR PATIENT, and RESIDENCY
See BOM entities: CANCER/TUMOR/CASE, MARKER, COMORBID CONDITION, RESIDENCY is established for CTC, IMAGE, IMAGE EVALUATION, SPECIMEN, SPECIMEN EVALUATION, DIAGNOSIS and PAYOR SOURCE covers CTC, FACILITY ADMISSION, FACILITY refers PATIENT to FACILITY, RESIDENCY is established for CANCER/TUMOR/CASE
See BOM entities: CONSIDERED TREATMENT MODALITY, PATIENT refuses CONSIDERED TX MODALITY, PROCEDURE (and all subtypes), COURSE.
See BOM entities: IDENTIFICATION, OVERRIDE
See BOM Relationship: PATIENT or CTC is included in SPECIAL STUDY, PATIENT or CTC is possibly reportable to SPECIAL STUDY
See Converted ICD Codes and Keywords
See Additional Disease Codes and Keywords (DC only)
SEER Reportability indicator (may be calculated on the fly instead of saved; otherwise save in CTC)
Local Reportability indicator (R1 - may be calculated on the fly instead of saved; otherwise save in CTC)
Additional special study variables (varies by study)
Status = incomplete

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Approvals

Description

Physician and patient agreement that the patient will participate in a special study as obtained by the registry.

Special studies that wish to contact a patient (and possibly some other kinds of studies as well) need to get physician and patient consent to include the patient in the study.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Some registries make the special study obtain these approvals, in that case, these would be out of scope
Some registries consider passive physician consent to be adequate. Then notify the physician that the following patients have been selected for a study on thus-and-such. If the physician doesn't contact them to object, they consider that to be passive consent.

Sensitivity

Data Items (if a group data flow)

Special Study ID
Consent type {Physician, Patient}
Date contacted
Staff ID who contacted.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Approval Response

Description

A response sent from a patient or medical practitioner that approves or disapproves the contacting of a patient for a special study.
Special studies that wish to contact a patient (and possibly some other kinds of studies as well) need to get physician and patient consent to include the patient in the study.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Some registries make the special study obtain these approvals, in that case, these would be out of scope
Some registries consider passive physician consent to be adequate. Then notify the physician that the following patients have been selected for a study on thus-and-such. If the physician doesn't contact them to object, they consider that to be passive consent.

Sensitivity

Data Items (if a group data flow)

Special Study ID
Consent type {Physician, Patient}
Consent Obtained? {Y, N}
Do not contact patient? (ever) {Y, N}
Date of response
Date contacted
Staff ID who contacted.

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Assigned Abstractor ID

Description
Given that there is an abstract which a SEER registry staff member must create, the Staff ID of the person who was assigned to create it.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
This may be either a specific person or a group of people. In some registries for some hospitals, multiple abstractors work at that location and the registry doesn't care which one abstracts as long as the abstract is created.
Might make more sense to put facility id here and have a cross reference of facility to possible abstractors. We did it this way to imply responsibility and try to limit falling through the cracks.

Sensitivity

Data Items (if a group data flow)
Staff ID (R1)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Assigned Abstract Facility Lead

Description
See Abstract Facility Lead
Abstract facility lead that has been assigned to a particular staff member and is being transferred to their computer for use in the field.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Abstract Facility Lead

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Assigned Active Follow-up Need

Description
See Active Follow-up Need

Active Follow-up Need that has been assigned to a particular staff member and is being transferred to their computer for use in the field.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Active Follow-up Need

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Assigned Census Tract Code

Description
The Censes Tract Code assigned to a Patient based on their address (usually address at diagnosis) and date of residence
This code has either been assigned by the computer and has a high enough certainty code, or has been reviewed by a human. In either case, it is considered acceptable.
DESIGN NOTE: there are pieces of information tied to a census tract that may be important to the patient set. They could be incorporated with this flow or kept in a separate table to reference at need.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Census tract code
(Latitude)
(Longitude)
(Coding System {1970, 1980, 1990, 2000})
(Census Tract block group)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Assigned Follow-back Need

Description
See Follow-back Need
Follow-back Need that has been assigned to a particular staff member and is being transferred to their computer for use in the field.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Follow-back Need

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Assigned Patient Set ID

Description
The Patient set id (case number) which is linked to an abstractor so that task of creating an abstract for that patient can be tracked and the status 'assigned'
DESIGN NOTE: may be helpful to know what date the abstraction was expected to take place. This may help in management.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Patient ID (in Registry)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Attempted Access Tracking Info

Description
Information allowing the registry to track who has attempted to log in to their system.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity
Trying to track unauthorized hits.

Data Items (if a group data flow)
Date of attempt
Time attempt made
Account
Password
IP address
Access Status {Success, Failure}

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Automated Request for Abstract

Description
A request sent to a facility that is generated automatically.
See Request for Abstract

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Request for Abstract
Note: Staff ID who generated request would be the computer.

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Available Media

Description
The types of media (e.g., ftp, paper, web) the Registry has available to use when responding to information requests.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Type of media
Method of entry (into system, data entry or just read rec)
Method of storage (save in filing cabinet, backup onto tape, scan in, etc)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Available Registry-Controlled File(s)

Description
Any available registry-controlled file. Registry-controlled files which have been created in the past and would possibly meet the needs of a future request.
These may be identified or de-identified.

See glossary for definition of registry-controlled file. A file which is kept under registry control and not released to public. May require more data manipulation than just data dump.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

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
Identified? {Y,N}
Data items included
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}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Available Reports/Extracts

Description

Reports or extracts which have been created in the past and would possibly meet the needs of a future request. These could be standard or ad hoc.

For example: Annual report (standard), extract of breast CTC patients for 1995-2000, survival of prostate CTC patients by age and stage.

See glossary for definition of extract and report. Short version:

Extract: 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.

Report: summary of information contained in the registry. Can be CTC data (incidence rates, etc) or registry operation data (monthly abstracts generated by abstractor). Would potentially include task lists (what still needs to be done).

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Report/extract identifier (name)
Type {Standard, Ad hoc}
Location (or copy, implementation decision)
Programs Used to create (R1)
Staff ID (who created, who to direct questions to)
Date created
Specifications (Text)
Data items included (R2)
Identified? {Yes, No}
Comments (text field for other considerations, quirks in ad hoc reports or extracts that may make it inappropriate for other requests)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Auxiliary History Information

Description

Audit trail for changes made to any of the auxiliary files.
These files currently include: FACILITY, ORGANIZATION, ORGANIZATION REPRESENTATVE, MEDICAL PRACTITIONER, MEDICAL PRACTITIONER FACLITY AFFILIATION, RULE, PERSON, PAYER SOURCE

Interested Registries

Interested:
Not Interested:

Local Procedures

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

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

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

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Blanked Record

Description

ACK. We need to delete a record from the health and supplemental data store and are currently showing it in the model by overwriting said record with a blanked record.
DESIGN NOTE: totally a design problem. We're not really interested in how the data is removed from the data store, but it isn't legal to have.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Blank space (ie release the storage space in the data store)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Calling Process

Description
The task that initiated the follow-back

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Process name
Basis type {Match, Edit, etc}
Basis ID (Match ID – however implemented, Edit Issue ID, etc)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Candidate Abstracts

Description
Abstracts that an abstractor found difficult to correctly abstract. These are submitted to the head abstractor for possible training use.
Candidate abstracts should have the possibility of increase the expertise of all abstractors in the registry.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See BOM ABSTRACT

Metrics
Frequency:
Volume:

Duration:
Quality/Error rate:

Cannot Fulfill Reason

Description

The reason the information request cannot be fulfilled. This is frequently something that may be fixed or change over time.
For example, media unavailable (pick another kind); Data unavailable (wait 6 months), etc

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information Request ID
Registry Staff ID (who reviewed)
Date reviewed
Reason unfillable (what are you waiting for, text)
On hold Review Date (Derivable)
Status (= on hold)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Census Tract Code

Description

The U.S. Census Bureau's assigned location code. This coding scheme tries to break areas into socio-economically similar groups as well as geographically contiguous areas.
The census tract code (that corresponds to a given address)
DESIGN NOTE: there are pieces of information tied to a census tract that may be important to the patient set. They could be incorporated with this flow or kept in a separate table to reference at need.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Registries would like to build file of all addresses associated with each particular census tract code.

Sensitivity

Data Items (if a group data flow)

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

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Certainty Code

Description

The degree to which the source of a census tract code is sure that the code matches the address. Usually, this would occur when the registry out-sourced the census tract coding procedure.
If this code's value is too low, the census tract and related information is considered uncertain.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Census tract Certainty code

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Changed Patient Set Data Item(s)

Description

A data item whose value has been updated as a result of consolidation, follow-up or otherwise incorporating new information into a patient set
May be the value from the new patient set information or a value distinct from the new or existing value arrived at by considering all relevant information.
Data items may also be changed during follow-up (active or passive) and during follow-back.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(the following is for a single changed data item)
Data item name
New value
Patient set Status: unedited

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Closed Account

Description

When an org rep leaves registry employment, their account is closed so they can no longer access the system from any location

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Account ID

Status (=Closed)

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Closed Date

Description

The date that a particular thing being tracked was closed, in this case an abstract facility lead, follow-up query, follow-back request, follow-back query, information request, health records request supplemental records request.

Can be set by computer when status is changed to closed; would be stored in history.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Closed month

Closed day

Closed year

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Coded Converted Valid Record

Description

See health record, correction record.

A valid paper health record that has had all text fields of interest coded and key words selected and all non-standard coding schemes converted to registry standards.

It has been keyed into electronic form. It has passed the broad CTC screen. It has been edited.

Still has to be checked for duplicates.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See health record, correction record
Status: converted edited (not a retained status)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Coded Health Record

Description
See health record
A reportable paper health record that has had all text fields of interest coded. (It still needs to be converted and checked for duplicates)
It has been keyed into electronic form. It has passed the broad CTC screen.
DESIGN NOTE: The data values are undergoing field edits to verify that nothing was mis-keyed. This may not be possible if the data items are standard, may have to wait until the record has been converted.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See health record, correction record.
Status: coded (not a retained status)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Collected Special Studies Variables

Description
For those studies where additional variables are needed, either to complete the screening process or because the registry agreed to collect them for the study, this is the collection of needed variables.
The most likely variable group is residency, but others may be included.
These variables must be obtained from the source facility. They were not included on the reportable record received by the registry.

Interested Registries
Interested:
Not Interested:

Local Procedures

Some registries only collect additional variables if they are needed to complete screening.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Varies by study

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Comments

Description

Any additional information that would facilitate the tracking.
This should be available for all tracking: abstract facility leads, follow-ups, follow-backs, information requests, health records requests, supplemental requests, etc.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Comments are a text field. May want multiple fields available

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Common ID(s)

Description

ID(s) that are in use by multiple, active contacting studies.
These may be patient set or health record ids. If a study is CTC based, the including patient set ID is used.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Source type {Patient set, Health Record}
Source ID

Metrics

Frequency:
Volume:
Duration:

Quality/Error rate:

Comparison Ratio(s)

Description

While doing consolidation, the registries wish to track how likely it is that they really have a good match. The Comparison Ratio is a cumulative score measuring how well data is matching up based on the data items that have been compared to that point.

I assume any score would have to take into account how many items have been compared, which items (if any) are different (different site more important difference than different number of nodes examined), and (if possible) how severe a difference (8 vs 9 nodes is less problematic than 1 vs 9 nodes).

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Comparison ratio (weighted # item matches/# items compared; need some weight based on severity of differences found)

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Comparison Results

Description

Information used to track comparisons of potential new data with existing data and evaluate whether to continue the 'consolidation' or abort the process and select a new match (or create a new data set)

Whether this data item matched and if not the severity of difference (if possible to calculate)

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

DESIGN NOTE: I don't believe this has to be permanent – just during the actual consolidation process.

Sensitivity

Data Items (if a group data flow)

Data item name (R1)

Comparison results {match/no match} (R1)

Severity of difference (if possible) (R1)

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Completed Patient Set

Description
See Patient Set
The patient set information that has been through auto create and consolidate processes, has all been incorporated into 1 patient set, has passed a final overall edit and has been reviewed for any oddities, or abstract facility leads that might be needed.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Patient Set
(would not include any recodes done in 5.0)
Registry Patient View Status: complete, edited (and all lower statuses)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Computer Derived Ethnicity Code

Description
The computer generated (selected or verified) Ethnicity Code for the Patient based on Patient Name and Additional Fields.
SEER requires this field. Ethnicity code is not enough.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
The Computer Derived part is key here.

Sensitivity

Data Items (if a group data flow)
Computer derived ethnicity code

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Confirmed Data Problem

Description
A data problem that the registry has investigated, verified an actual problem exists, and has corrected (with or without follow-back). The existence of this data flow implies that the information request fulfillment should be recreated. There are no modifications to the creation process, just the underlying data.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Information Request ID
Information Request Problem ID
Type of problem (=Data)
Description (text)
Registry staff ID (who was notified)
Date of problem
Decision (how to resolve, should come from data problem resolution)
Date resolved
Registry staff ID (who resolved)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Confirmed Format Problem

Description
A confirmed problem with the formatting of a Report or Data Extraction Registry agrees there is a problem with the layout or the media and has decided to correct it.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Information Request ID
Information Request Problem ID
Type of problem (=Format)
Description (text)
Registry staff ID (who was notified)
Date of problem
Decision (how to resolve)
Date resolved
Registry staff ID (who resolved)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Consolidated CTC Information

Description
Information about the cancer/tumor/case (site, histology, stage, eod so on) that is considered to be the best value given the information from all available sources. (Existing data set + new health record information: could potentially be the best value from 4 health records and a special study.)

Best value does not have to actually appear on any source document, it could be that value X and value Y would yield best value Z.
For the registry view, the consolidated data items that represent what all the reporting facilities collectively have told the registry about the patient. Would also include information from supplemental records that have been obtained, any information from special studies, and information gained directly from the patient or an informant during follow-up, follow-back, or a special study.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility view CTC info Status: consolidated (edited)
Registry view CTC info Status: consolidated (edited)
See BOM entities: CANCER/TUMOR/CASE, MARKER, COMORBID CONDITION, RESIDENCY is established for CTC, IMAGE, IMAGE EVALUATION, SPECIMEN, SPECIMEN EVALUATION, DIAGNOSIS and PAYOR SOURCE covers CTC, FACILITY ADMISSION, FACILITY refers PATIENT to FACILITY, RESIDENCY is established for CANCER/TUMOR/CASE
See BOM entities: IDENTIFICATION, OVERRIDE
See BOM Relationship: CTC is included in SPECIAL STUDY, CTC is possibly reportable to SPECIAL STUDY

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Consolidated Data Item

Description

A data item that has finished the consolidation process. The best value has been chosen based on all previous values and rules. It has been edited and any necessary corrections have been made.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Data item value
Status = consolidated??? (**DESIGN NOTE**: while we wouldn't retain data item statuses permanently, it might be useful to know while doing 4.0)

Metrics

Frequency:
Volume:
Duration:

Quality/Error rate:

Consolidated Facility Patient Info

Description

The Patient information composed of data sent only from a specific facility; also may include information that came from other data sources, but was sharable to and was accepted by the facility.
Information may include what we derive or determine from other information they sent. They might think the value is xxx but based on what they said elsewhere, we know they should think the value is yyy. E.g. they make a coding error.
What the facility knows (what they reported on)
This should be edited by the end of consolidation process

Interested Registries

Interested:
Not Interested:

Local Procedures

New Mexico is interesting in knowing which other facilities a patient has been seen at within the same organization. For example, if a patient was diagnosed at hospital A, which is part of Org alphabet soup. That org also contains path lab B, Hospice C and Hospital D. If the patient has a path report from B and had surgery at D, NM would like to store that patient has information from B & D in facility view A, has information from A & B in facility D, and has information from A & D in facility view B.

Policies/Business Rules

Registries get to decide which records create a facility view and which can go directly to registry view. They seemed interested in keeping a facility view for death certificates.

Sensitivity

Data Items (if a group data flow)

See BOM entities: PATIENT, INFORMANT FOR PATIENT, and RESIDENCY
See BOM entities: IDENTIFICATION, OVERRIDE
Other related Facility ID (R1 – local NM data item – affiliates with views for this patient)
Facility view patient info Status: consolidated (edited)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Consolidated Facility CTC Info

Description

The CTC information composed of data sent only from a specific facility; also may include information that came from other data sources, but was sharable to and was accepted by the facility.
Information may include what we derive or determine from other information they sent. They might think the value is xxx but based on what they said elsewhere, we know they should think the value is yyy. E.g. they make a coding error.
What the facility knows (what they reported on), not what they have performed.
Information about the cancer/tumor/case (site, histology, stage, eod so on) that is considered to be the best value given the information from all available sources. (Existing data set + new health record information:

could potentially be the best value from 4 health records and a special study.)
Best value does not have to actually appear on any source document, it could be that value X and value Y would yield best value Z.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Facility view CTC info Status: consolidated (edited)
See BOM entities: CANCER/TUMOR/CASE, MARKER, COMORBID CONDITION, RESIDENCY is established for CTC, IMAGE, IMAGE EVALUATION, SPECIMEN, SPECIMEN EVALUATION, DIAGNOSIS and PAYOR SOURCE covers CTC, FACILITY ADMISSION, FACILITY refers PATIENT to FACILITY, RESIDENCY is established for CANCER/TUMOR/CASE
See BOM entities: IDENTIFICATION, OVERRIDE

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Consolidated Facility Treatment Info

Description
The Treatment information composed of data sent only from a specific facility; also may include information that came from other data sources, but was sharable to and was accepted by the facility.
Information may include what we derive or determine from other information they sent. They might think the value is xxx but based on what they said elsewhere, we know they should think the value is yyy. E.g. they make a coding error.
What the facility knows (what they reported on), not what they have performed.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Facility view treatment info Status: consolidated (edited)
See BOM entities: CONSIDERED TREATMENT MODALITY, PATIENT refuses CONSIDERED TX MODALITY, PROCEDURE (and all subtypes), COURSE.

Metrics
Frequency:
Volume:

Duration:
Quality/Error rate:

Consolidated Patient Info

Description

The registry and facility views of the Patient information.
Information about the patient (name, address, dob, race so on) that is considered to be the best value given the information from all available sources. (Existing data set + new health record information: could potentially be the best value from 4 health records, a DMV record and a special study.)
Best value does not have to actually appear on any source document, it could be that value X and value Y would yield best value Z.
Information also includes data items that we derived or determine from other information sent.
This should be edited by the end of consolidation process

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See BOM entities: PATIENT, INFORMANT FOR PATIENT, and RESIDENCY
See BOM entities: IDENTIFICATION, OVERRIDE
See BOM Relationship: PATIENT is included in SPECIAL STUDY, PATIENT is possibly reportable to SPECIAL STUDY
(See New Facility Patient Info)
Other related Facility ID (R1 – local NM facility view data item – affiliates with views for this patient)
Facility view patient info Status: consolidated (edited)
Registry view patient info Status: consolidated (edited)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Consolidated Patient Set(s)

Description

See Patient Set
After consolidating the patient set (for the facility views and registry view, gathering the best information available and choosing the best value for each data item), the final edit and assigned appropriate ids, the status flag is set to consolidated and the patient set is saved.
The total best knowledge of the essential data items
For 14.0 Update Data Source, this is the lowest acceptable status.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Patient Set
Registry View Patient View Status: consolidated (and all lower statuses)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Consolidated Patient Set Snapshot

Description
See Patient Set
The consolidated patient set used in updating the facility's data
Consolidated is the lowest acceptable status. (Polished is also ok)
This is the information as it is being store for future reference

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Patient Set
Status = Consolidated (or better)
Facility ID (that snapshot is for)
Date of Snapshot

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Consolidated Registry View Patient Set

Description
After consolidating (creating the complete registry view) the patient set from the registry's point of view, the status flag is set to consolidated. This is the only view that needs to undergo 5.0 Polish Registry View Patient Set, as this is the view that is submitted to various organizations. For the registry, the consolidated data items that represent what all the reporting facilities collectively have told the registry about the patient. Would also include information from supplemental records that have been obtained, any information from special studies, and information gained directly from the patient or an informant during follow-up, follow-back, or a special study.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
They would like to see the facility IDs for the available views.

Sensitivity

Data Items (if a group data flow)

See Patient Set data flow
Registry View Patient View Status: consolidated (and all lower statuses)
DESIGN NOTE: also need some method of tracking the source of different data item values. Information from some sources can be released to any facility, but most sources are restricted. May be best able to do this through the matching links between a patient set and its supporting health and supplemental records. CURRENT SOLUTION: all information coming in is put into a view. Some views are marked restricted. If a data value is found only on restricted views (and registry view), it can not be release as per the relevant rule

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Consolidated Treatment Information

Description

Information about the treatment (type, date, amount so on) that is considered to be the best value given the information from all available sources. (Existing data set + new health record information: could potentially be the best value from 4 health records and a special study.) Best value does not have to actually appear on any source document, it could be that value X and value Y would yield best value Z.
For the registry view, the consolidated data items that represent what all the reporting facilities collectively have told the registry about the patient. Would also include information from supplemental records that have been obtained, any information from special studies, and information gained directly from the patient or an informant during follow-up, follow-back, or a special study.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility view treatment info Status: consolidated (edited)
Registry view treatment info Status: consolidated (edited)
See BOM entities: CONSIDERED TREATMENT MODALITY, PATIENT refuses CONSIDERED TX MODALITY, PROCEDURE (and all subtypes), COURSE.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Control Records

Description

Control records are those people who have been selected to represent the population at large without the disease/problem of interest.

They are typically from the supplemental records, but it depends on what the study is.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Special study ID
Record ID (R1)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Control Tracking Info

Description

Information about any existing controlling special study for patients being sent to the current study.
If a Patient Set or Health Record has been assigned a controlling special study and if this is relevant to the current study, this controlling study information should be sent with the patient information.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Patient Set ID/Health Record ID
(or Source Type; Source ID)
Coordination Needed? {Y, N}
Controlling Special Study ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Controlling Special Study ID

Description

ID of Special Study assigned by registry that will control patient contact for a particular patient within special studies.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Special Study ID

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Conversion Rules

Description
How to convert data items related to disease to desired format or coding scheme. May also wish to include a list of words or phrases of interest to the registry
Conversions are usually between different revisions of ICD or ICD-O. This most likely will take the form of a look-up table a computer can use.
For converting a hospital specific coding scheme to registry standards, this could be a look-up table, but would have to be constructed by registry staff as new coding schemes are developed by hospitals.
For deciphering text, this is likely some sort of manual, although some of this can probably be mechanized.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
(below are specific for converting)
Data item name
Incoming coding scheme
Desired coding scheme
Effective (start) date
End Date
Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …, conversion table, etc)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Converted and Reformatted Data

Description
The data from a Facility or Organization that has been converted to Local Registry Standards
ICD, ICD-O and text would not have been converted at this point.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Would like to track coding scheme converted to as well as coding scheme it arrived in. Registries may go to new revisions.

Sensitivity

Data Items (if a group data flow)

See Health Record
Data item name (R1)
Converted Data item value (R1)
Data Item Coding Scheme (R1)
Exact items depend on type of record received and whether the items received were in registry standard format.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Converted Health Record

Description

See health record
A health record that has had all text fields of interest coded and key words selected and all non-standard coding schemes converted to registry standards.
Specifically, this is going to editing (field and inter-field, as much as possible)
Could have been either electronic or paper (which has been keyed in)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Health Record
Status=converted (not a retained status)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Converted ICD Codes and Keywords

Description

Disease codes which have been converted and reformatted to Local Registry standards
Coded values and key words for the CTC disease from text fields on the record

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Would like to track coding scheme converted to as well as coding scheme it arrived in. Registries may go to new revisions (especially ICD and ICD-O)

Sensitivity

Data Items (if a group data flow)

Data item name (R1)
Converted Data item value (R1)
Data Item Coding Scheme (R1)
Keywords (R2)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate

Converted Other Codes and Text per Special Study

Description

After conversions that need to be done for the registry's normal business, any out-of-the-ordinary conversions that are being done to support a special study. This includes converting data items and translating text.

The results of the above: standardly coded data items and keywords outside of normal registry business (variables specifically requested by the special study).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Might wish to track coding scheme converted to as well as coding scheme it arrived in. Registries may go to new revisions (especially ICD and ICD-O). However, since these fields are collected only for a special study, it may not be necessary to track the coding scheme.

Sensitivity

Data Items (if a group data flow)

(exact data items vary by study)
Data item name (R1)
Converted Data item value (R1)
Data Item Coding Scheme (R1 ?)
Keywords (R2)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Coordination Needed (=Y)

Description

Setting Coordination Needed flag to Yes for the patient IDs affected.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Coordination Needed (=Y)
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Copy of Health File

Description
The copy of the health file saved at the time received for archive purposes. This is part of the Submission Information data flow.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Copy of health file
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Copy of Supplemental File

Description
The copy of the supplemental file saved at the time received for archive purposes. This is part of the Submission Information data flow.
Some supplemental sources require that their data be destroyed after a certain time span (may be 1 year, may be after use). This data flow is separate for this purpose.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Copy of Supplemental File
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Corrected Information Request

Description

Given that the Information Request Problem was a misinterpreted request, this would be the corrected (and confirmed correct) request specifications.

This would go to the beginning of the 12.0 process and be treated like a new request.

Interested Registries

Interested:

Not Interested:

Local Procedures

Some registries review all requests with the requesters so they can limit this kind of problem

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information Request ID
Information Request Problem ID
Type of problem (=Correction)
Description (text)
Registry staff ID (who was notified)
Date of problem
Decision (how to resolve)
Date resolved
Registry staff ID (who resolved)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Correction Rejected Notification

Description

Notification from the registry to the facility sending a correction record that the registry does not agree and did not accept the correction. This happens while consolidating the facility view – determine best value, but the exact level depends on what is being corrected.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Depending on the number of corrections contained in a correction record, it may be a good idea to allow for 'collecting' rejections and sending the notification of all corrections at one time.

Sensitivity

Data Items (if a group data flow)

(A submission problem about a record)
Submission ID
Record Affected (correction record within submission)
Date problem sent
Staff ID

Problem Description:

Patient ID (Registry and Facility?)
Data item (to be corrected)
Proposed new value (from correction record)
Value in registry data
Reason for rejection

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Correction Record

Description

A record that notifies the registry about a change to the original data submitted by the source. This could include additional values (such as treatment which occurred after submission) or changes to values (such as modifications to hist/site/beh found during a source-internal review)
New treatment information wouldn't be implying the original information was wrong; the hospital just didn't wait long enough.
Could be received on paper or electronically
DESIGN NOTE: Possible implementation may be for a group of data items to be corrected on the same record. Another possible implementation (external to system) is to send a new health record with a flag marking it as a correction. Must allow for these implementations, if needed by the registries or their facilities
Assumed for New Logical to include one data item
In New Logical, assumed correction records were externally created and received from an Organization or Facility. Registry staff can update in place.
By definition, would have to match patient, CTC, and facility.

Interested Registries

Interested:
Not Interested:

Local Procedures

New Mexico calls this a "Suggested Change Document" , as there is no way to force the registry to accept the change in question.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Patient ID
CTC ID (seq? Hist/site?)
Facility ID
(May not really have above 3 identifiers. Could use a Record ID instead: match to record, find patient set record goes with, link correction record)

(the following would repeat if the correction was for more than 1 item)
Date
Data Item Name
Old Value
New Value
Reason (text field)

(If an entire health record was sent, would probably be caught while checking for duplicates and sent directly to 4.0 consolidation processes)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Correction Record ID

Description

The health record ID for a correction record of interest

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(Health) Record ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Criteria for Abstraction

Description

These are rules that specify which leads and records need to have abstract produced. Policy driven.
Selection by Hospital, how long record has been sitting, by Abstractor
Examples include:
How 'old' is the cancer/tumor/case (6 month waiting period) – may result in 'abstract needed, delay until date' type status.
Can an abstract be obtained from this facility?
Was an abstract already received for this patient, CTC, facility? (don't want to duplicate work) (Implementation considerations: Could look at 'Abstract Facility Lead' or 'match status'?)
Does this CTC have rapid case ascertainment priority?
Is patient still alive? (best knowledge)

Also affected by 'how often is facility visited' – may do partial abstract with note that it must be re-examined later.
If all abstracts on task list have been collected, would then start on other leads – either the ones collected during the current trip or the ones slightly younger than 6 months. (would document need to re-examine).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Text of rule (ie Criteria for when a case should be abstracted)
Source of Rule (SEER, NAACCR, State,…)
Effective (start) date

End Date
Supporting tables
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Critical Values Exist Indicator

Description

A status flag which shows that critical data items have been reviewed and that all such items have a valid (non-missing) value. This is necessary in order to set the registry view patient set status to submissible. Must be determined after all data have been collected, cleaned and consolidated. Is only important on the registry view. Patient set should not be included in submission when this flag is false.

Interested Registries

Interested:
Not Interested:

Local Procedures

List of critical data items varies by registry. SEER items are the core group, but other items may also be included.

Policies/Business Rules

DESIGN NOTE: May make sense to have a flag for each CTC set as well as an overall patient set. If a patient is missing a critical item, the entire set should be withheld from use. If 1 CTC is missing a critical item, other CTCs may be perfectly acceptable to send to SEER.

Sensitivity

Data Items (if a group data flow)

(Report generated on the fly by computer based on values in patient set and registry definition of critical values)
Critical values exist? {Y, N}
Level of missing {patient, CTC}
CTC ID (if needed)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

CTC ID

Description

The ID number assigned by the registry to the CTC set.
This is assigned in 4.5.2 Assign IDs in the NPL models

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Registry CTC ID

(could include sequence number, record number)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

CTC ID info

Description

Information that identifies the CTC so an abstract facility lead can be created. Probably best to use the facility identifying information

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

CTC ID (in registry)
(Based on info available)
Facility CTC ID
Site
Hist
Date of Diagnosis

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

CTC Identifying Info

Description

Shows which CTC(s) for a patient are identified to be processed, tracked, etc.

The data items by which it is possible to distinguish 1 cancer/tumor/case from another

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Site
Histology
Behavior
Laterality
Sequence number (registry id, if assigned)
Date of Diagnosis

Metrics

Frequency:
Volume:

Duration:
Quality/Error rate:

CTC Info

Description

Information related to the cancer/tumor/case.
In 7.1, specific information that affects whether a CTC is eligible for follow-up.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

CTC ID (sequence)
Primary Site (location of cancer/tumor)
Morphology - Histology
Morphology - Behavior
Morphology – Grade

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

CTC Matched Info

Description

The 2 (or more) data groups that were determined to be a positive match at the cancer/tumor/case level. The data groups could be incomplete patient set, existing patient set, or health record (including correction record, reportable or non-reportable). This information will be used in 'consolidation'
DESIGN NOTE: the previously matched records and/or patient sets will be retrieved if needed.
Information related to the cancer/tumor/case.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See BOM entities: CANCER/TUMOR/CASE, MARKER, COMORBID CONDITION, RESIDENCY is established for CTC, IMAGE, IMAGE EVALUATION, SPECIMEN, SPECIMEN EVALUATION, DIAGNOSIS and PAYOR SOURCE covers CTC, FACILITY ADMISSION, FACILITY refers PATIENT to FACILITY, RESIDENCY is established for CANCER/TUMOR/CASE
See BOM entities: IDENTIFICATION, OVERRIDE
See BOM Relationship: (PATIENT or) CTC is included in SPECIAL STUDY, (PATIENT or) CTC is possibly reportable to SPECIAL STUDY

(Not all data items would be included because some variables (most of the CANCER/TUMOR/CASE data items) are derived or system based. The values from all data groups would be included)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

CTC Match Status (=No)

Description

CTC match status: whether a match was found at the CTC level for the data group in question.
Here, specifically no CTC match was found for the given data group

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Match level (=CTC)
Match status (with value set to no)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

CTC Requiring Abstract

Description

A CTC that needs to be abstracted now
These are abstract facility leads that are due. They have been reviewed by 2.6 Make Abstract Determination.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Abstract Facility Lead ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Current Data

Description

Data values as they stand in the live database at the time of update

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules
Would lock the Live database before sending this to Backup

Sensitivity

Data Items (if a group data flow)
All data items in database

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Current Data to Backup

Description
Data values from the live database being written to the backup data base

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
Should probably verify that backup data matches live database before unlocking the live data.

Sensitivity

Data Items (if a group data flow)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Current Date

Description
What more can I say?

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Month
Day
year
(This may be a date/time stamp)

Metrics
Frequency:
Volume:
Duration:

Quality/Error rate:

Data Item

Description

The name and value for a variable, as needed

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Data item name
Data item value

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Data Item Access Request

Description

Request by an org rep to access data – either to view or modify it.
DESIGN NOTE: request may truly come from a process (is this person authorized)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Date of attempt
Time of attempt
Org Rep ID
Data table
Data item name

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Data Item Access Status

Description

Response to org rep and process about whether the org rep is authorized to view the data or to view and modify the data

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Access Status {Success Read, Success Read/Write, Failure}
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Data Item Name

Description
The name of a variable – "Sex" or "Histology", etc
Using this during consolidation to track how well the data is matching so you can determine if you have a false positive match.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Data item name
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Data Mart Request

Description
A request (generally from a manager, Information Distribution staff or the special study support staff) describing a new data mart that needs to be created for future reports, analysis, special study, etc.
The data mart will be a replicated data store which is static for a specified period of time. Data marts may be updated nightly, never at all or somewhere in between.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Data mart name
Timing of desired updates
Data items needed
Structure desired
Metrics
Frequency:
Volume:

Duration:
Quality/Error rate:

Data Mart Specifications

Description

Description of a data mart that the system understands and can apply without human intervention

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Data mart name
Timing of desired updates
Data items needed
Structure desired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Data Problem

Description

A problem w/ the data included in an information request fulfillment that has been identified by the recipient.
Usually, this triggers an investigation of and possible change to information stored in the patient set data.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information Request ID
Information Request Problem ID
Type of problem (=Data)
Description (text)
Registry staff ID (who was notified)
Date of problem
Status

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Data Problem Resolution

Description

The registry's resolution to a data problem.

This includes a Registry's decision not to do anything about the issue or acknowledgement that this is an issue and the Registry is working on it. If the Registry is going to do something about it, the Registry just regenerates the request fulfillment with the correct data when it becomes available.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information Request ID
Information Request Problem ID
Decision (how to resolve)
Date resolved
Registry staff ID (who resolved)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Data Returned Flag

Description

Notes that data has been returned to the registry by the special study as agreed in the special study contract

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Special Study ID
Data returned by Study? {y, n}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Date Abstract Attempted

Description

Date abstractor went to a location and attempted or started to create an abstract (summarized patient medical records into standardized format) for a given patient, cancer/tumor/case.
Implies abstract was not completed. (otherwise would be Date abstracted)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Date
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Date Abstract Requested

Description
Date an abstract was requested from a facility that generates its own abstracts in response to an abstract being needed (2.6)
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Date abstract requested
Org Rep (who requested)
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Date Abstracted

Description
Data abstractor went to a location and created an abstract (summarized patient medical records into standardized format) for a given patient, cancer/tumor/case.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Date
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Date Accepted

Description
Date that the update notification is accepted by the facility. This tracks that it has been accepted and when.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Date accepted
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Date Assigned

Description
The date a follow-back task was assigned to a specific registry staff member
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Month
Day
Year
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Date Last Follow-Up Response Received

Description
The last time the Registry received a response to a Follow-up Query
This may not be the last follow-up for the patient (if passive follow-up is received)
This may not be a response to the last follow-up action performed (if someone has not responded to the registry regarding this patient.)
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Month response received
Day response received
Year response received
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Date of Diagnosis

Description
The date the Patient was first diagnosed with a particular CTC (by morphology, no recurrent CTCs or metastatic CTCs.)
Note, this is needed for census tract coding because census tract assignment changes over time. (probably only need year of diagnosis for this)
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Month of Dx
Day of Dx
Year of Dx (most important part as far as census tract coding)
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Date of Last Follow-Up Query

Description
The last time the Registry sent out a Follow-up Query
This may not be the last follow-up for the patient (if passive follow-up is received)
This may not have a corresponding response date (if someone has not responded to the registry regarding this patient.)
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Month of follow-up action
Day of follow-up action
Year of follow-up action
Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Date of Follow-Up Query

Description

Date(s) the Follow-up Query(s) took place.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Month of follow-up action
Day of follow-up action
Year of follow-up action

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Date of Last Contact

Description

The latest date for which the registry has ascertained the patient's vital status
Can be discovered through passive or active follow-up
Frequently, the date the patient has had contact with some facility or organization as discovered on an official record.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Month of last contact
Day of last contact
Year of last contact

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

DEA Fulfillment Tracking Info

Description

Tracking of the source submission sent by a data exchange partner in order to fulfill their agreement.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

DEA ID
Source Submission ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

DEA History Information

Description

Audit information for changes made to Date Exchange Agreements.

Interested Registries

Interested:
Not Interested:

Local Procedures

Of interest to IA, HI, NM

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Org Rep ID
DEA ID
Date of change
Old value
New value
Reason (text field, why was this made)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Death Certificate ID

Description

The death certificate number assigned by the state bureau of vital statistics. It is used to request the DC based on information in the Death file/index/list.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Death Certificate ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Death Certificate List

Description

A listing of all the patients that a death certificate is needed for

Interested Registries

Interested:
Not Interested:

Local Procedures

Some registries go to the vital statistics bureau and make copies of the death certificates needed. Others send this list to the bureau and await a file. (Some registries have electronic scanned copies on the original file, and can just print them/copy them as needed. This process does not need a list)

Many registries only obtain DCs for people who died of cancer/tumor and did not have a patient and CTC match. NM (and possibly others) also obtains DCs that match to any patient in their database.

Policies/Business Rules

DC number is needed to look up the death certificate. Patient ID helps the registry link the obtained DC back to the patient sets. The rest of the data items aid in verifying that the DC is the one expected. Sometimes multiple DCs will have the same number.

Sensitivity

Data Items (if a group data flow)

(These are the date items for 1 entry on the list, they are probably obtained from a report)
Patient ID (May be incomplete patient set ID)
Patient Name
Death Certificate Number
Date of Death
Cause of Death

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Death Certificate Records

Description

A collection of death certificates sent to the registry by the Vital Statistics Bureau at the registry's request

Interested Registries

Interested:
Not Interested:

Local Procedures

May have to pay to obtain these records

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(The following are the data items on a single record)
Deceased 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)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Deficiency Notification

Description

Notification sent the state regarding a lack of records from a particular facility.
This isn't stored

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility/org ID
Facility/Org Name
Date
Deficiency description

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Deleted Facility View

Description

A patient set facility view which during editing or QC, has been discovered to be not reportable.
Could be that text was miscoded or that the interaction of several variables causes the patient to be 'non-reportable', but was missed earlier.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Registries never delete anything. They mark the view as 'deleted', but it is still being stored in their databases. New information may come in later that changes the status back to valid. Also, external audits might count the patient as missing in the registry unless the registry has the reasoning behind its exclusion.

Sensitivity

Data Items (if a group data flow)

See Patient Set
Patient ID
Facility ID
Facility View Status: deleted
Date deleted (date of ACD)
Staff ID
Reason

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Deleted Patient Set (All Views)

Description

See Patient Set
A patient set, which during editing or QC, has been discovered to be not reportable.
Could be that text was miscoded or that the interaction of several variables causes the patient to be 'non-reportable', but was missed earlier.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Registries never delete anything. They mark the patient set as 'deleted', but it is still being stored in their databases. New information may come in later that changes the status back to valid. Also, external audits might count the patient as missing in the registry unless the registry has the reasoning behind its exclusion.

Sensitivity

Data Items (if a group data flow)

See Patient Set
Patient ID
Patient Set Status: deleted
Date deleted (date of ACD)
Staff ID (who deleted)
Reason deleted

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:
7

Deleted CTC Set

Description

A CTC set, which during editing or QC, has been discovered to be not reportable.
Could be that text was miscoded or that the interaction of several variables causes the patient to be 'non-reportable', but was missed earlier. For example, metastatic cancer/tumor reported as separate CTC.
Could be just a facility view or registry view.

Interested Registries
Interested:
Not Interested:

Local Procedures
Registries never delete anything. They mark the CTC set as 'deleted', but it is still being stored in their databases. New information may come in later that changes the status back to valid. Also, external audits might count the patient as missing in the registry unless the registry has the reasoning behind its exclusion.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See CTC Matched Information
See Treatment Matched Information
Patient ID
Facility ID (R1) (if not present, then all)
CTC ID
CTC Set Status: delete
Date deleted (date of ACD)
Staff ID
Reason

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Derived Data Items

Description
Data items whose values are composites of other variables. Sometimes calculations (like age or survival), sometimes summarizing information (summary treatment)
Could also include recodes here (collapsed grouping of data item values)
For Example:
Summary Treatment may be derived here from notes.
Age at Diagnosis (dodx – dob)
Survival Time (date of last contact – dodx)
Age at diagnosis recode (5 year grouping)
Site recode (more generalized groups: breast cancer/tumor, lung cancer/tumor, etc)
…

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Data item name
Data item value

Metrics
Frequency:
Volume:

Duration:
Quality/Error rate:

Description of Documentation Needed

Description

A description of the documentation needed by the registry from the requester in order for an information request to be filled
Usually this is IRB documentation or a Signed Collaboration Agreement

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information Request ID
Documentation Name (R1) (eg, IRB from St Judes, doesn't need to be permanently stored)
Comments

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Differences

Description

The differences between Data Item Values on the Data Source's (Facility or Organization) Original Abstract and the Registry's current Patient Set
OR
The differences between Data Item Values on the Registry's current Patient Set and the Last Patient Set Snapshot that was sent to the Data Source (Facility or Organization).
Confirmation of modifications the facility has notified the registry of and updates/additions to the data that the facility is allowed to know. For example, Death Certificate information is public knowledge, but a second CTC that this facility has not seen would not be allowable.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Accession Number (Facility's Patient ID)
Facility ID
Name of data item
Old value
New value
Reason for change (e.g. Age, 54, 55, DOB incorrect re DMV)
Date of change

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Do Not Contact Medical Practitioner Flag

Description

A simple 'yes' or 'no'.
This medical practitioner does not wish to be contacted by the registry (ever).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Some medical practitioner's may have preferred methods of contact (phone, mail), preferred times of contact (before 10 am), or preferred addresses (send all to primary office). This information is tracked separately in the profile.

Sensitivity

Data Items (if a group data flow)

Do not contact flag

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Do Not Contact Patient Flag

Description

A simple 'yes' or 'no'.
This patient does not wish to be contacted or should not be contacted for other reasons. (for example, patient is a minor, patient is mental incapacitated, patient is unaware that they have a cancer/tumor, patient is American Indian (can't contact by law))

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

DESIGN NOTE: This is 'Do Not Contact EVER'.

Sensitivity

Data Items (if a group data flow)

Do not contact flag
(may also wish to store reason or source – physician, parent, guardian – because this may change over time, for example a minor with a cancer/tumor)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Duplicate Facility Record

Description

A health or correction record that the registry has determined they have already received and processed. Hence they have no interest in this current one.
This record is discarded because there is already a copy of the record in the registry data stores. This deletion should also include the removal of any converted codes or keywords stored.
This may be a record duplicated within the same submission.
These are byte-for-byte type matches.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See health record, correction record.
Exact data item list depends on type of record. All information related to this iteration of the record should be removed.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Duplicate Facility Record Notification (byte for byte)

Description

Notification to source that the record has been received multiple times by the registry and a request to cease sending it. No new information is on this type of record, so it's not being used as a 'correction' record.
This isn't stored

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Registries will likely send duplication notices to the facility because of non-exact duplicate facility health records and ask that correction records be sent instead.

Sensitivity

Data Items (if a group data flow)

Received From (Facility/Org ID)
Current Submission ID (what the registry wishes to call it)
Current Received Data File identification (What the source called it, if anything)
Current Received Date
Current Record ID within submission (23rd record or whatever)
Original Submission ID (what the registry wishes to call it)
Original Received Data File identification (What the source called it, if anything)
Original Received Date
Original Record ID within submission (23rd record or whatever)

Number of times submitted (probably wouldn't send this unless it was more than 2)
Date duplication notice Sent
Staff ID (to direct comments to)
Comments (correction records, please stop, within same submission, etc)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Duplicate Record ID

Description

The health record id of the duplicated record. These are not byte-for-byte or near. They passed through the system and were caught during consolidation.
Information contained on these records should have been sent via corrections records.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Health Record ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Duplicate Record Notification

Description

Notification to source that a record of this type has been received for this patient, cancer/tumor/case from this source multiple times by the registry
A request to use a correction record if applicable
DESIGN NOTE: Most of the consolidation work for this record should have been done by the computer. Only involve the org rep when a difference is found.
This isn't stored

Interested Registries

Interested:
Not Interested:

Local Procedures

While some facilities resubmit records with modifications in the name of correction, some registries seem more into the correction record type than others. They would like to get all corrections via 'correction record' type and refuse to accept corrections in any other way.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Current Submission date
Current Submission identifier (Text: filename, id tag, … however the source identified it to the registry.)
Record Identifier in Current submission
Original Submission date
Original Submission identifier
Record Identifier in Original submission
Number of times submitted (probably wouldn't send this unless it was more than 2)
Date Sent (on notice, not stored)
Staff ID (to direct comments to. on notice, not stored

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Duplicate Submission

Description

A submission that has been determined to be 'exactly' the same as a submission that has been received before. These can be deleted and removed from the processing.
It should be noted in the submission information for the originally transmitted submission how many times it has been received.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Duplicate Supplemental Record

Description

A supplemental record that the registry has determined they have already received and have no interest in. It is kept; just no further processing is required.
No notification to submitting organization is sent.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

It would save time not to reprocess this record. However, it doesn't matter if it is reprocessed. The decision will probably be based on how easy it is to determine duplication and to remove the record from the process flow.

Sensitivity

Data Items (if a group data flow)
See supplemental record.
Exact data item list depends on type of record. All information related to this iteration of the record should be removed.
Would also include deleting any keywords or converted codes.

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Edit Info

Description
Tracking information about when a patient set was edited.
This is the original edit, not any QC done later.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Edit Date
Editor

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Edit Issue Tracking

Description
Tracking information for edit issues, including the problem, what data group has the problem, dates and resolutions.
For Facility problem:
Is the change just made the result of a facility error? That is, should it be reported to the facility as an error and 'counted' against them?
DESIGN NOTE: May be implemented as a checkbox (yes/no) flag to the user and the computer tracks all other information.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Patient ID / Health Record ID
Date edit issue discovered
Org Rep who discovered
Edit issue (R1 – description of problem or edit name)

Data item involved (R1a – there are multiple items for inter-field edits)
Facility Error? {Y, N}
Status (Resolved Org Rep; Resolved Follow-back; Pending follow-back, Open, Related data set deleted)
Date resolved
Resolution
Override ID/Health update ID/ACD ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Edit Level

Description

The level (weekly, monthly, pre-submission) of edits that the user desires to apply during the edit run. Based on this, a specified subset of the edit rules will be applied (this is specified by the registry during implementation of the system and they can change the subset over time)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Edit level

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Edit Statuses

Description

See descriptions for the 2 types of Edit Statuses, Inter-field Edit Status and Single Field Edit Status.
All edit statuses returned by 17.0 Edit Patient Set Into to the process that called it.
DESIGN NOTE: since the user only needs to see edits that failed, it would be nice to return an “all edits passed” message when appropriate.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Inter-field Edit Status
See Single Field Edit Status.

Metrics

Frequency:

Volume:
Duration:
Quality/Error rate:

Edit Tracking Info

Description

Whether or not a facility is at fault for an edit issue, the update or override that corrects the edit, and any updates to the edit status.
Must be passed from process that fixed the edits into the edit tracking system

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Org Rep who discovered
Patient ID/Health record ID
Facility Problem? {Y, N}
Status (Resolved Org Rep; Resolved Follow-back; Pending follow-back)
Override ID/Health update ID/ACD ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Edited Converted Valid Records

Description

Electronic records which have been reviewed for usability, converted to registry standards. Keywords of interest have been pulled out. The final version of the record has undergone field and interfiled edits as much as possible (inter-field may not be possible)
Usable records in this case are those which are not suffering from widespread missing data, corrupted fields, unacceptable values and the like. The registry is willing to continue working with the record as it is, resolving any issues through follow-back.
Conversion applies to any registry standard variables and any special study variables. Residency information has been extracted for screening purposes (if possible).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Depends on type of record (subtypes of health record, correction record and supplemental record). As many records as were in the submitted file.
Status=converted, edited (not a retained status)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Electronic Version of Health Record

Description
See Health Record
A paper health record that has been screened and is considered acceptable and has just been keyed into electronic form
This version of the health record should reflect what is on the original paper, not the converted form.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Health Record
Status=reportable coded

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Eligible Patients

Description
All persons who are eligible for a particular special study.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Special study ID
Source type (R1)
Source ID (R1)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Ethnicity Codes

Description
A formatted representation of an ethnic grouping (0=White, non-hispanic; 1=Black, non-hispanic; etc)
Multiple codes may be returned for a given person.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Ethnicity code
Certainty score

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Existing CTC Set Data Item

Description
A data item value from the existing CTC set which matched to the incomplete patient set currently being processed. Specifically, CTC information data items.
This would include missing values as well as valid values. It is not trying to imply that the value is different than the 'new' value.
In the situation where 2 or more non-patient set groups of data matched, this is representing the other options available for the value of the data item.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Data item value from existing patient set

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Existing Data Mart Specifications

Description
Data mart specifications that have been stored previously and now need to be modified

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Data mart name
Timing of desired updates
Data items needed
Structure desired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Existing Health Record(s)

Description

All health records which have come into the registry and been retained (they have to at least pass the broad filter in 1.0 in order to be stored) In 10.0 Manage Registry Operations, the health records are used for a variety of tasks, checking to see what has been reported to the registry as well as increasing staff expertise. Would want the record as sent to registry in order to accurately perform these tasks.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See health record (All data items on record)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Existing IDs and Reasons

Description

ID problems that have already been discovered and resolved by the registry.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility ID/Org ID
Problem ID (assigned by computer)
ID (ID assigned by facility that is in question)
ID type {Accession, slide, etc}
Problem Type {Duplicate, Skip}
Date discovered
Date resolved
Resolution (text)
Status

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Existing Meta Data About Table

Description
Data that exists which describes what data items are include in a table, what types those items are, any formats or edits that apply, etc.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Data item name
Data item ID
Location of data item
Type (string, int, float, etc)
Constraints (R1)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Existing Non-Reportable Health Info

Description
The information from a Cancer/Tumor/Case record that passed the broad filter but at the fine filter was not reportable to any of the following: SEER, Local, Special Study.
Would have been retained if it had a potentially reportable flag for SEER or Local. (Possibly retained in potentially reportable for special study only, but not likely)
This record was saved in the data store (health and supplemental records) after it was received and is now being used during matching or Make Abstract Determination because a match was found.
The physical implementation of record is not 'needed' here.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
(All data items on record and corresponding converted values)
See health record
See Converted ICD Codes and Keywords
See Additional Disease Codes and Keywords (DC only)
See Residency Info

Status: Non-reportable

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Existing Patient Set(s)

Description

Patient sets which have completed the 4.0 Match and Consolidate Patient Set process at least once. They have been stored in the Patient set data store and are being used in matching to (hopefully) gather new data.
In 10.0 they are being used for a variety of purposes, including determining what has been sent to the registry, what the registry must send out, if leads, follow-up or follow-back can be closed and for training.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Patient Set
(In match process, would need to have specifically the data items shown below. Since this will be going on to consolidation if match is found, need to be able to access all data items in patient set. This should be taken care of by having the match identifying info)
Patient ID
First name
Last name
Date of birth
SSN
BOM ADDRESS
CTC ID
Site
Histology
Behavior
Facility ID
Treatment type

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Existing Patient Set Data Item

Description

A data item value from the existing patient set which matched to the incomplete patient set currently being processed. Specifically, patient information data items.
This would include missing values as well as valid values. It is not trying to imply that the value is different than the 'new' value.

In the situation where 2 or more non-patient set groups of data matched, this is representing the other options available for the value of the data item.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Data item value from existing patient set

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Existing Report/Extract

Description

An existing Report or Extract that has already been produced
Could be standard or ad hoc
See glossary for definition of extract and report. Short version:
Extract: 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.
Report: summary of information contained in the registry. Can be CTC data (incidence rates, etc) or registry operation data (monthly abstracts generated by abstractor). Would potentially include task lists (what still needs to be done).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Actual Report/Extract
(obtained via Report/extract identifier (name) and Location)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Existing Report/Extract Copy

Description

Copy of an Existing Report/Extract (see data flow). Original remains in registry so that it can be used in the future and for archival purposes. May be actual photocopy or reprint, may be a copy of a data file sent out on disk.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Copy of the actual report/extract (sent to requester, not additional storage)
(obtained via Report/extract identifier (name) and Location)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Existing Treatment Set Data Item

Description

A data item value from the existing treatment set which matched to the incomplete patient set currently being processed.
This would include missing values as well as valid values. It is not trying to imply that the value is different than the 'new' value.
In the situation where 2 or more non-patient set groups of data matched, this is representing the other options available for the value of the data item.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Data item value from existing patient set

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Existing Unmatched Correction/Follow-Up Info

Description

See Acceptable Correction Info and Acceptable Follow-Up Info
Information from a Correction/Follow-up Record for which there was no Patient Match at the time received.
This may have happened because the correction/follow-up record arrived before the record that it was a correction/follow-up to.
This record was saved in the data store (health and supplemental records) after it was received and is now being used during matching in an attempt to find the record it corrects or follows up.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Acceptable Correction Info and Acceptable Follow-Up Info
Facility ID
Patient ID
CTC ID (?)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Expanded Request Information

Description
Additional information requested – above & beyond the requestor's original request.
This is treated as a new request. It has to be checked for validity and fillable status. May be able to use original request as base to start new fulfillment.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
Would become a new request. Decision might only need to be the Information Request ID of the new request.

Sensitivity

Data Items (if a group data flow)
Information Request ID
Information Request Problem ID
Type of problem (=Expanded)
Description (text)
Registry staff ID (who was notified)
Date of problem
Decision (how to resolve)
Date resolved
Registry staff ID (who resolved)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Expertise

Description
Expertise is knowledge about registry operations that any given registry staff member has. Internal knowledge and judgment making skills.
In 10.4 'Perform Reliability Study', specifically the expertise of an abstractor.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Not quantifiable, internal to person

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Facility/Organization ID

Description
The ID of the facility or organization who has not met expected submission levels so that the registry can notify them and the state authorities if necessary

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Facility ID **or**
Organization ID

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Facility Acceptance Notification

Description
Notice to the registry by the facility (or org) that an update notification has been accepted.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Date of Acceptance
Update accepted
(not sure exactly what else could be included, but this is all the registry cares about)

Metrics
Frequency:
Volume:

Duration:
Quality/Error rate:

Facility Code(s)

Description

The identification codes for the facilities associated with this patient set.
Aka Facility ID Number
Could be a registry assigned ID or a tax id number. Any code that uniquely identifies this facility within the registry

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility ID (R1)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Facility Contact Information

Description

Information needed to contact a facility: phone number, fax number, mailing address, and contact name or title.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility ID
Facility name
Department (R1)
Contact name and title (R1)
Mailing street number/name or PO Box
City
State (Canadian Province)
Postal Code (ZIP)
Phone number (R1)
Fax number
Email address (R1)
Web address
Preferred method of contact (R1)
Preferred time of contact (R1)

Metrics

Frequency:
Volume:
Duration:

Quality/Error rate:

Facility Identifying Information

Description

Shows which facility(s) for a patient/CTC are identified to be processed, tracked, etc.

The data items by which it is possible to distinguish 1 facility from another.

See Facility Code(s) data flow

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

May just need to store facility ID number. Rest will be stored in Org, Facility and Medical Practitioner Profile data store.

Sensitivity

Data Items (if a group data flow)

Facility ID number (in registry)

??Facility Name

??Facility Address

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Facility ID Needed

Description

Facility for which an abstract facility lead needs to be created

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

May just need to store facility ID number. Rest will be stored in Org, Facility and Medical Practitioner Profile data store.

Sensitivity

Data Items (if a group data flow)

Facility ID (in registry)

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Facility Info

Description

Information about a facility that can be used to identify it. This may also contain full contact information.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility ID (may be registry assigned)
Name
Mailing street number/name or PO Box
City
State (Canadian Province)
Postal Code (ZIP)
Phone number (R1)
Fax number
Email address
Web address
Contact name or title (R2)
Department (R2)
Preferred method of contact (R2)
Preferred time of contact (R2)
Distance from registry

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Facility Matched Info

Description

The facility ID for the facility view that is found to match to the incoming data group, if such a view exists.
This match would be discovered for data groups with patient match, or selected patient match.
This (match status) would indicate that the facility view will need to be consolidated for the patient, possibly cancer/tumor/case and possibly treatment, depending on the other match statuses.
See Local Procedures below!!!!!

Interested Registries

Interested: NM (local procedures)
Not Interested:

Local Procedures

NM: They have organizations which contain multiple facilities. They would like to track that other facilities within the organization have provided information in each relevant facility view. (I.E. ORG alpha soup has Hospital A, Hospice B, Lab C and Hospital D. Patient is diagnosed at A, had a path report generated by C and was treated at D. Ron would like Facility View A to note that patient has info from C & D, likewise for Facility View C and Facility View D)
NM: To accommodate the above: need to pass facility ID and facility Accession Number for the sibling facilities into the Create Facility View Patient Set process.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility ID

Affiliated Facility ID (R1 – where declare match=Y)
Affiliated Accession Number (R1 – from hrec or Pat facility view)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Facility Profile

Description

Information needed to contact a facility, phone number, fax number, mailing address and contact name or title.
Would also include best times/method of contact. (for example, do not call between 10-4)
Would also include if the facility can do its own abstracting

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility ID
Facility name
Type of facility
Bed size
Facility FAN
Department (R1)
Dept Location (R1) (could be location of lab, e.g. basement)
Contact name and title (R1)
Phone number (R1)
Email address (R1)
Preferred method of contact (R1)
Preferred time of contact (R1)
Type of records expected (R1)
Mailing street number/name or PO Box
City
State (Canadian Province)
Postal Code (ZIP)
Fax number
Web address
Distance from registry
Associated travel expenses
Season to visit
Abstract submission schedule
Policies (R2) (Facility policies that affect how registry staff completes work)
Affiliated Facility ID (R3)
Declare Match? (R3) {Y, N}
Parent Organization ID

Metrics

Frequency:
Volume:
Duration:

Quality/Error rate:

Field Abstract Facility Lead

Description

See Abstract Facility Lead

An abstract facility lead initiated in the field that needs to be transferred to the CRO for processing and resolving. Most likely a 'referred from' or 'referred to' facility.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Abstract Facility Lead

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Field Acceptable Health Record

Description

See Acceptable Health Record

Either a health record which was obtained in the field (such as a paper record that the registry wants to retain) or a health record that was created in the field.

Not all registries feel that health records obtained in the field and used to create abstracts need to be sent to the CRO. However, path reports gathered from a lab would probably need to be provided to the CRO.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Acceptable Health Record

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Field Follow-back Request

Description

See Follow-back Request

A follow-back request initiated in the field that needs to be transferred to the CRO for processing and resolving.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Follow-back Request

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

File Documentation

Description
Any documentation that is sent with a submission describing the file layout and data item formats included in the file. This may not be included for standard formats.
Whether or not this is included is not under registry control. If it has not been included and the registry needs it, they have to ask.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Submission ID
File documentation (electronic or paper)
File type
Record Layout (R1)
Field Format (R1b – field name/acceptable values/value meanings)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

File Format Questions

Description
See Submission Questions
Questions directed towards the source facility/organization specifically about how the file received in a submission is formatted.
This could cover file layout and data item formats.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Submission ID (what the registry wishes to call it)
Received Data File identification (What the source called it, if anything)
Received From (Facility/Org ID)
Received Date
Type of record received (R1)
# of Records Received (R1)
Question description (text)
Date question Sent
Staff ID (to the attention of, so on)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Fillable Request Status

Description

Given that a request is valid, can it be filled by the registry at this point? This request has passed the local, State and Federal rules. It is legal and acceptable to fill the request and it may proceed through the 12.0 process.
More of a trigger than a data flow. This status kicks off the next process, but is probably not necessary to do the next process.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

The registry would like to fill as many valid requests as possible. While they don't store invalid information request information, they would like to store valid requests.

Sensitivity

Data Items (if a group data flow)

Status (=Fillable, On hold, Rejected)
(if no, but will be fillable at known point in future, would be nice to be able to trigger a review)
Reason unfillable (what are you waiting for, text)
On hold Review Date (Derivable)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Back Disposition

Description

Which process or person the follow-back response needs to go to. I.E., if the follow-back request was generated in matching and the match is being held until answer is received, disposition would be 'send to matching'.
Would be nice to have some kind of email notification to the Staff member (where response should go or who sent the request) that the response has been accepted.
One possible disposition is to send to 8.2 Create Follow-Back Query. In that case, modification needed to query would have to be noted (technically this is resolution) – either rephrase or redirect (and to

whom). This could be caused if the information received does not answer the question and the registry needs to rephrase or redirect the question. It can also be caused if the information received is 'no longer our patient, please contact…', in which case the query is redirected.

The value of the disposition indicates the type of action that needs to be taken.
(Processes where 2nd column is "y" or "could" on our chart from 9/20/00). Updated per DFD's on 9/7/01. Updated 8/14/02

#	Process Number	Process Name	Does it trigger FB process?	Does it wait for or use FB response?
1.	1.2	Complete Final Local/SEER screen	Y	Could
2.	1.3	Complete Final Special Study Screen	Y	Could
3.	2.1	Create Abstract	Y	N
4.	3.6	Evaluate Special Study Communication	Y	Could
5.	4.1.1	Search for Patient Match	Y	Y
6.	4.2.1	Select Possible Patient Match	Y	Y
7.	4.1.10	Search for CTC Match	Y	Y
8.	4.3.1	Select Possible CTC Match	Y	Y
9.	4.1.11	Search for Treatment Match	Y	Y
10.	4.4.1	Select Possible Treatment Match	Y	Y
11.	4.2.2.2, 4.2.3.2 4.3.2.2, 4.3.3.2 4.4.2.2, 4.4.3.2	Determine Best Value for Consolidation • For Patient Information • For CTC Information • For Facility Set	Y	Y
12.	4.5.1	Incorporate All Info into Single Patient Set & Review	Y	Y
13.	4.6	Screen Non-Reportable Records Match	Y	Y
14.	5.1.3	Determine if Missing Critical Data Items	Y	N
15.	5.2.1	Evaluate Census Tract	Y	N
16.	5.2.2	Lookup Census Tract	N	Y
17.	7.3	Evaluate Active Follow-Up Responses	Y	Y
18.	7.4.3	Select Best Value from Active Follow Up	Y	Could
19.	8.3.1	Evaluate Response (Follow-back)	Y	N
20.	10.3.1.3	Contact Via Another Method	Y	N
21.	18.1	Compare and Resolve Text to Codes	Y	Y
22.	12.5.1.1	Produce Ad Hoc Report/Extract/Registry-Controlled File	Y	Could
23.	12.5.1.2	Produce Standard Report/Extract/Registry-Controlled file	Y	Could
24.	12.8	Attempt to Resolve Data Problem	Y	Could
25.	13.3.2	Convert Electronic Codes	Y	Could
26.	13.8.2	Convert Codes for Paper Records	Y	Could

17.0 just notes problem, calling process must decide what to do, including possibly follow-back.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Send response to (Staff member)
Disposition process (part of instructions, the process waiting for the Follow-Back response. For Example: Resolve Possible Patient Match, Create Follow-Back Query, … May be better to have broader process names here. Screening, Matching, Abstraction, Consolidate, Polish, Follow-up, Follow-back, Receiving, Reporting, Editing, Special Study)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Back Need

Description

This description came from the definition in the BOM.
Registry identification of one problem that could be related to multiple data items.
Problem could also be from 2 data groups (patient set/patient set, patient set/record or record/record). This could 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.
DESIGN NOTE: 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 (conflict with other sources or with an edit rule). May be caused by an edit issue, matching or just general edit (viewing) of data.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Follow-back need ID (used to be FB request ID)
Process which sent follow-back request
Staff ID Who sent follow-back request
Date of follow-back request
Source type {HRec, Pat, CTC}
Source ID
Data item (R1)

Data Item Value (R1) (includes unknown)
Follow-back Reason (optional to each request)
Action needed (part of instructions, may be text field or possibly multiple setting flag.)
Disposition process (part of instructions, the process waiting for the Follow-Back response. For Example: Resolve Possible Patient Match, Create Follow-Back Query, … May be better to have broader process names here. Screening, Matching, Abstraction, Consolidate, Polish, Follow-up, Follow-back, Receiving, Reporting, Editing, Special Study)
Send response to (Staff member)
FB Need Status
Org rep Assigned to
Date Assigned
Urgency {standard, high}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Back Need History Information

Description

Audit trail for changes made to a follow-back need.

Interested Registries

Interested:
Not Interested:

Local Procedures

IA, HI are interested in this.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

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

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Back Need ID

Description

The ID for a specific follow-back need, usually for tracking purposes.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Follow-back need ID

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Back Need to be Redirected

Description
See Follow-Back Query
If the response to a follow-back query was not received or the response did not fulfill the follow-back need, the query may need to be re-directed to another facility or org.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Follow-Back Need
Note: to be redirected

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Back Query

Description
A question constructed based on the follow-back need and directed to a specific person, facility or organization. A single follow-back need may spawn several follow-back queries – either by needing information from multiple sources or a failure to obtain a meaningful answer from the first source.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Follow-back query id
Patient ID (for facility)
CTC ID (if needed, for facility)
Data item (R1)
Question
Directed to
Send response to (Staff member, probably doesn't need to be stored)

Metrics
Frequency:
Volume:
Duration:

Quality/Error rate:

Follow-Back Query to be Closed

Description

See Follow-Back Query
If the follow back query has been answered or the determination has been made that it will never be answered, the corresponding follow-back query needs to be closed.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Follow-Back Query
Note: to be closed (temporary)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Back Query to be Modified

Description

See Follow-Back Query
A follow-back query that needs to be changed, possibly because it contained an error or more information is needed. It will be sent to the original recipient again.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Follow-Back Query
Note: to be modified

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Back Query to be Purged

Description

See Follow-Back Query
A follow-back Query that needs to be purged from the tracking system. Usually a query that has been closed for a registry specified time. Is possible a manager would want to clear a query prior to that.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

DESIGN NOTE: depending on registry desires, this could be an actual removal from the database. Alternatively, it could remain but not be shown to standard searches.

Sensitivity

Data Items (if a group data flow)

See Follow-Back Query

Note: to be purged (temporary)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Back Query Tracking Information

Description

Data items which allow the follow-back queries to be tracked over time in case of problems and to aid in future decisions about who to direct follow-back queries to.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Follow-Back query ID
Staff ID who sent Follow-back Query
Date Follow-back Query sent
Method of query (letter, field staff)
Medical practitioner/facility/org follow-back query sent to
Related Follow-back Need ID (R1)
Query Status

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Back Request

Description

The request spawned by a failed process, entered by a registry org rep, that follow-back be performed to obtain more information. Usually occurs when there is some lack of clarity in the data (a missing value, inconsistent data values (2+ items) or conflicting values (1 item, 2+ sources)).

This includes the patient, CTC, or facility information that is in conflict, missing or potentially new information that has to be discovered.

Could include “Search Own Data Base” for information

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Patient/Record ID (R1) (if this is an attempt to match, multiple records involved)
Data Item Name (R2)
Data Item Value (R2) (includes unknown)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Back Resolution

Description

The accepted answer to a follow-back need. Since a single need may initiate several queries, the resolution is attached to the need (the ability for the registry to carry out its business) rather than a query (the letter/phone call attempting to obtain an answer). A single query may also ask about many needs.
The staff member accepting the answer may wish to note supporting text.

It is possible that the Follow-back response does not answer the follow-back query. In that case, the follow-back disposition is to send to 8.2 Create Follow-Back Query. The resolution should note how the query should be modified – either rephrase or redirect (and to whom).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

DESIGN NOTE: a possible implementation for getting the follow-back information into the system could be the same method as is chosen for New Patient Set Information (see 7.0 conduct active follow-up and 2.0 conduct abstracting diagrams.)

Sensitivity

Data Items (if a group data flow)

Follow-back Need ID
Record/Patient ID (R1)
Data Item Name (R2)
Data Item Value (R2)
Supporting Text (optional per resolution, who answered question, any reasoning behind answer, etc)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Back Response

Description

A reply to a follow-back query which was processed concurrently with follow-up. That is, the follow-back query was included in a follow-up letter. This information must return to the follow-back staff to be processed and tracked.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

DESIGN NOTE: if it is decided that follow-up and follow-back are similar enough that they ought to be stored in the same tracking system, this wouldn't be necessary. The new information could flow into 4.0 and the tracking could be updated directly in 7.3 (evaluate responses)

Sensitivity

Data Items (if a group data flow)

Follow-back query id
Record/Patient ID (R1)
Data Item Name (R1b)
Data Item Value (R1b)
Supporting Text (optional per resolution, who answered question, any reasoning behind answer, etc)
Record ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Back Response Tracking Information

Description

Data items which allow the follow-back responses to be tracked over time in case of problems, future confusion about the response, and to aid in future decisions about who to direct follow-back to.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Follow-Back Query ID
Who received from (foreign key)
Staff ID (who received/resolved)
Date received
Record ID
Follow-back need status

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Up Activity Information

Description

Describes follow up activity(s) already completed.
History of previous follow-up attempts, whether they worked or failed to obtain follow-up. Includes who contacted and how.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Most interested in what happened the last time, but there is no reason that the entire history should be available if desired.

Sensitivity

Data Items (if a group data flow)

(Data items for a single action)
Staff ID (who performed Follow-up Action)
Date of Follow-up Action
Type of Follow-Up Action (letter to doctor, phone call with patient, …)
Who was contacted (Text? Name of person, facility,org)
Date Follow-up Response Received
Useful response? (date later than current) {Y, N}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Up Information

Description

Information that tells whether the Patient is dead or alive and the date of that knowledge. Also may tell cause of death if patient has died.
Note: Other information potentially received during follow-up is sent in different data flows, frequently to different processes.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Vital Status
Date of Last contact
Cause of Death
Source of information {org ID, Facility ID, other} (to know which views to update)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Up Need History Information

Description

Audit trail for changes made to a follow-up need.

Interested Registries
Interested:
Not Interested:

Local Procedures
IA, HI are interested in this.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Org Rep ID
Date of change
Old Value
New Value
Reason (text field, why was this made)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Follow-Up Query Tracking Information

Description
Tracking information about the follow-up query.
If follow-back questions are include, some link to the appropriate follow-back need should be retained.
A standard Follow-up query asks whether the patient is known alive or known dead and as of what date. If the patient has died, the registry would like to know from what causes (and probably place of death so a death certificate can be obtained.)

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
For efficiency, outstanding follow-back for a patient may also be included in a follow-up query. The registries have also found that people are more likely to respond when multiple questions are asked.
DESIGN NOTE: May make more sense to keep non-vital status questions as follow-back and track these questions through the follow-back mechanism.
DESIGN NOTE: Because the main difference between follow-up and follow-back questions is the variables being queried, it may make sense to track both follow-up and follow-back in the same place.

Sensitivity

Data Items (if a group data flow)
Follow-up need id (for tracking)
Patient ID
Registry staff ID who sent
Copy of communication
Follow-back need ID (R1- any follow-back included in this query)
Status {selected, performed, response received and query resent, response received and accepted}

Metrics
Frequency:

Volume:
Duration:
Quality/Error rate:

Follow-Up Response Information Updates

Description

The Follow-up response, (original document, letter, record, etc) received by the registry.

Interested Registries

Interested:
Not Interested:

Local Procedures

Some registries keep the actual response. Others just use the information and don't store the actual response. The data items are stored by Updated Follow-up Information data flow.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Active Follow-up Response
Useful response? {Y, N}
Staff ID who evaluated

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Format Issue Resolution

Description

The Registry's resolution to a formatting issue.
This could include a Registry's decision not to do anything about the issue.
If the Registry is going to do something about it, the Registry just regenerates the request fulfillment with the correct format.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information Request ID
Information Request Problem ID
Decision (how to resolve)
Date resolved
Registry staff ID (who resolved)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

FUP Non CTC Non SS Health Record ID

Description

The health record ID for a Non Cancer/Tumor/Case and Record Not Special Study Reportable health record that has been kicked out of the broad screen in 1.1.1 but WAS used for passive follow-up.
This record will be stripped of restricted information and retained in the health and supplemental data store in this reduced form.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Health Record ID

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Health Info Requests

Description
See Request for Health Record
All requests for health information made by the registry.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
(Health) Records Request ID
Staff ID (who requested)
Facility or Org ID
Date request made
Due Date (derivable based on request date and registry standards)
Receiving Staff ID (who received request fulfillment)
Date received
Status {open, close/filled, close/other, purge}
Comments

Type of request {specific, general} (in BOM these are separate entities)
For general request:
Record type requested (path reports, disease index, abstracts)
From date
Thru date
For specific request:
Type of record requested (follow-back, abstract, etc)
Number requested (Derived: number of specific requests in same letter)
Health Record ID
Patient information (from record, may be name, ssn, etc)

CTC information (from record, may be site, hist, etc)
Document number (from record, for example a DC number)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Health Info Requests to Close

Description
See Health Info Requests
If the health information requested has been received or the determination has been made that it will never be received, the corresponding health info request needs to be closed.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Health Info Request
Note: to be closed

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Health Info Requests to Comment

Description
See Health Info Request
After reviewing the health info request, comments may be added to facilitate in tracking the request.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Health Info Request
Note: to be commented

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Health Info Requests to Purge

Description
See Health Info Request

A health information request that needs to be purged from the tracking system. Usually a request that has been closed for a registry specified time. Is possible a manager would want to clear a request prior to that.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

DESIGN NOTE: depending on registry desires, this could be an actual removal from the database. Alternatively, it could remain but not be shown to standard searches.

Sensitivity

Data Items (if a group data flow)

See Health Info Request
Note: to be purged

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Health Record(s)

Description

Any type of Health Record (Abstract, path report, death certificate, etc)
See BOM entity Health Record
A record that has some information about the health status of a patient, treatment received, diagnosis information, analysis of specimen or image, so on.
Primarily used to initialize case finding or construct the bulk of the patient set (i.e. an abstract), but they are also used for passive follow-up. They can be received in the course of active follow-up or follow-back.
Can be received on paper or electronically
NOTE: sometimes the record doesn't come into the registry. The registry staff member goes out to the facility (i.e. a path lab) and screens the records on-site.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Patient ID (from source)
See BOM entity Health Record
Exact data items depend of the type of health record, but basically the flow is trying to represent all the data which was received by the registry as it was received.
Date Created
Document ID
Type of Record

Metrics

Frequency:

Volume:
Duration:
Quality/Error rate:

Health Record ID

Description

A tag the registry adds to a health record in order to make it easy to reference.
These includes correction and follow-up records.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(Health) Record ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Health Record Status

Description

Status of the health record information.
In 8.1, may need to set the health record status based on follow-back need. In other cases, health record status may be unaffected by outstanding follow-back.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Health record Status

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Health Record Update Notification

Description

The notification sent by the SEER registry to the facility or organization who provided a given health record that describes an update made to the health record by the registry.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility ID / Organization ID
Record ID
Date of Update
Description of Update (list of variables changed, old and new values and why variable was modified)
Date of Notification

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Health Record Update Tracking Info

Description

Information about edits to typos on a health record. Values are being appended to end of Health record prior to creation of patient set. Conversions aren't really considered updates. You aren't trying to change the meaning, just the format.
This incorporates the health record update.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Health Record ID
(In HRec Update)
Data item changed
Old Value
Updated Value (to what)
Org Rep ID
Date/Time (when changed)
Facility Counted Error? {Y, N}
Reason Code (Categorical: Converted to standards, Converted Up version, Converted Down version, Correcting mistake, applying follow-back, etc)
Comments/Reason for Update (Why changed)
Date of Notification

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

ID Problem Resolution

Description

The reason an ID was skipped by a facility. This must be retained for future reference

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Resolution (may be new number for one patient or reason for skipped number)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

ID Problem Tracking Info

Description
Tracking information for problems related to Facility assigned ID numbers. This could include accession numbers, slide numbers from labs, etc.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Problem ID (assigned by computer)
Date discovered
Date resolved
Resolution (text)
Status

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Identified Patient & CTC Match

Description
The patient and CTC match which has been selected and consolidated. The treatment match (if any) will be found within this data group (probably a patient set).

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Incoming Patient ID (data group of interest, could be record ID)
Incoming CTC ID
Matched Patient ID (of matched patient, could be record ID) (R1)
Matched CTC ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Identified Patient Match

Description

The patient match which has been selected and consolidated. The CTC match (if any) will be found within this data group (probably a patient set).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Incoming Patient ID (data group of interest, could be record ID)
Matched Patient ID (of matched patient, could be record ID) (R1)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Included Health Record ID

Description

Health Record IDs that were sent to a Special study for possible inclusion.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Health Record ID
(or Source= Health Record; Source ID)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Included Patient Set ID

Description

Patient Set IDs that were sent to a Special study for possible inclusion.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Patient set ID
(or Source=Patient Set; Source ID)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Incomplete Patient Set ID

Description

As soon as the registry decides that this cancer/tumor/case will be reported on, they can assign an ID.

DESIGN NOTE: It's hard to tell where the best place to assign the ID is. If you assign it now, after matching you may discover that you already have the patient in the database and need to merge the 2 IDs, not losing the new one and not reassigning it. If you wait until after matching, you may find that you have to dissolve the match at a later date and then would need a new ID. Depending on how IDs are constructed, this would mean that the ID was out of sequence.

DESIGN NOTE: it may be a good idea to assign a temporary id here in order to track the flow of information through the system. It may be possible to use the Acceptable health record ID. There is a process to assign a permanent ID at the end of Matching and Consolidation (when you 'know' all the information for that person has been gathered into one place.)

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Patient Set ID (assigned by registry)
Status =Incomplete

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Incomplete Patient Set Info

Description

A set of data that has been received and passed the screen for reportability. It is now ready for matching, consolidation or creation of patient information.
Patient Set which may be missing data item values.

This could also include a Death Tape Entry which would be sent to 6.0 in efforts to acquire the Death Certificate.
DESIGN NOTE: sometimes the registry staff member is on-site to do Conduct Screening and Conduct Abstracting. In those cases, the information may need to flow directly from Screening to Abstracting.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(All data items on the health record and corresponding converted values)
See Patient Set
WHICH SHOULD BE COMPRISED OF:
See health record (these variables would potentially include the same as Patient Matched Info, CTC Matched Info, Facility Matched Info and Treatment Matched Info data flows. Or Patient Set data flow. Some data items may have missing values. This is most likely a single facility's view of the patient.)
See Converted ICD Codes and Keywords
See Additional Disease Codes and Keywords (DC only)
SEER Reportability indicator
Local Reportability indicator
Special study ID (R2)
Special study eligibility indicator (R2 - one implementation could be to include the special study id as the indicator.)
Additional special study variables (varies by study)

Status = incomplete

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Increased Expertise

Description

Expertise is knowledge about registry operations that any given registry staff member has. Internal knowledge and judgment making skills.
In 10.4 'Perform Reliability Study', specifically the expertise of an abstractor.
Hopefully, during 10.4 and similar processes, this knowledge has become greater so that each staff member performs their tasks more correctly, with greater confidence and consistently with registry policies.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Not a measurable: internal to staff. Could possibly result in an additional local rule.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Information Acquisition Tracking Information

Description

The data items needed to track how CTC data is entering the registry operations. Are facilities sending records when requested? Are abstracts coming in as expected? Are the registry requests for other records (disease index, etc) being responded to (in a timely manner) and so on.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(Health) Records Request ID
Staff ID (who requested)
Date request made
Due Date (derivable based on request date and registry standards)
Receiving Staff ID (who received request fulfillment)
Date received
Status {open, close/filled, close/other, purge}
Comments

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Information Location

Description

Where information about a patient that may need to be deleted can be found.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Health Record ID **or**
Patient ID
CTC ID
View ID (Facility ID or Registry)

Data Item
Comment

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Information Request

Description

A request by person (from a registry staff member to John Q. Public), facility, org, so on, for data contained in the registry
The majority of external requests are for CTC data (incidence, survival, prevalence, …). Orgs and facilities may request information about the number of cases they have submitted or for a list of all the patients they have submitted. Registry staff may be requesting information about hospital submission, abstractor productivity reports, lists of outstanding follow-back queries or other information related to registry operations. An example of a request may be “All incidents of breast cancers in 1998.”

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information Request ID
Requested By
Request Date
Description of Request (text)
Purpose
Ongoing? {Yes, No}
Schedule (R1 – not all requests have this, some have recurring dates)
Status
Priority Flag
Type of Media Requested
Recipient
Payee (who should be billed if any)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Information Request Details

Description

Detailed information used to track an information request made to the registry.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information Request ID
Requested By
Request Date
Description of Request (text)
Status {Received, Valid, Pending Documentation, Rejected, Fillable, On hold, In-progress, Fulfilled, Coming Due (for recurring requests only, as set by registry), Reported Problem}
Purpose
Priority Flag

Ongoing {Yes, No}
Schedule (R1 – not all requests have this, some have recurring dates)
Type of Media Requested
Recipient
Payee

Invalid request reason
Registry Staff ID (who reviewed)
Date reviewed
Comments on Request

IRB ID (R2)
Collaboration agreement ID

Staff ID who Fulfilled the Request
Date Request was Fulfilled
Effort (time required)
Name of report/extract/registry-controlled file (how the request was fulfilled)
Reason unfillable (what are you waiting for, text)
On hold Review Date (Derivable – registry standards and date requested)
Comments from fulfillment

Information Request Problem ID (R3)
Type of problem (R3) {Data, Format, Expanded, Correction}
Description (R3 – text)
Registry staff ID (R3 - who was notified)
Date of problem (R3)
Decision (R3 – how to resolve)
Date resolved (R3)
Registry staff ID (R3 – who resolved)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Information Request History Information

Description

Audit trail for changes made to an information request or an information request problem.

NOTE: modification to a request is considered a 'problem' if the request has already been fulfilled.

Interested Registries

Interested:
Not Interested:

Local Procedures

IA, HI and NM are interested in tracking this.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Org Rep ID
Date of change
Modification
Reason (text field, why was this made)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Information Request Problem

Description

A problem with the fulfillment of an Information Request
Categories include: expanded request (they want information not originally asked for), misinterpreted request (they didn't get what they asked for), change in format (the data is fine, but needs different presentation), error in data (format is fine, meets request, but data contained is incorrect – 100% incidence rate)

Interested Registries

Interested:
Not Interested:

Local Procedures

Some registries may choose not to fix format problems
Some registries choose to personally review every information request with the requester prior to attempting to fulfill it to limit the number of misinterpreted and expanded requests.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Info request ID
Info Request problem id
Type of problem (see above: expanded, misinterpreted, format, data)
Date problem received
Description (what problem is)
Status
Who is notifying registry about problem

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Information Request to be Closed

Description

If the information request has been fulfilled or the determination has been made that it is invalid, the corresponding Information Request needs to be closed with the appropriate status.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Information Request
Note: to be closed

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Instructions to Fulfill

Description

The instructions to produce a report, extract, or registry controlled file needed to fulfill a standing request. (For example, the SEER submission that is due in August and February.)
This could be implemented as a calendar event type mechanism, the instructions are really 'complete request 123' and request 123 gives the details of what is required.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information Request ID
Due Date

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Instructions to Proceed

Description

Instructions to information request fulfillment staff about how to deal with an information request that is not Fulfilled or Rejected or an unresolved information request problem.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Information Request ID
Information Request Problem ID (if needed)
Instructions (text, possibly verbal)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Instructions to Reproduce Report/Extract/Registry-Controlled File

Description
Given that there was a confirmed format or data problem, the original request validity and fillable statuses should not have changed. Therefore, staff are instructed to reproduce the fulfillment with any necessary format changes.
A fulfillment with a data problem will just be re-generated once the registry database is corrected. A fulfillment with a format problem may need a different fulfillment method selected.
Could include instructions to wait until data problem resolved.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Information Request ID
Information Request Problem ID
Comment: Reproduce

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Inter-Field Edit Status

Description
Status of a valid data item found in patient set with respect to other items in the data set with respect to the edits.
Is the value of the item being checked consistent with other values currently in the data set? (Frequently, the entire patient set is being changed and the user may ignore an edit until the conflicting field has also been modified)
This includes conflicts with data within a single CTC (aka inter field) as well as conflict with data in other CTCs (aka inter record) – it is any field in the Patient set.
If edit status=failed, then this is an edit issue and must be stored for static data. If this occurs during consolidation or 18.1 Compare and Resolve Text to Codes, may not need to store these unless ’17.0 Edit Patient Set Info’ was called by the user, not by a process.
Referenced as a type of “Edit Status” – see “Edit Statuses”.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Inter-field edit status {passed, failed, override}
Edit name/specific error (ie site/type mismatch)
Date
Patient Set ID/Health Record ID

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Invalid Request Reason

Description
The reason why a request is not authorized -- an information request for which any of the following is true:
The nature of the request cannot be authorized per Local, State &/or Federal Rules as to what kind of information can be given out to whom.
The requester refuses to sign a Collaborators Agreement
IRB approvals were not granted

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Invalid request reason
Staff ID (who rejected)
Date reviewed
Comments
Status (=Rejected)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

IRB Approval Status(es)

Description
For an information request that requires Institutional Review Board (IRB) approval, the IRB information for each facility required.
For example, if a request requires approval from 3 facilities, each facility would need to send back IRB information. The request wouldn't be fully valid unless all 3 approved. If only 1 or 2 facilities approved the request, it can only be partially filled.

Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Information Request ID
IRB Facility ID (R1)
IRB Status {pending, approved, denied} (R1)
IRB Org Rep ID (who reviewed) (R1)
IRB Date Reviewed (R1)
IRB Date Approved (R1)
IRB Comments (R1)
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

IRB Documentation

Description
All documentation related to an institutional review board (IRB). For each facility affected, the IRB decision about whether or not a request should be honored, the date the decision was made, and any other comments that seem relevant.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Information Request ID
IRB ID
IRB Facility ID (R1)
IRB Status {pending, approved, denied} (R1)
IRB Org Rep ID (who reviewed) (R1)
IRB Date Reviewed (R1)
IRB Approval date (R1)
IRB Comments (R1)
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Last Patient Set Snapshot

Description
See Patient Set
After sending an update to a facility, a snapshot (historic picture) of what information was known at the time of the update was taken. The latest

snapshot is examined so that the current update doesn't repeatedly notify a facility about the old modifications to the data.
This snapshot allows the registry to confirm corrections that the facility has sent to them and to notify the facility of changes the registry has made since the last notification.
The snapshot only has to include the Selected View of the Patient Set used in the update. The registries would like to use the registry view, but may be forced to use the facility view because of legal restrictions.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Patient Set
Facility ID (that snapshot was taken for)
Date of Snapshot

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Local Active Follow-Up Rules

Description

Rules as to who is or isn't eligible for Active Follow-Up from the registry's point of view
Rules for determining the type of Active Follow-up to use (e.g., priorities, in NM cannot send a Patient Letter if the Patient's Race is American Indian, people under 20 have priority, etc)
Would include what kinds of FUP letters to send for specific cancers, application of PAT, MP and FAC do not contact flags. Also includes rules about who is assigned to do follow-up: does Follow-up Facility follow-up with patient or does the registry?
DESIGN NOTE: these can be quite complicated. Seattle has a matrix of rules by facility.
DESIGN NOTE: The registry staff need to be able to easily view these rules. If they discover a problem, they need to be able to check the rules to see if they are causing the problem and change them as necessary.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
Effective (start) date
End Date

Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie Type of Follow-up – media of contact, type of person/group contacted, acceptable response time)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Local Broad Reportability Rules

Description

The gross filter for those organizations that the registry has to report/submit to, not including SEER. For example, state health department, ACOS, so on. Could also include records the registry wishes to send as part of a data exchange agreement.
Probably a range of codes the disease must be within or text keywords that must be present.
Information which passes these rules is kept for quality assurance purposes. If the rules are too broad, there may be legal complications. If they are too narrow, the registry may miss reportable CTCs.
DESIGN NOTE: in some registries, screening rules vary by institution (how accurate are the record coders for that institution, what kind of words to they use, etc).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

It is possible that some organizations other than NCI get submissions from all SEER registries. However, most of the local rules will be specific to a particular registry or small subset of registries (such as the state of California).

Sensitivity

Data Items (if a group data flow)

Text of rule
Effective (start) date
End Date
Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …, conversion table, etc)

Example of Rule:
- Range for Site
- Range for Histology
- …

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Local Consolidation Rules

Description

Local instructions on how, what, when to consolidate – what values overrides what other values, etc.

Would include for a given data item, which other data items should be considered. (Size of CTC would need to consider if there was radiation and when CTC was measured in relation to radiation cycle.)

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)

Effective (start) date

End Date

Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER

Can a Human process this rule? {Y, N}

Can a Computer process this rule? {Y, N}

Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …, conversion table, etc)

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Local Guidelines/Instructions

Description

How to create an abstract from the point of view of the local registry and those they must report to. (for example, state law, current special studies)

Describes what is reportable (sometimes during abstracting they determine that the CTC isn't), what information is necessary to collect, standard accepted coding for given words/phrases, and important keywords that the abstractor should record.

Design Considerations

While some of this can be mechanized or placed in an on-line reference system, part is experience. The abstractors have manuals to reference, but these could probably be computerized (remember, some people prefer paper to computer screens).

Information to collect: how the data entry screen is presented.

Standard accepted coding: can be mechanized – type keyword, look-up box with shrinking options as more is typed.

Important keywords – manual and experience

What is reportable – manual and experience for vague wording, can be partially computerized to flash warning if entered data would fail fine filter.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Text of guideline
Effective (start) date
End Date
Source of Rule
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Local Reportable List

Description

Specifically, what is reportable locally.
List of sites, histologies, behaviors, etc. Some may need the combinations listed. Note, these really aren't different from rules.
DESIGN NOTE: in some registries, screening rules vary by institution (how accurate are the record coders for that institution, what kind of words to they use, etc).

Feeding into 1.1.1: Determine Potential CTC and Special Study, see SEER Broad Reportability Rules
Feeding into 1.1.2 Do Initial Screening for Local/SEER Reportability, see SEER Reportable List

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

It is possible that some organizations other than NCI get submissions from all SEER registries. However, most of the local rules will be specific to a particular registry or small subset of registries (such as the state of California).

Sensitivity

Data Items (if a group data flow)

Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
Effective (start) date
End Date
Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …, conversion table, etc)

Example of Rule:
Site code

Hist code
Beh code
Hist code not with given site code
…

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Local Reportablility Rules

Description

Feeding into 1.1.1: Determine Potential CTC and Special Study, see Local Broad Reportability Rules
Feeding into 1.1.2 Do Initial Screening for Local/SEER Reportability, see Local Reportable List
DESIGN NOTE: in some registries, screening rules vary by institution (how accurate are the record coders for that institution, what kind of words to they use, etc).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

see Local Broad Reportability Rules
see Local Reportable List

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Local Rules

Description

AKA Local Registry Standards
Rules for recoding and reformatting data to local registry standards from NAACCR format or Hospital Registry formats.
In the case where this is a conversion to a new revision of coding a data item, this most likely will take the form of a look-up table a computer can use. For converting a hospital specific coding scheme to registry standards, this could be a look-up table, but would have to be constructed by registry staff as new coding schemes are developed by hospitals. For converting text, this is likely some sort of manual, although some of this can probably be mechanized.
Rules about how text should be translated into codes. For example, how disease text should be shown in ICD site, hist, beh codes, how staging information should be captured.
Also would include which words were important and, for vague words, which ones should be considered to indicate cancer/tumor.
Criteria for what constitutes a duplicate facility record.
Includes rules for assigning ethnicity specialized to the registry.
Includes rules for acceptable census tract and how to evaluate it.

Includes rules for calculating, summarizing, resetting, invalid/missing codes and so on for derived data items. Would also give rules for collapsing recoded items.
Includes rules for determining what information from a patient set can be sent to a particular facility based on where the information was received from and knowledge the facility already has.
Includes rules for how many special studies a patient may be in, how long they are removed from the available pool, so on.
Includes editing rules: invalid codes for the fields and invalid combination of information in multiple fields.
DESIGN NOTE: these must be easy for the registry to change since they vary widely by registry and change much more frequently than SEER rules.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
(below are specific for converting)
Data item name
Incoming coding scheme
Desired coding scheme (values and meanings)
Effective (start) date
End Date
Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …, conversion table, rural/urban continuum table – FIPS to continuum code, etc)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Local, State & Federal Rules for Data Extraction

Description

Any rules that govern data extraction from a Registry.
For Example, those that govern privacy… that effect what information can be given out to a requester. The combinations of type of information and type of requester (what may be a valid request for a hospital might not be valid for John Q. Public)
Also, what kinds of requests need a signed collaboration agreement to be valid.
May involve getting IRB (Institutional Review Board) approval.
May involve contacting other institutions to get their approval for release. (i.e. state health department approval for release of cause of death and possibly mortality rates.)

These would control whether or not a request for an identified file is considered valid. The restrictions on identified files are much more strict.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
Effective (start) date
End Date
Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Log-in History

Description

Information allowing the registry org rep work, specifically when they logged in.
(big brother is watching.)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Account
Date of log-in (successful only)
Time of log-in
IP address

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Log-in Request

Description

Request for access to the registry operations system. Aka log-in.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Account
Password
IP address

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Log-in Status

Description
Notice about whether a log-in was successful or not.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Log-in Status {Yes, No}

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Log-in Status (=No)

Description
The org rep is currently logged off
This setting is achieved in 11.5.4 Log-off

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Log-in Status={No}

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Log-in Status (=Yes)

Description

The org rep is currently logged in
When Log-in Status=Yes, the org rep would be subject to log-off notifications in 10.7.8

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Log-in Status={Yes}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Log-off History

Description

Information allowing the registry org rep work, specifically when they logged off.
(big brother is watching.)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Account
Date of log-off (successful only)
Time of log-off
Log-off type {Normal, Inactive, System}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Log-off Needed Info

Description

Information provided by the calling 10.7 process about why a global log-off is needed, when it will occur and projected time until log-in will be possible.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Reason
Time to Log-off
Time to Log-in possible

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Log-off Notification

Description
Notice (possibly pop-up window?) to all ORG REPS who are logged in that a system shutdown is about to occur and they need to log off. Probably a standard format with variable information filled in from Log-off Needed Info.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Notice to ORG REPs who are logged in
(would probably be a standard notice, would include
Reason
Time to Log-off
Time to Log-in possible)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Log-off Request

Description
Request by Org Rep to exit the registry operations system. Aka log-off.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Account
IP address
Log-off command

Metrics
Frequency:
Volume:
Duration:

Quality/Error rate:

Look-up History Information

Description

Audit trail for changes made to any of the look-up tables.
These files currently include: 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.

Interested Registries

Interested:
Not Interested:

Local Procedures

IA, HI are interested in this.
NM, LA might be interested if they see these as auxiliary

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

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

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Match-Completed Health Info

Description

Health information that has completed the match process – could be matched or unmatched.
Would also include the patient set ID or non-reportable health record ID this information matched to OR any other information group that the incoming information matched to (only if a Match status=yes).
This includes information received from health records that do not become patient sets. If they were unmatched, 4.0 processing stops after the abstract facility lead was formed. When the AFL is reviewed, this data should be available.
If unmatched (or not completely matched), the following record types would go to 2.0 Conduct abstracting only: Disease index, discharge list, surgery log, and death index/death file. (They don't become patient sets)
This could be any of the following:

Unmatched incomplete health info
Patient matched info + new facility + new CTC info
Patient matched info + new facility + CTC matched info
Patient matched info + new facility + CTC matched info + new treatment info
Patient matched info + new facility + CTC matched info + treatment matched info
Patient matched info + facility matched + new CTC info
Patient matched info + facility matched + CTC matched info at registry view only, CTC at facility view unmatched

Interested Registries

Interested:
Not Interested:

Local Procedures

IA death file has enough information to become a patient set. They only need a few additional variables from the DC.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(All data items on record and corresponding converted values)
See health record (variables included would be same as those found in the following data flows: Patient Matched Info, CTC Matched Info, and Treatment Matched Info. Of course you'd only have the single value found on the incoming data group.)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Match-Completed Patient Set Info

Description

Patient set information that has completed the match process – could be matched or unmatched. It flows into 2.6 if it is incomplete – health info was not an abstract and failed to match on Patient, CTC or Facility.
The following record types go to 2.0 Conduct Abstracting after becoming patient sets within 4.0 Match and Consolidate Patient Set Info: Path rpt (path only), radiology rpt (facility rpt), death certificate (DC only), autopsy rpt (autopsy only), (as physician only cases) oncology rpt, cytology rpt, hematology rpt. A new patient set would have been created.
NOTE: Abstracts would have become new patient sets in 4.0 Match and Consolidate Patient Set Info only. Referrals mentioned on the abstract would cause an abstract facility lead to be created.
This could be any of the following:

Unmatched non-abstract patient set info
Patient matched info + new facility + new CTC info
Patient matched info + new facility + CTC matched info
Patient matched info + new facility + CTC matched info + new treatment info
Patient matched info + new facility + CTC matched info + treatment matched info
Patient matched info + facility matched + new CTC info
Patient matched info + facility matched + matched CTC info at registry view only; CTC at facility view unmatched.

Interested Registries

Interested:
Not Interested:

Local Procedures

IA death file has enough information to become a patient set. They only need a few additional variables from the DC.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Patient Set

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Matched & Consolidated Patient Set Info

Description

See Patient Set

Information from a patient set that has undergone process 4.0 Match and Consolidate Patient Set. This may not be a complete or submissible patient set, but is the best information the registry has at this point.
In 3.0 Support Special studies, this information is sent to the special studies in an effort to provide them with the best available to hopefully save time and questions later.

Interested Registries

Interested:
Not Interested:

Local Procedures

Not all registries bother to match and consolidate their patients before sending them to a special study

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Patient Set
Status = Consolidated

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Matched Patient Sets

Description

Patient set(s) that matched to new incoming information. Will be used to determine if an abstract is needed
For example, if a path report arrives, an abstract facility lead may be created. It is possible that the abstract will arrive before the lead comes due.

Interested Registries

Interested:
Not Interested:

Local Procedures

Some registries provide this information to their abstractors when they are working in the field (always want to have the most information possible) while others do not (want abstract to focus on information at facility, not overlook something because of other information in the matched patient set)

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Patient Set
Would have a Match entity linking this patient set to the Incomplete patient set info or would be noted in the abstract facility lead.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Matched Still Non-Reportables

Description

Non-reportable data groups that have been matched and then screened. However, even together, they are still non-reportable.
You don't want to lose the match information in case new information comes in.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Depends on data groups, mostly what we need:
Incoming Health Record ID (non-reportable Patient Set ID)
Matched Health Record ID (non-reportable patient set ID)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Match Identifying Info

Description

Uniquely Identifies the Match that was chosen – the "link".
Identifies match at appropriate level (patient, CTC, facility, treatment)
Identifies the Incomplete Patient Set(s), the existing Patient Set(s), the Health Record(s), the Supplemental Record(s), the Correction Record(s) and Non-reportable CTC information involved in the match.
In 18.5, new matches would have to be built to the newly separated patient or newly separated CTC.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(any 2 of the below)
Patient ID (R1- from patient set, incomplete thru submissible)
Facility ID (R1a)
CTC ID (R1b – from patient set, incomplete thru submissible)
Treatment Type (R1b1 – from patient set, incomplete thru submissible)
Health record ID (R2 - includes corrections and non-reportable)
Supplemental record ID (R3)

(Repeat for each data group that matched the incoming group)
Overall weighted score (only score used by person trying to match)
Match Level (R4; BOM shows this by having different entities for each match type.) {At Patient, At CTC, At Treatment}
Facility Match? {Y, N} (BOM shows this by having different entities for each match type.)
Alias/maiden name used? {Y, N} (Patient level match only)

Match Status (Possible, Accepted, Rejected)
(not generally needed)
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)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Matching Criteria

Description

Rules used to determine matches. Which data items are used, how to score data items, how to calculate overall score, level of overall score which can be considered a positive match with no review (95%, 100%)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Text of rule (ie how to match a data item)
Effective (start) date
End Date
Source of Rule (Registry, soundex, etc)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie, soundex matching table, scoring weights etc)
Data Item
How to match/score
Effect on overall score

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Matching Info

Description

Data groups which match to non-reportable CTC info. This data will be re-screened in combination with the non-reportable CTC info it matched to.
The data groups could be incomplete patient set, existing patient set or health record (including correction record, reportable or non-reportable).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(All data items on the health record and corresponding converted values) See health record (these variables would potentially include the same as Patient Matched Info, CTC Matched Info, Facility Matched Info and Treatment Matched Info data flows. Or Patient Set data flow. Some data items may have missing values. This is most likely a single facility's view of the patient.)

See BOM entities: PATIENT, INFORMANT FOR PATIENT, and RESIDENCY
See BOM entities: CANCER/TUMOR/CASE, MARKER, COMORBID CONDITION, RESIDENCY is established for CTC, IMAGE, IMAGE EVALUATION, SPECIMEN, SPECIMEN EVALUATION, DIAGNOSIS and PAYOR SOURCE covers CTC, FACILITY ADMISSION, FACILITY refers PATIENT to FACILITY, RESIDENCY is established for CANCER/TUMOR/CASE
See BOM entities: CONSIDERED TREATMENT MODALITY, PATIENT refuses CONSIDERED TX MODALITY, PROCEDURE (and all subtypes), COURSE.
See BOM entities: IDENTIFICATION, OVERRIDE
See BOM Relationship: PATIENT or CTC is included in SPECIAL STUDY, PATIENT or CTC is possibly reportable to SPECIAL STUDY
See Converted ICD Codes and Keywords
See Additional Disease Codes and Keywords (DC only)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Match Rejected Non-Exact Duplicate Record

Description

A record that originated from 13.4.1 and was labeled as a non-exact duplicated. When reviewed by an editor/consolidator it was determined that the record did not match to any of the possible 'duplicates' and so it needs to pass through the entire matching process.
Match updates with status=rejected would exist for those records this was a suspected match to.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Health Record

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Match Update Information

Description

Information related to changes in a match and the reasons for that change.

Status is sent in separate data flow. This is the comments and the date.

This information prevents promising, but 'rejected' matches from being reconsidered.

Within 18.5, the update would be Match Status=Rejected and why.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Match ID? (don't know if this is needed, not sure how else to tie together)

Date of Update

Match Status {possible, accepted, rejected}

Comments

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Medical Practitioner Code(s)

Description

The identification codes for the medical practitioners associated with this patient set.

For a Physician - License Number, otherwise, may be assigned by the registry

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Medical practitioner (ID)

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Medical Practitioner Contact Information

Description

Information about how to contact the medical practitioner

Would also include best times/method of contact. (for example, do not call between 10-4)

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Medical practitioner ID
Medical practitioner Name
Physician Code (Frequently Medical License Number, but other number may be assigned)
Title
Specialization
Mailing street number/name or PO Box
City
State (Canadian Province)
Postal Code (ZIP)
Preferred address?
Phone number
Fax number
Email address
Web address
Preferred method of contact
Preferred time of contact
Do not Contact {Y, N}
Affiliated Facility ID (R)
Primary Affiliation? {Y,N} (R)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Medical Practitioner Info

Description

Information about a medical practitioner that can be used to identify the practitioner, perhaps using a code/license number. This may also contain full contact information.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Physician Code (Frequently Medical License Number, but other number may be assigned)
Medical practitioner ID
Medical Practitioner Contact Info:
  Medical practitioner Name
  Title
  Specialization
  Mailing street number/name or PO Box
  City

State (Canadian Province)
Postal Code (ZIP)
Preferred address?
Phone number
Fax number
Preferred method of contact
Preferred time of contact
Do Not Contact

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Messages

Description
Messages from the system to the person attempting to access it about failures.
'Incorrect password'; 'Process disallowed, see manager'; 'Data access restricted, see manager'; etc type messages.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Message

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Meta Data About New Table

Description
Data that is retained about what data items are include in a new table, what types those items are, any formats or edits that apply, etc.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Data item name
Data item ID
Location of data item
Type (string, int, float, etc)
Constraints (R1)

Metrics
Frequency:

Volume:
Duration:
Quality/Error rate:

Modified Adds/Changes/Deletes

Description

See Adds/Changes/Deletes
In 10.12, when inappropriate information is deleted, ACDs for the same patient, same data field, after the inappropriate information has been removed. (These are ACDs that occurred prior to 10.12.2.1)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Adds/Changes/Deletes
Old Value – possibly modified
New Value – possibly modified

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Modified Follow-Back Query

Description

See Follow-Back Query
A follow-back query that has been changed to possibly clarify an earlier follow-back query or to find out more information

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Follow-Back Query

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Modified Health Record

Description

See Patient Set
A health record that has changed from a previous state.
In 10.12, specifically a health record that has had inappropriate data removed. It would need to be changed at the CRO and in the Field separately.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See health record

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Modified Health Record Update

Description
See Health Record Update Tracking Info
In 10.12, when inappropriate information is deleted, Health record updates for the same health record, same data field, after the inappropriate information has been removed. (These are HRec Updates that occurred prior to 10.12.2.1)

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Health Record Update Tracking Info
Old Value – possibly modified
New Value – possibly modified

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Modified Patient Set

Description
See Patient Set
A patient set that has changed from the last time it was accessed.
In 16.0, specifically a patient set that a field staff member has modified since they last performed an update (compare date last updated to latest ACD date)
In 10.12, specifically a patient set that has had inappropriate data removed. It would need to be changed at the CRO and in the Field separately.
In 18.5, this would include a patient set that has had information for a separate patient removed (where 1 patient set was discovered to refer to 2 people – the infamous twins) as well as a patient set that has had a new CTC set added (where 1 CTC set was discovered to refer to 2 CTCs – simultaneous primaries.)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Patient Set

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Multiple Receipt Indicator

Description
Something that indicates that a health record has been received multiple times.
This may be a y/n flag or a counter (+1 to the counter), but that hasn't been determined yet.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
While we may check to see if a supplemental record is an exact duplicate so we don't waste time processing it, we don't care how many times it's been sent

Sensitivity

Data Items (if a group data flow)
Received multiple times? (may be count or indicator)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

New Acceptable Health Record

Description
See Acceptable Health Record
Acceptable health records that need to be provided to the field staff. These have arrived (or been accepted) after the last time the field staff updated their health records.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Acceptable Health Record

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

New Access Information

Description
For any particular org rep, the access they are allowed; which processes can they initiate, what data can they view, what data can they change. This is the new access information caused by a change in the org rep's role, as determined by a manager.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Process ID (R1)
Process Access? (R1) {Yes, No}

Data Table ID (R2)
Data Item ID (R2)
Data Access? (R2) {None, Read only, Read/write}

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

New Differences

Description
See Differences
The differences that not been sent to the facility up to this point.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Differences

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

New Differences Sent

Description
See Differences

Differences which are sent to the facility because of this process, only new differences are sent.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Differences

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

New Differences Tracked

Description

See Differences

Tracking of differences that are sent to the facility because of this process, only new differences are sent. This is done so that the next time the same difference isn't resent.

Since this process is done by a computer, these should be easy for it to understand.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Differences

Date sent

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

New Facility Patient Info

Description

The facility's view of what the patient information values are.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility view patient info Status: in-progress (to be edited)
See BOM entities: PATIENT, INFORMANT FOR PATIENT, and RESIDENCY
See BOM entities: IDENTIFICATION, OVERRIDE
See BOM Relationship: PATIENT is included in SPECIAL STUDY, PATIENT is possibly reportable to SPECIAL STUDY

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

New Facility Treatment Info

Description

The facility's view of what the treatment information values are.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility view treatment info Status: in-progress (to be edited)
See BOM entities: CONSIDERED TREATMENT MODALITY, PATIENT refuses CONSIDERED TX MODALITY, PROCEDURE (and all subtypes), COURSE.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

New Facility CTC Info

Description

The facility's view of what the CTC information values are.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility view CTC info Status: in-progress (to be edited)
See BOM entities: CANCER/TUMOR/CASE, MARKER, COMORBID CONDITION, RESIDENCY is established for CTC, IMAGE, IMAGE EVALUATION, SPECIMEN, SPECIMEN EVALUATION, DIAGNOSIS and PAYOR SOURCE covers CTC, FACILITY ADMISSION, FACILITY refers PATIENT to FACILITY, RESIDENCY is established for CANCER/TUMOR/CASE
DESIGN NOTE: not all data items will be filled in, some must wait until treatment information has been compiled and then need human intervention to be created.

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Newly Reportable Matched Health Info

Description
Non-reportable data groups which have been matched and when reviewed, have been discovered to be reportable together.
Since these are likely to be records, not patient sets, they will most likely need to go to auto create processes.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Depends on data groups, mostly what we need:
Incoming Record ID (non-reportable Patient Set ID)
Matched Record ID (non-reportable patient set ID)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

New Password

Description
The password attached to an account within the registry.
This is a new password chosen by the org rep or IT manager to replace the original one.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Password

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

New Patient Info

Description
The registry and facility views what the patient information values are.
This information is incorporated into the patient set.

Interested Registries
Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See BOM entities: PATIENT, INFORMANT FOR PATIENT, and RESIDENCY

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

New Patient Set

Description

See Patient Set
In 18.5, a patient set that was created after the discovery that a single patient set in the database referred to multiple people.
This would include any views that needed to be created and would have been edited (17.0) before being saved.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Patient Set

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

New Patient Set Info

Description

Information that needs to be added to the patient set and was obtained incidentally to another process. Typically, the patient set it needs to be added to should be known

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Information obtained during follow-up that is not related to vital status or a follow-back query. Examples would be contact info (new phone number, new doctor, new address), change in primary physician, knowledge of a new CTC, correct race, age, so on. This is information that came in unexpectedly, not as a response to follow-back queries embedded in the follow-up query (sent back to 8.0).

Information obtained during Create Abstract which is not related to the CTC being abstracted (only registries which provide the abstractor with the entire patient set as known by the registry can reasonably expect this information).
Registries would like to be able to decompose data if needed. Currently, this is being handled by creating a correction record with the new patient set information on it. Other implementations can certainly be considered here.
DESIGN NOTE: currently shown for information gathered incidental to active follow-up (7.0) and conducting abstracting (2.0). Whatever implementation is chosen may also be a good way to get follow-back responses (8.0) into the system.

Sensitivity

Data Items (if a group data flow)

Data item name (R1)
Data item value (R1)
Source of information
Patient id

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

New Registry Patient Info

Description

The registry's view of what the patient information values are.
Here, the registry's information is based on one facility only.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Registry view patient info Status: in-progress (to be edited)
See BOM entities: PATIENT, INFORMANT FOR PATIENT, and RESIDENCY
See BOM entities: IDENTIFICATION, OVERRIDE
See BOM Relationship: PATIENT is included in SPECIAL STUDY, PATIENT is possibly reportable to SPECIAL STUDY

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

New Registry Treatment Info

Description

The registry's view of what the treatment information values are.
Here, the registry's information is based on one facility only.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Registry view treatment info Status: in-progress (to be edited)
See BOM entities: CONSIDERED TREATMENT MODALITY, PATIENT refuses CONSIDERED TX MODALITY, PROCEDURE (and all subtypes), COURSE.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

New Registry CTC Info

Description

The registry's view of what the CTC information values are. Here, the registry's information is based on one facility only.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Registry view CTC info Status: in-progress (to be edited)
See BOM entities: CANCER/TUMOR/CASE, MARKER, COMORBID CONDITION, RESIDENCY is established for CTC, IMAGE, IMAGE EVALUATION, SPECIMEN, SPECIMEN EVALUATION, DIAGNOSIS and PAYOR SOURCE covers CTC, FACILITY ADMISSION, FACILITY refers PATIENT to FACILITY, RESIDENCY is established for CANCER/TUMOR/CASE
NOTE: not all data items will be filled in, some must wait until treatment information has been compiled and then need human intervention to be created.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

New Treatment Info

Description

The registry and facility views what the treatment information values are. This information is incorporated into the patient set.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility view treatment info Status: in-progress (to be edited)
Registry view treatment info Status: in-progress (to be edited)
See BOM entities: CONSIDERED TREATMENT MODALITY, PATIENT refuses CONSIDERED TX MODALITY, PROCEDURE (and all subtypes), COURSE.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

New CTC Info

Description

The registry and facility views what the CTC information values are. This information is incorporated into the patient set.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility view CTC info Status: in-progress (to be edited)
Registry view CTC info Status: in-progress (to be edited)
See BOM entities: CANCER/TUMOR/CASE, MARKER, COMORBID CONDITION, RESIDENCY is established for CTC, IMAGE, IMAGE EVALUATION, SPECIMEN, SPECIMEN EVALUATION, DIAGNOSIS and PAYOR SOURCE covers CTC, FACILITY ADMISSION, FACILITY refers PATIENT to FACILITY, RESIDENCY is established for CANCER/TUMOR/CASE
NOTE: not all data items will be filled in, some must wait until treatment information has been compiled and then need human intervention to be created.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Non Cancer Special Study Reportable Information

Description

Information from a health record which has passed the broad screening rules for a special study but not for SEER or local.
For example: a tumor is non-cancerous (e.g., benign brain tumor), but it may meet the criteria for inclusion in a special study. Registries felt that most non-cancer special studies were like this (benign versions of cancer) and that in the future everyone may collect these.

Interested Registries

Interested:
Not Interested:

Local Procedures

Some registries may choose to retain this information even if it fails the fine filter in the name of quality assurance or because new information may come in that makes a non-reportable (failed fine filter) record reportable. However, this doesn't very likely because the registries don't seem to have as great a responsibility to not miss CTCs for special studies. They may see information from this data flow which fails the fine filter for special studies as the same as Non Cancer/Tumor/Case and Record Not Special Study Reportable.
Some registries may choose to use this information to create a patient set that is reportable to special study xxx only.

Policies/Business Rules

Defined by special study
Since there are many special studies, it may be useful to track which one the info is potentially reportable to. That way, you would be able to check the fine filter for the relevant study only.
They apply the no more than 1 special study within given time window to these people as well.
If this information is reported to a special study, it will be retained even when the special study is complete (marked non-reportable to SEER and so on).

Sensitivity

Data Items (if a group data flow)

See health record
Special study potentially reportable {Y, N} (R1)
Special Study ID (R1)
Attributes related to special study change by study.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Non Cancer/Tumor/Case and Record Not Special Study Reportable

Description

These are records that are non-Cancer/Tumor/Case and thus are not reportable to SEER or Locally. They are not reportable to a Special Study either.
Once a record is determined to have this status, it is dropped from the 1.0 (electronic records) or 13.0 (paper records) process
If these records are paper, they will be shredded.
If these records are electronic, the status should be noted in the Health and Supplemental Record Data until the record is deleted in 9.0. This will show that the record has been screened and is waiting for 9.0 to occur.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

These records are kicked out – cannot legally keep. Need to be removed from the health and supplemental data store (after passive follow-up).

They retain all Death Certificates (since they are a matter of public record). A patient's records may enter the registry after the DC and the DC may not mention cancer/tumors.
If the record was used for passive follow-up, need to retain person id, date of contact, (vital status) and source until new passive follow-up information is received. When new data is received, the rest of the record could be deleted. Would at very least have to strip HIPAA protected variables from health and supplemental data store.

Sensitivity

Data Items (if a group data flow)

(All data items on record and corresponding converted values)
See health record
See Converted ICD Codes and Keywords
See Additional Disease Codes and Keywords (DC only)
See Converted Other Codes and Text per Special Study

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Non CTC Non SS Health Record ID

Description

The health record ID for a Non Cancer/Tumor/Case and Record Not Special Study Reportable health record that has been kicked out of the broad screen in 1.1.1
This will be used to strip the record from the health and supplemental data store and the submission archive copy.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Health Record ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Non CTC Non SS Non FUP Health Record ID

Description

The health record ID for a Non Cancer/Tumor/Case and Record Not Special Study Reportable health record that has been kicked out of the broad screen in 1.1.1 and was not used for passive follow-up.
This record will be deleted from the health and supplemental data record store.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Health Record ID
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Non-Data Problem

Description
A problem with an information request that does not involve a problem with the data. Other problems include, but are not limited too, format issues, storage media, need for an expanded request, a misunderstood request.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Information Request ID
Information Request Problem ID
Type of problem { Format, Expanded, Correction}
Description (text)
Registry staff ID (who was notified)
Date of problem
Status
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Non-Exact Duplicate Facility Health Record

Description
DESIGN NOTE: This assumes that the duplicate check will be starting using some sort of key. If all 'close' records are found, after the 'exacts' have been processed, these are left.
Health records which have matched on some kind of key and hence been determined to be close to exact match. However, they are not exact matches and are being sent to 4.0 consolidation processes to review the differences.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules
Registries will likely send duplication notices to the facility because of these records and ask that correction records be sent instead.

Sensitivity

Data Items (if a group data flow)

See Health Record
Received multiple times (Either Y/N or Count of times received)
Note: not exact (temporary, after consolidated will be dropped. Either add a match relationship or increase the # of times received)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Non-Reportable CTC (Cancer/Tumor/Case) Info

Description

This is Cancer/Tumor/Case information that has passed the broad filter, but at the fine filter is not reportable to any of the following: SEER, Local, or Special Study.
Would definitely retain if it had a potentially reportable flag for SEER or Local
Would also include a health record which has passed the broad and fine screens, but is found to be not reportable to SEER, Local or any Special studies during the resolution of a match, determine if abstract needed or during the creation of an abstract.
Needs to be stored for quality assurance purposes
Since the record and its corresponding converted codes and keywords has already been stored (coming out of 13.0), all that needs to be stored is the modified status flag and reason.
This information could potentially be used by a special study as a control.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(All data items on record and corresponding converted values)
See health record
See Converted ICD Codes and Keywords
See Additional Disease Codes and Keywords (DC only)
Status: Non-reportable

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Non-Reportable Reason(s)

Description

The reason(s) a record is not Locally reportable , SEER reportable or Special Study reportable even though the record passed the broad filter. Retained for quality assurance reasons.

It is possible for a record to be reportable to one entity, but not to another. (Locally, but not to SEER). Would need to retain the reason in these cases.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Use these reasons in conducting QC audits
If non-reportable information matches to something later, will look at these reasons during 4.6 Screen Non-Reportable Records Match to determine whether the record has become reportable (usually due to new information arriving).
Special study reasons would be retained for internal audit purposes. Registries are not typically reviewed to verify that all reportable records have been sent. Records that are non-cancer but of interest to a special study are typically related to cancer (for example, benign brain tumor). Registry SMEs seemed to feel that this information may become reportable in the future. They wish to retain for their own knowledge what the reason for non-reportability is for these instances.

Sensitivity

Data Items (if a group data flow)

Non-Reportable Reason
Reporting Body {local (may not just be 1 item), SEER, Special Study}
(Staff ID – in ACD)
(time/date stamp – in ACD)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Non-Resolvable Non-Data Problem

Description

A problem with an information request that is of the types Format, Expanded or Corrected and the registry is unable or unwilling to adjust the request fulfillment to fix the problem.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information Request ID
Information Request Problem ID
Type of problem {Format, Expanded, Correction}
Description (text)
Registry staff ID (who was notified)
Date of problem
Decision (Registry has decided to take no action, possibly a why)
Date resolved

Registry staff ID (who resolved)
Status (=closed)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Not Eligible for Active Follow-Up

Description

Patients who are not eligible for active follow-up and are dropped from the Active Follow-up process
Reasons include: date of last contact acceptable; cervix in situ, no follow-up needed; vital status=deceased…

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Patient ID (registry)
Follow-up needed status=No
DESIGN NOTE: may not need to retain FUP needed status – just re-run a report when need to know.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Notification

Description

Communication sent from the Registry to a requester noting that a request has been received, its status (valid, fillable, in progress, rejected), projected completion date if applicable, further documentation that is needed and changes that should be made to the request (for example, to make it valid)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information request ID
Description (text)
Date received
Status
Registry Staff ID
Date of Notification
Projected date to be sent (doesn't need to be saved)

Documentation Needed (text – save in reason unfillable)
Changes Needed (text – save in reason unfillable)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Notification RCF Ready

Description

After the Registry Controlled File has been created and made ready for use, the registry needs to contact the requester that it is available for their use. This would happen after training.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information Request ID
Registry staff ID
Date (closed/fulfilled)
"File is ready"

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Notification to Coordinate

Description

Communication to a special study that one of the people they wish to include is involved in multiple, active, communicating special studies and that contact needs to be coordinated.
The contact information for the controlling study needs to be included.
The controlling study is the one who first notified the registry that they have chosen to include the patient in their study.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Form text (notice of multiple use)
ID list (patient or health record ID provided to the study that are in use elsewhere)
Controlling Study contact information (Study name, Contact person, Address)

Metrics

Frequency:

Volume:
Duration:
Quality/Error rate:

Open Abstract Facility Leads

Description

See Abstract Facility Leads
An abstract facility lead that has a status of open. This indicates that the lead has not been filled, however, could be due to an oversight.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Abstract Facility Lead
Status=open

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Open Information Request

Description

Information request made to the registry that has not yet been filled and/or sent.
These would be requests that are not documented as to why they are unfilled. Could also include requests that are pending additional documentation that have been on hold for an excessive length of time (as defined by the registry)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Information Request
Status {Received, Valid, Pending Documentation, Fillable, On hold, In-progress, Reported Problem}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Organization Contact Information

Description

Information needed to contact an organization: phone number, fax number, mailing address, and contact name or title.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

ID
Organization name
Type of Organization
Mailing street number/name or PO Box
City
State (Canadian Province)
Postal Code (ZIP)
Phone number
Fax number
Email address
Web address
Org Rep Name (contact – will likely be stored as an org rep with Contact Person = Y)
Child Facility ID (R)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Organization Info

Description

Information about an organization that can be used to identify it. This may also contain full contact information.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

ID
Name
Mailing street number/name or PO Box
City
State (Canadian Province)
Postal Code (ZIP)
Phone number (R1)
Fax number
Email address
Web address

Metrics

Frequency:
Volume:
Duration:

Quality/Error rate:

Org Rep ID

Description

The registry staff organization representative's ID.
Generally the person who was assigned to do something, who wishes to do or access something, or who completed some process for tracking purposes.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Org Rep ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Org Rep Info

Description

Information about a SEER registry org rep that is stored by the registry.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Name
Org Rep ID
Phone number
Comments
Role
Remote Access Allowed? {Y, N}
Allowed Log-In Time (9-5, all, etc)
Confidentiality Agreement

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Original Abstract Received from Facility

Description

For those facilities which send abstracts to the registry, the original information received from the facility is used in 14.0 Update Data Source the first time the process is done on the patient, cancer/tumor/case. This allows the registry to confirm corrections that the facility has sent to them

and to notify the facility of changes the registry has made from the original.
(2nd and later passes use the selected view patient set snapshot for this purpose)
DESIGN NOTE: there is no particular reason why this could not been done with any original record that can be used to form a patient set (path, radiology, oncology, cytology, hematology or autopsy report). They could serve the same purpose here. However, current policy is that this process is only done for those facilities that have their own cancer registry and they should be sending Abstracts. Don't believe registry would bother with 14.0 processes in the instance where no abstract was received.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
Only for facilities that have their own cancer registrar (and hence supply registry with abstract). Would also happen for facilities where registry staff creates the abstract for the facility's cancer registrar, but this is still an original abstract.

Sensitivity

Data Items (if a group data flow)
See BOM Abstract.

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Other Facility Referenced

Description
While working with information for a patient's cancer/tumor/case, reference may be made to where the patient was referred to or where the patient was referred from. These facilities/organizations should also have sent in an abstract.
Referred from facilities would always be expected to result in an abstract.
Referred to facilities may not result in abstracts because the patient may never choose to go to the facility.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Facility ID
Facility name
To or From?

Metrics
Frequency:

Volume:
Duration:
Quality/Error rate:

Other Guidelines/Instructions

Description

For example, ROADS or FORDS Manual, ICD-O-2, ICD-O-3, PCE – Patient Care Evaluation, AJCC, Comparative Staging Guide …
How to create an abstract from the point of view of national and international organizations (AJCC, ROADS/FORDS, WHO (ICD-O))
This seems to mostly focus on standard accepted coding for given words and phrases and approved ways to summarize information (such as AJCC staging)

Design Considerations

While some of this can be mechanized or placed in an on-line reference system, part is experience. The abstractors have manuals to reference, but these could probably be computerized (remember, some people prefer paper to computer screens).
Standard accepted coding: can be mechanized – type keyword, look-up box with shrinking options as more is typed.
How to Summarize – manual, should be able to mostly computerized this.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Text of guideline (ie Sex specific CTC sites must be consistent with sex of patient)
Effective (start) date
End Date
Source of Rule (organizations other than SEER that provide guidelines to the registries, for example State, COC, etc)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Other Patient Set Data Items

Description

See Patient Set
The data stored in patient set except for the data item currently being edited (which is already in the process).
Will be used to check for data consistency through-out the entire patient set.
This includes override flags

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Data item name (R1)
Data item Value (R1)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Other Rules

Description
Rules other than local or SEER that the registry may have decided upon for editing and how text should be translated into codes.
This may vary by hospital/physician and may be hard to codify.
Also would include which words were important and for vague words which ones should be considered to indicate a CTC.
For example, how disease text should be shown in ICD site, hist, beh codes, how staging information should be captured.
For example, registry may prefer to believe hospital A values over hospital B values based on past experience. When a registry chooses to override an editing error.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
Effective (start) date
End Date
Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Outgoing DEA Tracking Info

Description
Tracking of the information request fulfillment sent by the registry to a data exchange partner in order to fulfill their agreement.

Interested Registries
Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

DEA ID
Information Request ID
Date request fulfilled

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Outstanding Follow-Back Need

Description

During the course of active follow-up, the registry staff may desire to include any unanswered follow-back needs which should be directed to the same place. This flow provides information about the need.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

The registries believe this is more efficient (bug the facility/org/medical practitioner fewer times) and more likely to generate a response (for some reason, people tend to response when more questions are asked)

Sensitivity

Data Items (if a group data flow)

Follow-back need ID
Process which sent follow-back request
Staff ID Who sent follow-back request
Date of follow-back request
Source type {HRec, Pat, CTC}
Source ID
Data item (R1)
Data Item Value (R1) (includes unknown)
Follow-back Reason (optional to each request)
Action needed (part of instructions, may be text field or possibly multiple setting flag.)
Disposition process (part of instructions, the process waiting for the Follow-Back response. For Example: Resolve Possible Patient Match, Create Follow-Back Query, … May be better to have broader process names here. Screening, Matching, Abstraction, Consolidate, Polish, Follow-up, Follow-back, Receiving, Reporting, Editing, Special Study)
Send response to (Staff member)
FB Need Status
Org rep Assigned to
Date Assigned
Urgency {standard, high}

Metrics

Frequency:

Volume:
Duration:
Quality/Error rate:

Passive Follow-Up Data

Description

Information gained through passive follow-up, specifically from a record that the registry wishes to discard (for legal reasons).
This is the information the registry needs to retain to track follow-up. It contains no other information that the registry would have no legal right to have.

Interested Registries

Interested:

Local Procedures

Not Interested:

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

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

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Password(s)

Description

The password attached to an account within the registry.
(also the list of passwords)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Password

Metrics

Frequency:
Volume:
Duration:

Quality/Error rate:

Password, Account Information

Description

The password and account information assigned to a user of a Registry-Controlled file.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Password
Account

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Password, Account Information & Instructions

Description

The password, account information, instructions assigned to a user of a Registry-Controlled file.
Since registry-controlled files are stored under registry control, the recipient is not actually sent the file. They are given instructions about how to access the file, an account identifier and a password.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Password
Account ID
File Name
Location of File
Instructions on How to access (not stored)
Documentation of File (data items, formats, etc)
  Number of records
  File layout doc

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Patient Demographic Information

Description

Information about the patient characteristics not associated with CTC information.

In 5.1.2 Assign Ethnicity, this information is being used to determine a person's ethnic background. Multiple items are needed because of name changes due to marriage, ethnic prevalence in geographic areas (especially when 2 ethnic groups have similar names) and so on. Going into 7.1, includes address and other contact type information – informant, phone, etc

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Prioritize who needs to be followed-up with by age: under 20 crowd has poorest follow-up rates so highest priority. (They are harder because of name changes.)

Sensitivity

Data Items (if a group data flow)

First Name
Middle name
Last Name
Maiden Name
Marital Status
Race
Gender
State (Canadian Province) (of birth if possible)
County?

Street address (number and name)
City
State (Canadian Province)
Postal Code (ZIP)
Phone number (if available)
Date of Birth
Informant Name
Informant Address

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Patient ID

Description

The ID number assigned by the registry to the patient set. This is assigned in 4.5.2 Assign IDs in the NPL models

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Registry Patient ID

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Patient ID info

Description
Information that identifies the patient so an abstract facility lead can be created. Probably best to use the facility identifying information

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Patient ID (at registry)
(Based on available info in record)
Accession number in Facility
Patient Name
Patient SSN
Patient Address

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Patient Identifying Info

Description
Shows which patient was identified to be processed, tracked, etc. The data items by which it is possible to distinguish 1 patient from another.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Patient Name (R1 – first, middle, last; true name, maiden, aliases)
Medical Record Number (from facility/org, if known)
Social Security Number
Date of Birth
Sex
race
Patient ID (From Registry, if assigned)

Metrics
Frequency:
Volume:
Duration:

Quality/Error rate:

Patient Matched Info

Description

The 2 (or more) data groups that were determined to be a positive match at the patient level. The data groups could be incomplete patient set, existing patient set, health record (including correction record, reportable or non-reportable) or supplemental record. This information will be used in 'consolidation'

DESIGN NOTE: the previously matched records and/or patient sets will be retrieved if needed.

Information related to the patient.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See BOM entities: PATIENT, INFORMANT FOR PATIENT, and RESIDENCY, IDENTIFICATION

(Not all variables listed in these entities and relationships would be included because some seem to be computed or otherwise system based items instead of true data coming from outside sources. The values from all data groups would be included)

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Patient Match Status (=No)

Description

Patient match status: whether a match was found at the patient level for the data group in question.

Here, specifically no patient match was found for the given data group

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Match level (=Patient)

Match status (with value set to no)

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Patient Match Status (=Yes)

Description

Patient match status: whether a match was found at the patient level for the data group in question.
Here, specifically at least one patient match was found for the given data group

Interested Registries

Interested:
Not Interested:

Local Procedures

In NM, if the patient match status for a death certificate is yes, they wish to obtain the death certificate

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Match level (=Patient)
Match status (with value set to yes)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Patient Medical Records

Description

Another name for this is Medical/Vital Records
Could include Death Certificates
Records about a patient generated at a facility to accurately describe their medical interactions there and their medical history. The notes the physician takes during doctor's visits, path report write-ups from labs and other test results and so on. Could also include X-ray Image ID or CT Scan Id
Usually a stack of papers stapled/paper-clipped together in a folder.
Also referred to as the patient's chart.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Since this is external to the system, the exact papers which are included and the exact information on those papers is not critically important. The information the registry wishes to retain are the data items which make up an abstract (see patient set).
In the future, it may be possible to scan and store these records, but this would be a set of images. The obstacles to this are privacy concerns and legal mandates for securing personal medical information, not technology.

Sensitivity

Secure documents, not supposed to leave the facility, sometimes not supposed to leave the room.

Data Items (if a group data flow)

See Patient Set for list of potential data items
Stack of papers in folder.

Metrics

Frequency:
Volume:

Duration:
Quality/Error rate:

Patient Name

Description

Full name that the patient is know by

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

First name
Middle name
Last name
Maiden name

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Patient Response

Description

Response to whether or not a patient is willing to be interviewed for a special study.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Patient ID
Special Study ID
Response {Approved, Denied}
Date of Response
Do not contact patient (possible)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Patient Set(s)

Description

Patient information, along with CTC, facility and treatment information, is considered “patient set”.

All data that pertains to a patient, including patient, CTC, hospital specific and follow-up, treatment, diagnostic.

This contains all views of the patient set: all facility views and the registry view.

A "Patient Set" can have status of submissible, consolidated, in-process, awaiting follow-back, deleted, etc.
In 18.0, data items in the patient set are being verified as matching text within the set and against the source records.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See BOM entities: PATIENT, INFORMANT FOR PATIENT, and RESIDENCY
See BOM entities: CANCER/TUMOR/CASE, MARKER, COMORBID CONDITION, RESIDENCY is established for CTC, IMAGE, IMAGE EVALUATION, SPECIMEN, SPECIMEN EVALUATION, DIAGNOSIS and PAYOR SOURCE covers CTC, FACILITY ADMISSION, FACILITY refers PATIENT to FACILITY, RESIDENCY is established for CANCER/TUMOR/CASE
See BOM entities: CONSIDERED TREATMENT MODALITY, PATIENT refuses CONSIDERED TX MODALITY, PROCEDURE (and all subtypes), COURSE.
See BOM entities: IDENTIFICATION, OVERRIDE

See BOM Relationship: PATIENT or CTC is included in SPECIAL STUDY, PATIENT or CTC is possibly reportable to SPECIAL STUDY

Special study variables (since these change by study, registry staff needs to be able to add variables into the patient set as needed. One possible implementation would be a separate table for each study holding the defined study variables, the study id, the patient id & the CTC id)

For each view:
Facility/Org ID
Other related Facility ID (R1 – local NM facility view data item – affiliates with views for this patient)
Patient View Status {incomplete, deleted, consolidated, submissible, etc)
Patient Info Status
CTC View Status (R1)
CTC Info Status (R1)
Treatment Info Status (R1b)

DESIGN NOTE: 'Set' status flags are dependant on lower statuses. Registry View Patient Set Status is probably most important, although, if Registry Patient Info Status and CTC Set Status flags are submissible, that CTC may be submitted, even if other CTCs are in progress.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Patient Set Data Item

Description

The particular item, stored in patient set, for which edits are being run. A particular data item name and its value.

In 17.1, it is being checked as a valid code for the field and in 17.2 it is checked against other data items in the patient set to ensure it is not in conflict.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Data item name

Data item Value

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Patient Set Statuses

Description

Statuses of the patient set at various levels

In 8.1, may need to set the patient set statuses based on follow-back need. In other cases, patient set statuses may be unaffected by outstanding follow-back.

Because there are may levels of information and multiple views, this must be done carefully.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

For each view:

Patient Set Status

Patient Info Status

CTC Set Status (R1)

CTC Info Status (R1)

Treatment Info Status (R1b)

DESIGN NOTE: 'Set' status flags are dependant on lower statuses. Registry View Patient Set Status is probably most important, although, if Registry Patient Info Status and CTC Set Status flags are submissible, that CTC may be submitted, even if other CTCs are in progress.

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Patient Vital Status

Description

Whether a patient was Dead or Alive at the date of contact.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Vital Status {Alive, Dead}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Physician Response

Description

Response to whether or not a patient can be contacted by a special study staff.

Interested Registries

Interested:
Not Interested:

Local Procedures

Some registries consider a lack of response to be passive consent.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Physician ID
Patient ID
Special Study ID
Response {Approved, Denied}
Date of Response
Do not contact patient (possible)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Possible CTC Matches

Description

CTC matches to an incoming data group that the computer has selected from the entire database. These are not considered to be true matches, but rather have some probability score that they data groups refer to the same CTC.

The score and the matching data items should be provided to the user so a selection can be made.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(any 2 of the below)
Patient ID (R1- from patient set, incomplete thru submissible)
CTC ID (R2- from patient set, include Pat ID)
Health record ID (R4 - includes corrections and non-reportable)

(Repeat for each data group that matched the incoming group)
Match Level (BOM shows this by having different entities for each match type.) {=At CTC}
Match Status (=possible)
Overall score (weighted)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Possible Patient Matches

Description

Patient matches to an incoming data group that the computer has selected from the entire database. These are not considered to be true matches, but rather have some probability score that they data groups refer to the same patient.
The score and the matching data items should be provided to the user so a selection can be made.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(any 2 of the below)
Patient ID (R1- from patient set, incomplete thru submissible)
Health record ID (R4 - includes corrections and non-reportable)
Supplemental record ID (R5)

(Repeat for each data group that matched the incoming group)
Match Level (BOM shows this by having different entities for each match type.) {=At Patient }
Match Status (=possible)
Overall score (weighted)
Alias name used? {Y, N}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Possible Treatment Matches

Description

Treatment matches to an incoming data group that the computer has selected from the entire database. These are not considered to be true matches, but rather have some probability score that they data groups refer to the same treatment.
The score and the matching data items should be provided to the user so a selection can be made.
There will probably only ever be 1 possible match, the treatment information of the same type within a patient and CTC.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
(any 2 of the below)
Patient ID (R1- from patient set, incomplete thru submissible)
CTC ID (R2- from patient set, include Pat ID)
Treatment type (R3- from patient set, includes Pat ID & CTC ID)
Health record ID (R4 - includes corrections and non-reportable)

(Repeat for each data group that matched the incoming group)
Match Level (BOM shows this by having different entities for each match type.) {=At Treatment}
Match Status (=possible)
Overall score (weighted)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Potential Follow-Up Patient Information

Description
Information that tells whether the Patient is dead or alive and the date of that knowledge. Also may tell the cause of death if patient has died.
This information was obtained by the special study and may or may not be more up-to-date than the registry's information at the time the registry receives it.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
Registry staff trust some studies more than others. They may not choose to accept information received from a particular study.

Sensitivity

Data Items (if a group data flow)
Patient ID
Vital Status (Alive, Dead)
Date status known
Cause of Death (if deceased)

Special study ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Potentially Reportable Cancer/Tumor/Case Info

Description

Information from a health record which has passed the broad screening rules for SEER or Local and the status. May or may not have passed special study broad screen.
This information will be retained even if it fails the fine filter in the name of quality assurance. (If someone comes in and says "why wasn't this CTC reported", they want to have the data available to show they saw it and a reason why they didn't report it.) Also, new information may come in that makes a non-reportable (failed fine filter) reportable. (new staging, different histology)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Information about all potentially reportable cancer/tumor/cases is retained
Since there are many local reportable to groups and many special studies, it may be useful to track which one the info is potentially reportable to. That way, you would be able to check the fine filter for the relevant organizations only.

Sensitivity

Data Items (if a group data flow)

See health record
See Additional Disease Codes and Keywords
SEER potentially reportable {Y, N}
Local potentially reportable {Y, N} (R1)
Local organization (R1)
Special study potentially reportable {Y, N} (R2)
Special Study ID (R2)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Pre-Processed Transmitted Record Group

Description

See Transmitted Record Group
A transmitted record group that arrived in a non-standard format and needed pre-processing. The pre-processing has been completed and the record is ready to move on.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Transmitted Record Group
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Previous Differences Already Sent

Description
See differences
The differences already sent by the Registry to the data source that were tracked via 14.5 Track Differences Sent.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Differences
Date sent
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Previous Performance

Description
The number of records previously received from a particular facility or organization for a given time period.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
(This information comes in a report)
Facility/Org ID
Time period (R1)
Type of record (R1b)
Number of records (R1b – derived, count of type of record by facility)
Number of duplicates (R1b)
Metrics
Frequency:
Volume:
Duration:

Quality/Error rate:

Previous Submission Information

Description

Information about submissions of data to the Registry from Data Sources that have already been received

Used for checking for duplicate submissions and if found, determining when the original version was sent.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Submission ID (what the registry wishes to call it)
Received Data File identification (What the source called it, if anything)
Received From (Facility/Org ID)
Received Date
Registry Org Rep ID who received (may be system)
Type of record received
# of Records Received
Copy of File (for verifying duplicate submission)
Received multiple times (Either Y/N or Count of times received)
Date/Time processed
Registry Org Rep ID who processed

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Previously Transmitted Health Record(s)

Description

Health records received by the registry prior to the current record. They are stored to retain the original data received.

Here, they are being used to check for duplicate records: did this record already come into the registry?

Would include correction records

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See health record
Health record ID
(**DESIGN NOTE**: may want to include a key that would allow for easy checking of duplicate records. Even if we choose to check byte for byte, a key would narrow the search quickly. Then, if not exact, could go immediately to 4.0 consolidation processes.)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Previously Transmitted Supplemental Record(s)

Description

Supplemental records received by the registry prior to the current record. They are stored to retain the original data received.
Here, they are being used to check for duplicate records: did this record already come into the registry?

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See supplemental record
(Supplemental) Record ID
(**DESIGN NOTE**: may want to include a key that would allow for easy checking of duplicate records. Even if we choose to check byte for byte, a key would narrow the search quickly. Then, if not exact, could go immediately to 4.0 consolidation processes.)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Problematic ID

Description

An ID (such as an accession number or slide number) that is within the range obtained by the registry but has not actually itself been received or a single ID assigned multiple times.
For example – registry has numbers in the range 1 to 10, but is missing 7.
For example – 7 is assigned to John Doe and to Michael Smith.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility ID/Org ID
ID (ID assigned by facility that is in question)
ID type {Accession, slide, etc}
Problem Type {Duplicate, Skip}

Metrics

Frequency:

Volume:
Duration:
Quality/Error rate:

Process Access History (not sure if this meets need)

Description

Information allowing the registry org rep work, specifically what processes they used.
(big brother is watching.)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Account
Process ID
Date initiated
Time initiated

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Process Access Request

Description

Request by an org rep to initiate a process.
DESIGN NOTE: request may truly come from the process (is this person authorized)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Date of attempt
Time of attempt
Org Rep ID
Process ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Process Access Status

Description

Response to org rep and process about whether the org rep is authorized to start the process

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Access Status {Success, Failure}

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Proposed Collaboration Agreement

Description
An unsigned/"blank" confidentiality agreement that must be signed if a request is found to be valid
May contain some information about what the requester is expecting to receive.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Collaboration agreement ID
Collaboration agreement document
Date sent
Organization's/Person's name
Information Request ID

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Proposed New CTC Info Data Item

Description
A CTC data item value from the incomplete patient set currently being processed (wrapped into the existing patient set)
This name is not attempting to imply that the data item value is different or additional to the data items in the existing patient set. Just that a new set of information has been received and is being processed.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Data item value from new information
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Proposed New Patient Info Data Item

Description
A patient data item value from the incomplete patient set currently being processed (wrapped into the existing patient set)
This name is not attempting to imply that the data item value is different or additional to the data items in the existing patient set. Just that a new set of information has been received and is being processed.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Data item value from new information
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Proposed New Patient Set Info

Description
The incomplete patient set being consolidated as it stands after the current data item is modified based on all available information.
After each modification, the patient set should be edited to check for valid value in the data item and conflicts between the current data item and other data items. The user can ignore conflicts until all data items in the patient set have been consolidated (some errors may be corrected as they go), but they should be able to see what the problems are as soon as possible.
DESIGN NOTE: this editing is a background process which should occur when a change is made. The inter-field edit messages should be unobtrusive or the user should be able to turn them off.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Patient Set for complete list of data items
(will contain current value of data items)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Proposed New Treatment Info Data Item

Description
A treatment data item value from the incomplete patient set currently being processed (wrapped into the existing patient set)
This name is not attempting to imply that the data item value is different or additional to the data items in the existing patient set. Just that a new set of information has been received and is being processed.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Data item value from new information

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Purge Rules

Description
The rules that dictate what items are able to be purged and how long after an item has been closed should it be purged.
These rules are probably set by the registry.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Text of rule (ie Sex specific CTC sites must be consistent with sex of patient, comments)
Effective (start) date
End Date
Source of Rule
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Questionably Reportable Cancer/Tumor/Case Info

Description

A record for which the automated Local/SEER eligibility screening was inconclusive

These records will be stored and later manually reviewed to determine their status.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Implementation decision: really only need to be able to find this record again. Minimal requirement is:

Health Record ID

Reason for not determining (possibly - temporary)

Could store also store everything:

See Acceptable health info

See Converted ICD codes and keywords

See Residency info

See Additional disease codes and keywords (death certificate, autopsy)

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Questionably Reportable Info

Description

A record for which the automated broad screen was inconclusive

These records will be stored and later manually reviewed to determine their status.

We expect there will be times (especially when the 1.0 process is first implemented) where the computer will not be able to tell whether a record is reportable, but the staff (after manual review) will not want to keep the record. For example: ‘definitely not cancer’ type text might be hard to correctly classify because the computer will have ‘definitely’ and ‘cancer’ indicating reportable and ‘not’ indicating not reportable. Registry staff may feel they will not be audited on such a record. Hopefully as the rules for screening improve, the number of records that fall into this category will diminish.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Implementation decision: really only need to be able to find this record again. Minimal requirement is:
Health Record ID

Reason for not determining (possibly - temporary)

Could store also store everything:
See Acceptable health info
See Converted ICD codes and keywords
See Residency info
See Additional disease codes and keywords (death certificate, autopsy)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Questionably Reportable Special Study Info

Description

A record for which the automated special study eligibility screening was inconclusive
These records will be stored and later manually reviewed to determine their status.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Implementation decision: really only need to be able to find this record again. Minimal requirement is:
Health Record ID
Special study ID

Reason for not determining (possibly - temporary)

Could store also store everything:
See Acceptable health info
See Converted ICD codes and keywords
See Residency info
See Additional disease codes and keywords (death certificate, autopsy)
See Converted other codes and text per special study

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Random Sample

Description

Sometimes the special study's request specifies that eligible patients be chosen at random and sent to the special study.
This would be permanently saved as 'HRec or Pat or etc is included in Special Study'

Interested Registries
Interested:
Not Interested:

Local Procedures
Some registries select the random sample in house, others provide all eligible CTCs to the study and let the study do the selecting (which would be out of scope)

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Special Study ID
Source ID (R1)
Source type (R1) {Health rec, supplemental rec, Patient set, etc}

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Rapid Case Ascertainment Status

Description
Status=yes when the special study requires quick turn-around time for reportable CTCs.
If status=yes, the 6 months holding period prior to abstraction is unacceptable. The CTC needs to be given to the special study ASAP. This usually happens in studies that wish to interview the patients and are studying high-mortality CTCs.
Usually want to send this data to the study within 1 month of diagnosis. May not be practical based on location of facility.

Interested Registries
Interested:
Not Interested:

Local Procedures
How much work is done by the registry to prepare a record for a special study (as opposed to being done by the staff) is subject to local policy.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Rapid Case Ascertainment?

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Reason Abstract Not Returned

Description
Given that an abstract was requested from a facility, the reason why an abstract was not submitted.
IF this is coming from a referred to lead, the patient may never have arrived at the facility. Reason may be that the patient was never seen. Facility may also believe that the disease is not reportable

Interested Registries
Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Reason (text)
Facility Staff ID (who provided reason not abstracted)
Date (reason returned)
AFL Status (Closed (no abstract expected), Pending (suggested delay))

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Reason for Follow-Back

Description

Detailed text description of the problem. Also includes an urgency flag and possibly what action is needed (instructions for what needs to be done).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Text description of problem (optional to each request)
Action needed (probably text field, may also be able to use multiple setting flag.)
Urgency {standard, high}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Reason Medical Record Access Denied

Description

If the facility decides that the registry should not have access to a patient's medical record (most likely because they do not believe that the patient's disease is reportable), they need to communicate the reason to the registry

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Reason denied
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Reason Not Abstracted

Description
Given that an abstractor went to a location and started/attempted to create an abstract, the reason why an abstract was not submitted.
For example: Discovered not CTC, Discovered duplicate CTC, Records not available yet, etc.
IF this is coming from a referred to lead, the patient may never have arrived at the facility. Reason may be that the patient was never seen. Would want to give a status
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Reason (text)
Staff ID (whoever it was assigned to)
Status (Closed (no abstract expected), Pending (suggested delay))
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Received Paper Health Records

Description
Paper health records that have been received by the registry from an external data source
The 'submission' has been verified: the expected number of the expected type of record are present
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Health Record (on paper, not screened or converted) (R1)
(this is probably a stack of papers)
Metrics
Frequency:
Volume:
Duration:

Quality/Error rate:

Record Expectations

Description

Given that a registry has signed a contract with a special study, they would like to start 'requiring' information be returned to the registry. This seems to at least include whether the patient was used in the study, the date of last contact and outcome of contact (for interviewing studies) or vital status. These expectations should probably be stated clearly in the contract.

Registries did not sound as much concerned with record type or format as with information.

These are all patients the registry is already aware of. The registries wish for this information to improve the quality of the data they have collected.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Special study ID

SS returned Data items (to be sent by SS to registry. Could include)

Used in Study? {Y,N}

(for interviews)

Patient ID (Health record ID)

Date of Last Contact

Vital Status

outcome of contact

Optional:

race

dob

address

new CTC information

treatment types

(etc as defined by registry & Special study)

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Records Expected

Description

A description of the records that the registry expects to receive because of a data exchange agreement

This should include who is reportable from a Data Exchange partner.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
DEA ID
Information (types of records/CTCs) that registry expects to receive (Patients to receive)
- Site codes
- Hist codes
- Dates of Dx
- Residency

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Records Needed

Description
Records that the registry was expecting to receive from a particular facility or organization.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Record type needed
Time window of records
(i.e. Abstracts for Jan-June 2002)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Records Request Fulfillment Tracking Info

Description
When a facility or organization returns records requested by the registry, the request needs to be closed in the tracking data.
This includes supplemental or general health records requests.
Example: please send all path reports for April.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Record Request ID
Source Submission ID (gives who and when received)
Status {open, close/filled, close/other, purge}

Comments

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Records to be Sent

Description

A description of the records that the registry has promised to send out because of a data exchange agreement
This should include which records/patients are reportable to a Data Exchange partner.
Could include modifications to a patient set made after the information was sent to the partner the first time (ie, new information or a correction record is received). Whether this is done depends on if the registry believes the information will affect what the partner does with the information (data item), the source of the change and who the partner is.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

DEA ID
Information (types of records/CTCs) that registry has agreed to send (Patient to send)
- Site codes
- Hist codes
- Dates of Dx
- Residency

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Registry Created Abstract

Description

An abstract type record which was created by a SEER registry staff member. This is a trusted health record so it should not need to be converted.
DESIGN NOTE: it may be possible to create these while directly linked to the main registry system. In that case, they should be able to by-pass 13.0 entirely.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Because abstracts are created in the field, the 13.0 tasks to verify a good transmission of data may have to occur. Coding, duplicates and so on could be skipped.

Sensitivity

Data Items (if a group data flow)
See BOM ABSTRACT
(Data items which appear on the abstract record type. Should be similar to those in the data flows Patient Matched Info, CTC Matched Info, Facility Matched Info and Treatment Matched Info. Would be the facility's values for these data items)
Date created
Org rep (who created)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Rejection Reason

Description
Reason why the registry rejected a correction sent by a facility for a given data item.
Registry may have better information or may not agree with facility's reasoning.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Reason (text)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Related Adds/Changes/Deletes

Description
See Adds/Changes/Deletes
In 10.12, after inappropriate information is deleted, any ACD for the patient for the same data field must be modified to remove the data string in question.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Adds/Changes/Deletes

Metrics
Frequency:

Volume:
Duration:
Quality/Error rate:

Related Health Record Update

Description

See Health Record Update Tracking Info
In 10.12, after inappropriate information is deleted, any Health Record Update for the record for the same data field must be modified to remove the data string in question.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Health Record Update Tracking Info

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Reportable Unconverted Health Record

Description

A health record received on paper that has been determined to be of interest to the registry with text and key fields that have yet to be converted.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Registries screen paper records at the broad level before bothering to enter the data electronically. It saves time and effort by throwing out garbage prior to expending much effort.

Sensitivity

Data Items (if a group data flow)

See Health Record (still on paper)
Status=Reportable

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Reportability Status

Description

Whether the information the status is attached to is considered reportable by the registry. This could be reportable to SEER, local or a special study.

In 6.0 Request Death Certificate, this is most likely reportable to SEER or local. A reportability status of yes with patient or patient and CTC match statuses of no would mean that the DC was desired by all registries.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Reportable Status {Reportable, non-Reportable}
(Could collapse all reportable status type information into 1 or send all flags; reportable SEER, reportable Local, reportable Special Study)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Request for Abstract(s)

Description

When a potential cancer/tumor/case is found (see below) for which there is no abstract from the facility in the registry data, the registry requests that the facility/org (see below) create an abstract for the patient/CTC. Given that a facility/organization creates abstracts and submits them to the SEER registry, the registry periodically asks for disease indexes and so on to verify that no cancer/tumor/cases have fallen through the cracks. Also, sometime there may be a referred to/referred from mentioned by another facility.
Note, the registry is trying to obtain a type of record submitted to their database.
These requests may be created semi-automated or totally automatically

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Abstract Facility Lead ID
Facility ID
Record Request ID
Date requested (sent)
Patient Name (R1)
Patient ID (R1, at facility if known)
Cancer/Tumor/Case ID (R1, at facility if known, otherwise site, hist, beh, date of Dx so on may be given to help determine what to abstract.)
Staff ID generating request

Metrics

Frequency:
Volume:

Duration:
Quality/Error rate:

Request for Approval

Description

A request submitted to a medical practitioner or patient to obtain authorization to contact the patient for a special study.
Special studies that wish to contact a patient (and possibly some other kinds of studies as well) need to get physician and patient consent to include the patient in the study.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Some registries make the special study obtain these approvals, in that case, these would be out of scope
Some registries consider passive physician consent to be adequate. Then notify the physician that the following patients have been selected for a study on thus-and-such. If the physician doesn't contact them to object, they consider that to be passive consent.

Sensitivity

Data Items (if a group data flow)

Request type {Physician, Patient}
Special Study ID
Special Study description
Patient involvement description (not stored, just in letter. D from SS contract info)
Date contacted
Physician ID (who was contacted)
Staff ID who contacted.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Request for General Health Records

Description

General: Registry asks for all records available of a certain type so they can perform registry operations. Could be request for Disease index, all e-path reports, all abstracts (assuming hospital generates them), radiation logs, so on. They would be asking for all records for a given time period (would have requested prior records earlier)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Health Request ID
Org ID/ Facility ID

Date request made
Due Date (derivable based on request date and registry standards)
Type of request (=general)
Record type requested (path reports, disease index, abstracts)
From date
Thru date

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Request for Health Records

Description

Specific: Registry has some piece of information about a specific patient and would like further information for them. They are requesting specific health records. For example, patient is found on death list, registry requests death certificate.
General: Registry asks for all records available of a certain type so they can perform registry operations. Could be request for Disease index, all e-path reports, all abstracts (assuming hospital generates them), radiation logs, so on. They would be asking for all records for a given time period (would have requested prior records earlier)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(Health) Records Request ID
Facility or Org ID
Date request made
Due Date

Type of request {specific, general} (in BOM these are separate entities)
For general request:
Record type requested (path reports, disease index, abstracts)
From date
Thru date
For specific request:
Type of record requested (follow-back, abstract, etc)
Number requested (Derived: number of specific requests in same letter)
Health Record ID
Patient information (from record, may be name, ssn, etc)
CTC information (from record, may be site, hist, etc)
Document number (from record, for example a DC number)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Request for IRB Approval

Description
A request sent to the Institutional Review Board to obtain approval an information request.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules
This may be out of scope; the registries may want the requester to do this.
Sensitivity

Data Items (if a group data flow)
Information Request ID
Facility ID
Description of Request (text – in letter, not stored)
Date of Request
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Request for Interview

Description
If a special study desires an interview with a patient, after physician consent has been obtained, the patient must be contacted to get their consent to the interview.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules
If the special study is doing this, the interview may very well take place immediately. However, this is out of scope.
Some registries obtain this approval before releasing the patient to the study, others expect the special study staff to obtain this consent.
Sensitivity

Data Items (if a group data flow)
Request type {Physician, Patient}
Special Study ID
Special Study description
Patient involvement description
Date contacted
Staff ID who contacted.
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Request for Password

Description
A request for a password to a registry controlled file.
Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Information Request ID
Registry Controlled File name
Recipient Name (R1)
Phone number (R1)
Comments (R1)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Request for Patient Medical Records

Description
In order to create an abstract, the abstractor must have all the patient medical records. When a SEER registry staff member creates an abstract for a facility/org (usually off-site), they request the medical records for the patient they wish to abstract prior to going to the location.
NOTE: this doesn't have to be done by the abstractor; it's purely clerical in nature.
All patients to be abstracted during a visit are requested.
This helps increase productivity off-site. Also, since these records are secure, requesting prior to arrival prevents delays due to red tape.
NOTE: this isn't a byte file they are trying to acquire, it's usually a bunch of papers stapled/paper-clipped together in a folder.
Information from these records may be used on the Abstract, but the records themselves are not necessarily maintained in the registry database. Frequently the hospital will not allow you to remove patient records from the records area.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Patient Name (R1)
Patient ID (R1, at facility if known)
Date/Time coming
Staff Name who will arrive

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Request for Supplemental File

Description

A request by the registry to an organization that provides non-health information. These are always general type requests.
Frequently, the registry must pay to receive this data.
If the file was paid for and the original request is not fulfilled, it must be re-requested.
This information is mostly used in follow-up, but can also be used to obtain better personal information for a patient and to help resolve matches.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Supplemental Request ID
Staff ID (who made request)
Org ID/ Facility ID
Date request made
Record type requested (path reports, disease index, abstracts)
From date
Thru date
Payment amount (0 -> no payment)
Due Date (derivable based on request date and registry standards)
Status {open, close/filled, close/other, purge}
Comments

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Request Fulfillment Information (including HIPAA rqmts.)

Description

Tracking information about the filled request
To include HIPAA requirements
Need to keep track of file and what happens to it after the researcher is finished with it. (Signed agreement to delete file or whatever mechanism is in use at the registry)

For reports, extracts or registry controlled files where patients or CTCs are specifically given (non-aggregate data), need to track which patients and CTCs were included in each fulfillment.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information Request ID
Staff ID who Fulfilled the Request
Date Started
Date Request was Fulfilled
Effort (time required)
Name of report/extract/registry-controlled file (how the request was fulfilled)
Status (=Fulfilled)
Comments

For reports/extracts/RCFs that specifically identify patients or CTCs (non-aggregate data)
Source type {Pat, CTC} (R1)
Source ID (R1)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Request ID

Description
An identifier so that a request to review inappropriate data can be referred to by manager and staff.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Request ID
Org Rep ID (who discovered it)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Request Result

Description
Manager's decision about whether a piece of information should be deleted from the registry's data stores.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Request Result {Delete, Retain}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Request Status = Open, Standing, Reported Problem

Description

See Information Request
An information request with any of the following statuses:
Open variants: Received, Valid, Fillable, Pending Documentation, On hold, In-progress
Standing: Coming Due
Reported Problem

The different statuses helps registry staff member (management) to determine what action needs to be taken to close this request.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Information Request
Status (=Received, Valid, Fillable, Pending Documentation, On hold, In-progress, Coming Due, Reported Problem)
Ongoing (=Yes)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Requested Death Certificates

Description

A specific health records request: The registry's request to the vital statistics bureau for the death certificates with the given IDs.
The death certificates requested by the registry and the tracking information about the request

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(Health) Records Request ID
Staff ID (who requested)
Facility or Org ID (=Bureau of Vital statistics)
Date request made
Due Date (derivable based on request date and registry standards)
Status {open, close/filled, close/other, purge}

Comments

Type of request {specific, general} (in BOM these are separate entities)
Type of record requested (follow-back, abstract, etc)
Number requested (Derived: number of specific requests in same letter)
Patient information (from record, may be name, ssn, date of death if known, etc)
Document number (R1 –DC number)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Requested Disposition

Description

The process or person who should receive the follow-back response (according to the calling process)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

DESIGN NOTE: if the return of information is implemented as an email notification, this would probably be a person or group (return to abstractors or return to Jane Doe, not return to Conduct Abstracting)
DESIGN NOTE: could also be send to Jane Doe to resume abstracting.

Sensitivity

Data Items (if a group data flow)

Who (Staff ID) should be notified when completed
What process should be initiated after answer received

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Requested Special Study Modification

Description

A change to the special study contract – most likely criteria or time window – requested by the special study.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

IA, HI and NM are interested in tracking.

Sensitivity

Data Items (if a group data flow)

Special Study ID
Modification Desired
Date Requested
Org Rep Requesting (SS org rep)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Residency Information

Description

As much of the residency for the patient as can be determined given the information on the record. Coded/entered in registry standard.
At a minimum, need state and county code to determine if the patient is in the catchment area. Eventually, we need a full address, census tract and residency status.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Street address (number and name)
Apartment number/floor
City
State (Canadian Province)
Postal Code (ZIP)
County (FIPS)
Name of Facility (prison, nursing home, homeless shelter, etc)
Residency status

Census tract
Geo-coding (longitude, latitude)
Rural/Urban Continuum (based on county, only needed for Dx)
Rural/Urban Continuum Format {1993, 2003}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Resolution Criteria

Description

Criteria for deciding whether a possible match should be accepted. Some of this is experience and very hard to quantify. Some of it is personal knowledge of the patients involved (also can't be coded).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Text of rule
Effective (start) date

End Date
Source of Rule (SEER)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Resolvable Non-Data Problem

Description

A problem with an information request that is of the types Format, Expanded or Corrected and the registry is able/willing to adjust the request fulfillment to fix the problem.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information Request ID
Information Request Problem ID
Type of problem {Format, Expanded, Correction}
Description (text)
Registry staff ID (who was notified)
Date of problem
Decision (Resolution will occur and how to resolve)
Date resolved
Registry staff ID (who resolved)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Response to Follow-Back Query

Description

Response received in answer to follow-back query submitted.
Could be a letter, phone call, note from abstractor or others
An Organization or Facility could send a Health Record (e.g. path report, abstract) in response to a Follow-Back Query
Could be a note indicating that it's not reportable (e.g. it's benign)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Follow-back Query ID
Record/Patient ID (R1)
Data Item Name (R2)
Data Item Value (R2)
Supporting Text (optional per resolution, who answered question, any reasoning behind answer, etc)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Review Info

Description

Tracking information about when a patient set was reviewed by a supervisor.
This is not the original edit, but the verification that the edit was done corrected for QC purposes.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Review Date
Reviewer

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Review Information Request

Description

A request from a registry staff member to the appropriate manager asking if the manager could review a suspect piece of data to see if it should be deleted.
Mostly this is to get something on the manager's task list. It could just be an email to the manager.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Review information request

Metrics

Frequency:
Volume:
Duration:

Quality/Error rate:

Revoked Access

Description

When an org rep leave registry employment, all access codes are turned off.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Process ID (R1)
Process Access? (R1) {=No}

Data Table ID (R2)
Data Item ID (R2)
Data Access? (R2) {=None}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Scanned Image

Description

A scanned picture of a health record received on paper. Used for archiving. The original is shredded.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Health Record ID
Scanned Image

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Scheduled Date

Description

Date an event was scheduled to occur.
In 10.8 Manage Supplemental Info Acquisition, this is the date a request needs to be sent for a particular kind of data. For example, request for DMV file is sent June 1st.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Month scheduled
Day Scheduled
Year scheduled
ID of event scheduled (or just description)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Scheduled Information Request

Descriptions
See Information Request
An information request that comes due on a specific, recurring date (i.e. SEER Submission due every February and August)

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Information request
Ongoing(=Yes)
Date Due (some registry specified distance from today's date)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Scheduling Criteria

Description
Criteria of how often a hospital is visited, which staff member goes there, how long a cancer/tumor/case should 'age' before being collected, and so on.
Aids in scheduling staff to create abstracts off-site in the most efficient manner possible.
In some registries, this is more complex: considers distance, time and cost of visiting a facility. May also need to consider other facilities the abstractor is responsible for.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Text of rule (ie time from normal dx to normal abstraction; facility submission schedule, etc)
Effective (start) date
End Date
Source of Rule (local)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (facility ID, Staff ID, Availability code; facility ID, nearby facility IDs)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Screened Paper Records

Description

A paper health record that has already been screened (broad screen) to see if it is of interest to the registry
Specifically records which passed the screen as the others are discarded.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Health Record
Status = possibly reportable

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

SEER Active Follow-Up Rules

Description

Provide rules as to who is or isn't eligible for Active Follow-Up, from SEER's point of view.
For example, they don't need to follow-up with cervix in situ patients.

Interested Registries

Interested:
Not Interested:

Local Procedures

One group of rules would be how long a time span is acceptable from the point of a follow-up action until a response is received. For example, a phone call would need an immediate response, or a new action must be chosen. In HI, after a letter is sent, a 3 week delay is acceptable (after that, they would call) In LA, only 2 weeks is acceptable.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
Effective (start) date
End Date
Source of Rule (SEER)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

SEER Broad Reportability Rules

Description

The gross filter for SEER reportable CTCs.
Probably a range of codes the disease must be within or text keywords that must be present.
Information which passes these rules is kept for quality assurance purposes. If the rules are too broad, there may be legal complications. If they are too narrow, the registry may miss reportable CTCs.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Consistent across all registries

Sensitivity

Data Items (if a group data flow)

Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
Effective (start) date
End Date
Source of Rule (SEER)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables

for example:
Range for Site
Range for Histology

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

SEER Consolidation Rules

Description

SEER instructions on how, what, when to consolidate – what overrides what, etc.

Would include for a given data item, which other data items should be considered. (Size of tumor would need to consider if there was radiation and when CTC was measured in relation to radiation cycle.)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
Effective (start) date
End Date
Source of Rule (SEER)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

SEER Guidelines/Instructions

Description

For example, SEER Coding Manual, SEER EOD, POC, …
How to create an abstract from the point of view of SEER.
Describes what is reportable (sometimes during abstracting they determine that the CTC isn't), what information is necessary to collect, standard accepted coding for given words/phrases, and important keywords that the abstractor should record.

Design Considerations

While some of this can be mechanized or placed in an on-line reference system, part is experience. The abstractors have manuals to reference, but these could probably be computerized (remember, some people prefer paper to computer screens).
Information to collect: how the data entry screen is presented.
Standard accepted coding: can be mechanized – type keyword, look-up box with shrinking options as more is typed.
Important keywords – manual and experience
What is reportable – manual and experience for vague wording, can be partially computerized to flash warning if entered data would fail fine filter.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Text of guideline
Effective (start) date
End Date
Source of Rule (SEER)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

SEER Reportable List

Description

Specifically, what is reportable to SEER
List of sites, histologies, behaviors, etc. Some may need the combinations listed. Note, these really aren't different from rules.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Consistent across all registries

Sensitivity

Data Items (if a group data flow)

Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
Effective (start) date
End Date
Source of Rule (SEER)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables

Example of Rule:

Site code
Hist code
Beh code
Hist code not with given site code
…

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

SEER Reportability Rules

Description

Feeding into 1.1.1: Determine Potential CTC and Special Study, see SEER Broad Reportability Rules
Feeding into 1.1.2 Do Initial Screening for Local/SEER Reportability, see SEER Reportable List

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
see SEER Broad Reportability Rules
see SEER Reportable List

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

SEER Rules

Description
Rules about how text should be translated into codes. For example, how disease text should be shown in ICD site, hist, beh codes, how staging information should be captured.
Also would include which words were important and, for vague words, which ones should be considered to indicate CTC.
Includes editing rules: invalid codes for the fields and invalid combination of information in multiple fields

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
(below are specific for converting)
Data item name
Incoming coding scheme
Desired coding scheme
Incoming coded value to registry coded value conversion rule (probably a table of conversions)

Effective (start) date
End Date
Source of Rule (SEER)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Selected Ethnicity Code

Description
The ethnicity code a registry staff member decides best fits the patient. This may be the same as the computer derived code, but may be

different based on additional knowledge, experience or interaction with the patient (not necessarily interaction in the name of getting the ethnicity).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

DESIGN NOTE: in the future, SEER and the registries may need to be able to accommodate that an individual is allowed multiple ethnicities. Whether that is implemented as multiple codes per individual or a single code represents multiple ethnicities has not been determined at this time.

Sensitivity

Data Items (if a group data flow)

Ethnicity code

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Selected Fields of Included Health Record

Description

Fields from the Health Record that have been requested by the special study. Registry ID for record should be included for reference in the future.

Also includes tracking info for registry use (Date provided)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Special Study id (assigned by registry)
Source Type (= health record)
Source ID (Record ID)
Coordination Needed?
Controlling Special Study ID
Date provided
Exact fields sent depends on the study and record type
Fields may be standardly collected from health records, or may be normally discarded, but retained specifically for the special study.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Selected Fields of Included Patient Set

Description

Fields from the Patient Set that have been requested by the special study. Registry ID for the patient set should be included for reference in the future.
Also includes tracking info for registry use (Date provided)

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Source Type (= patient set)
Source ID (Patient ID, CTC ID)
Coordination Needed?
Controlling Special Study ID
Date provided
Exact fields sent depends on the study
May be standard fields in patient set, may be collected specifically for the special study.

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Selected Fields of Included Supplemental Record

Description
Fields from the Supplemental Record that have been requested by the special study. Registry ID for record should be included for reference in the future.
Also includes tracking info for registry use (Date provided)

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Source Type (= supplemental record)
Source ID (Record ID)
Date provided
(Exact fields sent depends on the study and record type)
(Fields may be standardly collected from supplemental records, or may be normally discarded, but retained specifically for the special study. Registries would not collect additional fields for supplemental records.)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Selected ID List

Description

If an information request asked for an Extract and the requester only used a subset of the patients set, the registry needs a list of IDs that are being used.

Depending on the request, the registry may send out a partial file and only send the full request fulfillment after IDs have been selected

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information Request ID

Source type {Pat, CTC}

Source ID

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Selected or New Patient Set

Description

Selected: the patient set selected as matched to the incoming incomplete patient set info.

New: if incomplete patient set info doesn't match to anything, the new patient set that is being created to contain the information in the registry database.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Patient Set

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Selected Patient Match Info

Description

Information identifying the patient match that has been selected from among the possibles.

Only applicable to a match to a patient set, it is being sent to search for facility match.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Incoming Patient ID (Record ID)
Selected Patient Set ID

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Selected Possibly Reportable Special Studies Information

Description
The records that have passed the broad special studies screen and have been through some portion of the fine screen. Additional variables need to be collected for these records.
A record may be screened, have additional variables collected and then be more accurately screened.
Records that full pass the fine screen become incomplete patient sets that are special study reportable.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Health Record ID
Special study ID
See Acceptable health info
See Converted ICD codes and keywords
See Residency info
See Additional disease codes and keywords (death certificate, autopsy)
See Converted other codes and text per special study

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Selected Registry-Controlled File Information

Description
If it was determined that a Registry-Controlled File could satisfy the Information Request, this would be information about the Registry-Controlled File that was selected.
See glossary for definition of Registry-Controlled file, short version is a file created and maintained by the registry and under their control. Passwords and training are needed to access. May be identified or de-identified.

Interested Registries
Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

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? {Yes, No}
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}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Selected Report/Extract Information

Description

If it was determined that a report/extract could satisfy the Information Request, this would be information about the report/extract that was selected.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Report/extract identifier (name)
Type {Standard, Ad hoc}
Location (or copy, implementation decision)
Programs Used to create (R1)
Staff ID (who created, who to direct questions to)
Date created
Specifications (Text)
Data items included (R2)
Identified? {Yes, No}

Comments (text field for other considerations, quirks in ad hoc reports or extracts that may make it inappropriate for other requests)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Selected Standard Report/Extract/Registry-Controlled File Format

Description

If it was determined that a standard report/extract/Registry-Controlled format could satisfy an Information Request, this would be information about the format that was selected.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Format identifier (name, SEER submission, SEER*Stat, etc. see below)
How to access format (program name, application location, so on)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Selected View of Consolidated Patient Set

Description

See Patient Set
The consolidated view, either registry or facility, used in updating the facility's data
The selection is based on registry policy: for this facility, do we use registry or facility view?
The same view should be used for all updates; the policy should be fairly static
Consolidated is the lowest acceptable status. (Polished is also ok)

Interested Registries

Interested:
Not Interested:

Local Procedures

Some registries merely use this to find differences, others actually send the snapshot to the facility.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Patient Set
Status = Consolidated (or better)

Metrics

Frequency:
Volume:
Duration:

Quality/Error rate:

Sibling Facilities

Description

Facility and the affiliated facilities where Declare Match = Y.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Facility ID
Affiliate Facility ID
Declare Match (=Y)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Signed Collaboration Agreement

Description

See Proposed Collaboration Agreement
Confidentiality agreement that has been signed by the recipient so a request will be found to be valid (and can move through the rest of the process)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Information Request ID
Collaboration agreement document WITH SIGNATURE
(Set Signed? to Y)
Date received
Staff id who received

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Single Field Edit Status

Description

Status of a data item found in patient set with respect to the single field edit. AKA field edit (Compare Individual Value to Rules)
Only valid items should go from 17.1 (Compare Individual Values to Rules) to 17.2 (Validate Value vs Other Data Items). Failed items should be returned to the calling process.
Is this value consistent with the field's format and acceptable values?

If edit status=failed, then this is an edit issue and must be stored.
Referenced as a type of “Edit Status” – see “Edit Statuses”.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Usually this occurs only when a value has been changed. However, registries are edit happy and may want to be able to request edits at will.

Sensitivity

Data Items (if a group data flow)

Single field edit status {passed, failed} (only need to note failed)
Reason (Which rule was broken – such as phone number, SSN; unacceptable value – such as gender=X; so on)
Date
Patient Set ID/Health Record ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Source Health Record(s) for Existing Patient Set

Description

See Health Record
These are the health records that were used to construct the patient set. Should be able to find these health records by links from the patient set to each record.
The information on the records will be used during consolidation so that all possible values for each data item will be available to the user.
These records also need to be available during 18.1 Compare and Resolve Text to Codes
DESIGN NOTE: they need to be able to see the scanned images of any records involved as well as the retained data ‘HREC’.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Health Record ID
See BOM Health Record
See BOM Health Record Updates (corrections to the records) (must be attached to Patient Set by Match)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Source Supplemental Record(s) for Existing Patient Set

Description

See Supplemental Record
These are the supplemental records that were used to construct the patient set.
Should be able to find these supplemental records by links from the patient set to each record.
The information on the records will be used during consolidation so that all possible values for each data item will be available to the user.
These records also need to be available during 18.1 Compare and Resolve Text to Codes

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Supplemental record ID
See Supplemental Record
(must be attached to Patient Set by Match)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Special Add/Change/Delete

Description
See Adds/Changes/Deletes
In 10.12, when inappropriate information is deleted, the ACD generated should not retain the old values (or we would still have the inappropriate data). The entire item can be automatically created since the reason is known.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
(identifies which particular place within patient set data)
Patient Set ID
CTC ID
Facility ID
Treatment Type(?)

Data item name
Old value = EMPTY
New value
Reason changed (text) = Inappropriate information removed
Date/time changed
Who changed (staff id)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Special Health Record Update

Description

See Health Record Update Tracking Info
In 10.12, when inappropriate information is deleted, the Health record update generated should not retain the old values (or we would still have the inappropriate data). Everything but Facility Counted Error can be automatically created since the reason is known.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Health Record ID
(In HRec Update)
Data item changed
Old Value = EMPTY
Updated Value (to what)
Org Rep ID
Date/Time (when changed)
Facility Counted Error? {Y, N}
Reason Code (Categorical: = Correcting mistake)
Comments/Reason for Update (Why changed) = Inappropriate Information Removed

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Special Study Broad Criteria

Description

A gross filter that a record or Patient Set must meet in order to be included in a Special Study.
Probably a range of codes the disease must be within or text keywords that must be present. May also include cohort definitions (females, 65+, so on)
Information which passes these rules may be kept for quality assurance purposes. If the rules are too broad, there may be legal complications. If they are too narrow, the registry may miss reportable CTCs. Missed CTCs are less important in special studies than for SEER and Local rules.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Special Study ID
Effective Begin Date
Effective End Date

Special Study Reportability Criteria (aka RULE)
This depends on the special study and will have to be added for each study as they are given to the registries. Examples might be:
Acceptable Sites
Acceptable Ages
Acceptable Histologies
Acceptable Dx Dates
Acceptable counties of residence
Desired variables (also depends on special study)
Facility ID (R1) (if IRB approval not obtained from all facilities)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Special Study Contact Information

Description

The study name, contact person name, phone number and address. In 3.8, the contact information for the controlling study is provided to the other studies. The other studies contact information is merely used to send the notification.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Special Study name
Contact (Researcher) name
Contact Phone Number
Contact Address

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Special Study Criteria

Description

Criteria that a record or Patient Set must meet in order to be included in a Special Study.
Would include list of variables that need to be selected on (and hence converted) and specific codes or code combinations desired. It would also include variables that have been requested, both standard and non-standard (which would have to be collected).

For Non-standard variables, should include a coding scheme of some sort.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Special Study ID
Effective Begin Date
Effective End Date
Location check needed?

Special Study Reportability Criteria (Text)
This depends on the special study and will have to be added for each study as they are given to the registries. Examples might be:
Acceptable Sites
Acceptable Ages
Acceptable Histologies
Acceptable Dx Dates
Acceptable counties of residence
Desired variables (also depends on special study)
Facility ID (R1) (if IRB approval not obtained from all facilities)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Special Study Follow-Back Request

Description

The special study, while working with the data, has discovered a problem, inconsistency, or missing item and is asking the registry to do the follow-back.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Registries seem to prefer that the special studies contact the patients and doctors as little as possible (both for confidentiality and irritation reasons). Also, the registry will probably need to correct the information in their own database. Therefore, they would prefer to do the follow-back themselves, and not have the special study do it.

Sensitivity

Data Items (if a group data flow)

Source type {HRec, Pat, CTC}
Source ID (as assigned by registry)
Data item (R1)
Data Item Value (R1) (includes unknown)
Follow-back Reason (the description of the problem)

Special Study ID (Who is requesting)
Date follow-back requested

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Special Study ID(s)

Description
ID of Special Study assigned by registry
In 3.8.2, the IDs of multiple studies using the same patient.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Special Study ID

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Special Study Identifier

Description
Identifies a Special Study within the registry. Used to flag which special studies a patient, person, etc. was provided to. (A patient may be provided to a special study, but not included in it because they weren't selected)

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Special study ID (assigned by registry)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Special Study Information

Description
Information about a Special Study, not including criteria for selection

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Special Study ID (may be registry assigned)
Special Study name
Contact (Researcher) name
Contact Phone Number
Contact Address
Method of delivery (does someone walk hard copies over or encrypted email, or etc)
Schedule of delivery (1 shot when complete cohort? Weekly? Includes dates)
Rapid case ascertainment? {Y, N}
Interview desired? {Y, N}
Registry to obtain consent? {Y, N}
Registry to do random selection? {Y, N}
Number of desired patients

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Special Study (SS) Patient Contact Information

Description

Some special studies contact the patients to do interviews, therefore, they may have better contact information about the patient.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Patient ID
Date of Last Contact
Outcome of contact (dead, alive do not contact, alive completed interview, etc)
May include:
- Patient Name (first, last, middle)
- Current Address (Street, city, state, zip)
- Phone Number
- Do not Contact Flag
- Informant Name
- Informant Address
- Informant Phone number

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Special Study Patient Inclusion Indicator

Description

Returned by Special study to the registry, this indicates whether a special study used this patient in their final cohort and the result of any contact with the patient.

NOTE: not everybody who is sent to a special study is used. If a registry is trying to prevent a person from being used in multiple studies, this would allow the registry to free this patient for other studies.

NOTE: patient may be included in multiple special studies. Need to indicate for each.

This data is included in the Special Study Tracking Information to track which patients are used in a study and in the Patient Set to track which studies a patient is included in.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Special Study ID

Source Type {HRec, SRec, Pat Set}

Source ID

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)

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Special Study Patient Inclusion Information

Description

Returned by Special study to the registry, this indicates whether a special study used this patient in their final cohort and the result of any contact with the patient.

NOTE: not everybody who is sent to a special study is used. If a registry is trying to prevent a person from being used in multiple studies, this would allow the registry to free this patient for other studies.

NOTE: patient may be included in multiple special studies. Need to indicate for each.

This data is included in the Special Study Tracking Information to track which patients are used in a study and in the Patient Set to track which studies a patient is included in.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Special Study ID

Source Type {HRec, SRec, Pat Set}
Source ID
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)
Date of last contact by study? (if contacted, to set window during which patient should not be contacted for additional studies.)
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.)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Special Study (SS) Updated Patient Set Information

Description

If during the course of a special study, the researchers obtain better information about data items in the patient set, the Registry would like to get that information.
This information may be obtained through medical practitioner contact, Patient interview or other sources of data which the registry does not utilize.
Would like it to at least include Date last contacted and Outcome of contact.
NOTE: the media this information comes in on and the format of the information is widely varied by study and sometimes within a study. It is not always electronic and data entry may need to occur before information can be processed.

Interested Registries

Interested:
Not Interested:

Local Procedures

Some registries note the information but do not add it to the database because they feel it would skew the quality of the data – not every patient set has been involved in a special study, so they don't have an equal chance at getting this kind of information.
Some registries will only accept certain data items, only accept information from certain research groups, only accept data in certain circumstances (patient interview occurred) to protect against incorrect corrections.

Policies/Business Rules

Since the registries do not currently get this information, they would have to include this in the special study contract.

Sensitivity

Data Items (if a group data flow)

Special study ID
Patient ID
CTC ID
Record ID (if patient id hadn't been assigned when data sent to study)
Record type (=health)
Data Item name
New Data item value
Reason (patient interview, … - comes in on record, may only be stored in ACD)
Date of last contact by special study

Outcome of contact (deceased, do not contact, valid… - would probably affect other variables, may be a local variable in some registries.)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Specific Record Request Fulfillment Tracking Info

Description

When a facility or organization returns a record specifically requested by the registry, the request needs to be closed in the tracking data.
Specific request: please send Jane Doe's death certificate.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Record Request ID
Health Record ID (would provide date received)
Status {open, close/filled, close/other, purge}
Comments (would include information on partial fulfillment)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Staff Productivity Report

Description

Requested by manager trying to do 10.11 from the 12.0 reporting task. 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).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Iteration of Standard Report

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Standard Registry-Controlled File

Description

A Registry-Controlled file used to fulfill this request. It is or is expected to be a standard (repeatedly needed) file.
See glossary for definition of Registry-Controlled file, short version is a file created and maintained by the registry and under their control. Passwords and training are needed to access. May be identified or de-identified.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

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 }
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? {Yes, No}
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}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Standard Report/Extract

Description

The standard report or extract produced.
A Report or Extract used to fulfill this request. It is or is expected to be standard (repeatedly needed).
See glossary for definition of extract and report. Short version:

Extract: 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.
Report: summary of information contained in the registry. Can be CTC data (incidence rates, etc) or registry operation data (monthly abstracts generated by abstractor). Would potentially include task lists (what still needs to be done).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Actual report/extract
(obtained from Location)
Type (=Standard)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Standard Report/Extract/RCF Formats

Description
Format information for a standard report or extract we expect to produce numerous times (like NM monthly reports) or a generalized report that satisfies many request (like SEER*Stat).
Includes report layout and data items included on the report or extract.

Examples
SEER*Stat
SEER*Prep
Incidence Survival
NAACCR Submission Reports
SEER Submissions (1st on List)
SEER Edits
Data Exchange – NAACCR Format
NCDB – NAACCR Format
NPCR – NAACCR Format
Edits – Internal
Annual Report – (by Registry)

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Format identifier (name, SEER submission, SEER*Stat, etc.)
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})

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Standard Transmitted Record Group

Description
See Transmitted Record Group

A transmitted record group that has arrived in a standard format. No pre-processing is needed before the record moves on.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Transmitted Record Group

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

State Regulations

Description

The registry's home state and its regulations regarding CTC data submissions.
The rules regarding what a facility/organization is required to send to the registry.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
Effective (start) date
End Date
Source of Rule (State)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …, conversion table, etc)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Status = Closed

Description

The status of a particular thing being tracked, in this case a abstract facility lead, follow-up query, follow-back request, follow-back query, information request, health records request supplemental records request.
In this case, the status is closed: completed or has been determined that it will not be responded to. Could still show up in searches.

Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
status
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Status = Purged

Description
The status of a particular thing being tracked, in this case a abstract facility lead, follow-up query, follow-back request, follow-back query, information request, health records request supplemental records request.
In this case the status is purged: has been closed for a registry specified length of time or manager wishes to clear the books of all tracking for this.
DESIGN NOTE: depending on registry desires, this could be removed from the database or left in as unavailable to standard searches.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
status
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Status = Not Purged

Description
The status of a particular thing being tracked, in this case a abstract facility lead, follow-up query, follow-back request, follow-back query, information request, health records request supplemental records request.
In this case, the status is something other than purged. For example, a search for things that are still open and things that are closed.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
status
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Status = Retry

Description
After an attempt at follow-up, follow-back, or abstraction has been unsuccessful, someone (management) determines that this attempt needs to be retried and possibly sent to a new destination.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Status
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Stripped Health Record

Description
A health record that has been stripped to retain only passive follow-up Data.
This version of the record is saved under the same Health record ID as the original record for data integrity.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
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 (will not be called this on the record: probably date of admission or date of discharge, etc)
Follow-Up Status (D)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Submissible Registry View Patient Set

Description

This “Submissible” status implies finalized (at the moment)/ analyzable/reportable
See Patient Set.
The registry view of the best information available for a patient set after it has been edited, recoded, given derived variables, ethnicity codes, census tracts and so on. The ‘seal of approval’ for this view.
The total best knowledge of the essential data items plus the fiddly bits that reporting agencies want (recodes, census tracts, etc)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Patient Set
Patient registry view Status: Submissible

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Submission ID

Description

The submission ID (assigned by the registry) for the submission that a particular health record belongs to.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Submission ID

Metrics

Frequency:
Volume:
Duration:

Quality/Error rate:

Submission Information

Description

Information about the submission to the Registry from a Data Source
Partly tracking of how/when data is entering registry, also can be used for checking for duplicates.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Transmission ID (Sender defined, some registries track & some don't)
Received From (Facility/Org ID)
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)
Type of Media
Status {Okay trans, Corrupted trans}

(The following repeat with each file that is part of the communication)
Submission ID (what the registry wishes to call it)
Received Data File identification (What the source called it, if anything)
Type of record received
Number of Records Received
Copy of File (for verifying duplicate submission if electronic)
Received multiple times (Either Y/N or Count of times received)
Date/Time processed
Registry Org Rep ID who processed

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Submission Notification

Description

This is sent to the facility or organization which sent the Health Record letting them know that the registry received their records, etc. (e.g., Received 140 abstracts on 1/14/01; also need to send list of IDs received so they can tell who is missing if the counts are off.)
NOTE: in BOM, the submission notification includes problems and questions, in the BPM, these are separate data flows.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Notification of receipt is about entire batch. Problems may be about a single record (the 5th record was blank), a group of records (These 20

records had no gender coded) or the entire batch (Race was coded as missing for all 100 record in the file, please resubmit). For more detail, go to the problem data flow.
DESIGN NOTE: Want to send a list of patients included in the submission back to the submitter. While this is a report generated by process 12.0, may want to include some kind of 'auto create' feature for it.

Sensitivity

Data Items (if a group data flow)

Submission ID (what the registry wishes to call it)
Received Data File identification (What the source called it, if anything)
Received From (Facility/Org ID – notification will be sent here)
Received Date
Type of record received (R1)
# of Records Received (R1)
Received By (Registry Staff ID – should be the person sending the notification)
Status {sent back/error, confirmation/got it, query (need more info), }
Text (any identifying file information, file name, file id number from hospital, etc. This is a text field because different sources probably have different ways of identifying things.)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Submission Problems

Description

Problems with the receipt of data from a Facility or Organization. This may be about a single record, a group of records or the entire file.

E.g. you sent bad data – rejected file– please correct and resend
E.g. you sent duplicate data (duplicate file)
E.g. Received 25 records, cover letter said 30 sent
E.g. Gender invalid in all records (from 13.3 or 13.6 processes)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Would like to track problems so can verify they have been resolved.

Sensitivity

Data Items (if a group data flow)

Problem description (text)
Records affected (text: 5th rec, these 20, entire file…)
Suggested response (text: resubmit the record(s), resubmit the file)
Date Problem Sent
Staff ID (to the attention of, so on)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Submission Questions

Description

Questions concerning the receipt of data from a Facility or Organization Related to entire file, such as 'What is the file lay out?' or 'What is the encryption key?'. Individual record questions would be handled as follow-back.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Would like to track questions so can verify that answers have been received.

Sensitivity

Data Items (if a group data flow)

Question description (text)
Date question Sent
Staff ID (to the attention of, so on)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Supplemental Record(s)

Description

Records which contain no information on the health status of a patient, purely personal data. This includes DMV, voters' registration and the like. These are used to validate name, address, SSN type of data as well as for follow-up dates.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Can sometimes be provided to a special study for controls. This has to be acceptable to the agency that produced the record.

Sensitivity

Data Items (if a group data flow)

(Exact data items depend of the type of supplemental record, but basically the flow is trying to represent all the data which was received by the registry as it was received may include some or all of the following)
Sent to Special study? {Y, N}
Type of record

Patient ID (from registry if sent)
First Name
Last Name
SSN
Street address
City
State (Canadian Province)
Postal Code (ZIP)

DOB
Date of contact (Coverage started or use – CMS, HMO; renewal or exam – DMV; filing – IRS; DODth – SSA; DOB (of child) – State/Canadian province of birth; voted or registered – Voters Reg)

Vital status at filing time – IRS only
City of Death – SSA death record
State/Province of Death – SSA death record

Date created
Document ID

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Supplemental Record ID

Description
A tag the registry adds to a supplemental record in order to make it easy to reference.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
(Supplemental) Record ID

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Supplemental Record Person(s) Information

Description
Information about any person, not necessarily a patient, as noted on a supplemental record. Ex: things in supplemental/auxiliary data, such as DMV data.
This may be used to confirm/complete information about a patient.
Includes “a.k.a.” info, demographic info (such as driver’s license), etc.
This is also used to generate controls for information requests (registry-controlled files)

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
First Name

Last Name
SSN
Street address
City
State (Canadian Province)
Postal Code (ZIP)
DOB

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Supplemental Record Request

Description

A request by the registry to an organization that provides non-health information. These are always general type requests.
Frequently, the registry must pay to receive this data.
If the file was paid for and the original request is not fulfilled, it must be re-requested.
This information is mostly used in follow-up, but can also be used to obtain better personal information for a patient and to help resolve matches.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(Supplemental) Record Request ID
Org ID
Staff ID (who made request)
Date (request was made)
Record type requested
From Date
Thru date
Payment amount (0 -> no payment)
Date due (If data not received by this time, check to see where it is)
Status {Open, Closed, Purged}
Comments
Date received
Staff ID who received

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Supplemental Record Request to be Closed

Description

See Supplemental Record Request
If the supplemental information requested has been received or the determination has been made that it will never be received, the corresponding supplemental record request needs to be closed.

If the file was paid for and the original request is not fulfilled, it must be re-requested.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Supplemental Record Request

Note: to be closed

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Supplemental Record Request to be Purged

Description

See Supplemental Record Request

A supplemental record request that needs to be purged from the tracking system. Usually a request that has been closed for a registry specified time. Is possible a manager would want to clear a request prior to that.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

DESIGN NOTE: depending on registry desires, this could be an actual removal from the database. Alternatively, it could remain but not be shown to standard searches.

Sensitivity

Data Items (if a group data flow)

See Supplemental Record Request

Note: to be purged

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Supplemental Record Request to be Resent

Description

See Supplemental Record Request

If a supplemental file that was paid for was not received, it must be re-requested. (To the same organization)

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Supplemental Record Request
Note: to be re-sent

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Supplemental Request Tracking Information

Description
The data items needed to track how supplemental data is entering the registry operations. Are organizations sending records when requested? So on.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Supplemental request ID
Staff ID (who made request)
Facility/Org ID (request was made to)
Date (request was made)
Record type requested
(time window for records)
From date
Thru date

Due Date (If data not received by this time, check to see where it is)
Payment amount
Source Submission ID (R1)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Terms

Description
What the registry and data exchange partner have agreed to.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
DEA ID

DEA Partner ID (Org ID or Fac ID)
Format for transfer of data (NAACCR96, XML, etc)
Type of record to send (abstract, ?)
Data items to send (probably text strings)
Start date of agreement
(End date of agreement – blank unless agreement voided)
Schedule for data transfer (monthly 1/1, 2/1, 3/1, …; quarterly 1/1, 4/1, 6/1, …)
Comments

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

This Year's Performance

Description
The number of records received so far from a particular facility

The number of records received so far from a particular facility or organization for the current time period.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
(from a report from RECORD)
Facility/Org ID
Time period (R1)
Type of record (R1b)
Number of records (R1b)
Number of duplicates (R1b)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Training Complete Date

Description
The date a new org rep's security, confidentiality and sensitivity training has been completed.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Training completion date

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Transmitted File

Description

A file that the registry has received from an external data source that contains patient information

This is an electronic file (disk, tape, ftp, etc) that has successfully entered the registry without appearing damaged. It appears to have the correct number of records of the expected type.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Submission ID (what the registry wishes to call it)
Electronic File of records

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Transmitted Record Group

Description

Records that have been sent to the registry and are usable. (They didn't get corrupted in transfer, the file wasn't a retransmission, got same # they said they sent.)

These records have undergone all pre-processing needed. They have been unencrypted, concatenated, and otherwise shaped into a usable format.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Depends on type of record (subtypes of health record, correction record and supplemental record). As many records as were in the submitted file.

Status=pre-processed (not a retained status)

Metrics

Frequency:
Volume:
Duration:

Quality/Error rate:

Treatment Matched Info

Description

The 2 (or more) data groups that were determined to be a positive match at the treatment level. The data groups could be incomplete patient set, existing patient set, or health record (including correction record, reportable or non-reportable). This information will be used in 'consolidation'.

DESIGN NOTE: the previously matched records and/or patient sets will be retrieved if needed.

Information related to the treatment.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See BOM entities: CONSIDERED TREATMENT MODALITY, PATIENT refuses CONSIDERED TX MODALITY, PROCEDURE (and all subtypes), COURSE.

It's likely that not all items will come in through this data flow, as some data items are derived or system based. The values from all data groups would be included

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Treatment Match Status (=No)

Description

Treatment match status: whether a match was found at the Treatment level for the data group in question.

Here, specifically no Treatment match was found for the given data group

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Match level (=Treatment)

Match status (with value set to no)

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Type of Follow-Up Expected

Description
Indicates the follow up tracking status for a Patient Set.
All of these values are derivable.

Interested Registries
Interested: NCCC
Not Interested:

Local Procedures

Policies/Business Rules
We want to keep history of these changes, especially to know CTCs not originally in Active Follow Up but now in Active Follow Up.

Sensitivity

Data Items (if a group data flow)
Type code (derivable) {Dead – no follow up, Active Follow Up, Active CTC but no Follow Up (in situ cancer of the cervix uteri only)}

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Type of Follow-Up Letter Sent

Description
The specific type of letter that was sent in conducting Active Follow-Up
Letter to physician, letter to patient, letter to informant…

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
May want to allow registries to add values to this.
They could want to track which form letter was sent.

Sensitivity

Data Items (if a group data flow)
Type of letter {physician, informant, …} (this is a sub-group of type of follow-up action and will probably be combined)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Type of Follow-Up Query

Description
Type of follow-up action that was selected for this patient for this follow-up event (e.g., sending a letter, making a phone call, making a visit)

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Type of action {letter, phone call, visit}
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Type of Last Follow-Up Letter Sent

Description
The last type of letter that was sent in the name of Active Follow-Up Letter to physician, letter to patient, letter to informant…
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Type of letter (this is a sub grouping of type of follow-up action)
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Type of Last Follow-Up Query

Description
Type of follow-up query that was selected for this patient for preceding follow-up event. (e.g., sending a letter, making a phone call, making a visit)
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Type of Action {letter, phone call, personal visit, etc}
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Unassigned Census Tracts

Description
Results when no census tract was assigned to an address. This usually means the address is not standardized or it is new (post census) and so not marked in the census files.
Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Patient ID
Street address (number, name)
Street side
City
State (Canadian Province)
Postal Code (ZIP)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Uncertain Census Tracts

Description
Results when an address is not clearly within a census tract and therefore the certainty code is 'too low'

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
Too low for certainty codes is defined by the registry.

Sensitivity

Data Items (if a group data flow)
Patient ID
Street address (number, name)
Street side
City
State (Canadian Province)
Postal Code (ZIP)
Census Tract
Census Tract Coding System
Census Tract block group
Census Tract Certainty Code (< Acceptable Certainty Level)
Latitude
Longitude

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Unmatched Correction Info

Description
The information contained on a Correction Record for which there is no patient match, no facility match and possibly no CTC match (depending on data items included) at the time received.
This may happen if the correction record comes in before the actual record that it is a correction to.

This will establish an abstract facility lead.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

These are kept and used in the 4.0 Match processes

Want the ability to proactively seek the information (i.e. abstract) that is being corrected. Although current parlance calls said seeking "follow-back," it's now modeled as generic abstraction, via creation of an Abstract Facility Lead. Would definitely need to have time lag available to set (may want to wait x amount of time prior to actually doing conduct abstracting because of the correction record). Time lag is easily handled with scheduling criteria for abstracting, given that Abstract Facility Lead has enough info.

Sensitivity

Data Items (if a group data flow)

Facility ID

Patient ID

CTC ID (?)

(Data Item Name, Old value, New value, Reason are items on the record, but shouldn't be needed to do the match.)

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

Unmatched Follow-Up Info

Description

The information contained on a Follow-Up Record for which there is no Patient Match, no facility match and possibly no CTC match (depending on the data items included) at the time received. See Follow-Up Record in the BOM text for additional information.

This may happen if the follow-up record comes in before the actual record that it is a follows up about.

Interested Registries

Interested:

Not Interested:

Local Procedures

In NM, a follow-up abstract may be acceptable if there is no facility match, if and only if a sibling facility abstract has been received.

Policies/Business Rules

These are kept and used in the 4.0 Match processes

Sensitivity

Data Items (if a group data flow)

Facility ID

Patient ID

CTC ID (?)

Date of Last Contact

Vital Status

(Additional information – could be a full abstract, could be additional treatment information. Seems to vary by facility and method of obtaining follow-up at facility)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Unmatched Health Info for Passive FUP

Description

If the health information is undergoing 4.0 Match and Consolidate Patient Set Info purely in the name of passive follow-up and no patient match was found, the information exits the process.
This information may reenter the process after it has been screened, but because of the time involved and the desire to improve follow-up information as soon as possible, registries may choose to send the records as soon as they complete 13.0

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Health record
Only things of true interest were:
Patient ID
Name
SSN
Date of Birth
Sex
Race
Date of Contact
Vital Status at contact

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Unmatched Health->Lead Info

Description

Some health records (see BOM Type of Record) do not become patient sets, they only become abstract facility leads. This is because they typically do not contain enough data to form a viable patient set.
Health records which become patient sets may also be used to spawn abstract facility leads based on the match statuses, previously obtained record types and local policy. This NEVER includes Abstracts.
The information contained on a health record (as above) for which there is no patient match, no facility match and possibly no CTC match (depending on data items included) at the time received.
This will establish an abstract facility lead.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Facility ID
Patient ID
CTC ID
Health Record ID
(other data items aren't needed to create the lead)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Unmatched Non-CTC Rpt

Description
Non-reportable CTC information that has not matched to anything. This information exits this process, although it remains in the registry data.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
(All data items on record and corresponding converted values)
See health record
See Converted ICD Codes and Keywords
See Additional Disease Codes and Keywords (DC only)
Status: Non-reportable

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Unmatched Supplemental Info

Description
See Supplement Record
Supplemental information that has not matched to anything. This information exits the process, but remains in the registry data for future use.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Supplement Record

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Unresolved Follow-Back Need Status

Description

Open follow-back need (either didn't receive a response or response didn't fulfill need)
Would also include instruction about next action to take

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

(Follow-back need) Status=unasked or unanswered
Unresolved follow-back need instruction {first attempt; resend; resend with rephrasing; redirect} (probably not stored)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Unresolved Information Request Problem

Description

See Information Request Problem
A problem with an information request that has yet to be resolved
Since a valid Resolution is that the registry chooses not to 'fix' the problem, all information request problems should be closed eventually.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Information Request Problem
Status {Reported Problem}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Access Information

Description

For any particular org rep, the access they are allowed; which processes can they initiate, what data can they view, what data can they change.

This is information that has been changed from the original settings

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Process ID (R1)
Process Access? (R1) {Yes, No}

Data Table ID (R2)
Data Item ID (R2)
Data Access? (R2) {None, Read only, Read/write}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Active Follow-Up Need

Description

Updated information about the need to obtain more recent patient's date of last contact information.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Patient ID
Date discovered

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Address at Diagnosis

Description

See address at diagnosis.
After an attempt to assign the census tract code, the registry may determine that the address at diagnosis had an error and they would attempt to correct it (either fix a typo, do follow-back)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Street address (name and number)
Street side
City
State (Canadian Province)
Postal Code (ZIP)
County

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Copy of Health File

Description
The modified copy of the health file saved at the time received for archive purposes. Any records which failed the broad screen have been removed from this copy and likely replaces with a check number of some kind (so duplicate submissions can be found).

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Copy of health file

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Database Structure

Description
When a change is made to the tables within the database, the new structure must be added to the Live and Backup databases.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
??
New Table
Data item within table (R1)
Data item description (R1, string, int, etc; other settings needed by the db).

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Data Mart

Description

A data mart that has been filled with the most current data
The first time, this would not replace anything, but successive times would replace the older version of the data mart with current information.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Varies by Data Mart Specifications

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Data Mart Specifications

Description

Data mart specifications that have been modified at the request of the end user.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Data mart name
Timing of desired updates
Data items needed
Structure desired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Updated DEA

Description

Data Exchange Agreement information that has been modified in some way.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

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 – blank unless agreement voided)
Schedule for data transfer (monthly 1/1, 2/1, 3/1, …; quarterly 1/1, 4/1, 6/1, …)
Comments

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Facility Info

Description

See facility information
New information may be received about a particular facility or information about a new facility may be received. It must enter the Org. Facility & Medical Practitioner Profile data store.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Facility Information
Status: new or Update

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Follow-Back Need

Description

Updated information about a registry identified problem that requires contact with the source of information. (follow-back need)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Follow-back need ID
Process which sent follow-back request
Staff ID Who sent follow-back request
Date of follow-back request
Source type {HRec, Pat, CTC}
Source ID
Data item (R1)
Data Item Value (R1) (includes unknown)
Follow-back Reason (optional to each request)
Action needed (part of instructions, may be text field or possibly multiple setting flag.)
Disposition process (part of instructions, the process waiting for the Follow-Back response. For Example: Resolve Possible Patient Match, Create Follow-Back Query, … May be better to have broader process names here. Screening, Matching, Abstraction, Consolidate, Polish, Follow-up, Follow-back, Receiving, Reporting, Editing, Special Study)
Send response to (Staff member)
FB Need Status
Org rep Assigned to
Date Assigned
Urgency {standard, high}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Follow-Back Query Tracking Information

Description

See Follow-back Query Tracking Information
The tracking information for the current outgoing query. A single follow-back request may generate multiple queries and each query would have tracking information.
Data items which allow the follow-back queries to be tracked over time in case of problems and to aid in future decisions about who to direct follow-back to.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Follow-back query ID
Staff ID who sent Follow-back Query
Date Follow-back Query sent
Medical practitioner/facility/org follow-back query sent to
Related Follow-back Need ID (R1)
Status

Metrics

Frequency:
Volume:

Duration:
Quality/Error rate:

Updated Follow-Up Info

Description

Updated information that tells if patient is dead or alive and the date of that knowledge. Also, cause of death if patient died.
This information is added to the patient set: registry view, patient level.
Depending on source of follow-up information, a facility view patient level may also be updated.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Date of Last contact
Vital Status
Cause of Death
Source of information {org ID, Facility ID, other} (to know which views to update)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Follow-up Tracking Information

Description

Data items which allow the responses to follow-up to be tracked over time in case of problems and to aid in future decisions about which follow-up method to use.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Follow-up Need id
Staff ID (who evaluates the response)
Date Response Received
Useful response? (date later than current) {Y, N}

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Medical Practitioner Info

Description

See medical practitioner information

New information may be received about a particular medical practitioner or information about a new medical practitioner may be received. It must enter the Org. Facility & Medical Practitioner Profile data store.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See Medical Practitioner Information
Status: new or Update

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Meta Data About Table

Description

Data that has been modified to reflect the new structure of data within a table. This includes data items are include in a table, what types those items are, any formats or edits that apply, etc.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Data item name
Data item ID
Location of data item
Type (string, int, float, etc)
Constraints (R1)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Organization Info

Description

See organization information
New information may be received about a particular organization or information about a new organization may be received. It must enter the Org. Facility & Medical Practitioner Profile data store.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Organization Information
Status: new or Update

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Password

Description
The password attached to an account within the registry.
This is a updated password chosen by the org rep or IT manager to replace the original one being stored.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
Password

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Patient Data

Description
Data from follow-back that has been incorporated into the patient set

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
(part of ACD)
Updated Data Item Value

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Updated Patient Set

Description
See Patient Set

A patient set that has changed from the last time it was accessed.
In 16.0, specifically a patient set that needs to be provided to a field staff member and has been changed since the last time they performed this task (compare date last updated to latest ACD date.)

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Patient Set

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Valid Correction Record

Description
See Correction Record.
A correction record which has passed the data checks to this point. Record is readable, follows expected record layout and data item formats provided by source.
It is now ready to be converted.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See correction record
Status flag set to ‘Valid record’

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Valid Health Record

Description
See Health Record
A health record which has passed the data checks to this point. Record is readable, follows expected record layout and data item formats provided by source, does not appear to have wide spread problems (entire sections blanked out and so on).
NOTE: Since no conversion has taken place yet, the health record includes unconverted text, codes, etc.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See health record
Status flag set to 'Valid record'

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Valid Patient Set

Description
See Patient Set
A patient set which has passed quality control checks on the consistency of text information to coded values in the data items.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
See Patient Set
Status: valid from QC

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Valid Patient Set Data Item

Description
A data item which passed its field edit and is going to the inter-field edit process.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)
(this information is temporary, status is only saved if it's invalid)
Data item name
Data item value
Status {Valid}

Metrics
Frequency:

Volume:
Duration:
Quality/Error rate:

Valid Request Status

Description

This request has passed the local, State and Federal rules. It is legal and acceptable to fill the request and it may proceed through the 12.0 process.

More of a trigger than a data flow. This status kicks off the next process, but is probably not necessary to do the next process.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Status (=Valid, Pending Documentation, Rejected)
IRB ID (R1)
Collaboration agreement ID

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

Valid Supplemental Record

Description

See Supplemental Record

A supplemental record which has passed the data checks to this point. Record is readable, follows expected record layout and data items formats provided by source, does not appear to have wide spread problems (entire sections blanked out and so on).

NOTE: Since no conversion has taken place yet, the supplemental record includes unconverted text, codes, etc.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

See supplemental record
Status flag set to ‘Valid record’

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

<DATA FLOW NAME>

Description

Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Data Stores

NOTE: Some of the "data stores" that follow may be better considered as "data flows" or "external objects". They haven't been analyzed in much detail.

Abstraction Criteria

Description

Rules which specify which leads and records need to have abstract produced. Policy driven.
How 'old' is the cancer/tumor/case (6 mth or older: waiting period for treatment) – may result in 'abstracted needed, delay until date' type status.
Can an abstract be obtained from this facility?
Was an abstract already received for this patient, CTC, facility? (don't want to duplicate work)
Does this CTC have rapid case ascertainment priority? (collect info within a month of diagnosis)
Is patient still alive (best knowledge)

Also affected by 'how often is facility visited' – may do partial abstract with note that it must be re-examined later.
If all abstracts on task list have been collected, would then start on other leads – either the ones collected during the current trip or the ones slightly younger than 6 months. (would document need to re-examine).

LA: these are stable
HI: varies around Feb 1st, (temporary variance) Would be nice to know how old lead is.

Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules
Registries will have to be able to add and update the Abstraction Criteria.
Sensitivity

Data Items (if a group data flow)
Text of rule (ie Criteria for when a case should be abstracted)
Source of Rule (SEER, NAACCR, State,…)

Effective (start) date
End Date
Supporting tables
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}

Metrics

Frequency:
Volume:
Duration:

Abstract Facility Lead

Description

Information about abstracts which the registry expects or needs to receive. Can be discovered through Referred to/from notations from other facilities, special study gained information, DC information, disease indexes and other case finding tools. Could also be discovered in correction record comes in but matches to nothing. May be mentioned in a special study communication.
Need good management to be able to 'close' leads when new information comes in, even though in may not come in through Conduct Abstracting.
Also storing an audit log for changes made to AFLs (IA and HI interested)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Abstract Facility Lead ID (for tracking)
Patient ID (Assigned by registry)
CTC ID (Registry, sequence?)
Health Record ID
Facility ID
Source (text, disease index, referred from re hosp xyz)
Org Rep ID who entered
Date lead created
Abstract to be done by? {Registry, Org Rep ID if assigned, Facility}
Date Abstract Requested
Org Rep ID who requested
"Do Not Abstract Before" date (if lead arrives within month of diagnosis, registry may wish to wait to pursue obtaining the abstract.)
Date lead closed (date abstracted, abstract received or reason not abstracted provided – date attempted)
Reason lead closed {Abstract received, not abstractable} (derived)
Reason not abstracted (text)
Facility Staff ID (who provided reason not abstracted)
Org Rep ID who abstracted/provided reason (registry staff)
Status {On hold, Requested/Assigned, Received/Closed, Closed/Other, Purged}
Comments

From History of change:
Org Rep ID (R1)

Date of change (R1)
Old Value (R1)
New Value (R1)
Reason (text field, why was this made) (R1)

Metrics

Frequency:
Volume:
Duration:

Access Attempts

Description

The information about attempts to access a registry's system. This includes successful and failed attempts.
This information is periodically reviewed to check for hacker hits.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

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

Metrics

Frequency:
Volume:
Duration:

Access History

Description

Information about when a user logged on, logged off and what processes they accessed during that time.
May be best to have Process information repeating within a log-in/log-off window.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Account
IP address
Date of log-in (successful only)
Time of log-in
Date of log-off (successful only)
Time of log-off
Log-off type {Normal, Inactive, System}

(not sure if these will meet need)
Process ID
Date initiated
Time initiated

Metrics

Frequency:
Volume:
Duration:

American Joint Committee on Cancer (AJCC)

Description

American Joint Committee on Cancer: Staging guide.
Site-specific TNM staging system for physicians, with designations for the CTC, Nodes, and Metastasis.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

By Site:

Text of rule (ie Staging rules for specific site)
Effective (start) date
End Date
Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …, conversion table, etc)

Metrics

Frequency:
Volume:
Duration:

Auxiliary & Look-up History

Description

Audit trail for changes made to any of the auxiliary files.
Auxiliary files currently include: FACILITY, ORGANIZATION, ORGANIZATION REPRESENTATVE, MEDICAL PRACTITIONER, MEDICAL PRACTITIONER FACLITY AFFILIATION, RULE, PERSON, PAYER SOURCE
Look-up tables currently include: 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.

Interested Registries

Interested:
Not Interested:

Local Procedures

IA, HI, NM, LA are interested in the auxiliary file tracking
IA, HI are interested in the look-up table tracking

NM, LA may be interested in the look-up table tracking if they consider it to be auxiliary.

Policies/Business Rules

Sensitivity

Data Items (if a group data flow)

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

Metrics

Frequency:
Volume:
Duration:

Backup DataBase

Description

A copy of everything in the database stored for recovery purposes.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

All!

Metrics

Frequency:
Volume:
Duration:

CTCs Requiring Abstracts

Description

Temporary data store for all CTCs that require abstracting at this time. After the abstract facility leads are reviewed, those which need to be handled are stored here until the work load can be delegated.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Abstract facility lead ID

Metrics

Frequency:
Volume:
Duration:

Census Tract Data

Description

Data based on the U.S. Census Bureau's system of assigning location codes to addresses. This coding scheme tries to break areas into socio-economically similar groups as well as geographically contiguous areas.
List of addresses (street number, name, possibly side of street, city, state) and the corresponding census tract.
These codes change every 10 years when the Census data changes.
Registries would like to build file of all addresses associated with each particular census tract code.

Interested Registries

Interested:
Not Interested:

Local Procedures

Some registries use the Tiger File.
Some registries outsource this (ex: Atlanta).
New Mexico has its own file.
NJ: suggested that it would be nice to be able to share among the registries.

Policies/Business Rules

Sensitivity

Data Items

Street address (number, name)
Street side
City
State (Canadian Province)
Postal Code (ZIP)
(May be returned if originally provided to the census data source)
Name of Facility (prison, nursing home, homeless shelter, etc)
Apartment number/floor
County

Census Tract (R1)
Census Tract Coding System (R1) {1970, 1980, 1990, 2000}
Census Tract Certainty Code (R1)
Census Tract block group (R1)
Latitude
Longitude

Metrics

Frequency:
Volume:
Duration:

Collaboration Agreements

Description

All documentation about collaboration agreements are stored here.
This would include signed copies of the agreement.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Actually getting the collaboration agreements needed for a special study is probably out of scope of this system (done when special study contract is being created). However the registries will most likely wish to store this information for legal purposes

Sensitivity

Data Items

Collaboration Agreement ID
Special Study ID or Information Request ID (Obtaining IRBs for special studies is somewhat outside scope)
Organizations/Person's Name
Date proposed Collaboration agreement sent
Collaboration agreement document
Date collaboration agreement received
Signed? {Y, N} (replace unsigned copy with signed)
Staff id who received collaboration agreement

Metrics

Frequency:
Volume:
Duration:

Collaborative Staging Guide

Description

Collaborative staging guide, agreed upon by a joint committee. It attempts to create a staging system that all groups can agree to and will be consistent across all data.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

By Site:

Text of rule (ie Staging rules for specific site)
Effective (start) date
End Date
Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …, conversion table, etc)

Metrics

Frequency:
Volume:
Duration:

Comparison Results Info

Description

Used during consolidation process to store information about how likely it is that they really have a good match. If the comparison score becomes unacceptable, they can abort consolidation and go back and select another match or decide that there is no match.
For each item, information includes did item match, severity of difference, and a cumulative score measuring how well data is matching up to this point.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

DESIGN NOTE: I don't believe this has to be permanent – just during the actual consolidation process.

Sensitivity

Data Items

Data item name (R1)
Comparison results {match/no match} (R1)
Severity of difference (if possible) (R1)
Comparison ratio (number of matches/number of data items) weighted by severity if possible.

Metrics

Frequency:
Volume:
Duration:

Conversion Rules

Description

Where the rules concerning how to convert data items related to disease to desired format or coding scheme are stored. May also wish to include a list of words or phrases of interest to the registry
Conversions are usually between different revisions of ICD or ICD-O. This most likely will take the form of a look-up table a computer can use.
For converting a hospital specific coding scheme to registry standards, this could be a look-up table, but would have to be constructed by registry staff as new coding schemes are developed by hospitals.
For deciphering text, this is likely some sort of manual, although some of this can probably be mechanized.
DESIGN NOTE: These are not all simple rules. Some rules would be strictly M=1, F=2, etc. Others may have to look at multiple fields to determine the correct value. For example, if a single group sends in records from multiple facilities, would need to determine where record came from before choosing correct values.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
(below are specific for converting)
Data item name
Incoming coding scheme
Desired coding scheme
Effective (start) date
End Date
Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER

Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …, conversion table, etc)

Metrics

Frequency:
Volume:
Duration:

Data Exchange Agreement

Description

An agreement that the registry has entered into with some other organization. It states that the registry will send information that is of interest to the other organization in return for information of interest to the registry being sent to them.
Only sending information to other groups authorized to receive such information.
Agreement may state which patients, what kind of information and so on. For example, state registry agrees to exchange information with surrounding states' registries so that patient sets are directed to the appropriate registry by residency.
Last until otherwise stated.

Also includes audit trail for changes made to the agreement.

Interested Registries

Interested:
Not Interested:

Local Procedures

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.

Policies/Business Rules

DESIGN NOTE: would be nice if the sending of records to data exchange partners could be automated (quarterly) so that information is sent out with minimal staff interaction.

Sensitivity

Data Items

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
Both of the above could include:
Site codes
Hist codes
Dates of Dx
Residency

Format for transfer of data (NAACCR96, XML, etc)
Type of record to send (abstract, ?)
Data items to send (probably text strings)

Start date of agreement
(End date of agreement – blank unless agreement voided)

Schedule for data transfer (monthly 1/1, 2/1, 3/1, …; quarterly 1/1, 4/1, 6/1, …)
Comments

Source Submission ID (R2 – what fulfilled DEA)
Information Request ID
Date fulfilled (R3 – when latest data sent to exchange partner)

Org Rep ID (R1)
Date of change (R1)
Old value (R1)
New value (R1)
Reason (text field, why was this made) (R1)

Metrics

Frequency: HI: 15-25; LA: 7 CA regions, 2 states; IA: 13 neighboring states; AT: all neighboring states (5?)
Volume:
Duration:

Data Mart

Description

Structured replicated data based on specifications
Data is stored this way so that the data can be accessed in a static arena which will avoid slowing down the live database processing.
This method can be used for any data needs where some time delay is allowable. These could be recreated every night, so the data would not be overly old.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Varies by data mart

Metrics

Frequency:
Volume:
Duration:

Data Mart Specifications

Description

Stored description of all desired data marts that the system understands and can apply without human intervention

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Data mart name

Timing of desired updates
Data items needed
Structure desired

Metrics

Frequency:
Volume:
Duration:

Edit Issue Tracking Information

Description

Information that allows the registry to A) track edit issue discovery, B) track which edit issues have been resolved.
Information is stored here only when an edit issue is discovered.
DESIGN NOTE: Registries may not wish to store edit issues that are 'discovered' during consolidation or 18.1 Compare and Resolve Text to Codes. Since data is changing as the staff member is working, they may 'create' edit issues that will be resolved before the person considers themselves to be 'finished'. They may prefer to only track issues in these processes if the user requests editing, not the process.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Patient ID / Health Record ID
Date edit issue discovered
Org Rep who discovered
Edit issue (R1 – description of problem or edit name)
Data item involved (R1a – there are multiple items for inter-field edits)
Facility Error? {Y, N}
Status (Resolved Org Rep; Resolved Follow-back; Pending follow-back, Open, Related data set deleted)
Date resolved
Resolution
Override ID/Health update ID/ACD ID

Metrics

Frequency:
Volume:
Duration:

External Org Rep Data

Description

List of people external to the registry staff who have been granted access to a registry controlled file.
Contains security information such as account, password and access information.
This allows the registry to track who has access to the different files and to terminate access if they feel the information is being misused.
Each file may have several users, each user may be able to access several files

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Name
Phone number
Comments
Registry Controlled File ID (R1)
Training completion date (R1)
Account
Password
Status {Open, Closed} (would be closed if employee leaves)

Metrics

Frequency:
Volume:
Duration:

Facility and Registry Patient Set Differences

Description

The differences between Data Item Values on the Data Source's (Facility or Organization) Original Abstract and the Registry's current Patient Set
OR
The differences between Data Item Values on the Registry's current Patient Set and the Last Patient Set Snapshot that was sent to the Data Source (Facility or Organization).
Confirmation of modifications the facility has notified the registry of and updates/additions to the data that the facility is allowed to know. For example, Death Certificate information is public knowledge, but a second CTC that this facility has not seen would not be allowable.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Facility ID
Accession Number (Facility's Patient ID)
Name of data item (R1)
Old value (R1)
New value (R1)
Reason for change (e.g. Age, 54, 55, DOB incorrect re DMV) (R1)
Date of Change (R1)
Date sent (R1)
Date Accepted (R1)

Metrics

Frequency:
Volume:
Duration:

Facility View Snapshot

Description

See Patient Set
After sending an update to a facility, the snapshot is the historic picture of what information was known at the time of the update so that future updates don't repeatedly notify a facility about the same modifications to the data.
DESIGN NOTE: Although this says facility view, it is really the view sent to the facility, which may be the registry view. The registries would like to send the registry view information (because it's the best), but may be forced to send the facility view because of legal issues.

Interested Registries
Interested:
Not Interested:

Local Procedures
Some registries merely send differences, others send the entire snapshot.

Policies/Business Rules

Sensitivity

Data Items
See Patient Set
Status = Consolidated (or better)
Facility ID (that snapshot was taken for)
Date of Snapshot

Metrics
Frequency:
Volume:
Duration:

Follow Back Tracking Information

Description
Data items which allow the follow-back queries and responses to be tracked over time in case of problems, future confusion about the response, and to aid in future decisions about who to direct follow-back to.
Also includes audit trail of changes made to follow-back needs.

Interested Registries
Interested:

Local Procedures
Not Interested:

Policies/Business Rules

Sensitivity

Data Items
Follow-back need ID
Process which sent follow-back request
Staff ID Who sent follow-back request
Date of follow-back request
Source type {HRec, Pat, CTC}
Source ID
Data item (R1)
Data Item Value (R1) (includes unknown)
Follow-back Reason (optional to each request)
Action needed (part of instructions, may be text field or possibly multiple setting flag.)

Disposition process (part of instructions, the process waiting for the Follow-Back response. For Example: Resolve Possible Patient Match, Create Follow-Back Query, … May be better to have broader process names here. Screening, Matching, Abstraction, Consolidate, Polish, Follow-up, Follow-back, Receiving, Reporting, Editing, Special Study)
Send response to (Staff member)
FB Need Status
Org rep Assigned to
Date Assigned
Urgency {standard, high}

Follow-back query ID (R1)
Staff ID who sent Follow-back Query
Date Follow-back Query sent
Medical practitioner/facility/org follow-back query sent to
Method of query
Staff ID (who received/resolved)
Date received
New Data Item Value (R1)
Supporting Text (optional per resolution, who answered question, any reasoning behind answer, etc)
Record ID
Query Status

Org Rep ID (R3)
Date of change (R3)
Old Value (R3)
New Value (R3)
Reason (text field, why was this made) (R3)

Metrics

Frequency:
Volume:
Duration:

Follow-up Tracking Information

Description

Information that allows the registry to A) track whether follow-up actions have been responded to, B) track which follow-up actions have already been tried this time for this patient, C) track which follow-up actions have been successful in the past for each patient.
Also includes audit trail of changes made to follow-back needs.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Follow-up Need ID
Patient ID (assigned by registry)
Date discovered
Status {Open, letter sent, closed, purged}
Date follow-up action
Type follow-up action
Who was contacted

Copy of communication
Staff ID who sent
Date response received
Useful response? (date later than current) {Y, N}
Date of last contact
Vital Status
Cause of Death
Source of information {org ID, Facility ID, other} (to know which views to update)
Staff ID who evaluates
Follow-back need ID (R2 – if sent at the same time)

Org Rep ID (R1)
Date of change (R1)
Old Value (R1)
New Value (R1)
Reason (text field, why was this made) (R1)

Metrics

Frequency:
Volume:
Duration:

Health and Supplemental Record Data

Description

This includes records with health related information (Health Record Data) and non-health related information (Supplemental Record Data). Includes data items found on the records, recoded, converted data items and keywords attached to the record, residency information based on info in the record, tracking information such as statuses, special study ids that the record has been included in, type of record and Record ID assigned by registry.
Potential statuses include acceptable, reportable, non-reportable
Supplemental record data is not health data, but other data where demographic and contact data is used. It is semi-permanent.
Supplemental record information is “person” information, not “patient” information.
Supplemental record information contains the following record types: DMV Records, Voters’ Registration, Census Tract, CMS (HCFA) file, Newspaper, Insurance Demographic Information (HMOs)
Health Record Data is “patient” information and includes the following types of records:

1. **Abstracts:**
   - Hospital Abstract (Complete/Initial Abstract, Follow-Up Abstract)
   - Follow-Up Abstract
2. **Case Finding Source:**
   - Autopsy Report
   - Cytology Report
   - Hematology Report
   - Indian Health Services (IHS) Record
   - Oncology Report
   - Path Report
   - Radiology Report
   - Radiotherapy Report
   - Special Study record
   - Death Certificate/State Death file
   - Disease Index (List)
   - Hospital Discharge File (List)

National Death Index
Surgery Log (List)
Correction Record
Follow-up Record

Obituary (Newspaper – follow-up only)

3. **Supplemental:**
   DMV Record
   Voters Registration
   Insurance Demographic Information (HMO)
   CMS (HCFA) File
   SSDI – Social Security Death Index
   IRS records
   State birth record

Interested Registries

Interested:
Not Interested:

Local Procedures

Some registries keep supplemental data long term, some don't.

Policies/Business Rules

Sensitivity

Data Items

Depends on record: exactly which data items come directly from that,
Acceptable (Health, Supplemental, Correction) Record
Record ID
Date Created
Document ID
Type of Record
Scanned Image (only for records that arrived as paper)
See Converted ICD Codes and Keywords
See Additional Disease Codes and Keywords (DC only)
See Residency Information
See Converted Other Codes and Text per Special Study
Status flags (R1) {acceptable, non-reportable, reportable, incomplete, follow-back pending}
Sent to Special study? {Y, N}
Special Study ID (R2)
Special study potentially reportable {Y, N} (R2)
Reason(s) for Non-Reportable Special Study (R2)
Reason(s) for Non-Reportable CTC
Received multiple times (Either Y/N or Count of times received)
Follow-back Need ID (R3)

(Update tracking)
Data item changed (R4)
Old Value (R4)
Updated Value (R4 - to what)
Org Rep ID (R4 – who changed)
Date/Time (R4 - when changed)
Facility Counted Error? {Y, N} (R4)
Reason Code (R4 - Categorical: Converted to standards, Converted Up version, Converted Down version, Correcting mistake, applying follow-back, etc)
Comments/Reason for Update (R4 - Why changed)
Date of Notification (R4)

Metrics

Frequency:
Volume:
Duration:

ICD-O

Description

The ICD-O coding manual that the registry is currently considering standard. (International Classification of Diseases for Oncology) Used for Histology, Site and Behavior. (Morphology)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

We are currently on 2 headed towards 3.

Sensitivity

Data Items

(This may be best implemented as a giant table with meta data 'ICD-O-3 coding doc, effective 1/2003, per WHO, scanning by computer, clarification by human)

Text of rule (ie what code is assigned to a particular text string)
Effective (start) date
End Date
Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables:
Histology code
Text description of hist code

Site code
Text description of site code

Behavior code
Text description of behavior code

Metrics

Frequency:
Volume:
Duration:

ID Problems

Description

Contains tracking information for registry discovered ID problems. These problems include duplicated ID assignments (2 people with same number) as well as skipped numbers (registry has 1-10, but is missing 7).
Resolutions should also be maintained here.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Facility ID/Org ID
Problem ID (assigned by computer)
ID (ID assigned by facility that is in question)
ID type {Accession, slide, etc}
Problem Type {Duplicate, Skip}
Date discovered
Date resolved
Resolution (text)
Status

Metrics

Frequency:
Volume:
Duration:

Information Acquisition Tracking Information

Description

Information about who is supposed to be sending the registry information, on what schedule and how many records/patients they expect (this is an estimate usually based on past performance) for tracking purposes.
Tracking of what information the registry has received.
Would also track requests that have been made and whether or not they have been fulfilled. This includes general records requests (please send all abstracts) and specific records requests (requests for Death Certificates by number based on the death file/list/index).
Failsafe to ensure that abstract facility leads don't fall through the cracks and that all specific requests are met or reasons are given for no response.

This information would periodically be managed to assess if requests were fulfilled. It should be checked against as records are received in '13.0 Confirm Receipt of Records'

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

(Health) Records Request ID
Staff ID (who requested)
Facility or Org ID
Date request made
Due Date (derivable based on request date and registry standards)
Status {open, close/filled, close/other, purge}
Comments
Fulfilling Health Record ID (R1)
Fulfilling Source Submission ID (R1)

Type of request {specific, general} (in BOM these are separate entities)
For general request:

Record type requested (path reports, disease index, abstracts)
From date
Thru date
For specific request:
Type of record requested (follow-back, abstract, etc)
Number requested (Derived: number of specific requests in same letter)
Abstract Facility Lead ID
Health Record ID
Patient information (from record, may be name, ssn, etc)
CTC information (from record, may be site, hist, etc)
Document number (from record, for example a DC number)

Metrics
Frequency:
Volume:
Duration:

IRBs

Description
All documentation about the results of each Institution Review Board decision are stored here.
Each facility affected by a Special Study or Information Request that involves privacy concerns needs to be noted.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
The IRBs obtained by special studies are out of registry scope as far as requesting the approval, however, the registry will probably wish to store the results for legal purposes.

Sensitivity

Data Items
IRB ID
Special Study ID or Information Request ID (Obtaining IRBs for special studies is somewhat outside scope)
Facility ID (whose IRB)
Date IRB approval requested
Status {pending, approved, denied}
Org Rep ID (who reviewed) (R1?)
Date Reviewed
Date approved
Comments

Metrics
Frequency:
Volume:
Duration:

Live DataBase

Description
Everything in the database. It's listed this way because the processes involved access or affect the entire database.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items
All!
Metrics
Frequency:
Volume:
Duration:

Local Rules Manual

Description
From the specific registry, how to properly code different data elements required by non-SEER obligations. Includes which elements needed, acceptable codes and meaning of codes.
Rules about what makes a cancer/tumor of interest and guidelines about how to summarize the information found on the medical records as well as what information (variables) are required.
Needs to include rules for current on-going special studies: criteria for inclusion, data items needed, how to code, dates of study.
DESIGN NOTE: needs to be easy to change this data store.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Data Items
Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
Effective (start) date
End Date
Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …, conversion table, etc)

For local standards:
Data item name
Data item format (R1 – acceptable codes, or set up – phone numbers have (3digits)-3digits-4digits.)
Data item value meaning (R1 – text translation)

For Special Study (R2):
Criteria for inclusion (R2A)
Spec Study Data item (R2B)
Spec Study Data item format (R2B)
Spec Study Data item value meaning (R2B)
Start Date of Study (R2)
End Date of Study (R2)

Metrics

Frequency:
Volume:
Duration:

Match Criteria

Description

Rules used to determine matches. Which data items are used, how to score data items, how to calculate overall score, level of overall score which can be considered a positive match with no review (95%, 100%) The match criteria for any particular data item in any given run is affected by the availability of the data item and the amount of missing values for the item.

Patient: Name, DOB, SSN, Gender (fields that are matched on)

DESIGN NOTE: registries would like to standardize this. More standardized methods within and across registries would allow more sophisticated algorithms to be created and maintained. The implementation of these standards would have to be flexible: not every matching run has the same data items available; different weights may be associated with the data items for each run; different rates of surety may be acceptable for different runs. Please note, sometimes matching is run during the generation of a report/extract and different data items are desired as output.

Interested Registries

Interested:
Not Interested:

Local Procedures

NM: Name – weight affected by how common it is. Equivalent names (William vs bill) and Soundex names are considered. Middle initial matches first name type matches, aliases and maiden names are considered.
NM: DOB – exact match vs partial match have different scores. Partial match included exact month and year, day is wrong. Exact month and day, year off by 1, and so on.
NM: SSN – weight affected by number of digits that match (all 9 digits match, 8 digits match)
NM: Gender – very little credit added for match, but points taken away if it doesn't match.
NM: for CTC match, rules about 2nd primary vs recurrence must be considered.

Policies/Business Rules

Sensitivity

Data Items

Text of rule (ie how to match a data item)
Effective (start) date
End Date
Source of Rule (Registry, soundex, etc)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie, soundex matching table, scoring weights etc)
- Data Item
- How to match/score
- Effect on overall score

Metrics
Frequency:
Volume:
Duration:

Meta Data

Description
Data that is retained about what data items are include in which table, what types those items are, any formats or edits that apply, etc.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items
Data item name
Data item ID
Location of data item
Type (string, int, float, etc)
Constraints (R1)

Metrics
Frequency:
Volume:
Duration:

Org, Facility and Medical Practitioner Profile

Description
Contains Organization, Facility and Medical Practitioner contact information. In addition to name, address, etc. could include practitioner's specialty, license number, …

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items
ID (assigned by registry)
Name
Mailing street number/name or PO Box
City
State (Canadian Province)
Postal Code (ZIP)
Fax number
Email address
Web address

For MP:
Title (R1) (MD, DO, DDS etc)
Specialty (R2)

Physician Code (Frequently Medical License Number, but other number may be assigned)
Preferred method of contact
Preferred time of contact
Phone number (R3)
Do not Contact {Y, N}
Preferred address? {Y, N} (dr may have multiple office address, this would note which one mail should be sent to)
Affiliated Facility ID (R4)
Primary Affiliation? {Y, N} (R4)
Email Address (R4)

For Organization:
Type of Org
Phone number
Child Facility ID (R2)

For Facility:
Facility FAN
Case Finding Department (R2) (Location, could be person or facility/department within facility)
Case Finding Contact (R2) (will likely be stored as 'ORG REP, Contact Person=Y)
Case Finding Type (R2) (what type of records are expected)
Case Finding Source Location (R2) (could be location of lab, e.g. basement)
Case Finding Phone number (R2)
Preferred method of contact (R2)
Preferred time of contact (R2)
Distance from registry
Associated travel expenses
Season to visit
Abstract submission schedule
Policies (R3) (Facility policies that affect how registry staff completes work)
Type of Facility
Bed size
Affiliated Facility ID (R4)
Declare Match? (R4) {Y, N}
Parent Org ID

Metrics

Frequency:
Volume:
Duration:

Other Technical References

Description

Other guides on coding, published external to the registry and to SEER, which are helpful in making coding decisions. Industry/Occupation coding, for example.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
Effective (start) date
End Date
Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …, conversion table, etc)

Metrics

Frequency:
Volume:
Duration:

Patient Care Evaluation (PCE)

Description

Formal studies initiated by the Commission on Cancer.
For site of cancer/tumor, the criteria for inclusion in the PCE group and the data elements that must be collected for the PCE.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Text of rule (ie cohort inclusion criteria, data items needed)
Effective (start) date
End Date
Source of Rule (COC)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (Data item name: data item codes: code meaning)

Metrics

Frequency:
Volume:
Duration:

Patient Set

Description

Information that pertains to a patient and his/her related CTC(s), facility(s) and treatment information.
Patient sets can have status of submissible, consolidated, in-process, awaiting follow-back, deleted, etc.
Registry and facility views would be linked together and stored here.
Incomplete patient sets that are determined to be invalid would be stored here – along with status and reason for the decision. This is for QC and in case future information changes the status (so you don't have to start from scratch)
Would include status flags, reasons for status where appropriate, special study IDs the patient has been included in, override flags.

Do not contact patient, ethnicity, census tract, medical practitioner codes, etc are part of patient set

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

See Patient Set data flow (potentially, any red BOM entity)
Status flags (R1)
Follow-back Need ID (R3)
Reason not reportable SEER
Reason not reportable Local
Special study IDs (R2)
Reason not reportable Special Study (R2)

Metrics

Frequency:
Volume:
Duration:

Patient Set (Tracking)

Description

"Tracking" information that pertains to the Patient Set (i.e. when adds, changes, deletes were made, by whom, etc. History for the data item, dates of edits or reviews)
Review would include ACD as well as patient info.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Patient Set ID
CTC ID
Facility ID
Treatment Type(?)
Data item name
Old value (R1)
New value (R1)
Date/time modified (R1)
Staff ID who modified (R1)
Reason modified (R1)

Edit Date (R2)
Editor (R2)

Review Date (R3)
Reviewer (R3)

Metrics

Frequency:
Volume:
Duration:

Patient Set Match Info

Description

Information that allows the registry to easily find records and patients sets which have been accepted as linking together.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

DESIGN NOTE: Possible design, each entry only has 2 data groups represented, when listing matches, select 'incoming' data group, all entries including that data group are displayed. (1 patient set matches to 3 health records and 2 supplemental: 5 entries, all displayed when patient set is selected). This would be easier to break apart if matches were determined to be false. (could reject patient set to 1 health record, leave other matches intact)

Sensitivity

Data Items

(any 2 of the below)
Patient ID (R1- from patient set, incomplete thru submissible)
Facility ID (R1a)
CTC ID (R2- from patient set, include Pat ID)
Treatment type (R3- from patient set, includes Pat ID & CTC ID)
Health record ID (R4 - includes corrections and non-reportable)
Supplemental record ID (R5)

Match Level (R7? BOM shows this by having different entities for each match type.) {At Patient, At CTC, At Treatment}
Facility Match? {Y, N} (BOM shows this by having different entities for each match type.)
Match Status (R6– possible, accepted, rejected)
Overall score (weighted)
Data item probability (R8)
Data item score (R8 - weighted)
Alias name used? {Y, N}

Date of Update (R6)
Update comment (R6)

Metrics

Frequency:
Volume:
Duration:

Patterns of Care (POC)

Description

Rules for collecting specific data items necessary to generate a Patterns of Care file that would not ordinarily be collected. Would include who to collect this information for.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Text of rule (ie cohort inclusion criteria, site ranges, hist ranges, age ranges, so on; data items needed)
Effective (start) date
End Date
Source of Rule (SEER)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (Data item name: data item codes: code meaning)

Metrics

Frequency:
Volume:
Duration:

Problematic Addresses

Description

A temporary store for those addresses that were not assigned a census tract or that had a low certainty code. The addresses are placed here until they can be further investigated by registry staff.
This store contains the referenced patient ID, the address used to assign census tract (successful or not) and any census tract information that was received.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Patient ID
Street address (number, name)
Street side
City
State (Canadian Province)
Postal Code (ZIP)
Census Tract
Census Tract Coding System
Census Tract Certainty Code
Census Tract block group
Latitude
Longitude

Metrics

Frequency:
Volume:
Duration:

Questionable Records

Description

Records that are deemed as questionable after being Initially Screened for Local/Seer Reportability or Special Studies Reportability by the

computer are stored here until they can be manually reviewed and their reportability status determined.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Implementation decision: really only need to be able to find this record again. Minimal requirement is:
Health Record ID
Special study ID

Reason for not determining (possibly)

Could store also store everything:
See Acceptable health info
See Converted ICD codes and keywords
See Residency info
See Additional disease codes and keywords (death certificate, autopsy)
See Converted other codes and text per special study

Metrics

Frequency:
Volume:
Duration:

Registry-Controlled File(s)

Description

The Registry-Controlled Files which have been produced – ad hoc or standard.
See glossary for definition of registry-controlled file. 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.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

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? {Yes, No}
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}

Metrics

Frequency:
Volume:
Duration:

Reports/Extracts

Description

Reports or extracts which have been created in the past and would possibly meet the needs of a future request. These could be standard or ad hoc.
Extracts can be identified or de-identified. The release of these are controlled by Determine if Valid Request
For example: Annual report (standard), extract of breast cancer/tumor patients for 1995-2000, survival of prostate cancer/tumor patients by age and stage.
See glossary for definition of extract and report. Short version:

Extract: 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.
Report: summary of information contained in the registry. Can be cancer/tumor data (incidence rates, SEER*Stat output**,** etc) or registry operation data (monthly abstracts generated by abstractor). Would potentially include task lists (what still needs to be done).

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Report/extract identifier (name)
Type {Standard, Ad hoc}
Location (or copy, implementation decision)
Programs Used to create (R1)
Staff ID (who created, who to direct questions to)
Date created
Specifications (Text)
Data items included (R2)
Identified? {Yes, No}
Comments (text field for other considerations, quirks in ad hoc reports or extracts that may make it inappropriate for other requests)

Metrics

Frequency:
Volume:
Duration:

Report, Extract, Registry-Controlled File Request Tracking Information

Description

Information to aid in tracking the path of an information request through the registry. Will allow registry to track outstanding requests, effort involved, and current status of request.
The information request (a request by person, facility, org, so on, for data contained in the registry.)
The reason a request is not authorized (A. The nature of the request cannot be authorized per Local, State &/or Federal Rules as to what kind of information can be given out or B. The requestor refuses to sign a Collaborators Agreement)
A proposed collaboration agreement that must be signed if a request is found to be valid. May contain some information about what the requester is expecting to receive.
Collaboration agreement that has been signed so a request will be found to be valid (and can move through the rest of the process). Can replace the unsigned version.
Whether the valid request can be filled by the registry at this point.
Information about the request fulfillment. Would include HPPA requirements.
For requests for identified files, the restrictions about releasing the data (either in extract or registry-controlled file) are much more strict.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Information Request ID
Requested By
Request Date
Description of Request (text)
Status {Received, Valid, Pending Documentation, Rejected, Fillable, On hold, In-progress, Fulfilled, Coming Due (for recurring requests only, as set by registry), Reported Problem}
Purpose
Priority Flag

Ongoing {Yes, No}
Schedule (R1 – not all requests have this, some have recurring dates)
Type of Media Requested
Recipient
Payee

Invalid request reason
Reason unfillable (what are you waiting for, text)
On hold Review Date (Derivable – registry standards and date requested)
Registry Staff ID (who reviewed)
Date reviewed
Date of notification
Comments on Request

IRB ID (R2)
Collaboration Agreement ID

Staff ID who Fulfilled the Request
Date Started
Date Request was Fulfilled
Effort (time required)
Name of report/extract/registry-controlled file (how the request was fulfilled)
Comments from fulfillment
For reports/extracts/RCFs that specifically identify patients or CTCs (non-aggregate data)
Source type {Pat, CTC} (R5)
Source ID (R5)

Information Request Problem ID (R3)
Type of problem (R3) {Data, Format, Expanded, Correction}
Description (R3 – text)
Registry staff ID (R3 - who was notified)
Date of problem (R3)
Decision (R3 – how to resolve)
Date resolved (R3)
Registry staff ID (R3 – who resolved)

Org Rep ID (R4)
Date of change (R4)
Modification (R4)
Reason (text field, why was this made) (R4)

Metrics

Frequency:
Volume:
Duration:

Report of This Year's Performance (Paper)

Description

A report of the number records (by type) sent by a particular facility for selected time periods. (monthly, quarterly, year to date)
Would have to report on or remove duplicate records received from the counts
Specifically, this kind of report for the current year

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Facility/Organization ID
Time period (R1)
Record type (R1b)
Number of records (R1b)
Number of Duplicates? (R1b)

Metrics

Frequency:

Volume:
Duration:

Report of Previous Performance (Paper)

Description

A report of the number records (by type) sent by a particular facility for selected time periods. (monthly, quarterly, yearly)
Would have to report on or remove duplicate records received from the counts
Specifically, this kind of report for previous years

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Facility/Organization ID
Time period (R1)
Record type (R1b)
Number of records (R1b)
Number of Duplicates? (R1b)

Metrics

Frequency:
Volume:
Duration:

Resolution Criteria

Description

Store of criteria for deciding whether a possible match should be accepted. Some of this is experience and very hard to quantify. Some of it is personal knowledge of the patients involved (also can't be coded). This may be stored in people's brains. If it could be codified, it would be part of match criteria.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Text of rule
Effective (start) date
End Date
Source of Rule (SEER)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables

Metrics

Frequency:
Volume:
Duration:

ROADS or FORDS Manual

Description

Registry Operations and Data Standards. Required data set and detailed instructions for registry operations and coding of malignancies for hospital based cancer programs participating in the approvals program of the Commission on Cancer and available from them. FORDS is the newest version of this manual. ROADS is used for Year of DX before 2003, FORDS is used for Year of DX 2003 and after.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Text of rule (ie Sex specific CTC sites must be consistent with sex of patient, comments. May include comparison of different reporting agencies rules on a particular subject)
Effective (start) date
End Date
Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …, conversion table, etc)

Metrics

Frequency:
Volume:
Duration:

Rules for Purging

Description

The rules that dictate what items are able to be purged and how long after an item has been closed should it be purged.
These rules are probably set by the registry.
FOLLOW-BACK: They would like to be able to set purge rules by how serious the follow-back need was. For example, they would not wish to purge follow-back needs where a critical data item was in question, but would be willing to purge items about non-critical data items. This would probably vary by registry.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Text of rule (ie Sex specific CTC sites must be consistent with sex of patient, comments)
Effective (start) date
End Date

Source of Rule (Registry, State, whoever else determines rules that the registries must abide by other than SEER
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …, conversion table, etc)

Metrics

Frequency:
Volume:
Duration:

Scheduling Criteria

Description

Information about how to schedule registry abstractors to do abstracting
Includes who works at which hospital, how often they go there, etc
Also includes when to abstract a CTC (x time after diagnosis, except for rapid case ascertainment)
DESIGN NOTE: should be easy to modify this data store as this information changes regularly.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Text of rule (time from normal dx to normal abstraction; facility abstract submission schedule, etc)
Effective (start) date
End Date
Source of Rule (local)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (facility ID, Org Rep ID, Availability code – hopefully derivable based on Fac ID and Org Rep ID; Facility ID, nearby facility ID; etc)

Metrics

Frequency:
Volume:
Duration:

SEER Coding Manual

Description

From SEER (NCI), how to properly code different data elements required by SEER. Includes which elements needed, acceptable codes and meaning of codes.
Rules about what makes a cancer/tumor of interest and guidelines about how to summarize the information found on the medical records as well as what information (variables) are required.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Text of rule (ie Sex specific CTC sites must be consistent with sex of patient)
Effective (start) date
End Date
Source of Rule (=SEER)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …, conversion table, etc)

For local standards:
Data item name
Data item format (R1 – acceptable codes, or set up – phone numbers have (3digits)-3digits-4digits.)
Data item value meaning (R1 – text translation)

Metrics

Frequency:
Volume:
Duration:

SEER EOD

Description

SEER extent of disease
Currently, site-specific 10-digit codes used for extent of disease in the SEER program
In the past, has been 2 digit, 4 digit and 13 digit.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

By Site:

Text of rule (ie Staging rules for specific site)
Effective (start) date
End Date
Source of Rule (=SEER)
Can a Human process this rule? {Y, N}
Can a Computer process this rule? {Y, N}
Supporting tables (ie Prostate:M, Ovarian:F, Cervix:F, …, conversion table, etc)

Metrics

Frequency:
Volume:
Duration:

SEER Registry Org Rep Data

Description

The registry staff list and the related information.

Contains security information such as account, password and access information.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Name
Org Rep ID
Phone number
Comments
Training completion date
Role
Account
Password
Remote Access Allowed? {Y, N}
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}

Metrics

Frequency:
Volume:
Duration:

Special Study Contract

Description

The actual contract between a special study and the registry. Contains information about what is being requested, for what dates, what the data will be used for, who is in charge.
Store IRB approval dates, who approved and 'docket number'.
FROM SPECIAL STUDY: Information from here would include: start date, end date, contact person, study name, study id (might be registry assigned), site/hist/beh codes of interest (criteria for selecting cohort), rapid case ascertainment flag, type of screening needed (locations is more difficult), interview desired flag, list of desired variables, criteria for data contained in non-standard variables, number of desired patients. (NCS: hard to tell exactly where the information should be stored)
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.
If a special study group requests a change be made to the special study contract (usually criteria or time span), the accepted changes are noted here as well. They are modification to a contract.
Out of Scope! Registry Manager and PI help develop Special Study contracts, we merely need a place to store this information for later retrieval.

Interested Registries

Interested:

Not Interested:

Local Procedures

Fees are assessed against special studies for the additional work done:

LA: only charge if RCA , there is a fee for provide paths, a higher fee if location review for eligibility is needed. (# paths needed * fee for RCA type) Special Study staff collections additional information required, so LA only needs to track # of paths. LA does not obtain consent, do random selection or collect SS variables.

HI: Charged based on expected or actual cost (assuming given cost per abstract done or per hour). Tracking time to collect info. would give info. needed.

ATL: generally a flat fee based on expected costs. If several studies use same extra data, cost may be pro-rated depending on study size.

UT: budget based on expected costs. Time taken to collect data. UT obtains consent (MP & PAT), does random selection. (researcher must get additional vars)

IA: Mostly based on historic effort/ costs, number of CTCs involved. They track the staff effort to collect, travel expenses and transfer costs (from lab top to investigator). IA obtains consent (MP & PAT), does random selection, gathers SS vars.

DT – duration of study, number collected, staff available, additional data items needed.

Policies/Business Rules

Sensitivity

Data Items

Special Study ID (may be registry assigned)
Special Study name
Contact (Researcher) name
Contact Phone Number
Contact Address
Source of funding
Date approval letter sent
IRB ID (R1)
Collaboration Agreement ID
Effective Begin Date
Effective End Date
Rapid case ascertainment? {Y, N}
Interview desired? {Y, N}
Location check needed? {Y, N} (for billing, finding address is more expensive than just reviewing the path report)
Special Study Reportability Criteria (Text?)
site/hist/beh codes of interest (R2)
Criteria for non-standard variables (R3)
Desired variables:
Special study specific variable name (R4)
Special study specific variable format (R4)

Registry to obtain consent? {Y, N}
Registry to do random selection? {Y, N}
Number of desired patients
Cost to Special Study
Method of delivery (does someone walk hard copies over or encrypted email, or etc)

Schedule of delivery (1 shot when complete cohort? Weekly? Includes dates)

SS returned Data items (R5) (data the registry wants the special study to send back. Used in study flag is only current requirement)

Modification Desired (R6)
Date Modification Requested (R6)
SS Staff Requesting (R6)
Org Rep ID (Registry staff making change) (R6)
Date of Change (R6)

Metrics

Frequency:
Volume:
Duration:

Special Study Tracking Data

Description

Information about what was sent to special study and when.
Registries would like to store (repeating) for each patient provided to the special study Patient ID and Date Provided.
After the special study has gotten data from the registry and have commenced the study, they may obtain further information. The registries would like the following from the special studies: List of patients actually included in study (may be different from those sent), patient set information that the special study has obtained (through interviews, through other sources, so on), information on new cancer/tumor/case that the special study obtains.

Interested Registries

Interested:
Not Interested:

Local Procedures

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 known to meet. DT sounded very formalized. They probably meet first, because they may be the ones deciding if IRBs are needed.

Policies/Business Rules

Sensitivity

Data Items

Special Study id (assigned by registry)
Data returned by Study? {y, n} (saved in BOM as relationship SOURCE SUBMISSION is result of SPECIAL STUDY)

Source Type {patient set, health record, supplemental record} (R1)
Source ID (R1)
Date provided (R1)
Coordination Needed? {Y, N} (R1)
Controlling Special Study ID (R1 – 1 for each ID, default is this study}
Consent type {Physician, Patient} (R1a)
Date contacted (R1a)
Staff ID who contacted (R1a)
Used in Study? (R1) {Y, N} (**DESIGN NOTE**: this may in physical be replaced by flag with values {possibly rpt, non-rpt (would need non-rpt reason), sent, used, not used})

(Exact fields sent depends on the study and record type) (R1)
(Fields may be normally collected from supplemental records, or may be normally discarded, but retained specifically for the special study. Registries would not collect additional fields for supplemental records.)

Metrics

Frequency:
Volume:
Duration:

Standard Report/Extract/Registry Controlled File Format Info

Description

Information about format of a report/extract/registry-controlled file that the Registry expects to generate on a regular basis or something that could be handled by a set package (i.e. SEER Stat).
Includes report layout and data items included on the report, extract, registry-controlled file. Also whether a file is identified or de-identified.

Examples

SEER*Stat
SEER*Prep
Incidence Survival
NAACCR Submission Reports
SEER Submissions (1st on List)
SEER Edits
Data Exchange – NAACCR Format
NCDB – NAACCR Format
NPCR – NAACCR Format
Edits – Internal
Annual Report – (by Registry)

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

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})

Metrics

Frequency:
Volume:
Duration:

Submission Data

Description

Information related to the receipt of data – “submissions” to a Registry from a Data Source
Partly tracking of how/when data is entering registry; also can be used for checking for duplicates.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Transmission ID (Sender defined, some registries track & some don't)
Received From (Facility/Org ID)
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)
Type of Media
Status {Okay trans, Corrupted trans}

(The following repeat with each file that is part of the communication)
Submission ID (what the registry wishes to call it)
Received Data File identification (What the source called it, if anything)
Type of record received
File documentation (electronic or paper)
  File type
  Record Layout (R1)
  Field Format (R1b – field name/acceptable values/value meanings)
Number of Records Received
Copy of File (for verifying duplicate submission if electronic)
Received multiple times (Either Y/N or Count of times received)
Date/Time processed
Registry Org Rep ID who processed

Status {sent back/error, confirmation/got it, query (need more info), }
Text (any identifying file information, file name, file id number from hospital, etc. This is a text field because different sources probably have different ways of identifying things.)

Problem description (text, could also be reason for rejecting correction)
Records affected (text: 5th rec, these 20, entire file…)
Suggested response (text: resubmit the record(s), resubmit the file)
Date Problem Sent
Staff ID (to the attention of, so on)

Question description (text)
Date question Sent
Staff ID (to the attention of, so on)

Metrics

Frequency:
Volume:
Duration:

Supplemental Acquisition Tracking Info

Description

Information about who is supposed to be sending the registry supplemental information, on what schedule and what type of file/records they expect to receive for tracking purposes
Tracking of what supplemental information the registry has received.
Would also track requests (usually purchases) that have been made and whether or not they have been fulfilled.

It is unclear at this time whether this information would periodically be managed to assess if requests were fulfilled or if this could be checked against as records are “scrubbed” in ’13.0 Confirm Receipt of Records’

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Supplemental Request ID
Staff ID (who made request)
Org ID/ Facility ID
Date request made
Record type requested (path reports, disease index, abstracts)
From date
Thru date
Payment amount (0 -> no payment)
Due Date (derivable based on request date and registry standards)
Fulfilling Source Submission ID (R1)
Status {open, close/filled, close/other, purge}
Comments

Metrics

Frequency:
Volume:
Duration:

Surname File

Description

Spanish and Asian Surname Files.
This file is used to allow the computer to assign ethnicity based on name (and any other fields that have been found to be relevant). The exact composition of the file and the ethnicities assigned to a particular name would depend on the registry. (different locations have different ethnic compositions that they must be sensitive to, they are using different programs.)
Name List for Race/Ethnicity records feed into Surname file

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Surname
Probable ethnicity
Certainty score

Metrics

Frequency:
Volume:

Duration:

Temporary FUP

Description

A purely temporary data store holding the Health record IDs for all records used in passive follow-up.
If the record was found to be non-CTC and not special study reportable, it will be stripped down to the essential data. Need to know which records were used for follow-up in order to maintain data integrity.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Health Record ID

Metrics

Frequency:
Volume:
Duration:

Temporary Information Review Requests

Description

A temporary holding area for requests by the staff that a manager review a information about a patient to see if it is inappropriate for the registry to have.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Request ID
Health Record ID **or**
Patient ID
CTC ID
View ID (Facility ID or Registry)

Data Item
Comment

Metrics

Frequency:
Volume:
Duration:

Temporary Non-CTC

Description

A purely temporary data store holding the health record IDs of those records which fail the broad screen. These will be stripped from the health and supplemental record data store and from the submission archive copy of the file.

If a record was used in passive follow-up, the full record will be replaced with a stripped down version containing follow-up information only.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Health Record ID

Metrics

Frequency:

Volume:

Duration:

<DATA STORE NAME>

Description

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Data Items

Metrics

Frequency:

Volume:

Duration: