REGISTRAR PIP

Visit SEER*Educate: A comprehensive training platform for registry professionals

Targeted Disease Index Processing . . . is it Worth the Effort?

Casefinding Background

How much is enough when it comes to casefinding? Before trying to answer that question we decided it might be best to provide a little background on casefinding. We have probably all struggled with figuring out which casefinding sources we need to review to correctly identify cases to include in our registry to meet national and state standard setter reporting requirements as well as our internal administrative needs.

While we all recognize a review of only one casefinding source type will result in underreporting at both the facility and regional level, we would probably all agree pathology files are a critical "must have" when it comes to initiating casefinding. After all, between 90-95% of our facility or regional caseload will be identified if our casefinding procedures include pathology records as one of our sources.

After processing pathology reports, what casefinding source do we process next? Here are just some of the likely non-path sources we could consider:

- Disease Indices
- Imaging reports
- Surgery schedules
- Non-surgical treatment files (e.g., nuclear medicine, radiation oncology, medical oncology)
- Admission and discharge documents

With each source added for processing, we may find new cases not identified on any previous casefinding source we processed. In a perfect world in which we have enough staff to do all we could possibly do; many might opt to use all the available casefinding sources as a crosscheck on the completeness of pathology reporting and to identify clinically diagnosed cases. However, a perfect world is likely one of imagination and not one in which most registry staff exist. Sadly, reality bites!

Choices must be made to optimize the staff resources assigned to casefinding activities. Factors likely considered in determining our approach to supplementing pathology casefinding boil down to one or a combination of the following:

- Type of facility and patient services offered
- Staffing level available to perform casefinding activities
- Processing approach to each casefinding source (i.e., active, passive or a combination of both)
- Volume of records available for each casefinding source
- Availability of an electronic process to assist in processing each source
- Potential of each casefinding source to identify new cases not previously found using pathology reports

Standard Procedures . . . The Reality

Creating a standard casefinding process for all facilities in a region is ***not a one size fits all*** decision. Between potential available sources and the factors we need to consider in deciding a casefinding

CSS is funded by the National Cancer Institute's SEER Program, Contract Number HHSN261201800004I

approach for a facility, it's clear there can be multiple effective ways to identify the cases required to be reported.

As important as identifying the sources selected for review, we also need to think about other aspects of the casefinding process that include:

- Establishing the timing of processing the various sources
- Deciding whether all or a subset of records available from each source should be considered for review

Sources should be processed in the priority order established at your facility starting with pathology reports. To assess the added benefit of using each additional source, it is important to process each subsequent source ***fully and separately*** prior to moving on to the next source. Fully processing a source involves more than simply creating a file of potentially reportable cases. It includes a review of enough of the medical record to ascertain reportability of the case for our facility.

Being mindful of the process timing schedule associated with each source allows us to determine when the cost associated with adding another casefinding source to our procedures outweighs the benefit of continuing to expand the number and types of sources used to identify new cases. If all sources are processed simultaneously, that assessment cannot be done quickly and effectively.

The Cancer Surveillance System's (CSS) Changing Procedure

The decisions faced by hospital registrars when it comes to casefinding are similar for those of us who manage central registries. At CSS, our casefinding procedures have changed over the years. The catalysts?

- Level staffing
- Annual growing number of records being submitting for the central registry's primary casefinding sources (i.e., pathology reports and disease index files)

Procedures can't remain the same if staffing levels are constant and the number of casefinding records to process and medical records to review continue to climb. For us, the number of electronic pathology records being submitted climbed as anticipated as we observed the population and the number of reportable cases for the region increase over time.

For CSS nearly 95% of all our cases are histologically confirmed. For this reason if there is a pathology report somewhere for a resident in our region, we work hard to find it. Some laboratories generating pathology reports for our residents are not located in our region. Identifying, tracking, and setting up reporting agreements with these non-SEER Washington and out-of-state laboratories have proven to be worth the effort to pursue in order to enhance our completeness of reporting.

For other registries, the completeness of reporting is approximately 90%-95% following casefinding using only pathology reports. It is hard to tell if the variance is due to an actual lower histologic confirmation rate or an inability to locate pathology reports to histologically confirm a reportable disease process for the cases in those registries.

The following decision should be a no brainer for every hospital and central registry to ensure the majority of the hospital's and region's reportable cases are identified:

- 100% of all available pathology reports are to be processed using active casefinding procedures

For over 40 years, the second primary casefinding source used by CSS has been the disease index. While the number of additional pathology reports grew at a rate that corresponded to the growth of the population, the

CSS is funded by the National Cancer Institute's SEER Program, Contract Number HHSN261201800004I

number of disease index records submitted by hospitals exploded following the introduction of the Epic EMR software in many facilities in the region.

Hospitals use of Epic resulted in an observed increase in the range of records submitted to the central registry on the magnitude of 10 to 40 times compared to what was previously submitted pre-Epic. For example, for one mid-sized hospital we went from processing 400 disease index records a month to 16,000 records. Even after aggressive consolidation of these records, we still had more records landing on a chart review list than we had previously.

We recognize using multiple casefinding sources ensures complete reporting of both histologically and non-histologically confirmed cases. However, it quickly became clear without a careful review of what was most critical to assess from the incoming disease index and ultimately keep on the chart review list, we would be faced with the prospect of losing the disease index entirely as an effective secondary source of casefinding. We realized there was no way CSS staff or hospital registrars could find the manpower to review all the cases a disease index might indicate required a review. Bottomline, which disease index records do we keep for processing and which do we toss?

Check Out the Numbers for Active Casefinding

Each year the SEER (Surveillance, Epidemiology and End Results) Program provides estimates of the expected total number of cases CSS should be reporting for not only the region but also for each primary site. So, the logical starting point for us was to check the primary site case counts not meeting the SEER anticipated annual reporting benchmarks for the region after completing pathology casefinding. After learning which primary sites were underreported, we decided to start by limiting our active disease index review to only the codes corresponding to those SEER-identified potentially underreported primary sites in our region. Currently, these disease index records do not have a patient/tumor level match in the central registry from any facility.

Active disease index casefinding involves requesting the review of all qualifying medical records to determine reportability of the case for both the hospital and the central registry. The following represents just a few examples of disease index codes we opted to include and the rationale behind including them for active surveillance.

- A growing number of urologists had their patients' pathology specimens read by national laboratories located outside our reporting area. While there are likely pathology reports that exists, they were not being reported to us because a non-Washington state laboratory was reading them. As a result, we observed nearly a 20% underreporting for prostate primaries.
  Result: Disease Index codes associated with prostate cancer were included for processing.

- In a prior casefinding quality control review conducted by CSS staff we found over 45% of the benign brain and CNS tumors are not histologically confirmed at diagnosis. It can take years before they are surgically treated producing a pathology specimen because these patients are oftentimes placed on a serial scanning protocol until they are symptomatic from the tumor. In order to report the number of these tumors more accurately and in a timely manner we needed to perform disease index casefinding on these case types.
  Result: All disease index codes associated with benign and borderline tumors were included for processing.

- The third case type observed often missing in our pathology casefinding files represents patients who died quickly from their disease, opted for no treatment, or who were not identified until the central registry performed its required casefinding procedures using death certificates. For example, in our region over 10% of liver and pancreas primaries are initially identified on death certificates rather than from hospitals in our reporting region.
  Result: All disease index codes associated pancreas and liver malignancies were included for processing.

After making our initial code selection and performing casefinding using only a subset of the solid tumor and heme/lymphoid disease index codes found on the SEER and State Reportability Lists, we learned we needed to further refine which of these codes should force a chart review at each facility. The reason? During the review of

CSS is funded by the National Cancer Institute's SEER Program, Contract Number HHSN261201800004I

our quality control findings, we observed variability in terms of the percentage of additional new cases by primary site added to our database for each disease code reviewed at each facility. We observed differences were primarily related to two things:

- The types of cases typically worked-up and/or treated at each facility
- How each facility's medical record department in the CSS region chose to code the same disease process in their disease index

You'd think a single disease process would be coded the same way at all facilities. That is not the case in our region. Fortunately, the CSS electronic casefinding program allows us the flexibility to perform a targeted review by disease index code and facility, which allows our selected subset of codes to be reduced based on the likelihood of finding a new clinically diagnosed case at the facility where casefinding is currently being performed. Table 1 shows the codes used to perform active casefinding at one hospital in the CSS region. There is a similar table for every facility reporting to CSS. (References to specific hospitals in this article are de-identified per CSS policy.)

Table 1
Hospital De-Identified
Potential Disease Index Codes to Use for Active Casefinding

Code(s)	Description	Include in Active Casefinding
All C & D codes	No restriction for facility - all tumor and heme/ lymphoid codes reviewed	
C15 - C15.9	Esophagus	
C16 - C16.9	Stomach	
C17 - C17.9	Small Intestine	
C18 - C20	Colon & Rectum	Yes
C22 - C25.9	Liver, Biliary tract, Pancreas	Yes
C34 - C34.9	Lung	
C43-C43.9	Melanoma of skin	Yes
C46	KS	
C56 - C56.9	Ovary	
C61	Prostate	Yes
C64 - C65	Kidney/Renal Pelvis	
C67-C68	Bladder	
C69-C69.92	Eye	Yes
C70-C72.9	CNS	Yes
C75 - C75.9	Endocrine	Yes
C76 - C76.8	Ill-defined, other (Primary)	
C77 - C80.0	Ill-defined, Other, and Unspecified (Secondary)	

CSS is funded by the National Cancer Institute's SEER Program, Contract Number HHSN261201800004I

C80.1	Malignant (primary) neoplasm, unspecified	
C81 - C96.9	Heme and Lymphoid	Yes
D03 - D03.9	Melanoma (in situ)	Yes
D07.5	Prostate (in situ)	Yes
D32 - D33.9	CNS (benign)	Yes
D35.2-D35.4	Pituitary, craniopharyngeal duct, pineal gland (benign)	Yes
D42 - D43.9, D49.6	CNS (uncertain)	Yes
D44.3 - D44.5	Pituitary, craniopharyngeal duct, pineal gland (uncertain)	Yes
D45 - D47.4	Heme and Lymphoid	Yes
D75.81, D76.3	Heme and Lymphoid	Yes
Q85.00	Neurofibromatosis, NOS	
Q85.01 and Q85.02	Neurofibromatosis Type 1/2	Yes
R90.0	Intracranial space-occupying lesion found on diagnostic imaging of central nervous system	Yes
Z85.46	Prostate	Yes
Z85.6 - Z85.79	Heme and Lymphoid	Yes
Z85.820	Melanoma	Yes
Z85.84 - Z85.848	Eye and CNS	Yes
Z86.011	CNS (benign)	Yes

A Central Registry Option: Closing Casefinding Holes with a Passive Procedure

In western Washington, since the early 1990's, cancer patients have often chosen to be seen at more than one hospital for their patient care. The level of this practice pattern may not have been demonstrated at all the other SEER central registries at that time. In 2021, we continue to see this practice pattern where a patient in our region may be histologically diagnosed at Hospital A but continue non-surgical treatment at Hospital B.

A central registry has the potential to easily perform a ***passive*** processing of disease index records to identify ***clinically diagnosed*** cases. Without the help of the disease index, a Hospital B facility would find it more challenging to identify their pathologically diagnosed cases from a Hospital A facility. Unless the Hospital B facility performs a review on the original slides to produce a pathology report, their hospital laboratory has no pathology report available for casefinding because processing of these biopsy and surgical specimens and producing the corresponding pathology reports were done elsewhere (Hospital A).

Table 1 indicates a subset of the codes from SEER's ICD-10-CM Casefinding List we use to perform active casefinding at any hospital in our region. For Hospital B, we currently use those codes highlighted in yellow because historically the other codes did not identify new analytic cases at this facility.

Which disease index codes did we choose to ***passively*** process through our casefinding automated program?

CSS is funded by the National Cancer Institute's SEER Program, Contract Number HHSN261201800004I

- ***All*** disease index codes identified on the complete ***SEER's ICD-10-CM Casefinding List*** of reportable codes (i.e., codes on Table 1 plus others not listed) are used for every **subsequent** facility with a matching patient/tumor reported from a **prior** facility in the region.

Let's run through a full example to demonstrate our procedure. Breast disease codes are not **actively** processed in our disease index casefinding. We believe at a regional level we receive all pathology reports for newly diagnosed breast cases.

Hospital A's pathology laboratory submits to CSS a report for a newly diagnosed left breast primary. At CSS, we add that breast primary into our database and eventually we will receive the corresponding abstract from Hospital A.

Subsequently, the patient was seen at Hospital B for non-surgical treatment, as indicated on Hospital B's disease index with a left breast malignancy code. We have the capability to potentially add this breast case to the casefinding list for the Hospital B registrar to consider performing a chart review to determine whether the patient/tumor is considered analytic for their hospital too.

The final version of the qualifying records identified passively for inclusion on a Hospital B's casefinding list is further restricted by rules we developed to identify patients with the highest likelihood of being analytic at a subsequent facility. We check for the following to identify the subset of cases that meet one of the two following criteria:

- The disease index record must also include a treatment code in addition to a reportable disease code
- The admission to the subsequent facility must be within 9 months of diagnosis for all sites except breast, which must be within 12 months

NOTE: 12 months was chosen for breast because many of the first course treatment protocols in our region extend beyond 12 months.

Hospitals in our region can opt to receive casefinding lists from the central registry that include active and/or passively identified cases we processed using their disease index.

One Facility's Results

To demonstrate how effective the disease index proved to be in identifying new analytic cases not found on pathology reports from this hospital, we've included the results of a casefinding audit in Table 2. The disease index chart review audit performed at the hospital included evaluating the effectiveness of using a combination of active and passive casefinding procedures using the disease index codes to identify clinically diagnosed cases over a 12 month time period.

For each hospital, including the audited hospital, we start the quality control process by deciding on the disease index codes to process actively and passively for the hospital. Based on the completeness of the pathology report submissions for each hospital we can choose to include all or only some of the disease index codes to supplement casefinding efforts at that hospital.

The hospital targeted in this quality control review does an excellent job of submitting complete and timely pathology reports to the central registry used to initiate casefinding procedures. In deciding which disease index codes to actively process we considered the fact this hospital provides services in outside treatment units associated with the hospital and has specialty clinics where patients have been clinically diagnosed, monitored on various watchful wait protocols, or prescribed oral systemic treatment. Analytic cases from these services are required to be identified and abstracted for the hospital registry. Oftentimes no pathology report is generated in the hospital laboratory for these types of patients. We decided it was not necessary to perform active casefinding

CSS is funded by the National Cancer Institute's SEER Program, Contract Number HHSN261201800004I

efforts on all potential disease index codes designated by standard setters for casefinding and selected only those highlighted on **Table 1** in yellow.

Table 2 summarizes the findings of the audit for the hospital by case type. There were a total 1,838 identified cases included on lists generated after performing active and passive casefinding was completed. Following the review of these medical records, 342 new cases were added to this hospital's registry. In addition, new cases, and corrections to previously reported cases from other facilities were submitted to the central registry.

Table 2
Hospital De-Identified
Percentage of New Analytic Cases Identified Using Disease Index

Site/Site Grouping	Number of Records to Review	New Analytic Cases Identified	% of Reportable New Cases Added
Unknown	9	4	44.4%
Heme/Lymphoid	285	79	27.7%
Brain/CNS - Malignant	77	20	26.0%
Thyroid	27	7	25.9%
Brain/CNS - Benign/Borderline	81	18	22.2%
Breast	455	94	20.7%
Prostate	179	35	19.6%
Respiratory/Intrathoracic	132	22	16.7%
Kidney/Renal Pelvis/Urinary	94	14	14.9%
GI Tract	163	24	14.7%
Head and Neck	54	6	11.1%
Testis	9	1	11.1%
Female Genital Tract	67	6	9.0%
Eye	26	2	7.7%
Liver/Biliary/Pancreas	83	6	7.2%
Skin	72	4	5.6%
Bone	9	0	0.0%
Soft Tissue	16	0	0.0%
Total	**1,838**	**342**	**18.6%**

Types of clinically diagnosed cases identified at this hospital:

- Biopsies refused but clinical assessment of malignancy made. Patients died within a few days of admission or were referred to hospice (multiple sites)
- Blood work (CLL , ovary primaries)
- Scan diagnosis (benign CNS, lung, kidney, prostate (PI-RADS 5 cases), lymphoma, unknown primaries)

CSS is funded by the National Cancer Institute's SEER Program, Contract Number HHSN261201800004I

The disease index helped us find the following types of Class 20-22 analytic cases who received all or part of first course treatment procedures at this hospital:

- Aspirin (essential thrombocythemia primaries)
- Brachytherapy (eye primaries)
- Cabergoline (pituitary primaries)
- Chemotherapy treatment started elsewhere but completed here (many different sites)
- I-131 (thyroid primaries)
- Lupron shots (prostate)
- Radiofrequency ablation (liver primaries and other cancers that spread to the liver for which this procedure was performed on the liver metastasis)
- Tamoxifen, aromatase inhibitors (breast primaries)
- Watchful waiting protocols recommended and completed at this hospital (prostate, kidney, indolent forms of MDS, CLL, lower grade follicular lymphoma, and benign CNS tumors)

It appears our decision to include bone and soft tissues disease codes in active casefinding failed to identify any cases. This has been the case for a couple of years. For this reason we will drop these codes for this facility from active disease index processing and include them solely for passive processing.

Conclusion

We need to rethink how we implement local casefinding efforts often described as involving a strategy to "cast a net far and wide to capture all of the reportable cancer cases." There are many sources we can use to perform this activity. For each additional source used, we will improve our potential of identifying more eligible cases required to be included in our registry.

We know we need to include more than pathology reports, the first source often used to initiate casefinding activities, otherwise ***clinically diagnosed*** cases will not be identified and reported. If a hospital registrar does not use a source other than pathology to casefind, the result is underreporting by 5%-10%. This potential lack of more complete data using only pathology also leaves the registry staff ill-prepared to address issues involving clinical patient care and the needs of hospital administration more accurately. Ultimately, we are all faced with deciding how to respond to the question, "After completing casefinding using pathology reports, what do we use next?"

Selecting the sources to identify non-histologically confirmed cases and deciding how to work with those sources to optimize the number of additional cases found given the effort spent performing casefinding activities for each additional source used requires we track and analyze our efforts. This is necessary because registries do not have the time or manpower to manually review all the medical records identified using every potential casefinding source available.

It is necessary to think "biggest bang for the buck" when it comes to developing a casefinding strategy to identify patients who were never biopsied at a facility but were either clinically diagnosed or who received only non-surgical treatment at that facility. The continuous tracking and analyzing of non-path casefinding efforts will provide the information needed to know when and how to modify an institution's procedures when using each additional source to try to identify these patients being seen at a facility.

CSS is funded by the National Cancer Institute's SEER Program, Contract Number HHSN261201800004I