REGISTRAR PIP

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Are We Missing 2020 Reportable Cases? Maybe . . . But Probably Not

Before providing a more comprehensive response to the question posed in the title of this Registrar PIP edition, a little background is in order because, as we all know, context is everything. If everyone is aware of some of the central registry procedures, it will be easier to understand how we came to our conclusion about the completeness of reporting for 2020.

Almost two years ago we began to change the timing of performing casefinding. Now is a good time to share why the change was made and how that change may have helped us make an early identification of the potential under vs. delayed reporting for 2020 incident cases.

In 2019 we wanted to move toward concurrent processing of casefinding sources to improve the timeliness of identifying potential new incident cases. We initially targeted procedures involving histologically confirmed cases because approximately 95% of all reportable cases have at least one positive pathology report generated for each primary site that flows through our casefinding process.

Advantages of Concurrent Pathology Casefinding

By achieving our goal of concurrent pathology casefinding we hoped to be able to more quickly:

- Learn the potential volume of incident cases for the region and the minimum number of anticipated analytic cases to expect from each reporting facility in the region
- Assess the impact on each hospital registry's ability to maintain their past abstract reporting timeliness
- Review each laboratory's reporting completeness to identify and request missing reports be submitted to the central registry
- Identify reasons for potential underreporting that might be occurring by primary site
- Contact ***nonreporting laboratories*** identified as the originating facilities in ***review of slides*** pathology reports from laboratories currently submitting pathology report files
- Inform SEER about any issues related to our ***observed*** and their calculated ***expected*** incidence volumes at least 10 months prior to our data submission including:
  - ✓ Facilities not reporting
  - ✓ Facilities' inability to perform timely analytic abstracting
  - ✓ Impact on site-specific incidence rates due to standard setter changes in reportability guidelines (e.g., ICD-O-3, STR, Heme Database, SEER Manual, etc.)

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Incidence Completeness Levels

For historical context, at the end of December 2010 our incidence completeness was 81.82% for 2010. At that time, there were increasing requests from Fred Hutch study investigators submitting funding requests for us to identify potential cancer cases more quickly. If we more quickly identified cancer cases, their projected patient counts for studies could more accurately be estimated in grants. They would be in a more competitive position when proposed studies required rapid case identification if the infrastructure for performing that activity was part of the registry's routine operations. Further improving the timeliness of identifying cases to support research efforts became an even higher priority for CSS from 2010 forward.

Depending on whether the percentage complete is going up or down from one time period to the next, every 1.92% difference in completeness represents a week of time being either added to or subtracted from the casefinding turnaround time. Between December 2010 and December 2015, we dropped the turnaround time to identify new cases from an average of 9.5 weeks (81.82%) to 5.1 weeks (90.20%) for all casefinding sources. By the end of December 2016, our turnaround time dropped again to 4.4 weeks (91.64%).

Table 1 shows the changes in our cumulative percentage incidence completeness by month throughout the year and at year's end for 2015-2021. We added 2010 into the table so you could see our starting point. The improved speed and completeness in identifying new cases we achieved by December 2016 gave our investigators an advantage when it came to accurately "crunching the numbers" needed to apply for grants to support their patient-involved research efforts. It also allowed the registry to monitor all the areas of performance described above.

Table 1
Potential Cumulative Percentage Incidence Completeness by
Reported Month and Diagnosis Year
(Linear Regression Method)

	2010	2015	2016	2017	2018	2019	2020	2021
Jan	0.00%	2.03%	1.51%	1.79%	2.39%	2.56%	**4.74%**	**4.76%**
Feb	1.39%	6.85%	6.94%	5.87%	7.53%	7.77%	**11.36%**	**11.66%**
Mar	8.94%	14.53%	15.38%	13.50%	14.72%	**15.67%**	**18.62%**	
Apr	18.68%	22.86%	23.62%	20.41%	22.76%	**23.86%**	**23.62%**	
May	25.79%	30.14%	31.24%	27.72%	30.14%	**30.92%**	**28.27%**	
June	34.24%	38.15%	39.67%	36.88%	38.01%	**39.71%**	**34.79%**	
July	41.90%	47.67%	47.51%	46.27%	45.63%	**49.51%**	**42.38%**	
Aug	50.31%	55.98%	55.99%	54.50%	54.55%	**59.39%**	**49.41%**	
Sep	57.18%	63.38%	65.52%	63.61%	61.90%	**67.90%**	**56.61%**	
Oct	64.92%	73.26%	73.79%	73.46%	71.09%	**76.82%**	**64.03%**	
Nov	73.55%	81.01%	82.30%	80.68%	78.79%	**84.59%**	**72.05%**	
Dec	81.82%	90.20%	91.64%	89.33%	86.41%	**93.13%**	**80.10%**	

Note: Table cells indicate the **observed** percentage of incidence completeness compared to the annual **expected** volume NCI staff anticipated when they prepared incidence estimates.

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Goal Achieved . . . Goal Lost

Achieving a performance-related goal is one thing; maintaining that high standard is another. One can quickly lose an advantage created if you don't continuously monitor performance and take corrective action when necessary. When confronted with "the numbers" reflected in Table 1 for 2017 and 2018 it was clear our turnaround time was slipping. In December 2017 our turnaround time fell to an average of 5.6 weeks (89.33%) and by December 2018 it dropped still further to 7.1 weeks (86.41%). Clearly, it was time to make the needed changes to reestablish the reporting timeliness levels achieved two years before. First, we had to figure out why it happened.

To identify new and subsequent primaries we initiate our casefinding quality control procedures by performing linkages of pathology report files to the CSS database and review those reports for reportability. Disease index sources are subsequently processed. Nothing changed between 2015 and 2018 in terms of the casefinding source processing order. Yet it was clear that at the end of 2017 and 2018, our completeness levels dropped when compared to December of 2015 and 2016 percentages.

After reviewing our procedures, we determined this drop in turnaround time was primarily attributed to the decision to restrict CSS staff electronic medical record (EMR) reviews until there was an entire day of work available at a single facility before assigning someone to the facility to perform casefinding quality control activities. Most of the time, we scheduled a reviewer to a single facility each day. This scheduling pattern was established more than 45 years ago when CSS staff used to perform 100% of the medical record reviews on-site at the hospitals and when driving to multiple hospitals in a single day was impractical.

Following the unwanted change in the turnaround time, we asked ourselves, "Why do we need to restrict staff access to a single facility each day?" After all, CSS has remote access to nearly all the EMRs in the region. Why couldn't reviewers access multiple facilities a day rather than a single facility? The solution seemed a simple one. Generate a pull list every day for each facility and assign someone to review those EMRs immediately. After all, "going" to a new facility no longer involved driving from one place to another; it only means one has to log out of one facility's EMR and log into a different one while sitting in front of our own computer screen.

Re-establishing a Goal

While change is unsettling for almost all of us, without change there is no improvement. For 2019 we planned to schedule daily EMR reviews at every facility to identify histologically confirmed new incident cases with the goal of surpassing the former December 31st high completeness level of 91.64% achieved in 2016. That goal was certainly easier to conceptualize than to implement. It took approximately five to six months to identify all the steps in the new procedure, create an implementation plan, train the staff, execute the new procedure, and ultimately have everything running smoothly.

We have always initiated casefinding quality control procedures with pathology sources because the majority of laboratories now report their files to us on a daily basis while disease indices are reported from hospitals to us on a bi-weekly or monthly schedule. Sometimes, issues occur at hospitals causing the disease index files to be delayed by more than 30 days from the end of the month. Given the current reporting schedule of disease indices, initiating the casefinding process with disease indices would not be the best way to improve the timeliness of case identification.

The obvious choice to improve the timeliness of incidence reporting was to continue to initially target procedures involving pathology sources for three reasons:

- The majority of pathology files are reported to the central registry within 24 hours of the pathologist finalizing the report.
- The majority of our incident cases (~95%) have at least one pathology report associated with the tumor.

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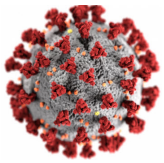
- Study cases typically involve patients with histologically confirmed disease because the cell type is often one of the data items used to select cases. Patients without histologic confirmation of disease are oftentimes too sick for a biopsy or they refuse to have one. These patients will likely not be able or willing to participate in a study.

Typically it takes three to eight days for a pathology report to be generated on a specimen before the pathology report is included in a daily file sent to CSS. Our goal was to determine whether a potential incident case could be confirmed within 48 hours or less from the time it was initially received at the central registry. If we were able to do that, the turnaround time for all ***pathology sources*** could potentially drop to less than an average of one and a half weeks from the biopsy date to the date a potential incident case is identified at the central registry.

Goal Reached . . . then COVID-19 Hit



By November of 2019 we were, in fact, processing all ***pathology reports*** within 48 hours of receipt of those files. In **Table 1** above you can see that by December 2019 the average turnaround for ***all sources*** was 3.6 weeks (93.13%) for cases diagnosed in 2019. Keep in mind that even though we were identifying incident cases in under a week and a half from pathology reports, the processing of ***disease index records*** also impacts the overall casefinding turnaround time.

In addition to tracking the cumulative percent incidence completeness for the current year, we also track the cumulative percent incidence completeness by month for the previous year. (See **Table 2.**) Cases for prior diagnosis years continue to be reported even though the majority of today's efforts involve processing casefinding sources for the current diagnosis year. We are interested in learning the magnitude of delayed reporting and how long it takes to reach 100% of the expected volume of cases for the prior year.

The observed reporting turnaround time for pathology reports and disease indices, **Table 2** (gray cells) indicates that by December 2019 incidence reporting for 2018 cases reached 99.33% of what SEER expected. By December 2020 incidence reporting for 2019 cases topped 100% of what SEER expected. Notice there is never more than a two to three percentage point difference in the cumulative percent incidence completeness from 2017-2020 for any given month of the year until you check the January 2021 against the prior years' January cumulative percentages for incidence completeness (**Table 2** yellow cells) when it dropped almost ten

Table 2
Potential Cumulative Percentage Incidence Completeness by
Reported Month and for Prior Diagnosis Year
(Linear Regression Method)

	As of 2017 completeness for 2016	As of 2018 completeness for 2017	As of 2019 completeness for 2018	As of 2020 completeness for 2019	As of 2021 completeness for 2020
Jan	**93.96%**	**95.82%**	**92.63%**	**96.15%**	**82.93%**
Feb	**96.72%**	**98.18%**	**95.22%**	**97.45%**	**84.30%**
Mar	97.80%	99.08%	96.32%	98.35%	
Apr	99.73%	99.49%	97.59%	98.91%	
May	100.43%	99.85%	98.04%	99.29%	
June	101.14%	100.32%	98.42%	99.46%	
July	102.22%	100.75%	98.94%	99.64%	
Aug	102.21%	101.14%	99.05%	99.71%	
Sep	102.26%	101.25%	99.15%	99.74%	
Oct	102.53%	101.64%	99.23%	99.28%	
Nov	102.94%	101.85%	99.28%	99.98%	
Dec	102.95%	101.90%	**99.33%**	**100.20%**	

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percentage points lower than the prior low for any previous January. If a registry is both current in processing pathology sources and they have been tracking completeness levels historically on a monthly basis, they have the capability to notice rapid and/or significant changes in reporting completeness that occur over time.

Access to near real-time information on the percent identified volume of incident cases expected in our region at the end of 2019 put us in a position to observe whether or not the spread of COVID-19 impacted cancer reporting throughout all of 2020 and into early 2021. We anticipated a drop in potential cancer incidence reporting after learning from registrars their facilities were reducing the level of cancer care provided once hospital resources were redirected to care for the influx of acutely ill COVID-19 patients. Registrars also noticed a reduction in the access to hospital outpatient clinics that was probably the result of a growing patient reluctance to visit these clinics and risk potentially exposing themselves to COVID-19.

The first confirmed COVID-19 case in the United States was in Washington on January 21, 2020. By March 19th, we had 1,376 confirmed cases in the State and 74 deaths with 60 of the deaths occurring in King County, the most populated county in the State. When checking the anticipated cumulative percentage of cancer cases identified by month in **Table 1** (blue cells) between 2019 and 2020, you can see that beginning in April of 2020, the cumulative percentage for each month in 2020 was noticeably less than during the same month in 2019. The cumulative percentages should have been approximately the same given the fact we were still processing all pathology reports within 48 hours of receipt.

One thing we know for certain, we were not receiving and processing pathology sources in 2020 at a slower pace than we had in 2010 when we had a greater than 10 week turnaround time to complete pathology and disease index casefinding. However, **Table 1** appears to indicate that might be the case given the 2020 observed percentage of completeness by the end of December 2020 indicated we'd reached only 80.10% of the SEER expected level of completeness.

Prior to our initiating casefinding procedures for a given year, the National Cancer Institute releases a preliminary ***expected projection*** for the current in-progress diagnosis year. NCI released its initial incidence projections for diagnosis year 2020 prior to the pandemic being diagnosed. Those estimates have not yet been updated to factor in the impact of COVID-19. Historically, every SEER diagnosis year's ***expected projection*** target has been higher than the previous diagnosis year (except 2021) due to continued population growth in the SEER 13-country region.

Given that pathology casefinding is nearly complete for 2020, even if there are new pathology sources for 2020 that we have yet to identify or laboratories that did not send complete files, we are likely not going to reach the SEER expected volume of 33,960 malignancies (behavior /2 and /3) for diagnosis year 2020 given that our observed volume is currently 27,759 as of 2/28/2021. According to the information in **Table 2**, over the last five years the percent complete for the ***prior*** year has only changed from four to nine percentage points from January to December of the ***current*** year. Given we observed 82.93% (using linear regression model) of the SEER expected level of completeness for 2020 by January of 2021, we anticipate ultimately reporting approximately 87% - 92% of the 2020 expected volume after procedures including disease index processing, death clearance and quality control are completed.

Conclusion

At this point, it is probably a bit challenging at a program level for SEER to evaluate with certainty the impact of the pandemic on 2020 cancer incidence reporting and quickly produce updated ***expected*** incidence counts for all their registries for three reasons:

- Regional variation exists in terms of both the timing and level of COVID-19 disease spread across the country

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- Lack of nearly 100% regional, rapid-reporting of pathology reports across the entire SEER Program to be able to identify potential incident cases quickly

- Majority of central registries perform casefinding quality control on pathology and disease index sources ***after*** hospitals submit analytic abstracts (CSS performs this activity ***prior*** to hospitals submitting analytic abstracts) and no hospitals in our region are concurrently abstracting.

It is clear the COVID-19 pandemic and associated stay-at-home orders established in Washington state limited patient access to cancer care. Reduced access appears to have resulted in the short-term interruption in cancer care delivery from May through December 2020 in our region.

How will the delay in cancer screening and treatment impact survival? Will we see more patients presenting in 2021 with cancer and will they present at a more advanced stage of disease? While we must wait for more data to learn the answers to those questions, if our preliminary check of the current data holds true, it is highly likely most hospitals ***will not*** be reporting the same number of analytic cases for 2020 as they did in 2019. The drop in the number of cancer incident cases appears real at a regional level for the CSS reporting area for 2020 because in January and February 2021 the percentage completeness returned to the pre-pandemic levels for those same months (See **Table 1** green cells).

One word of caution, if SEER adjusts the 2021 ***expected*** number up significantly, this will negatively impact the cumulative percent complete for January and February of 2021. If that occurs, we will need to lower the cumulative completeness percentages starting in January 2021. Unfortunately, this might also mean we have yet to return to the pre-pandemic levels of cancer screening and cancer treatment as indicated in **Table 1**.

If, after completing your 2020 case reporting, you believe you've done a thorough job identifying and abstracting those cases and the result is a lower than originally anticipated number of analytic cases, you may be missing cases . . . but probably not. After confirming your counts, discuss with your Cancer Committee how the pandemic impacted the cancer services your facility was able to provide during 2020 and how that directly impacted everyone's "numbers" both regionally and the hospital level.

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