Identify and Implement Best Practices for Cancer Registry Operations

YEAR 2

March 31, 2021

“The more we share, the stronger we become.”

Acknowledgment

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Attribution

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Partners

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The North American Association of Central Cancer Registries, Inc. is a professional organization that develops and promotes uniform data standards for cancer registration; provides education and training; certifies population-based registries; aggregates and publishes data from central cancer registries; and promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care to reduce the burden of cancer in North America.

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The National Association of Chronic Disease Directors (NACDD) and its more than 7,000 members seek to strengthen state-based leadership and expertise for chronic disease prevention and control in states and nationally. Established in 1988, in partnership with the Centers for Disease Control and Prevention, NACDD is the only membership association of its kind to serve and represent every chronic disease division in all states and U.S. territories. For more information, visit chronicdisease.org.

Background and Significance

The American cancer surveillance system is one of the most developed and standardized disease surveillance systems in the world. The National Program of Cancer Registries (NPCR) of the Centers for Disease Control and Prevention (CDC) is a significant leader in cancer surveillance and has collected population-based cancer incidence data in the United States since 1995. NPCR currently supports central cancer registries in 46 states, the District of Columbia, Puerto Rico, the U.S. Pacific Island Jurisdictions, and the U.S. Virgin Islands—representing 97 percent of the U.S. population. NPCR's data provide the foundation for the medical community, policymakers, and members of the public to understand and address the nation's cancer burden. Data are most useful when available in a timely manner; however, national cancer surveillance organizations, including the CDC, currently require complete reporting of cancer data within 24 months of diagnosis, leading to a 2-year lag between diagnosis and reporting. In addition, the CDC now requires reporting within 12 months of diagnosis, but many registries are unable to fully meet this standard, which precludes the accurate reporting of cancer incidence rates at an earlier time. Factors known to delay reporting include the need to consolidate reports from multiple institutions for each cancer case, the fact that the first course of cancer treatment often extends for months after diagnosis, state laws regarding cancer reporting, and a shortage of trained staff. For these reasons, CDC initiated a comprehensive review of these complex problems to better understand challenges to achieving completeness and identify potential best practices among central registries that might improve the timeliness of reporting.

Project Overview

In 2019, to address the concerns outlined above, the CDC contracted with the National Association of Chronic Disease Directors (NACDD), which then subcontracted with the North American Association of Central Cancer Registries, Inc. (NAACCR)—an organization uniting cancer registries, government agencies, professional associations, and private groups interested in enhancing the quality and use of cancer registry data—to analyze methods to improve registries' compliance with the 12-month data reporting standard. The NAACCR, in turn, brought together leading authorities in the field and experienced practitioners to address these concerns in a thoughtful and carefully designed two-pronged approach. This bifurcated model incorporated a multidimensional analysis that involved a systematic statistical review of current and proposed completeness models to determine which might capture the most accurate assessment of completeness, along with a wide-ranging analysis of registry operations to determine best practices and strategies to improve the compliance of cancer registries with NPCR's 12-month data standard and appraise many additional aspects of registry operations that were of interest to the NPCR.

For the first prong, a Statistical Expert Panel comprising distinguished thought leaders in the field of cancer surveillance and biostatistics examined the statistical validity of completeness measures currently in use, then assessed alternative models and explored enhancements to models that might lead to improvements. This work proved to be extremely complex, and it was agreed at the end of the first year that the expert panel would continue its assessment of the models and move toward a recommendation for a more comprehensive approach to estimating completeness of reporting.

For the second prong, an Operations Expert Panel evaluated current best practices for collecting and processing cancer incidence data within 12 months of diagnosis by working with

representatives from registries with various levels of compliance with the 12-month standard. The registries participated in written assessments, interviews, and focus groups.

An in-person summit was held for each of the statistical and operational parts of the project. Finally, a detailed report of the findings from both approaches was submitted to the NACDD and NPCR for their consideration.

Upon completion of Year 1, the NPCR program worked with the NACDD and NAACCR to identify priorities and set a robust agenda to move forward to develop a more thorough and judicious understanding of the statistical models and—based on the findings from Year 1—selected several avenues for further development, which were aimed at enhancing registry operations. Priority steps included the following:

1. Continue to assess completeness measures and recommend a method that will be suitable for implementation across all central cancer registries. Methods should be vetted with states and stakeholders.

2. Carefully evaluate the methods used by registries to process electronic pathology records by applying LEAN processes to identify best practices.

3. Compile state regulations and laws into a searchable database that will allow states to identify various practices that ensure full reporting of cancer in a timely manner. This database will be assessed to identify legislative and regulatory best practices that could be used as models in other states.

4. Undertake a field evaluation of NPCR auto-consolidation methods. The NPCR program has invested considerable resources into developing auto-consolidation routines that may prove useful to states; however, these methods have not been tested in the real-world setting. Three states will be selected to test these strategies and evaluate the effectiveness of machine-based versus staff-based consolidation.

5. Bring registries together in a series of virtual workshops to discuss best practices and share knowledge. The focus will be on comparing different registry operations methods to learn which methods are the most effective in different settings.

In the second year of the project, the CDC, in collaboration with the NACDD, asked the NAACCR to initiate five different projects that were designed to engage and involve central registries in highly interactive and focused dialogue aimed at sharing success stories, solving common problems, and building consensus around best practices. This is a report on the results of this work that includes the following:

1. The findings and recommendations of the Statistical Expert Panel on Central Registry Completeness

2. A Six Sigma Lean Green Belt analysis of electronic pathology reporting in central cancer registries

3. A state law and regulation searchable database and analysis of legislative and regulatory best practices used among states to improve reporting and registry operations

4. An evaluation of the NPCR Automated Data Item Consolidation that compared multiple automated consolidation methods to manual consolidation for selected critical data items in a real-world data to determine the optimal use of automated consolidation methods

5. A summary of best practices workshops' findings and tools to guide registries to improve data reporting and registry operations with a focus on developing and evaluating data management reports, establishing strong communication and relationships with hospitals, improved reporting from non-hospital sources, and managing best practices around COVID-19 response

This Year 2 report compiles the results and recommendations from all five of the priority areas above in independent reports. These reports are designed for use within the NPCR and for distribution to participating NPCR registries. In addition, a series of Quick Tip Sheets is included that capture the findings of each project (except for the completeness estimation) in an easy-to-use format that will offer central registries guidance and direction on best practices that they might adapt to their own state operations. Recommendations for the CDC NPCR program were requested and appear in each project report.

Findings and Recommendations of the Statistical Expert Panel on Central Registry Completeness

March 15, 2021

Acknowledgment

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Introduction

This report contains the findings and recommendations of the Statistical Expert Panel with respect to measuring completeness of case ascertainment at central cancer registries in the United States. One core function of central cancer registries is the publication of population-based incidence rates, which requires that all cases be reported and counted. Evidence suggests that the completeness of case reporting in the United States has improved in the last 10 years. Although it is impossible to know what cases may be missing, delayed reports and reports from death certificates suggest that only a few percent of cases are not reported within the required 23-month time frame nationwide.

For more than a quarter century, completeness has been measured by the North American Association of Central Cancer Registries, Inc., (NAACCR) and the National Program of Cancer Registries (NPCR) in a consistent manner: An expected number of cases is calculated based on cancer mortality rates and adjusted for the demographic structure of each state's population, and the reported number of cases is compared to this expected number. This report expands on that approach to produce a suite of indicators that are more sensitive to diverse aspects of case reporting.

Statistical methods for estimating case completeness can be classified into two primary types. *Internal methods* are those that predict case counts based on registries' own reporting history. *External methods* are those that predict case counts based on variables that are external to central registries. These include mortality rates, population demographics, socioeconomic indicators, and information from health surveys. Each of these types of methods has its own sets of limitations, some of which are discussed below. To overcome the limitations inherent in each method, the Statistical Expert Panel proposed a solution that makes use of both methods as part of a suite of completeness indicators. For registries that perform well using both methods, there is higher confidence in the completeness of their data than is achieved from using either method on its own. The same is true for registries that do not perform well on either measure. For registries that perform well on one measure but not the other, a set of process measures is proposed to help resolve the discrepancy and assist registries in identifying potential gaps in reporting.

The concept is illustrated in Figure 1, which reports internal and external completeness scores for 56 U.S. registries for cases diagnosed in 2017 and reported in 2019. The plot has been color-coded into zones representing completeness scores above both thresholds (green), one threshold (yellow), and no thresholds (red). The thresholds used here are for illustrative purposes only, although they do correspond to values that have been used historically. Forty-six registries were above both thresholds, one was below both thresholds, and nine were below one threshold and above the other.

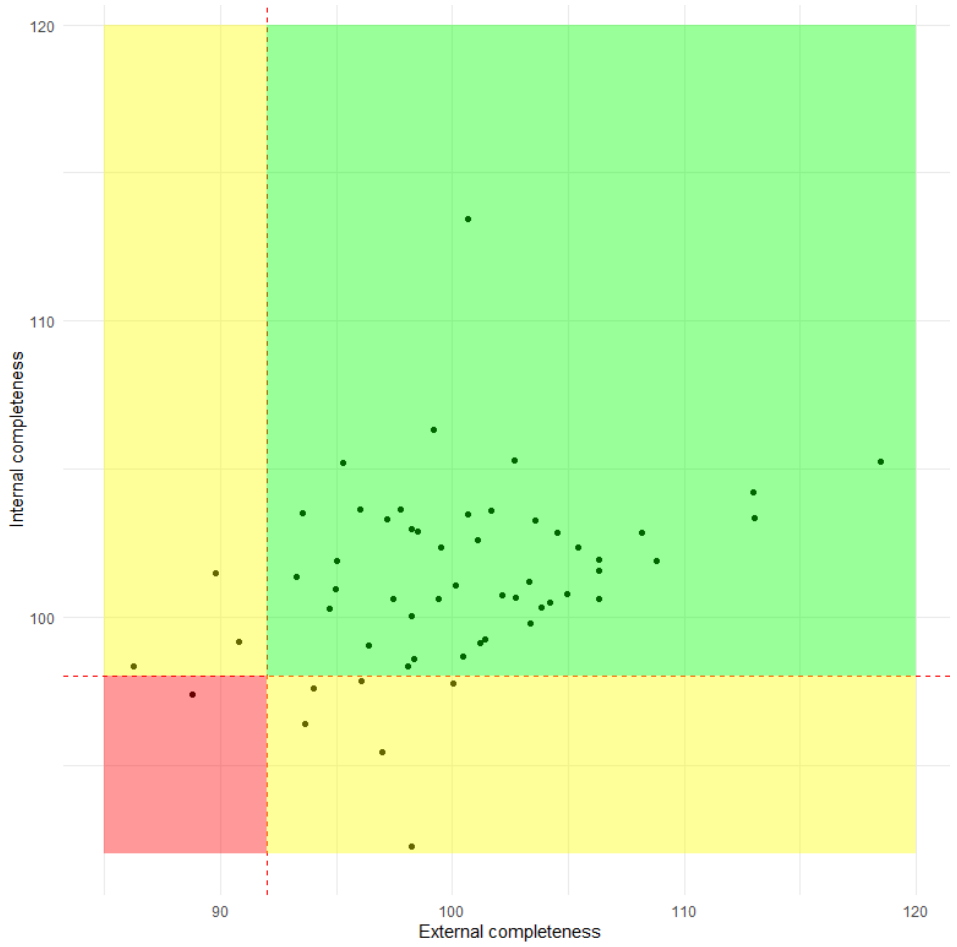

Figure 1. Internal versus external completeness measures for cases diagnosed in 2017. Each point corresponds to a registry.

One would expect that independent measures of a quantity such as completeness should agree, but the correlation in Figure 1 is quite low. The reason for this is believed to be that the two methods are sensitive to different characteristics of the data. The internal method is sensitive to registries that have a substantial drop in cases in a single year. It is not sensitive to registries that have consistently underreported cases for a number of years. The method looks for adherence to a trend; if the trend is to underreport, then the registry will be adhering to that trend. The external method, in contrast, is sensitive to registries that appear to be underreporting relative to other registries. A registry that does so consistently will be identified as such each year. But because the method assumes the average registry has complete data, it is not sensitive to national trends in reporting. For example, because of the delayed rollout of the coding rules for cases diagnosed in 2018, it is likely that completeness declined nationally, but the threshold is still based on a percentage of the average registry, where the average registry is presumed complete. The lack of agreement between the internal and external measures is the reason additional measures should be taken into consideration when evaluating completeness.

The following sections provide technical detail about the proposed internal, external, and secondary methods.

Internal Method

The internal measure of completeness consists of comparing each registry's reported cases to the number that was expected based on a projection of case counts from recent years. The method proposed is an extension of the method currently employed within the Surveillance, Epidemiology, and End Results (SEER) program to evaluate its member registries, and it is also used informally by many NPCR registries in evaluating their own progress toward completeness benchmarks. It has the advantage of being intuitive and easily calculated at any point in time. A disadvantage of this method, as described above, is that if a registry consistently underreports cases, it may still perform well with this measure.

In our proposal, each registry's expected case counts are computed individually for all site, gender, age, and race groups combined. It also is separately calculated for individual cancer sites. All data submissions are used in this process, except in a few situations when data points for registry/year/site are treated as missing, and completeness measures are not provided. Details about missing data are presented in Appendix A.

The input data consist of data from submissions dating back to 2001. Trends are defined using joinpoint regression, a method that finds the best-fit straight-line segments through a time series, with the number of line segments flexible. Here, a maximum of three line segments is permitted (that is, no more than two joinpoints connecting the line segments are permitted). The expected case count for the latest year is extrapolated from the line segment ending in the previous year. For more detail on this and other methodological points, see the technical Appendix A.1 for the internal completeness method.

An example is shown in Figure 2. First, the expected case count for 2017 of 27,956 is derived by linearly extrapolating the upward trend seen from 2014 to 2016. Next, this expected count is adjusted by the state's historic case reporting delay factor (1.018) relative to that of the nation's (1.041). This means that for this state, one would expect about 1.8 percent more cases to eventually be reported after the first submission, while for the country as a whole one would expect 4.1 percent more cases. To adjust the expected case count for the fact that this state is doing better at its first report than the country as a whole, the expected case count is adjusted down by the ratio of the delay factors, i.e., 1.018 ÷ 1.041 = 0.978. The delay-adjusted expected count is thus 27,956 × 0.9779 = 27,348. Conversely, if the delay factor for this registry was worse than the national average, then the delay-adjusted case count would be adjusted upward.

The actual reported count of 27,084 is then divided by the delay-adjusted expected count to yield an estimate of completeness. In this example, the completeness is 99.0 percent. This means that *relative to the nation as a whole* (adjusting for age, race, sex, ethnicity, and mortality), this state has 99.0 percent of its cases reported. Note that this is different from having achieved 99.0 percent of its long-term final case count.

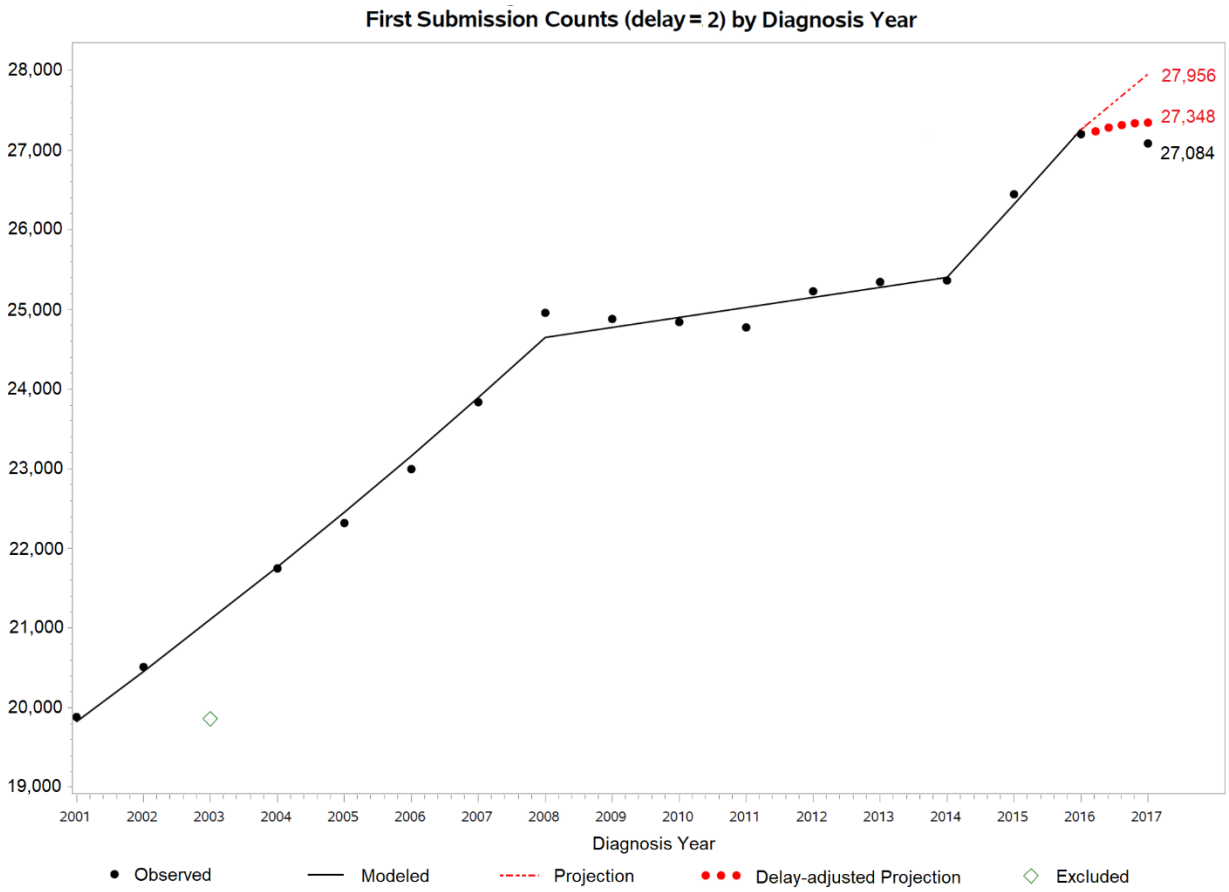

Figure 2. Joinpoint model used to derive expected case count in the internal completeness method

External Method

The external method of calculating completeness is similar to the internal method in that it compares each registry's reported cases to an expected number of cases to derive a proportion. The external method, however, uses factors outside the registry's own data in determining the expected number of cases. This section recalls the current approach for calculating completeness, introduces a new regression-based approach, and touches on some extensions for the new regression approaches that were considered.

Existing Approach. The existing method used by NAACCR and NPCR for measuring completeness is an example of an external method. With this method, the expected count (e.g., expected number of cancers) for a given registry is as follows:

$$\text{Expected count} = \left[\frac{\text{SEER or NPCR reference incidence}}{\text{US Mortality}}\right] \times \text{Local mortality},$$

where an expected count is calculated separately for each age group, sex, race/ethnic group, and selected cancer sites. These counts are then summed to obtain a single expected count. The ratio of the observed to expected counts is then taken as a measure of completeness. This ratio is multiplied by 100 to obtain a completeness score.

Proposed Regression Based Approach. The Statistical Expert Panel explored an alternative regression-based approach for estimating the expected case counts using regression models that can predict the expected number of cancers. For each cancer site, this report effectively proposes estimating the expected count for a given age group, sex, and race/ethnic group by the following model:

$$\text{Log(Expected Count)} = f_A(\text{Age}) + f_S(\text{Sex}) + f_R(\text{Race/Ethnic group}) + f_M(\text{Mortality})$$

where the functions, f, and other details are provided in Appendix A.2. Again, the expected counts are summed across all demographic groups and cancer-sites to obtain a single expected count ($\hat{Y}$), which is then compared with the observed number (Y). The Statistical Expert Panel reports the estimate of completeness, $\hat{C} = 100 \times Y/\hat{Y}$, the corresponding 95 percent confidence interval, and the probability that the true completeness exceeds pre-specified thresholds.

The Statistical Expert Panel considered two modifications to this proposed regression-based approach to improve the prediction of cancer incidence. They first considered using additional demographic and behavioral information about the population in each of the registries. This information—drawn from the American Community Survey (ACS) of the U.S. Census, the Behavioral Risk Factor Surveillance Survey (BRFSS) of CDC, and the Area Health Resources File (AHRF) produced by the Health Resources and Services Administration—was captured in the set of 33 additional variables listed in Appendix A.3. The variables were chosen based on a hypothesized association with cancer incidence or because they have been historically included in similar modeling projects. The ACS and AHRF variables were available at the county level, and the BRFSS variables were available at the state level. Most were not available by age or race/ethnicity categories. For most cancer sites, including these additional variables in the model did not improve the accuracy of the predictions and, therefore, for simplicity the Statistical Expert Panel chose to use the base model described above.

Second, the Statistical Expert Panel considered fitting the regression models using county-level data. Again, this additional level of complexity did not significantly improve the accuracy of the predictions or warrant further consideration.

Given that the proposed external method and existing NAACCR completeness method use the same inputs (mortality, site, age, sex, race/ethnicity) one might expect them to have similar results. Indeed, this is the case. Figure 3 shows a scatterplot of the two methods for the same year of data. The coefficient of determination (*R*-squared) between the two is 0.64, indicating good agreement. Thus the regression approach can be seen as a generalization of the NAACCR method, one that allows more flexibility to measure the relationships between covariates and incidence rates and that allows a wide array of additional variables to be added.

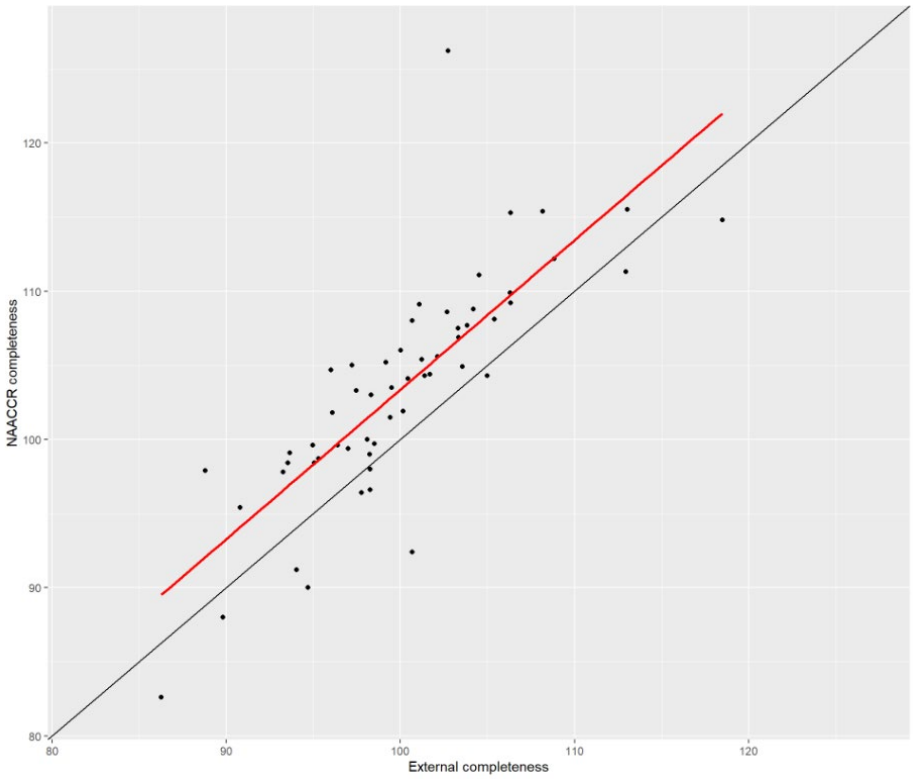

Figure 3. Comparison of existing NAACCR completeness method with external method for cases diagnosed in 2017. The red line is the best-fit line between the two variables (R^2 = 0.64); the black line is the line of equal values.

Secondary Process Measures

Recognizing that no universal agreement exists between the proposed internal and external methods and that a registry may perform poorly on one or the other despite its implementing best practices to ensure complete case ascertainment, the Statistical Expert Panel further proposed a series of five process measures as a third indicator of completeness. The process measures are premised on the idea that the overall mix of cases reported to a registry is generally consistent in terms of site distribution, clinical characteristics, and types of reporting sources when compared to other registries. If one or more of these is out of balance, it may be suggestive of wider problems with the data collection process. In contrast, if each of these is within normal parameters, then confidence in the adequacy of the overall data completeness would increase. The Statistical Expert Panel proposed five such measures for consideration. Although thresholds are suggested for each of these measures, they could be modified. The thresholds were based on input from registry directors and national and international practices.

1. Percentage of cases with ill-defined site. The anatomic site of origin of a tumor is among the most fundamental pieces of information that is collected. When this is absent, very little can be done with the case analytically, and such cases are rarely included in surveillance and research activities. Under the reasoning that missing data have a strong tendency to cluster, the proportion of cases with an ill-defined site can be seen as a marker for the existence of additional cases that were not reported at all. This measure is sometimes used by registries in other areas of the world.

Figure 4 shows that in no registries were more than 3 percent of all cases coded to ill-defined site and in one registry more than 2.5 percent of cases were coded to ill-defined site. The seven yellow points correspond to seven registries under secondary review—that is, they achieved favorable completeness scores based on either the internal or external methods but not on both. These are drawn from the 10 points in the red or yellow zones in Figure 1, after removing three that had a reasonable probability of exceeding the threshold after accounting for uncertainty related to registry size (this is explained further in the Sample Report following this section). In Figure 4, each of these seven points has a typical value relative to other registries. The highest-valued registry here is an outlier, falling outside the whiskers of the box-and-whiskers plot, defined here as exceeding the 75th percentile by more than 1.5 times the interquartile range. The red dashed line at 3 percent indicates a possible threshold for this measure, although 2.5 percent or any value that is an outlier also could be justified.

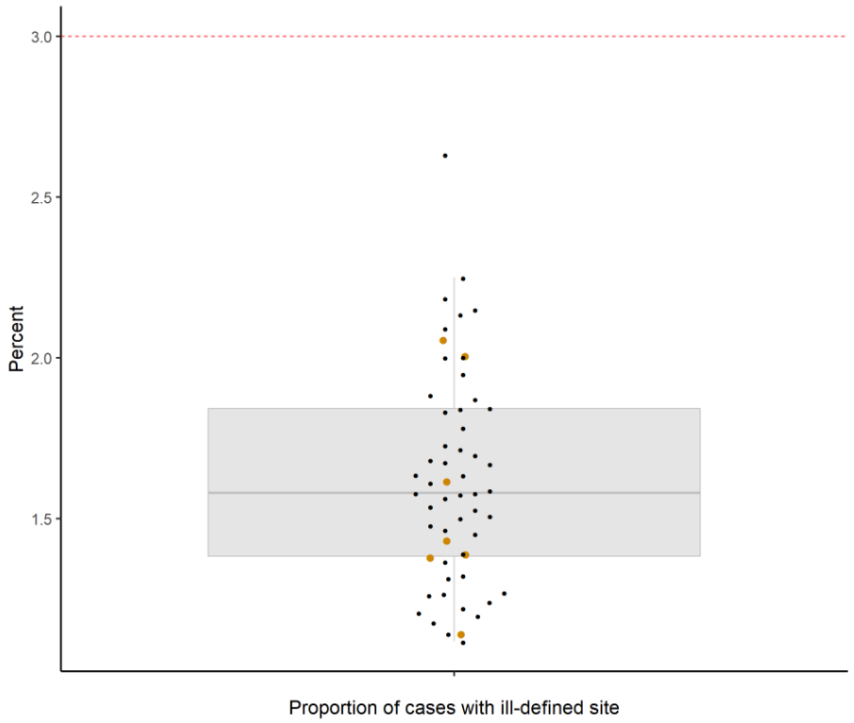

Figure 4. Proportion of cases with ill-defined site, by registry, 2017 diagnosis. Each point corresponds to a registry. Yellow points represent registries of potential concern as explained in the text.

2. Proportion of myeloma and leukemia cases. Focusing on cancer sites that are known to have a tendency to be underreported or to have substantially delayed reporting can be indicative of more widespread reporting issues. In contrast, if a registry appears to have good reporting for these sites, it is more likely that it has good reporting for all sites. The two major site groupings with the largest delay factors as calculated and published by SEER in recent years are, by far, leukemia and myeloma. For cases diagnosed in 2017 and submitted in 2019, the delay factor for leukemia was 1.13 and myeloma was 1.11, compared with 1.04 for all sites combined. The delay factors for all other individual sites tabulated were between 1.03 and 1.05, with the exceptions of uterus (1.02), prostate (1.06), and liver (1.06). Figure 5 shows the proportion of leukemia and lymphoma cases by registry. The only outlier was a registry with a value just above the proposed threshold of 3 percent, but it was not among the seven registries

of concern. This could indicate that this registry is generally complete but one may want to look at the reporting of these two sites more specifically. It is possible, of course, to meet a data completeness standard while being deficient in a specific cancer site. The proportion of myeloma/leukemia also is influenced by the underlying cancer risk in the population. In particular, the registries that tend to be near the bottom of this distribution (those around 4 percent) tend to be those with very high percentages of white populations. This raises the possibility of using race-adjusted proportions rather than absolute proportions, which is not presented here but would be easy to implement.

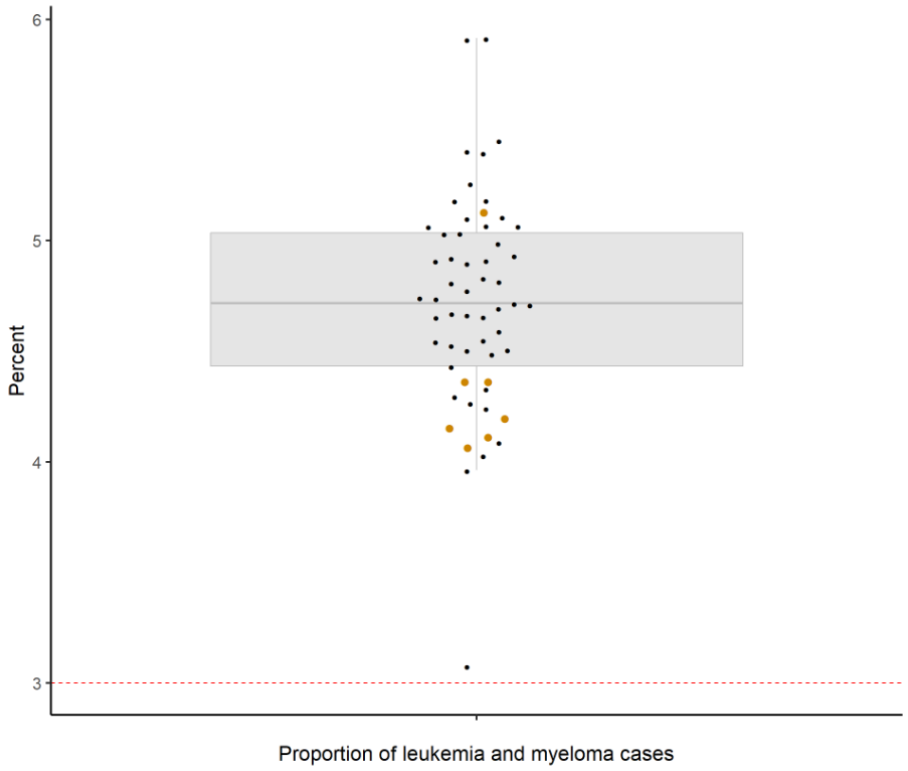

Figure 5. Proportion of leukemia and myeloma cases, by registry, 2017 diagnosis. Each point corresponds to a registry. Yellow points represent registries of potential concern as explained in the text.

3. Percent of brain tumors with benign behavior. The collective body of years of national cancer data reporting suggest that about 70 percent of all brain tumors are benign (Ostrom et al., 2020). A central registry that deviates too far from this range may have a problem with either benign or malignant tumors' being underreported. Figure 6 shows one severely outlying registry with a value well below 50 percent and a second registry exactly at the proposed threshold of 55 percent. The latter is among the seven registries of concern. No registries exceed the other proposed threshold of 80 percent. The registry falling below 50 percent, incidentally, has shown this pattern year after year. Again, it may be indicative of a problem with a specific type of reporting that is not sufficient to impact the overall completeness by a large degree.

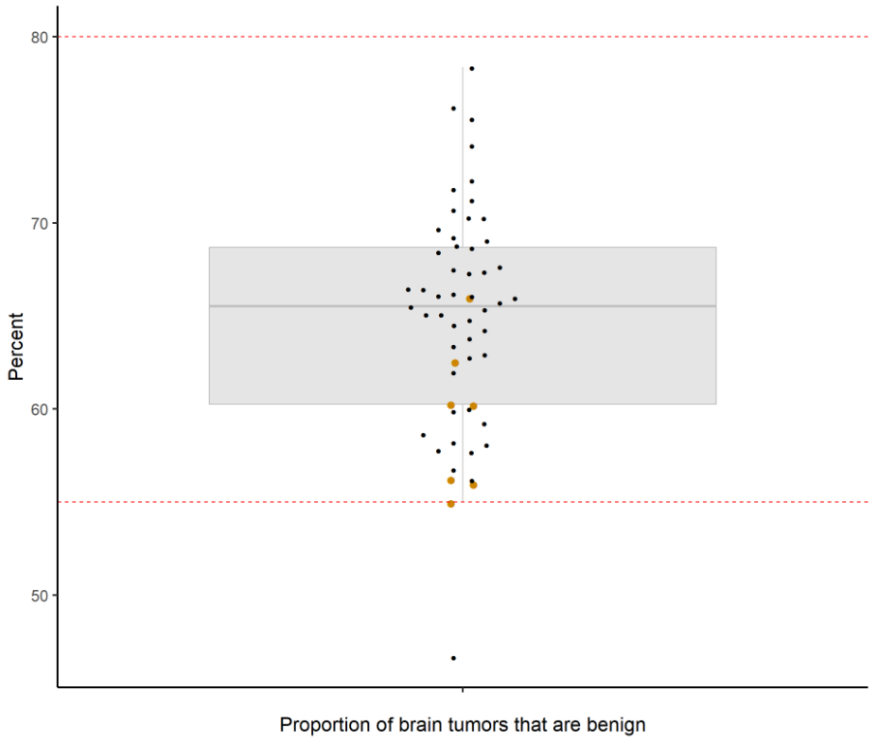

Figure 6. Proportion of brain tumors that are benign, by registry, 2017 diagnosis. Each point corresponds to a registry. Yellow points represent registries of potential concern as explained in the text.

4. Percentage of cases that are microscopically confirmed. Over recent years, approximately 94 percent to 95 percent of all reported cancers have been microscopically confirmed nationally, and this figure exhibits little variation among registries (CDC, 2020). When this value falls far outside of this range, it can indicate potential underreporting of either clinical or pathologic cases. Figure 7 indicates that four registries fell below a proposed threshold of 92 percent, but none of these were among the seven registries of concern, and none qualified as outliers. No registries exceeded the proposed upper-limit threshold of 97 percent.

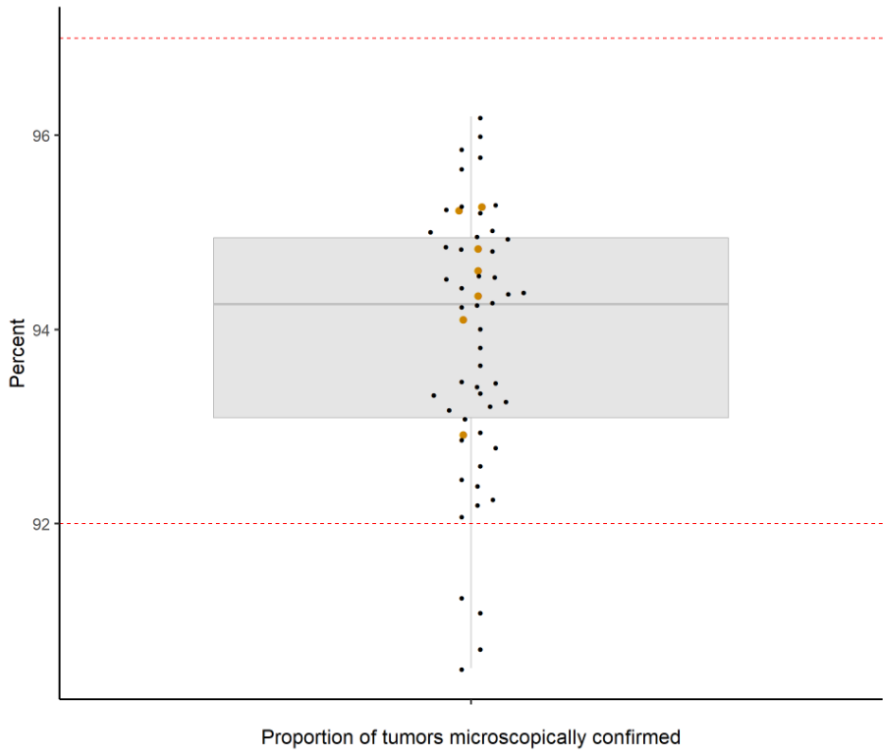

Figure 7. Proportion of tumors microscopically confirmed, by registry, 2017 diagnosis. Each point corresponds to a registry. Yellow points represent registries of potential concern as explained in the text.

5. Proportion of death certificate only (DCO) cases. As proportion DCO cases is already a data certification standard, this measure has a certain redundancy, but its use here is not entirely redundant. Generally speaking, the correlation between DCO proportion and completeness should be high, because death certificates function as a primary backstop to detect missed cases. If a cancer diagnosis is not reported while a patient is alive, it will be reported on the death certificate if that cancer is a primary cause of death, although recommended practice is to also review cases where cancer is listed as a contributing cause of death. This practice does not mean that death certificates pick up all missed cases, but rather that death certificates pick up a substantial proportion of the missed cases. If a DCO rate is unusually high, therefore, in the case of disagreement between the internal and external modeling methods, the balance tips in favor of incomplete reporting. In contrast, a registry with a low DCO rate would be tipped in favor of complete reporting. In Figure 8, two registries are seen to have exceeded the existing standard of 3 percent, neither of which was among the seven registries of concern.

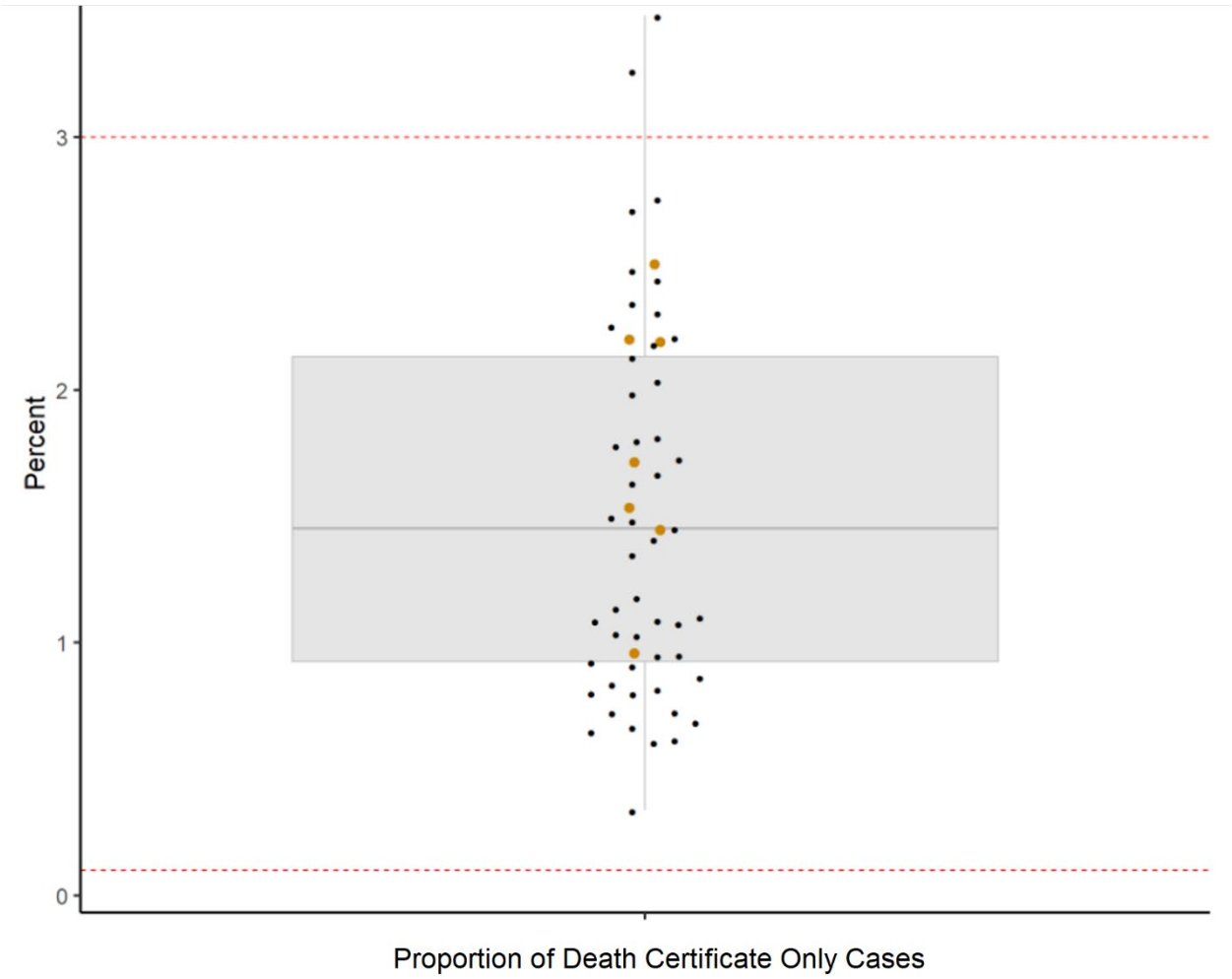

Figure 8. Proportion of tumors reported only by death certificate, by registry, 2017 diagnosis. Each point corresponds to a registry. Yellow points represent registries of potential concern as explained in the text.

In addition, we are proposing that there also be a minimum threshold for DCO cases. Occasionally, registries have reported zero or virtually zero DCO cases, which is implausible. (There will always be a very small share of patients who die at home from cancer without ever being treated, for example). We are proposing to set this threshold at 0.1 percent. No registries were near this threshold.

Summary of secondary process measures. Among the seven registries for which there was a suggestion of a problem with reporting completeness because of falling below either the internal or external threshold, all seven met the secondary process measure thresholds, although one was exactly at the proposed threshold for the proportion of brain cancers with benign behavior. Using the logic of our proposed approach, each of these registries would meet the standard for completeness.

Sample Report

In this section, we present an example of the kind of information that could be conveyed to each registry. Each state would be issued a report comprising three tables. The first table (appearing as Figure 9 in this report) reports the internal and external completeness scores for the most recent data submission. The completeness scores are the ratios of the observed to expected numbers of cases, which also are provided. The small differences in the observed counts reflect cases with unknown age and/or sex that were included in the internal method, but not the external method, which requires these values to be known. Also in this table are the 95 percent confidence intervals around the completeness scores and the probability that the score is above a specific threshold. As we have been doing throughout this report, we chose scores of 98 for the internal method and 92 for the external method, but any other value can be substituted here. It is recommended that registries assess these measures in the context of their own reporting before thresholds are set and applied.

(registry name) All Sites Completeness Estimates
Submission Year = 2019; Diagnosis Year = 2017

Internal				External			
Observed	Predicted (Delay-adjusted)	Completeness (95% CI)	Probability of completeness > 98	Observed	Predicted	Completeness (95% CI)	Probability of completeness > 92
27,084	27,348	99.0 (96.6, 101.4)	0.80	27,084	28,100	96.4 (95.1, 97.7)	> 0.99

Figure 9. Sample report table of the individual registry report, showing internal and external completeness statistics. CI: Confidence Interval

Including probabilities above a threshold accounts for the vast differences in registry sizes. If a large registry (for example, Texas) and a small registry (for example, Vermont) each had an internal completeness score of 97, the likelihood that Vermont's value is a chance fluctuation is much higher than it would be for Texas, given Vermont's much smaller case load. Elsewhere we have used the liberal assumption that a probability above 20 percent meant that the registry's score was close enough to meet the threshold. Note that when a registry's score exactly meets the threshold, the probability of exceeding the threshold is exactly 50 percent—the addition or deletion of a single case would move the score to just above or just below the threshold.

The second table (Figure 10) shows the numbers of reported and expected cases and the associated internal and external completeness scores by cancer site. Registries may use this information as general guidance to help determine which specific sites may be underreported. Not every cancer site that is shown to be underreported using either the internal or external measures is necessarily problematic. Rather, registries should evaluate these measures based on knowledge of their own operations and examine further those that match their own experience. A low score on both measures would indicate a stronger candidate for review.

(registry name) All Sites Completeness Estimates
Submission Year = 2019; Diagnosis Year = 2017

	Internal			External		
Site	Observed	Predicted (Delay-adjusted)	Completeness	Observed	Predicted	Completeness
All Sites	27,084	27,348	99.0	27,084	28,100	96.4
Brain and ONS	336	346	97.1	336	354	95.0
Breast (Female)	3,691	3,864	95.5	3,691	4,081	90.5
Cervix	238	229	103.9	238	213	111.7
Colon and Rectum	2,525	2,631	96.0	2,525	2,383	106.0
Corpus and Uterus NOS	665	684	97.3	665	788	84.4
Esophagus	284	284	99.9	284	292	97.1
Kidney and Renal Pelvis	1,083	1,090	99.3	1,083	1,066	101.6
Leukemia	690	683	101.0	690	761	90.7
Liver and IBD	506	542	93.3	506	526	96.1
Lung and Bronchus	3,929	3,865	101.7	3,929	4,237	92.7
Lymphoma	1,085	1,041	104.2	1,085	1,218	89.1
Melanoma of the Skin	1,330	1,510	88.1	1,330	1,351	98.5
Myeloma	440	424	103.7	440	465	94.7
Oral Cavity and Pharynx	802	822	97.6	802	752	106.7
Ovary	343	350	98.1	343	320	107.2
Pancreas	733	814	90.0	733	829	88.4
Prostate	3,894	3,618	107.6	3,894	3,547	109.8
Stomach	429	390	109.9	429	376	114.1
Urinary Bladder	1,099	1,123	97.9	1,099	1,168	94.1
Other Sites	2,982	3,090	96.5	2,982	3,373	88.4

Figure 10. Sample report table of individual registry report showing internal and external observed and expected cases by site. ONS: Other Nervous System, NOS: Not otherwise specified, IBD: Intrahepatic bile duct.

The third table (Figure 11) shows internal and external completeness scores by site and year. This table is intended to assist registries in getting a sense of how their reporting has performed over time.

(registry name) Completeness Estimates by Site and Diagnosis Year
Submission Year = 2019

	Internal											External										
	Diagnosis Year											Diagnosis Year										
	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
All Sites	.	.	103	99	97	97	101	96	101	105	106	99	93	93	96	95	96	94	96	94	94	96	98	96
Brain and ONS	.	107	113	92	91	92	111	96	85	96	97	97	95	97	106	100	91	93	110	96	87	94	96	95
Breast (Female)	.	104	107	97	95	95	100	102	102	103	100	96	96	93	96	94	94	93	94	95	95	95	95	90
Cervix	.	124	95	116	94	101	115	106	115	108	111	104	98	112	94	112	98	99	117	106	108	103	115	112
Colon and Rectum	.	99	103	94	91	98	106	110	99	94	98	96	98	103	104	102	102	99	104	104	108	104	110	106
Corpus and Uterus NOS	.	101	102	95	102	93	95	98	103	98	96	97	86	82	81	77	86	79	83	81	85	85	79	84
Esophagus	.	109	96	103	97	101	92	99	90	107	95	100	96	101	95	102	100	105	94	104	93	105	96	97
Kidney and Renal Pelvis	.	96	102	103	94	90	103	93	93	99	97	99	90	93	97	102	101	95	105	101	99	104	104	102
Leukemia	.	123	112	101	90	99	100	97	102	101	100	101	76	93	93	93	82	84	82	83	86	86	88	91
Liver and IBD	.	113	117	103	103	103	95	102	93	98	101	93	78	81	90	83	89	99	84	92	84	89	96	96
Lung and Bronchus	.	100	105	100	98	97	97	95	95	100	103	102	98	95	102	95	97	97	99	93	94	94	94	93
Lymphoma	.	.	96	105	107	98	100	103	100	103	101	104	81	84	79	84	88	81	82	84	83	86	85	89
Melanoma of the Skin	.	103	102	99	89	84	109	89	94	123	124	88	97	98	105	108	109	101	106	88	86	98	106	98
Myeloma	.	102	99	106	117	93	105	108	109	104	112	104	84	91	83	87	95	79	86	89	92	90	98	95
Oral Cavity and Pharynx	.	92	98	98	101	93	101	99	96	100	102	98	125	109	111	109	113	104	112	107	106	106	108	107
Ovary	.	.	.	104	97	95	103	106	100	97	99	98	94	90	103	99	98	95	105	108	100	101	106	107
Pancreas	.	102	116	97	106	110	94	94	96	100	102	90	92	90	104	92	100	105	94	97	95	96	99	88
Prostate	.	103	94	95	94	92	90	95	94	113	117	108	95	93	94	97	102	99	103	102	99	106	108	110
Stomach	.	.	113	84	107	109	107	98	108	95	102	110	83	97	98	90	95	100	101	96	105	99	103	114
Urinary Bladder	.	105	101	98	105	103	92	105	95	97	93	98	85	89	89	86	95	94	85	98	90	91	90	94
Other Sites	.	102	109	100	96	95	96	97	99	102	100	97	84	86	90	87	86	84	84	84	86	90	93	88

Figure 11. Sample report Table of individual registry report showing internal and external completeness estimates by site and diagnosis year. ONS: Other Nervous System, NOS: Not otherwise specified, IBD: Intrahepatic bile duct.

Finally, the report contains the five secondary process measures that have been presented previously in this report, with the recipient registry's own data points labeled. See Appendix A.6 for full sample state reports.

A Note on Scale

In general, when using external methods, the expected count across all registries is set equal to the observed count across all registries, meaning that the average observed/expected ratio is 1 (or 100%) and that roughly half of registries will be above this value and roughly half below. Because most central registries in the United States are believed to have close to 100 percent completeness, the observed/expected ratio often is treated as if it is a direct measure of completeness, which is not true. Completeness has an upper limit of 100 percent, which is reached when all cancer diagnoses have been reported. The external completeness measure has an *average* of 100 percent, which is quite different. Although an average score of 100 percent is a familiar convention, there is no mathematical requirement for this, and it could be rescaled to any other value. For example, the average registry could be set at 800 so that the range in a typical year would be around 680 to 920, with values less than 720 of special concern. We encourage a change in the way the external completeness measure is discussed, replacing the concept of a percentage with that of a score or value, regardless of whether any rescaling is applied.

Summary and Suggestions for Further Development

This report has presented a multifactorial approach for assessing the completeness of case reporting to central cancer registries that draws on multiple independent measures. This approach yields completeness measures that are more robust than methods that have been used historically, while at the same time being more liberal, in the sense that incorporating a

broader set of criteria makes it less likely that a registry will be incorrectly identified as having data that is insufficiently complete.

These measures were presented to a cross-section of NPCR registries on December 21, 2020, to a positive reception. Our recommendation is that all NPCR-funded registries be given time to evaluate the proposed approach in depth and assess the implications for their own data before proceeding with any implementation. NAACCR plans to work closely with registries and the NPCR program to help registries explore these measures.

Once again, note that the various cutoffs and threshold values included here are for illustration only and include a mixture of values that have been used historically and others that have not been. The focus should not be on these threshold values but rather on the methods that generated them. After these indicators have been evaluated fully by the surveillance community, we may begin to discuss the utility and benefit of establishing common thresholds. In reviewing their reports, registries should consider each of the measures, even where they seem to contradict.

Over the long term, the delay factor is a quite good estimate of completeness. That the national delay factor at the 24-month submission point for all sites combined is about 1.04 means that registries were about 96 percent complete at the time of submission, assuming all cases were eventually reported. Obviously, because some cases will never be reported, this 96 percent represents an overestimate, but not a particularly large one. Registries employ many processes to capture delinquent cases and have a good sense based on decades of experience of where problems lie. It may not seem possible to quantify the never-reported cases, but this is not an uncommon problem in science. The field of wildlife ecology, for example, is routinely tasked with the problem of estimating a population size based only on limited sightings of animals, and a rich methodological literature exists around this problem.

Assume that after taking this into consideration, the average registry completeness at the time of 24-month submission ticks down to 95 percent. The question, then, is how to identify which registries are well below that. We obviously cannot wait 4 or more years to get the answer by seeing how the late cases trickle in. In fact, it would be nice to know this even sooner than 24 months, if possible. (Appendix A.4 discusses the implication of looking at data completeness after 12 months). One way to tackle this problem would be to take a deep dive into a large and representative sample of cases that were reported after 2 years to ascertain the pathways and mechanisms by which this happened. Are facilities sending in their cases years after the due date, are these cases coming from nontraditional reporting sources, are they coming out of suspense files within registries themselves because of past data quality issues or because of an oversight, are they patients who lived in multiple states or countries? Such a deep dive would not only help better predict what an initial completeness score might be, but also give registries immediate guidance in how to attack these problems at the present moment. An analysis of this type was not possible with a team comprising members not affiliated with central registries, with no access to this level of data. But it is something that could be undertaken within the existing NAACCR volunteer structure.

With respect to the methods described in this document, opportunities exist to refine them further. For example, in the external method, although no additional census or BRFSS or AHRF variables were found to significantly improve the model globally, it may be the case that additional variables would help on a site-specific basis. For example, there was some indication that one or more socioeconomic variables improved the predictions of breast cancer. For the secondary process measures, it may be possible to develop additional site-specific measures

beyond the ones proposed here for leukemia/myeloma and brain cancer. As with most aspects of our field, the models and methods are ever-changing, and the topic of data completeness should continue to be viewed as dynamic rather than closed. Increased emphasis on ensuring that registries are carrying out processes that increase confidence in the completeness of their data is warranted.

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The Statistical Expert Panel comprised a broad-based constituency including thought leaders in biostatistics of cancer surveillance. Members include the following:

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Eric J Feuer, Ph.D., Li Zhu, Ph.D., NCI
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Trevor Thompson, CDC
Joe Zhou, IMS

Additional Contributors—NAACCR staff and consultants and registry directors.

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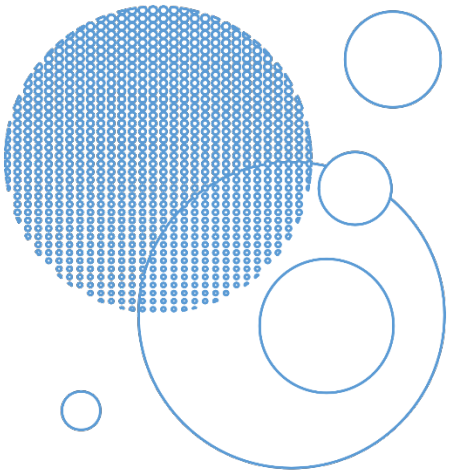

A Six Sigma Lean Green Belt Analysis of Electronic Pathology Reporting in Central Cancer Registries

January 2021

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Overview

Although hospitals have long been the primary source of cancer reporting to central registries, reporting by pathology laboratories helps to ensure that cancers diagnosed outside of the traditional hospital setting are captured by the central registry. Compared to hospital reporting, electronic pathology laboratory reporting to central registries is a relatively recent development, and each state has developed its own unique process for its management. As a result, a great deal of variability exists in the format and content of pathology reports submitted to central registries, as well as in the way reports are processed by each registry. A team composed of NAACCR staff, cancer registry subject-matter experts, and Lean Six Sigma Greenbelt students from Rutgers University undertook a study to identify the challenges and variations in the electronic pathology reporting processes used by four population-based state cancer registries and propose possible solutions to make these reporting process more efficient across states. Unfortunately, significant variability among registries in electronic pathology reporting processes makes it is difficult to identify measures necessary to make comparisons across registries. However, despite the unavailability of comparison data, the team was able to identify common themes across registries regarding the benefits and challenges of electronic pathology reporting. The key findings of the study are outlined below. The full report that follows includes detailed reporting of the Lean Six Sigma methodology used, benefits and challenges identified, and recommendations for process improvement.

Key Findings

- Electronic reporting by independent pathology laboratories is necessary to ensure complete ascertainment of cancer cases.
- Electronic reporting by independent pathology laboratories is an essential element of a population-based cancer surveillance system.
- Despite the availability of no-cost software, the current state of electronic pathology reporting involves significant manual processes requiring substantial staff time.
- Currently available no-cost software programs neither reduce processing time nor improve data quality and may, in fact, increase manual workload.
- Some central registries may not be receiving the full benefits of electronic pathology reporting because of insufficient capacity to handle the manual work necessary to fully utilize all reports.
- Large-volume registries experience greater challenges to electronic pathology reporting due to the manual workload, which is directly proportional to caseload.
- The current electronic pathology processes used by most central registries are not sustainable and will not support either the expansion of reporting by additional facilities or the increased caseload posed by a growing and aging population.

Introduction

Central cancer registries (CCRs) collect, analyze, and store cancer-related data for surveillance, research, and public health. Although specific requirements vary, all U.S. states and territories mandate the reporting of cancer to the central registry by hospitals and other health care facilities and providers, including laboratories. Pathology laboratories have long reported on paper or in non-machine-readable formats like PDF, but electronic pathology reporting in a standardized, machine-readable format is increasingly preferred and is thought to reduce the burden on cancer registries.

In general, electronic pathology reporting requires (1) identifying reportable cases from among all laboratory specimens, (2) ensuring secure transmission of the reports from the laboratory to the CCR, and (3) coding of key data elements, such as patient and tumor identifiers, using cancer registry standards. Most registries accomplish this using a tool provided by either the Centers for Disease Control and Prevention (CDC) or the National Cancer Institute (NCI). The CDC provides registries with access to its Public Health Information Network Messaging Service (PHIN-MS) for identification and transmission of cases and with eMaRC+ software for coding. The NCI-supported software E-Path, managed by Inspirata, Inc., accomplishes all three steps. Registries have incorporated these systems into their general operations in different ways based on their infrastructure, caseload, available resources, and overall experience. Variations within the reporting process can lead to barriers that may negatively impact the timely collection of cancer data.

Lean and Six Sigma are process improvement tools that have been widely used to increase efficiencies in production by various top-level businesses, including Motorola and Toyota. More recently, many in the health care industry have adopted a combined Lean Six Sigma (LSS) approach for enhancing the quality and efficiency of health care. A team of LSS Green Belt students and the faculty at Rutgers University Master of Health Administration program (RMHA) collaborated with the North American Association of Central Cancer Registries (NAACCR), the National Association of Chronic Disease Directors (NACDD), and the CDC to perform a Lean analysis of the electronic pathology reporting structure. The project aimed to apply the LSS framework to identify the challenges and variations in the electronic pathology reporting processes used by four states and propose possible solutions to make these reporting process more efficient across states. A secondary aim was to determine the utility of LSS in improving registry operations.

DMAIC is a key tool in the LSS model. The DMAIC methodology relies heavily on data to **D**efine, **M**easure, **A**nalyze, **I**mplement and **C**ontrol processes. Often applied to complex problems with an unknown cause, it is a cornerstone of the LSS paradigm. Unlike the familiar Plan, Do, Study, Act (PDSA), DMAIC places greater emphasis on pre-intervention planning and data collection with three distinct steps—Define, Measure and Analyze—before any improvement is implemented. A key advantage of DMAIC is its applicability to complex processes, making it an ideal tool for use in cancer registries.

The Rutgers LSS students conducted in-depth interviews with central registries in four states. The states were selected to represent the diversity of registries in the United States with regard to size, structure, and operations. The characteristics of the participating registries are summarized in Table 1.

Table 1. Participating Registry Characteristics

	Registry A	Registry B	Registry C	Registry D
Population	8.8 million	11.6 million	5.1 million	1.05 million
Registry software system	SEER DMS	Registry Plus	Registry Plus	Registry Plus
Pathology transmission system	Inspirata E-path* & PHIN-MS	PHIN-MS	PHIN-MS	PHIN-MS
Pathology screening/ coding system	Inspirata E-path* & SEER DMS	eMaRC+	eMaRC+	eMaRC+
2016 cancer incidence (invasive)	52,065	66,927	27,921	6,090

*Registry A receives reports from hospital-based laboratories and some independent laboratories through Inspirata E-path; only independent laboratory pathology reporting was included in this analysis.

*D*MAIC: Define

The Define phase of DMAIC identifies the project goals and deliverables. In this case, it also required the LSS team to develop a general understanding of central registry operations. The tools used in this phase of the Lean Process were the Project Charter, Stakeholder Analysis, and Process Maps.

Project Charter

A project charter introduces the project and defines the project scope, problem statement, and objectives, as well as the roles and responsibilities of the team members. After thorough consideration and consultation with NAACCR staff and registry subject-matter experts, the LSS team generated the project charter shown in Figure 1.

Lean Project Charter

Start Date: 12/05/2019
Planned End Date: 6/15/2020

Problem Statement: There is uncertainty around the best process for using electronic pathology reports so as to maximize their value in improving completeness and timeliness while reducing the extra manual labor that surrounds their use.

Objectives: (1) To define how four diverse model states process electronic pathology reports; (2) To assess the differences in efficiencies and outcomes associated with various electronic pathology reporting processes; and (3) To identify defects and opportunities for improvement within the current processes.

Project Scope Information:
- In scope: Pathology reports received in machine-readable structured electronic format from independent lab by the four model cancer registries and the methods used to process them.
- Out of scope: Pathology report structures, state laws & regulations, hospital-based lab reports

Executive Sponsor(s): Stephanie Hill & Ann Marie Hill

Project Owner: Betsy Kohler

Process Improvement Facilitators: Jill Anderson & Green Belt Students

Ad Hoc Member(s): NAACCR Consultants

Figure 1. Project charter.

Stakeholder Analysis: ARMI

ARMI is a project management tool that scrutinizes the stakeholder (team) involvement in any project. It represents the different levels of support required, and the acronym stands for **A**pproval of team decisions; **R**esource to the team, who will provide expertise and skills on an ad hoc basis; **M**embers of the team whose expertise is needed regularly; and an **I**nterested party who will be continuously informed on direction and findings. The ARMI worksheet in Figure 2 indicates various levels of support and involvement for the team.

Key Stakeholders	Define	Measure	Analyze	Improve	Control
Stephanie Hill	A, R, I	A, R, I	A, R, I	A, R, I	A, R, I
Betsy Kohler	A, R, I	A, R, I	A, R, I	A, R, I	A, R, I
Jill Anderson	A, R, M, I	A, R, M, I	A, R, M, I	A, R, M, I	A, R, M, I
Ashli Clarke	A, M, I	A, M, I	A, M, I	A, M, I	A, M, I
Sabrina Caramant	A, M, I	A, M, I	A, M, I	A, M, I	A, M, I
Nida Rahman	A, M, I	A, M, I	A, M, I	A, M, I	A, M, I
Melissa Beatty	A, M, I	A, M, I	A, M, I	A, M, I	A, M, I
Aakanksha Deoli	A, M, I	A, M, I	A, M, I	A, M, I	A, M, I
Lori Havener	A, I	A, I	A, I	A, I	A, I
Ann Marie Hill	A, R, I	A, R, I	A, R, I	A, R, I	A, R, I
NAACCR Consultants	A, R, I	A, R, I	A, R, I	A, R, I	A, R, I

Communication Plan			
Information or Activity	**Information Channel**	**Who**	**When**
Project Status	Email	PI Facilitators, GB students, consultants	Weekly
Tollgate Review	Email, in-class review	PI Facilitators	Weekly
Project Deliverables	Emails, Group Me, Phone	GB Students	Weekly

A – Approval of team decisions
R – Resource to the team; one whose expertise and skills may be needed on an ad hoc basis
M – Member of the team, one whose expertise will be needed on a regular basis
I – Interested party; one who will need to be kept informed on direction and findings

Figure 2. ARMI worksheet.

Process Maps

A process map illustrates the set of activities carried out to complete a process. Process mapping helps to visualize the problems and errors within the process and to identify opportunities for improvement. In this case, the process maps also demonstrate the variability in how different states implement electronic pathology reporting. The process maps for electronic pathology reporting were developed based on in-depth discussion with each of the four model states (Figures 3–6).

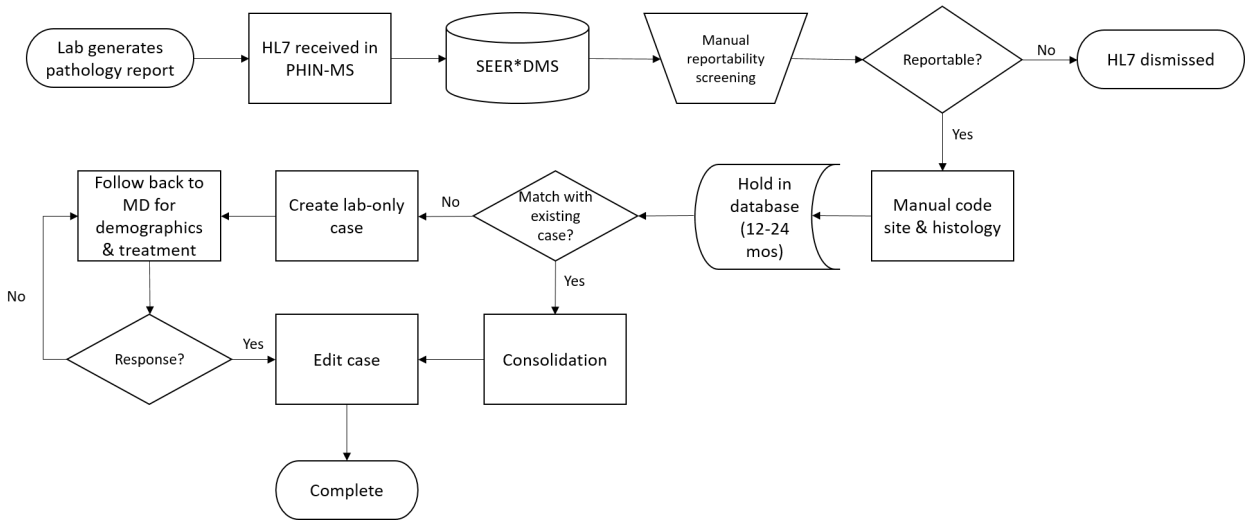


Figure 3. Registry A electronic pathology process map.

Key points

- Registry A receives electronic-pathology reports from independent laboratories through both PHIN-MS and Inspirata E-Path.
- All electronic pathology reports are imported into the main registry database (SEER*DMS) as they are received.
- Registry A manually screens and codes all electronic pathology reports from independent laboratories within the SEER*DMS system (40–50 reports per hour).
- eMaRC+ is not used by Registry A because of the quality of auto-coding and because it would convert all electronic pathology reports to NAACCR Abstract (NA) format. The registry workflow within SEER*DMS requires that electronic pathology reports remain in HL7 format.
- Pathology reports are used to create cases only after cases from all other sources have been processed.

Registry A uses a combination of Inspirata E-Path and PHIN-MS to receive electronic pathology reports from both independent and hospital-based laboratories. This project focused on independent laboratory reporting, but it should be noted that hospital-based laboratory reporting can be used to validate hospital reporting completeness, and the registry credits these reports with identifying thousands of otherwise unreported hospital cancer cases each year with minimal effort on the part of the central registry. Registry A receives and processes nearly 129,000 electronic pathology reports per year from hospital-based and independent laboratories but manually screens and codes only reports of hematopoietic cancers from hospital laboratories and all reports from independent laboratories, totaling more than 40,000 such reports annually. All automated and manual screening and coding are performed within the main cancer registry system, SEER*DMS.

Registry A tested the use of eMaRC+ software but identified several of the following drawbacks that made its use counter-productive:

- The need to create a full NA in eMaRC+ requires manual work that is unnecessary in the majority of cases. Most NA data items are not available in a pathology report but already exist in an NA in the registry database. Therefore, coding and reviewing them in eMaRC+ is redundant and represents a non-value-added step.

- The workflow in the registry database, SEER*DMS, requires electronic pathology reports to be in HL7 format, which cannot be produced by eMaRC+.

- Auto-coding and screening performed by eMaRC+ is unreliable and does not reduce or eliminate the need for manual review.

During the consolidation process, electronic pathology reports are used to validate clinical information, such as date of diagnosis, primary site, histology, prognostic factors, and treatment. Data from hospital cancer registries often are found to be incorrect or less specific when compared to information in the pathology report. These errors are used as an opportunity to identify hospital registrar training needs.

Registry A identified rapid case reporting, identification of missed cases, and validation of clinical information as some important benefits of electronic pathology reporting. A major challenge to pathology reporting for Registry A is the volume of manual work involved in screening and coding electronic-pathology reports from independent laboratories and in following back to physicians for demographic and other information for laboratory-only cases.

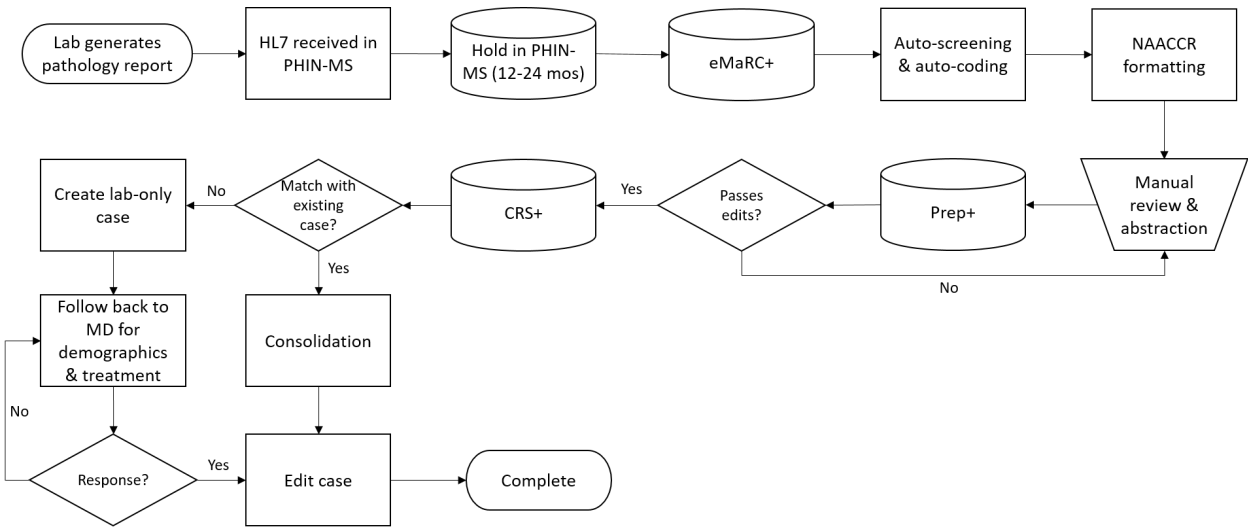


Figure 4. Registry B electronic pathology process map.

Key Points

- Registry B receives electronic pathology reports from independent laboratories through PHIN-MS.

- All electronic pathology reports are screened and auto-coded by eMaRC+ as a batch once per year.
- All electronic pathology reports are manually reviewed and edited after auto-coding in eMaRC+ because of the inaccuracy of eMaRC+ auto-coding and the need to complete additional fields in the NA to ensure it passes edits (2–6 reports per hour).
- All reportable electronic pathology reports are imported into the Registry B cancer registry database, CRS Plus.
- Pathology reports are used to create cases only after cases from all other sources have been processed.

Registry B receives electronic pathology reports from independent laboratories through PHIN-MS and processes them in eMaRC+. The advantage of the electronic pathology reporting that Registry B cited is receiving the pathology reports electronically to identify unreported cases and missing information.

However, Registry B experiences a few challenges with the process. The Registry B caseload is too large to manually look up each electronic pathology report in the cancer registry database. Without a way to electronically match the reports in eMaRC+ with the registry database in CRS Plus to identify otherwise unreported cases, Registry B must process all electronic pathology reports, which includes coding and editing an NA in eMaRC+ and Prep+. This contributes significantly to the manual workload involved in the process, which includes entering the data into eMaRC+ to complete the NA; running edits in Prep+ and correcting them in eMaRC+; finding the matches and deduplication; and following back with the physicians for missing information. Because all this work is manual, Registry B finds it very time-consuming. Registry B also noted that eMaRC+ auto screening for reportability is unreliable, and cases marked non-reportable often are reportable; 100 percent manual review is required to ensure that no cases are missed.

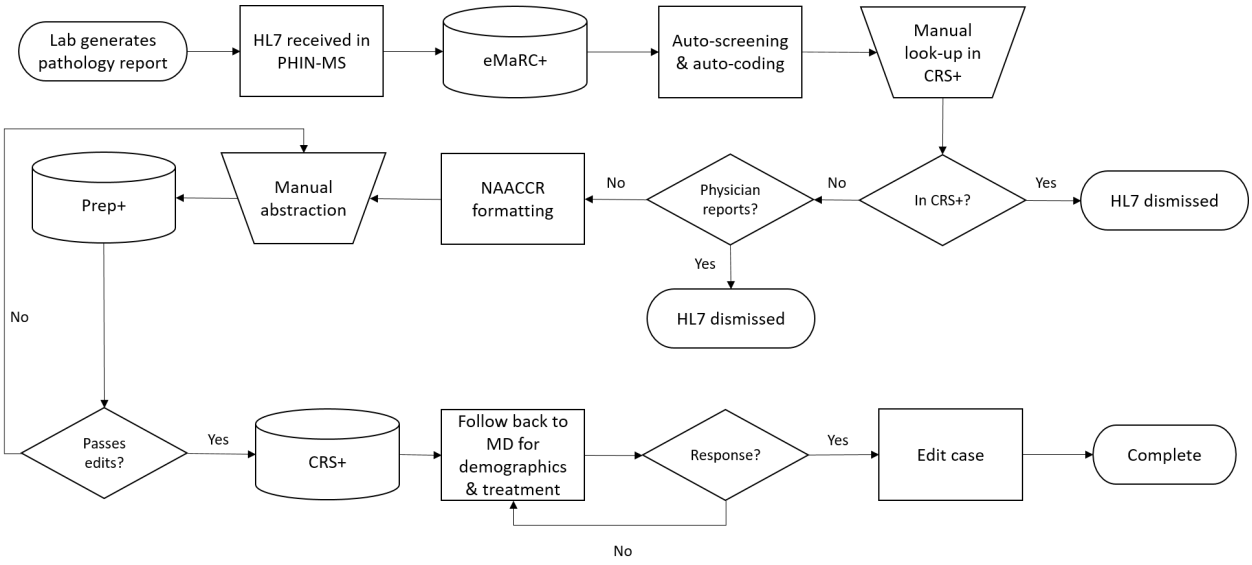


Figure 5. Registry C electronic pathology process map.

Key Points

- Registry C receives electronic pathology reports from independent laboratories through PHIN-MS.
- All electronic pathology reports are screened and auto-coded by eMaRC+ as they are received (within 5 days).
- Electronic pathology reports are manually looked up in the main registry database, CRS Plus.
- The Registry processes electronic pathology reports only for cases not already in CRS Plus or when the ordering physician reports to the CCR. The decision to process an electronic pathology report into the registry database is subjective, based on the reviewer's expectation of the probability of receiving the case from another source.
- NA are completed manually in eMaRC+ for all reportable electronic pathology reports.

Registry C receives electronic pathology reports from independent laboratories through PHIN-MS and processes them in eMaRC+ and Prep Plus. Staff manually review all electronic pathology reports to determine which to process into the registry database based on whether they expect to receive the case from the ordering physician. The reports are processed as they are received. Registry C identified the major advantage of the electronic pathology reporting process as its being a tool to find missing cases that otherwise were not reported.

The challenges that Registry C faces are similar to what other states face and include the need for extensive manual labor, lack of interoperability with other registry systems, and lack of integrated edit checks in eMaRC+.

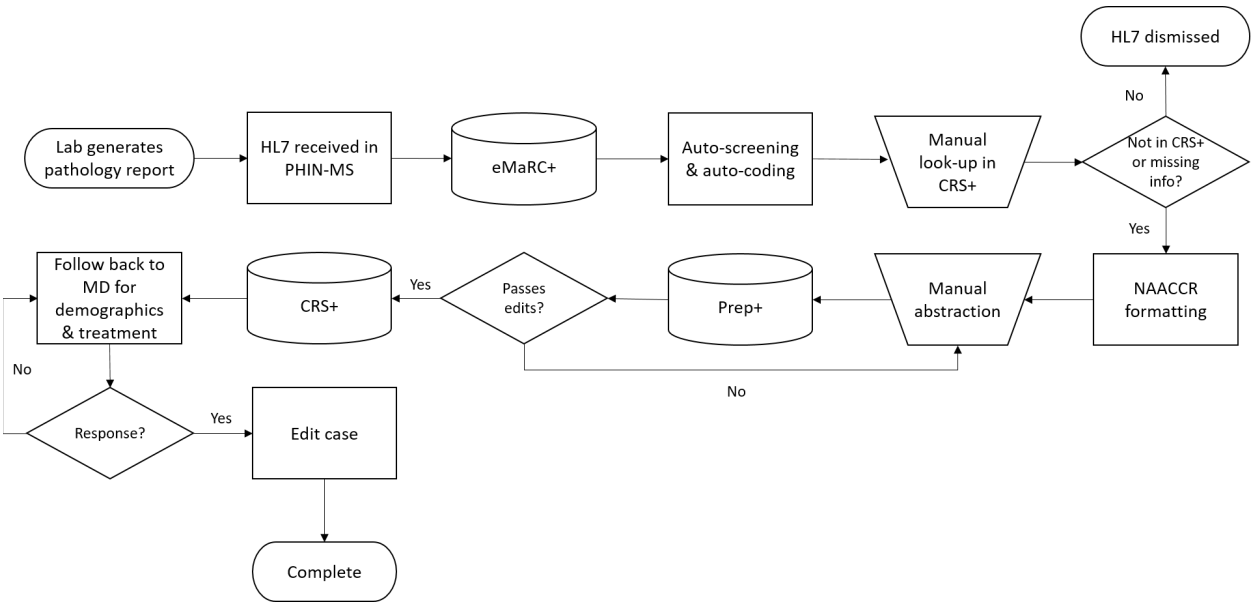


Figure 6. Registry D electronic pathology process map.

Key Points

- Registry D receives electronic pathology reports from independent laboratories through PHIN-MS.
- All electronic pathology reports are screened and auto-coded by eMaRC+ as they are received.
- NA are completed manually in eMaRC+ for all reportable reports.
- Cases are manually looked up in the registry database.
- Only electronic pathology reports for unreported cases or for cases with missing information are processed.

Registry D receives electronic pathology reports from four independent laboratories through PHIN-MS and processes them in eMaRC+ and Prep Plus. Registry D reported that the benefits of the electronic pathology reporting process were keeping records, identifying missing cases, and receiving information directly from pathologists.

In contrast, the biggest challenge for Registry D is receiving all the electronic pathology reports. Currently, only four laboratories send electronic pathology reports to Registry D; it is unknown how many laboratories are not reporting and how many cases may be missing from those laboratories. Registry D also reported the lack of automated screening and matching within the eMaRC+ as a challenge.

Threats and Opportunities

Based on the process maps and considering the cancer surveillance reporting structure and the importance of cancer reporting, the team identified potential threats and opportunities in the timely availability of quality cancer data (Figure 7). The most significant threats to cancer registries involve the expanding workload due to the rising number of cancer cases and the expansion of data items required for collecting, manually consolidating, and editing, combined with increasingly constrained financial resources. Central registries will continue to be expected to “do more with less.” Compounding this is the threat of a growing number of patients’ receiving cancer care outside the traditional hospital setting, requiring central registries to rely on reporting by nonhospital sources, such as independent laboratories.

Although cancer surveillance faces a number of threats, opportunities are open to the registry community. Technological advances in computational science have made artificial intelligence and advanced natural language processing more available than ever before. These tools have the potential to significantly improve the automated abstraction of data from unstructured text. Likewise, the availability of big data provides opportunities for linkages to supplement and enhance manual data collection processes. And last, the cancer surveillance community has vast collective expertise that can and should be leveraged in the development of new methods and best practices.

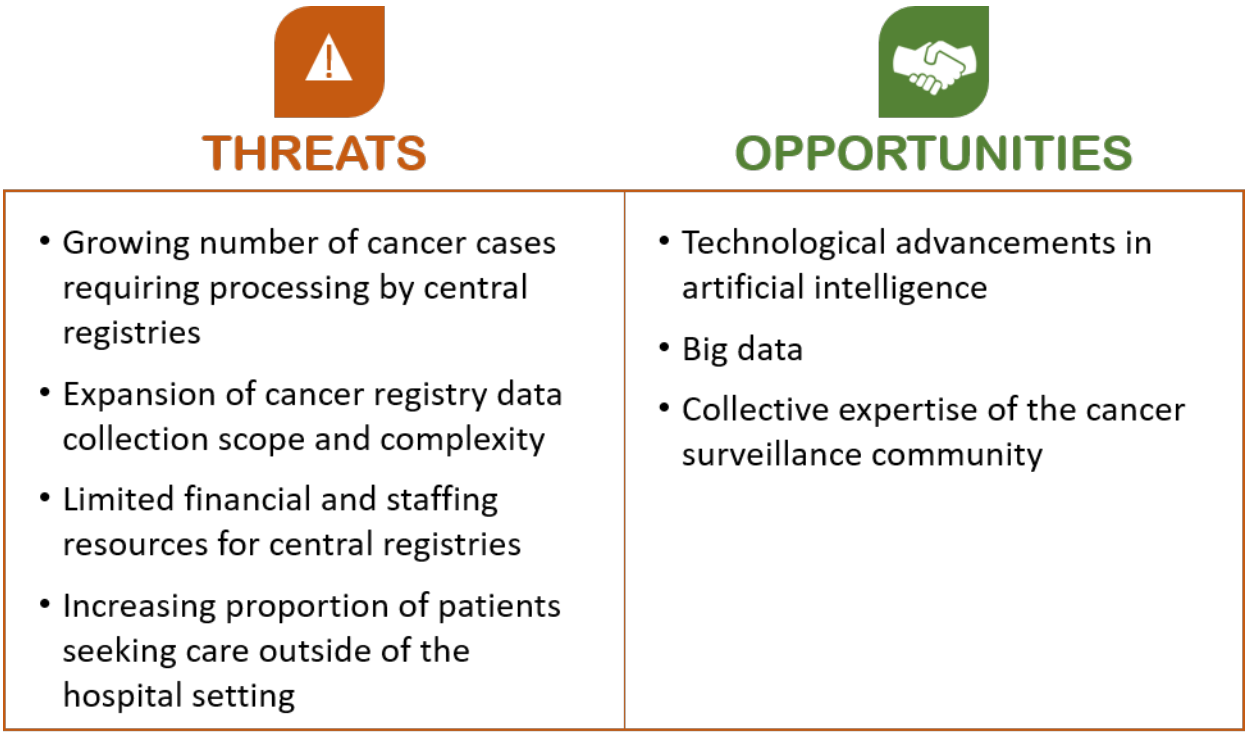


Figure 7. Threats and opportunities.

D*M*AIC: Measure

The Measure phase of DMAIC is fundamental to evaluating the assumptions made regarding the problems and errors within a process during the Define phase of a process improvement project. It further delves into the process and relies heavily on information collected from the subject-matter experts.

Because registries use different terminology to describe their processes, developing clear operational definitions was an important element in the Measure phase. For this project, the following operational definitions are used:

- **Consolidation:** Unification of all pertinent documents pertaining to a single cancer diagnosis
- **Screening task:** Reviewing reports to determine reportability and completeness of data
- **Abstract:** Summary of all information pertaining to a single cancer diagnosis
- **Gold Standard:** Meets reporting deadlines and internal best practices
- **Reportable:** Cases that meet criteria to be included in incidence calculations
- **Deduplication:** Process of eliminating duplicate copies

Data Collection Plan

Data were collected primarily through telephone interviews with key staff at each participating registry. NAACCR consultant subject-matter experts and executive sponsor were present for all interviews to assist the team in interpreting and summarizing information. Registries provided general process documentation for the LSS team to review ahead of the interview, and questions were designed to investigate the variations within the electronic pathology reporting process across the model states. The interviews focused on the advantages of the current electronic pathology reporting process, challenges faced, and state-specific recommendations to improve the process.

Although defining the process used by each registry was relatively straightforward, identifying a consistent set of metrics that could be easily collected across all four registries was more challenging. During a typical LSS project, team members would collect data through on-site observation. However, due to geographic distance, the short time frame of the project, and the nature of cancer registry work spanning many months, direct observation was not possible. The LSS team had to rely on data previously collected by each registry or on retrospective collection of data on processes already performed. The advantages and disadvantages of each method are discussed in Table 2.

Table 2. Data Collection Methods

Method	Advantages	Disadvantages
Data previously collected	• No additional data collection work	• Not available for all registries • Inconsistently collected across registries
Retrospective data collection	• Ability to apply consistent definitions across all registries	• Software-dependent • Limited availability of canned reports • Reliant on registry resources and knowledge of generating reports. • Not available for tasks performed outside of a software program

Significant time and effort were devoted to identifying metrics that could be provided by all four model registries. Several challenges were observed in one or more registries, impeding the team's ability to collect comparable data across all four registries:

- Registries do not regularly track process metrics.
- Registries lack the necessary experience in writing complex queries to extract process data from software applications.
- No-cost software applications lack easy access to metrics for monitoring processes.
- Different software applications are required to process electronic pathology reports, creating the need for manual labor.
- Metrics are not available for tasks performed manually (i.e., manual look-up)
- Differences in processes across registries make comparison of associated metrics challenging.

Data collected from each registry using a combination of methods are included in Table 3 and discussed below.

Table 3 Data Metrics Compared Across Model States

Measure	Registry A	Registry B	Registry C	Registry D
Population	8.8 million	11.6 million	5.1 million	1.05 million
Registry software system used	SEER*DMS	CRS Plus	CRS Plus	CRS Plus
Pathology transmission system	PHIN-MS & Inspirata E-Path	PHIN-MS	PHIN-MS	PHIN-MS
Pathology processing system	Inspirata E-Path & SEER*DMS	eMaRC+ & Prep Plus	eMaRC+ & Prep Plus	eMaRC+ & Prep Plus
Annual incident cases	60,000	75,000	30,000	6,000
Total cancer records received annually	300,000+	130,000	31,000	7,000
Number of electronic pathology reports received annually	130,000	2,900	Thousands	N/A¥
Number of electronic pathology reports processed annually into registry database	130,000	2,900	600–700	N/A¥
Number (%) of incident cases received from laboratories only (no other reporting source)	2,800 (4.7%)	N/A¥	600–700 (2-2.3%)	N/A¥
Number of consolidations performed annually	~45,000	~55,000	N/A¥	~7,500
Electronic-path reports imported into registry data	All	All reportable	Only unique	Only unique
Number of non-reportable cases	8,385 (2017)	450 (2017)	10%	Varies by facility, 1–100%
Number of manual screening tasks	40,675 (2017)	2,900	Thousands	N/A¥
Screening time	40–50 reports per hour	10–30 minutes per report (screening + data entry into eMaRC to complete NA)	20 minutes per report	1 week for all reports
Consolidation time (minutes per case)	~12	~10–30	N/A¥	~15–20
Consistently meets CDC 12-month completeness standard	Yes	No	No	N/A¥

¥Registry did not provide this information.

Registry A

With a population of 8.8 million, Registry A has approximately 60,000 incident cancer cases per year. Each year Registry A receives more than 300,000 individual records of cancer, including 130,000 electronic pathology reports. Registry A performs more than 40,000 manual electronic path screening tasks and 45,000 manual consolidation tasks each year. Pathology screening tasks, which include assigning reportability and coding primary site, histology, behavior, and grade, are performed at a rate of 40–50 tasks per hour. Consolidation tasks, which include visual editing of key data items and resolution of all edits, are performed at a rate of five tasks per hour. Registry A consistently meets the 12-month completeness standard.

Registry B

With a population of 11.6 million, Registry B has approximately 75,000 incident cancer cases each year. Registry B receives approximately 130,000 individual records of cancer annually, including 2,900 electronic path reports. All 2,900 electronic pathology reports are manually reviewed to validate eMaRC+ auto-coding and reportability and to complete the NA. These tasks are performed at a rate of 2–6 per hour. Registry B performs approximately 55,000 manual consolidation tasks each year, at a rate of 2–6 per hour. Registry B met the 12-month completeness standard for the first time in 2018.

Registry C

With a population of 5.1 million, Registry C has an annual cancer incidence of approximately 30,000 cases. Registry C receives approximately 31,000 individual reports of cancer each year, not including the thousands of electronic pathology reports received. Because Registry C manually screens electronic path reports and does not process reports for diagnoses already in the registry, it could not provide data on the total number of electronic pathology reports received each year beyond describing it as in the “thousands.” Registry C imports into its registry database approximately 600–700 electronic pathology reports annually for cases not reported by another source (mostly dermatology and urology cases). Registry C estimates that screening tasks are performed at a rate of 20 per hour. Registry C reported that it has never met the 12-month completeness standard.

Registry D

With a population of 1.05 million, Registry D is the state with the smallest population among the model states, with an annual cancer incidence of approximately 6,000 cases. Registry D performs approximately 7,500 consolidation tasks annually at a rate of 3–4 per hour. Registry D was able neither to provide data on the number of records received nor to report on its record of meeting the 12-month completeness standard.

Problem Areas in the Process Maps: Storm Clouds

Considering all the data collected, problem areas were identified for electronic pathology reporting for each state. These problem areas are identified as storm clouds in the process maps below.

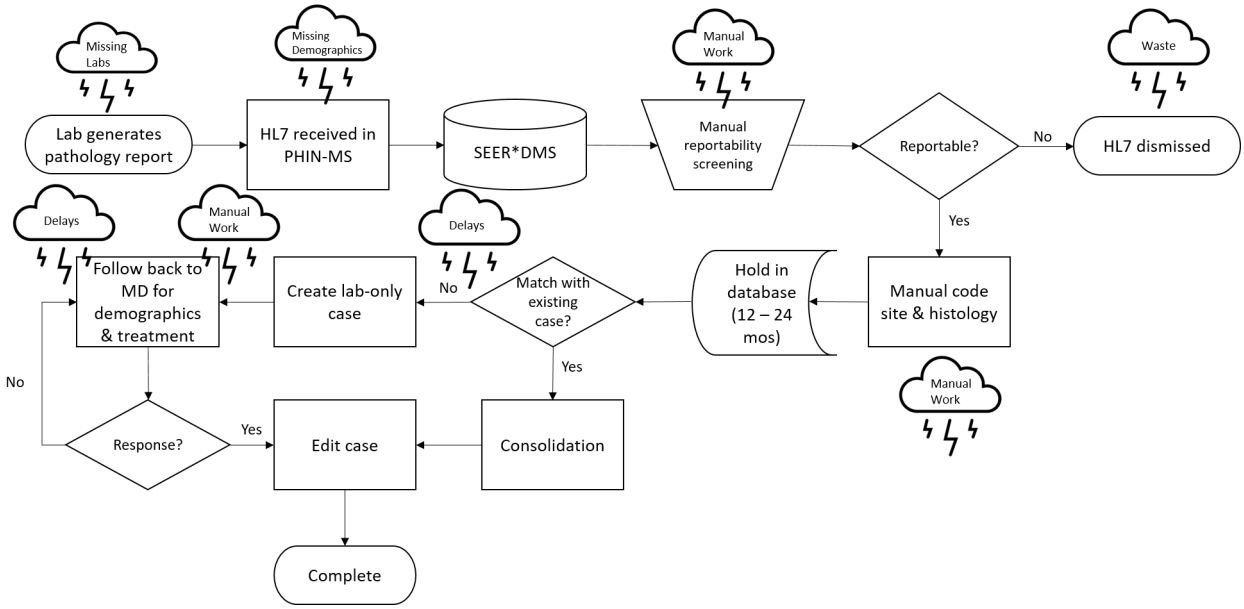


Figure 8. Registry A storm clouds

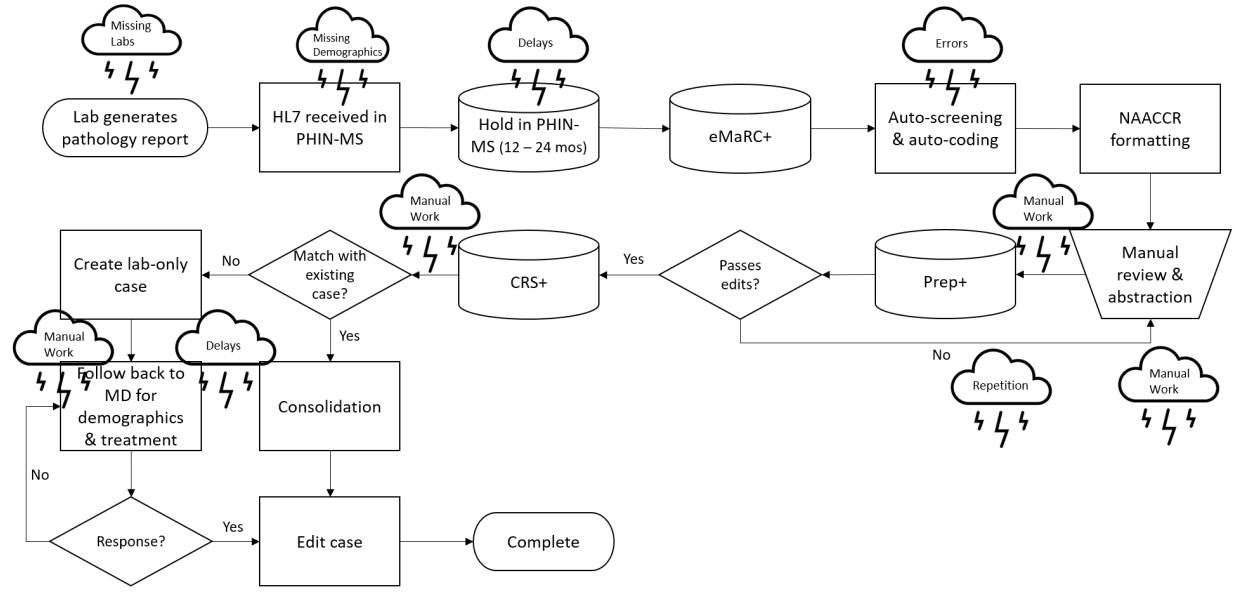


Figure 9. Registry B storm clouds.

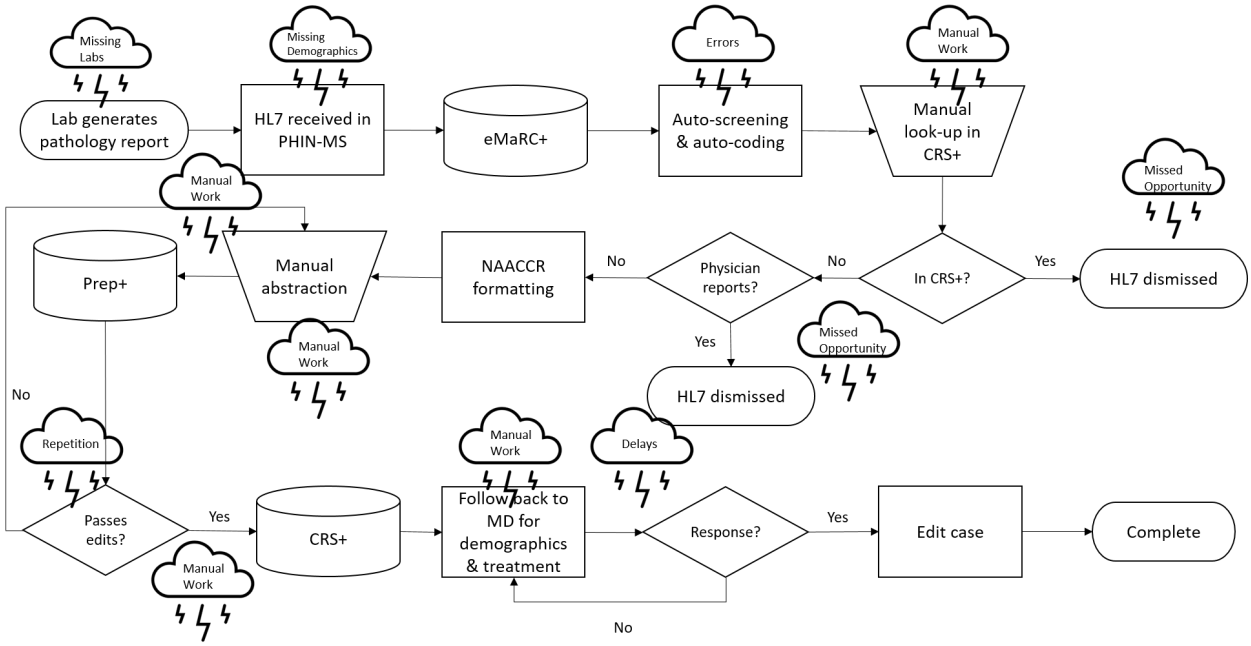


Figure 10. Registry C storm clouds.

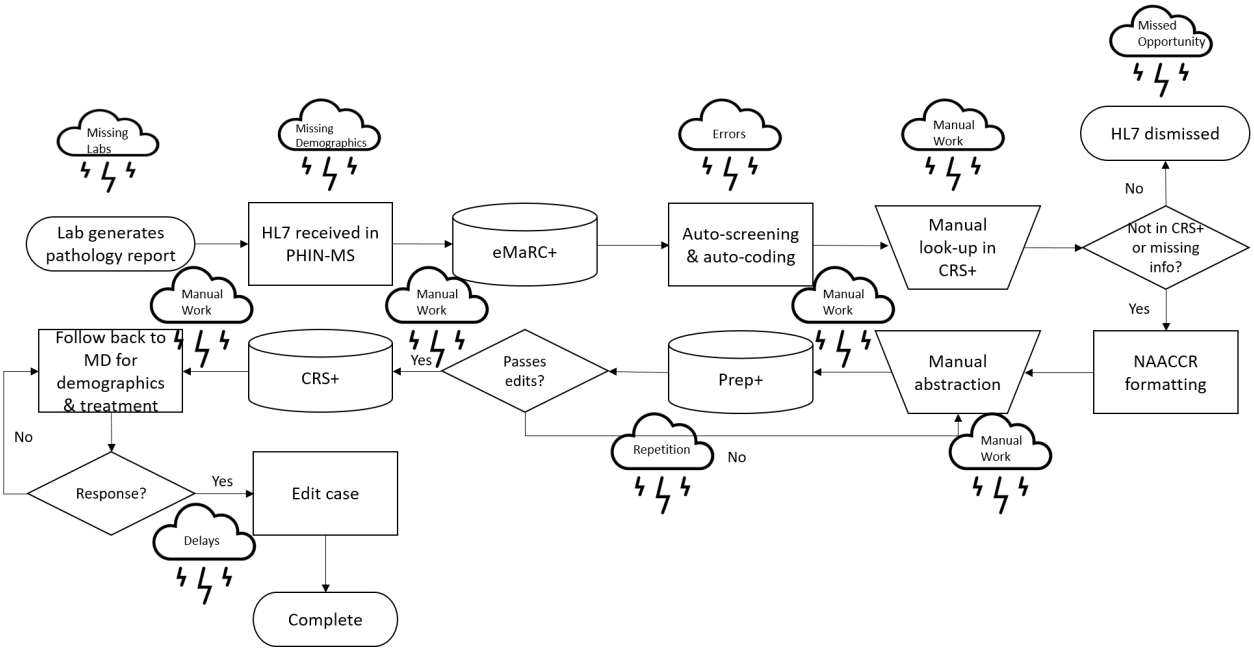


Figure 11. Registry D storm clouds.

Common Challenges Faced by Registries with E-Path Reporting Process

It is now well established that each state has a different electronic pathology reporting process and, therefore, each state's process has unique benefits and challenges that make it difficult to suggest common solutions. Furthermore, registries use electronic pathology reports to different degrees. However, some challenges are common to all four registries' processes. For example, a lack of interoperability between software systems is a common problem. Moreover, all four states require some degree of manual labor for processing electronic pathology reports and following back for additional information. Common challenges identified across all states are listed in Figure 12.

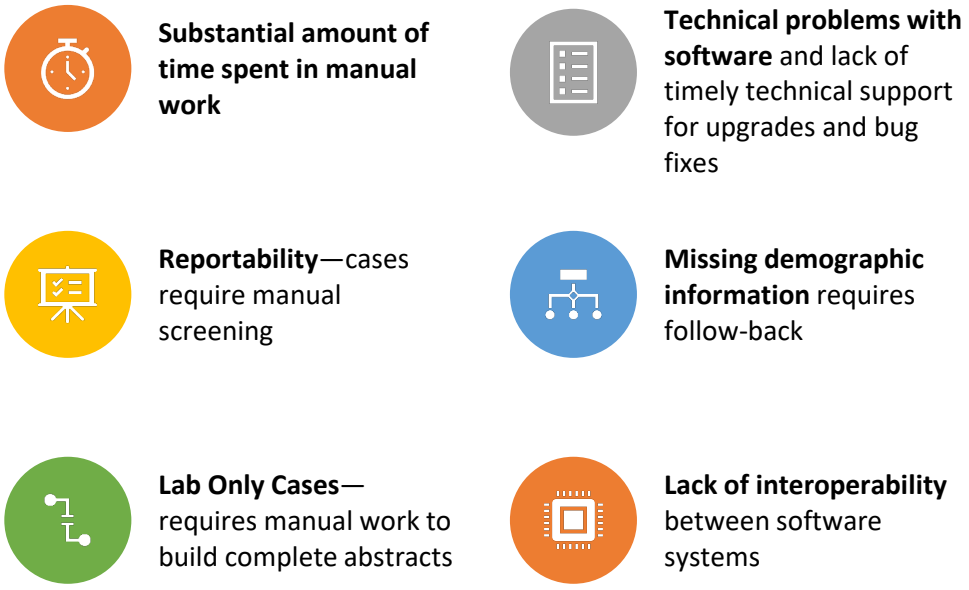


Figure 12. Common Challenges.

The key observations across multiple registries are summarized in Table 4.

Table 4. Electronic Pathology Benefits and Challenges Reported by Registries

Benefits				
	REGISTRY A	**REGISTRY B**	**REGISTRY C**	**REGISTRY D**
Identification of missed cases	Y	Y	Y	Y
Quality control	Y	Y	N	N
Collection of information missing from reports received from other sources.	Y	Y	N	Y
Education and training	Y	Y	N	N
Hospital case finding audits	Y	N	N	N
Challenges				
	REGISTRY A	**REGISTRY B**	**REGISTRY C**	**REGISTRY D**
Electronic-pathology reports missing key demographics	Y	Y	Y	N
Time-consuming manual follow-back	Y	Y	Y	N
Accuracy of eMaRC+ auto-coding and reportability	Y	Y	N	N
Duplicate electronic pathology reports	Y	Y	N	N
Creating NAs in eMaRC+	Y	Y	N	N
Managing edits in Prep Plus	N/A	Y	Y	N
Non-reportable cases submitted	Y	Y	Y	N
Technical problems with eMaRC+ and timely availability of upgrades	Y	Y	N	Y
Lack of interoperability/ integration of software	Y	Y	Y	Y
Lack of standardized process metrics	Y	Y	Y	Y
Lack of jurisdiction over national laboratories/reliance on CDC to onboard laboratories and address issues	N	Y	Y	Y

Benefits

The registries cited varying degrees of benefit from electronic pathology reporting, with all four registries reporting the identification of missing or otherwise unreported cases as the primary benefit. Between 2.3 percent and 4.7 percent of the registries' cancer cases were reported by laboratories as the sole source ("lab only"). This supports the role of electronic pathology reporting in ensuring complete ascertainment of cases. In fact, the one registry that consistently met the 12-month reporting standard also had the highest proportion of cases from laboratories only. Most of the registries also benefited from using electronic pathology reports to supplement missing or non-specific information pertaining to cases from other sources. Registries that process all electronic path reports (regardless of reporting by other sources) indicated an additional benefit of validating and correcting case information from other sources (e.g., date of diagnosis, histology, site-specific data items, treatment dates). The results of these quality control activities also were used for education and training. One registry also used hospital-based electronic pathology laboratory reports path reports to conduct case-finding audits of hospitals.

Challenges

Lack of interoperability—or communication—between software systems was a challenge cited by all four registries. Examples include the following:

- *Inability of CRS Plus to import and process HL7-formatted records.*

  Electronic pathology reports are received in HL7 format. Because the CRS Plus software cannot accept records in this format, they must first be converted to NA formal using eMaRC+.

- *Inability to filter electronic pathology reports in eMaRC+ based on cases already in CRS Plus.*

  Doing so would allow the registry to prioritize those electronic path reports that would create new cases and improve overall completeness while reducing manual workload. Smaller registries are currently manually comparing cases between the two systems, but this approach is not feasible for registries with large caseloads. One registry tested the use of LinkPlus as a possible solution but concluded that it did not ultimately reduce manual work.

- *Lack of edits built into eMaRC+.*

  Under the current system, electronic pathology reports in eMaRC+ are converted to NA format, which requires the manual coding of data items that do not exist in the electronic pathology record. Because eMaRC+ does not include edits, the cases must then be exported and processed through a separate edits software. Errors identified by the edits software must then be corrected in eMaRC+, the cases re-exported and run through the edits software again. This cycle continues until all edits are resolved. Registries reported this redundancy as a source of delay and frustration.

DMAIC: Analyze

The Analyze phase of DMAIC considers the data collected and dissects the problem further to explore the possible causes. As indicated in the previous section, the model states use methods to store and process information making this phase challenging to execute. After identifying two main problems in the electronic pathology reporting process, a root cause analysis was performed for each. Processes also were compared and contrasted across model registries.

Root Cause Analysis

As the name suggests, a root cause analysis is conducted to identify the root cause of the problems in the process under consideration. The “5 Whys” method was used to perform the root cause analysis on the main problem identified in the Project Charter: that uncertainties surround the best method of usage for electronic pathology reports (Figure 13).

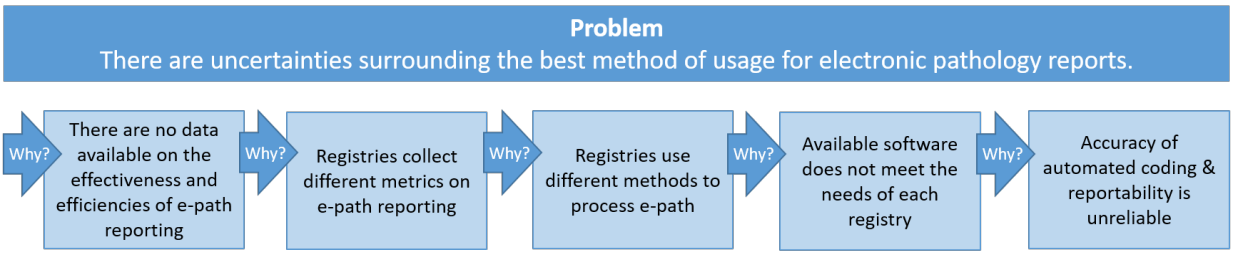


Figure 13. Root cause analysis—5 Whys

The root cause analysis identified deficiencies in the existing software as the root cause of the problem. Because of these deficiencies, each registry has each developed its own work-around processes that are primarily manual.

A second problem was identified during the Measure phase of the study: Electronic pathology reporting places a substantial manual burden on cancer registries. A second root cause analysis was used to examine the factors contributing to manual workload (Figure 14).

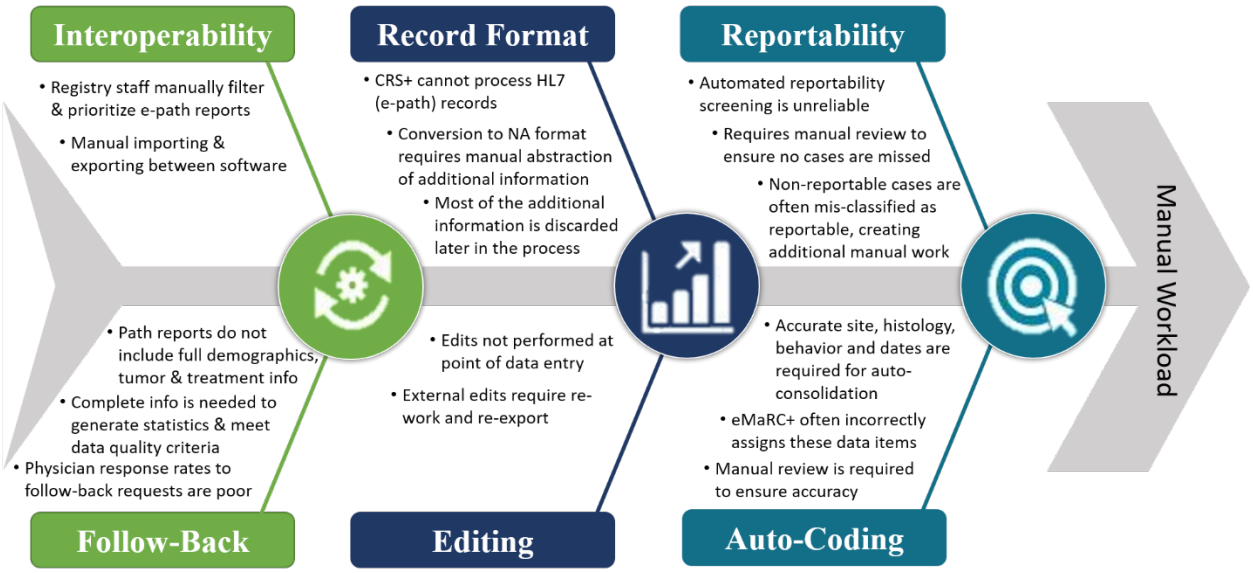


Figure 14. Root cause analysis—Ishikawa Diagram

Process Comparison

Because caseload and registry size influence processes, efficiencies, and—particularly—challenges, the states with similar caseloads were compared in an attempt to adjust for this effect. The two large registries (A and B) were compared, as were the two smaller registries (C and D).

States with Large Caseloads

The two model states with larger caseloads had similarities and differences in their processes. Notable similarities included the following:

- Receiving electronic pathology reports from independent laboratories.
- Manually reviewing all electronic pathology reports from independent laboratories.
- Using electronic pathology reports for case-finding only after all other reporting sources are complete.
- Following back to physicians for missing information.

Despite Registry A's manually screening a significantly greater number of electronic pathology reports than Registry B, Registry A consistently meets the 12-month submission standard and Registry B does not. Therefore, it is important to analyze where the registries differ in their processes. Some notable differences identified were the following:

- Software systems used to screen, code, and process electronic pathology reports.
- Registry A manually assigns reportability, primary site, and histology, whereas Registry B relies on eMaRC+ to assign these values and conducts 100 percent manual review. By eliminating the use of eMaRC+ and instead performing manual screening and

coding of all electronic path reports, Registry A achieves 10 times greater efficiency than Registry B (Table 5).

Table 5: Comparison of Registries with Larger Populations

	Registry A	Registry B
Process	Manual coding of HL7	eMaRC+
Average tasks per hour	45	4
Total tasks	41,000	2,900
Total FTE (electronic pathology)	0.5	0.4
Annualized tasks per FTE	87,750	7,800

States with Smaller Caseloads

Likewise, the two registries with smaller caseloads had similarities and differences in their processes; however, due to the magnitude of the difference in caseload between the two smaller states, the strength of the comparison is not as significant. Some similarities between Registries C and D included the following:

- Use of eMaRC+, Prep+ and CRS Plus.
- Electronic pathology reporting by independent laboratories only.
- Manual look-up of electronic pathology cases in CRS Plus.
- Not processing all electronic pathology reports.

In addition to the difference in caseload, Registries C and D also differed in these ways:

- Number of laboratories reporting.
- Timing of electronic pathology report processing.
- Method used to determine whether an electronic pathology report is processed into the registry database.

Table 6: Comparison of Registries with Smaller Populations

	Registry C	Registry D
Process	Manually filter e-path for new cases	Manually filter e-path for new cases
Tasks per hour	20	3–4
Total FTE[1] (electronic pathology)	1	1
Follow back	Does not perform follow back	~200 cases

DMA/C: Improve

The Improve phase of the DMAIC process focuses on finding solutions to the problems and their causes identified in the previous sections.

Potential Solutions

Based on interviews with the model registries, the project team conceived several potential solutions to the challenges identified in the Measure and Analyze phases (Figure 15).

[1] Full-time equivalent employee

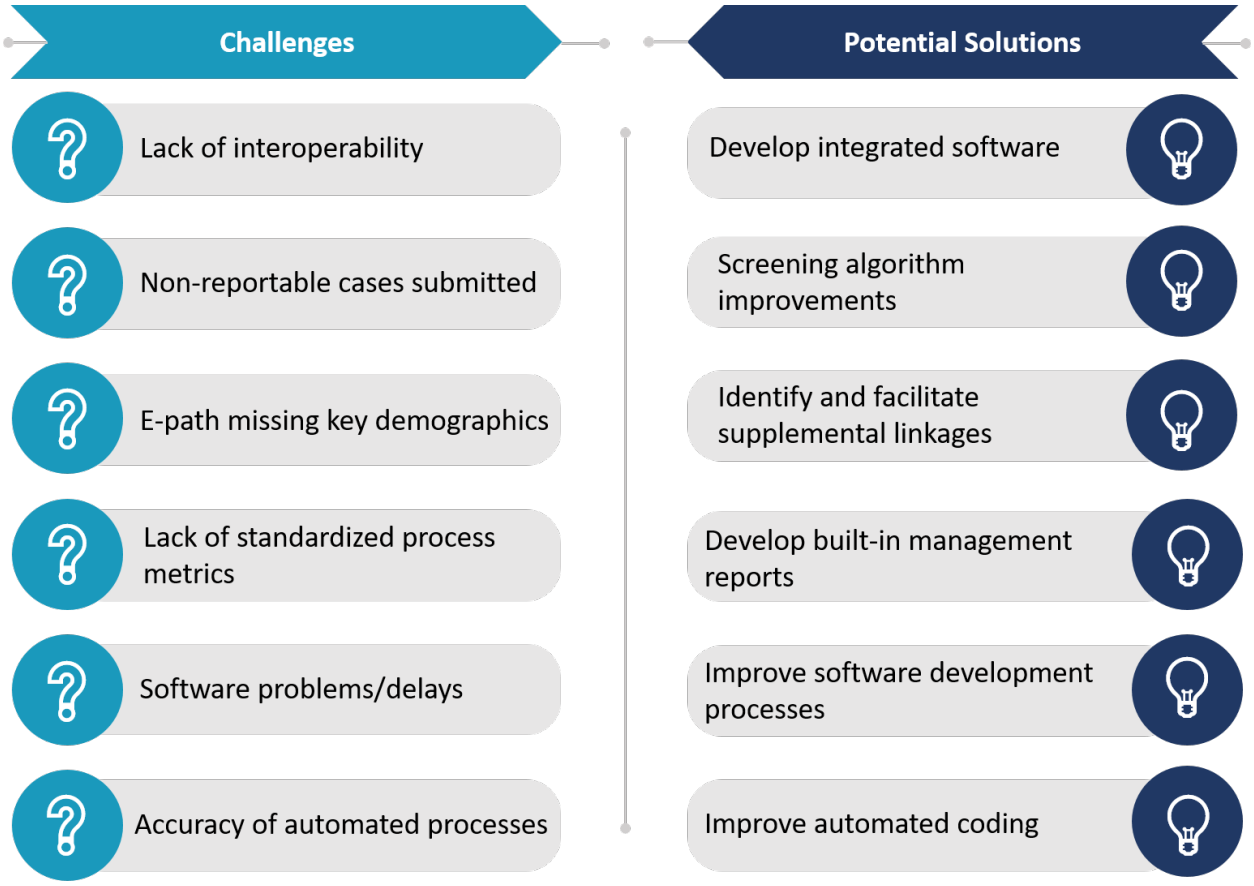


Figure 15. Challenges and Potential Solutions.

Develop Integrated Software

The development of a software platform that integrates all steps in the electronic path process—from screening and coding of electronic path records to consolidation and editing of the final case—would reduce the burden of manual work and redundant work on registries. The software should have the capability to process electronic pathology records directly, eliminating the need to complete a full abstract for each pathology report.

Screening Algorithm Improvements

Algorithms and rules that determine the reportability of electronic path reports should be improved to increase their sensitivity and specificity. This may be accomplished by reviewing samples of misclassified reports and adjusting automated rules accordingly. It may be beneficial to assign a probabilistic score or uncertainty quotient to the reportability classification of each report, allowing registry staff to prioritize screening cases with the highest uncertainty and reduce the need to manually screen 100 percent of electronic pathology reports.

Identify and Facilitate Supplemental Linkages

To reduce the burden of manual follow-back to obtain complete case information, the program should identify and facilitate linkages with data sets that contain patient demographic and tumor information. A reduced data standard for laboratory-only cases also should be considered,

although the need for some data items (i.e., race, state at diagnosis) cannot be eliminated without affecting stratified incidence rates.

Develop Built-in Management Reports

Management reports for monitoring process metrics should be built into an integrated data management software platform; however, it is necessary to eliminate the need for external processes (processes performed outside the software) for the management reports to capture accurate process metrics.

Improve Software Development Processes

Registries reported experiencing delays in the availability of software upgrades and in the responsiveness of technical support staff to software bugs and other issues. The software development process should be examined for delays and other issues, and improvements made. In addition, if one is not already in place, a ticketing system in which users can view support request status and turnaround time should be implemented.

Improve Automated Coding

A similar approach is recommended to addressing automated coding as was suggested for improving screening algorithms. Improvements should include a combination of improved accuracy of coding and an uncertainty quotient to allow users to prioritize cases requiring manual review.

DMAIC: Control

The Control phase of DMAIC describes the systems that are put in place to measure and monitor the new process and ensures the sustainability of the changes/improvements made to the process.

In the Improve phase, the LSS team put forth recommendations for improvements to enhance the use of electronic path reporting in cancer surveillance. In the Control phase, the team suggests ways that the effectiveness of these improvements can be monitored, including the ongoing collection of metrics through a dashboard built into registry software. Recommended metrics for the dashboard include the following:

- Number of electronic pathology reports received.
- Percent of reportable/non-reportable electronic pathology reports received.
- Number of laboratory-only cases (by primary site)
- Number/percent of electronic pathology reports matching with a record from a hospital or physician office.

Conclusion

The primary aim of this project was to identify strategies that might reduce the manual labor involved in processing electronic pathology reports and thereby improve the timeliness and completeness of cancer surveillance reporting. Under the ideal state, electronic pathology reporting would be used to collect cancer incidence data in near-real time, allowing central registries to generate preliminary incidence data within 12 months of the end of the diagnosis year, or sooner. However, achieving the ideal state requires several conditions that have not been met:

- Electronic pathology reporting coverage must include the majority of all pathologically confirmed cancer diagnoses. This would require the expansion of current electronic pathology reporting to additional independent laboratories as well as hospital-based laboratories.

- Automated reportability screening and coding of—at a minimum—primary site, histology, behavior and date of diagnosis must be improved to eliminate the need for manual review of the majority of reports.

- Elimination of requirements that laboratory-only cases pass validation and edits for data not included in the pathology report (e.g., stage, treatment).

- Auto-consolidation routines must be developed or improved to reduce or eliminate the need for manual consolidation of more complete cancer reports received after the electronic pathology report for a particular case.

None of the four model registries assessed was found to be using what could be described as a "best practice" for electronic pathology reporting, although some processes were more effective and efficient than others.

Electronic reporting by pathology laboratories is an essential element of a population-based cancer surveillance system. The following key benefits were identified in this assessment:

- *Identification of cases not reported by other sources.*

  States reported that up to 5 percent of incident cases are reported by laboratories only. This represents a significant proportion of cases and may account for underreporting by registries with less-than-optimal electronic pathology reporting processes.

- *Validation and correction of abstracted data reported by other reporting sources.*

  Most central registries do not access clinical documentation directly; rather, they rely on cancer registrars and physician office staff to abstract pertinent information and submit it to the central registry. Electronic pathology reports contain information documented by the clinician and can therefore be used to verify abstracted information, such as primary site, histology, stage, and other site-specific factors. Abstraction errors identified in this manner are an important opportunity to educate hospital cancer registrars.

- *Collection of information missing from reports received from other sources.*

Hospital registrars often do not have access to information from procedures performed outside the hospital setting. The abstract submitted to the central registry is therefore based on the information available to the hospital registrar at that time. For example, a biopsy of a skin lesion in a physician's office reveals invasive melanoma. Wide excision performed at the hospital shows melanoma in situ with no evidence of invasion. The hospital reports this to the central registry as a melanoma in situ, based on the information available in the hospital record. If the central registry has received the electronic pathology report of the outpatient biopsy, however, the case can be correctly documented as an invasive melanoma. Some registries, however, may not be realizing the full benefits of electronic pathology reporting because of a number of challenges they encounter:

- *Current electronic pathology processes require manual work.*

  Manual work includes transferring files among multiple software programs; screening for reportability; coding or verifying automated coding of key data elements; completing the full NA for each pathology report; resolving edits; matching to existing cases; consolidating with existing cases; and performing follow-back to physician offices for laboratory-only cases.

- *Manual workload is directly proportional to the number of electronic pathology reports received.*

  Larger registries are disproportionately burdened by manual workload. Smaller registries that receive only a few hundred electronic pathology reports annually can absorb manual work into their regular operations, but larger registries that receive tens or hundreds of thousands of electronic pathology reports are not able to do so.

- *Currently available no-cost software programs do not reduce processing time.*

  A comparison of two similarly sized registries revealed that efficiencies could be increased by 10 times with improved, seamless software.

Ultimately, the current electronic pathology reporting model used by most central registries is not sustainable and will not support the expansion of reporting. The conclusions drawn from this study assume that the experiences of the four model states are representative of registries of comparable size throughout the United States. Although this may not be true in all cases, based on information collected from focus groups and interviews conducted previously, most central registries experience similar challenges and barriers in electronic pathology reporting.

Recommendations

Based on the analysis described in this report, we recommend the following steps be taken by CDC and by central registries to improve electronic pathology reporting:

CDC

As demonstrated by the root cause analysis, many of the challenges faced by states in electronic pathology reporting are related to software. Therefore, we recommend that CDC—

- Invest in the development of an integrated cancer registry software platform that—
    - Has the ability to process electronic pathology reports as HL7 messages without the need to convert them to NA format and allow the HL7 messages to be uploaded directly to the database.
    - Performs automated reportability screening and coding of primary site, histology, behavior, and event date with a high degree of accuracy and flags for manual review cases for which there is uncertainty.
    - Links incoming HL7 electronic pathology reports with existing patients and tumors with a high degree of accuracy and flags for manual review cases for which there is uncertainty.
    - Uses auto-consolidation rules when an incoming record has known values and the existing case has unknown values.
    - Has built-in edits.
    - Auto-fills values (i.e., “9”) for cases created from HL7 records.
    - Incorporates a follow-back manager module.
    - Provides on-demand reports of electronic pathology processing statistics.
- Provide registries with technical support and software upgrades in a timely manner.
- Develop a reduced edit set for cases with a laboratory as the only reporting source (laboratory only)

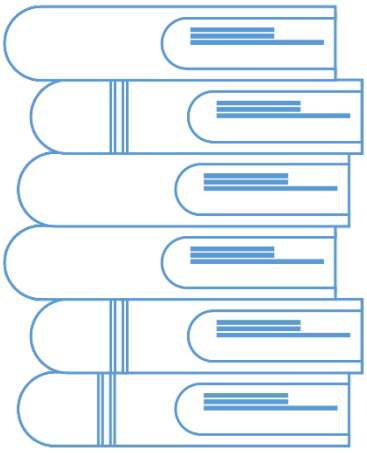
Central Registries

Although many of the challenges faced by states in electronic pathology reporting are related to limitations in the available software, states may consider implementing some strategies to make the best use of electronic pathology reports. It is important to note that registries may gain varying degrees of benefit from these strategies, depending on their caseload and other factors.

- Pathology Screening
    - Screen for reportability and code electronic pathology reports as they are received.
    - Analyze the accuracy of automated screening and coding by cancer site; prioritize manual review of sites with the highest error rate from automated processes.
- Processing
    - Wait to import pathology reports into the registry database until most hospital cases have been processed.
    - Work with vendor staff to make use of available auto-consolidation routines in the registry software.

    - If electronic pathology reports cannot be imported directly into the registry, use an external linking software to identify new cases.

- Follow-Back
    - Review electronic pathology reports to identify referring physicians; contact these physicians to enroll them in electronic reporting using Web Plus or Abstract Plus. Make use of linkages with hospital discharge data, health information exchanges, and other sources to supplement demographic data.



A State Law and Regulatory Searchable Database and Analysis of Legislative and Regulatory Strategies to Identify Best Practices Among Central Cancer Registries

March 2021

Acknowledgment

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Project Goals

1. Create a searchable database of central cancer registry laws and regulations.
2. Provide access to critical elements of the laws and regulations that support improved central cancer registry (CCR) completeness and timeliness.
3. Understand the legal and regulatory processes that central registries use to change laws and rules.
4. Identify practices to improve CCR operations through legal and regulatory strategies.

Background and Significance

Historically, most CCRs were legislatively created state entities, and state laws define the authority, roles, and responsibilities of the CCRs. As a result, most registries are either direct state agencies—as in the case of programs embedded within state departments of health—or are empowered by states to function as agents for them, such as registries located in academic centers, independent health organizations, or medical centers. In either case, all CCRs are subject to these laws and must follow the directives and language included in them. Registry laws vary from state to state; some are very broad in scope, others more detailed and explicit, and still others embedded within more general health surveillance or public health laws. In addition, CCRs may be affected by a range of related state laws, including privacy, confidentiality, and budgetary legislation. As such, laws and the legal environment have an important impact on CCRs' structure, resources, and function.

Administrative codes and regulatory rules are developed in the executive branch of government and usually interpret, implement, or prescribe the requirements of the law.[1] These have the force of law but must be authorized within the statutes related to them and must follow the scope defined in that law. In the case of central registries, authority to develop administrative codes and rules is usually designated to the commissioner, director, or leader of the department or board of health or another associated state department. State departments follow very specific procedures to create and maintain codes and rules. In some states, review by either a legislative body or an attorney general also may be required. Administrative codes and regulatory rules help CCRs define terms; identify who must report data; describe what data may be collected and reported and how; lay out privacy and confidentiality protections; enumerate how data may be used for research; enable interstate exchange of data; and delineate fees, penalties, or reimbursement of costs for failure to comply. For these reasons, codes and rules hold significant influence for CCRs and may contribute to successful operations.

Although some states created cancer registries in the 1930s and '40s, most were established in the 1970s and '80s as a result of growing public concerns surrounding cancer. With the enactment of the National Cancer Registry Act in the 1990s, all states either initiated or updated legislation related to central registries with support from the Centers for Disease Control and Prevention (CDC). A three-to-one (federal-to-state) funding match was required to apply for CDC funding. As a result, state funding for CCRs often is provided as state appropriations, either within general funds or as special line items. A review of legislative activity since the 1990s indicates that only nine states have changed or amended their laws in the past 10 years. Regulations are updated either on a schedule stipulated by their department or as needed by the agency. Twenty-six states updated regulations in the past 10 years. It also appears that state funding for many cancer registries has stagnated with either stable 1990s funding levels

maintained despite inflation and increased workloads, or cuts and decreases to budgets occurring.

As part of the project entitled *Identify and Implement Best Practices for Cancer Registry Operations*, funded by CDC to the National Association of Chronic Disease Directors (NACDD) in collaboration with the North American Association of Central Cancer Registries, Inc. (NAACCR), several states indicated that strategies to strengthen laws would be desirable, especially around penalties or fines for reporting deficiencies and improving reporting timeframes.[2] This led to a discussion among the National Program of Cancer Registries (NPCR), NACDD, and NAACCR to find ways to offer more resources and support to CCRs that need to deal with the challenges and opportunities that exist within the legal and regulatory environment. NPCR requested a searchable database of central registry laws and regulations to help states track any changes or updates to such laws and regulations and provide model language or best practices for adoption. NAACCR accepted responsibility for this project and launched the initiative. As the project developed, it also was decided that more in-depth analysis would help elucidate the legal and regulatory processes that registries follow and identify strategies that some states use to address legal and regulatory issues. As a result, expert interviews with 10 states were organized and implemented by NAACCR.

Methodology

1. *Create a searchable database of central registry laws and regulations and provide access to critical elements of the laws and regulations that support improved central registry completeness and timeliness. (Goals 1 & 2)*

A searchable database of central registry laws and regulations was created for use by registry staff, related policymakers, and the interested public. After discussion, it was agreed to modify an existing NAACCR database called the Cancer Registry Information (CaRI) Database because it offered the structure and flexibility desired for this project. CaRI is designed to capture, and make available in a single location, helpful information for researchers interested in using CCR data; it was built several years ago at the request of NPCR to maintain such data. Information available in the CaRI Database for each registry includes the following: Registry and Institutional Review Board review requirements, data request process, consent requirements, fees for requests, and general information about the registry contacts, available data, and participation in various types of studies. Information on and links to state laws and regulations were added to this database for this project. The system is populated by cancer registry staff and reviewed annually at a minimum. The CaRI Database is housed on the NAACCR website, and the data are publicly accessible. For this project, student interns from the Edward J. Bloustein School at Rutgers, The State University of New Jersey were recruited to research all state laws and regulations related to CCRs. A draft design of the database was embedded in the CaRI query system. It was structured to capture links to all relevant laws, current regulatory rules, and administrative codes. Such database components as legal citation, year data collection began, central registry location, reporting deadline, and reporting entities were incorporated. Data elements were organized for filtering and searchable queries. Information from 65 central registries was uploaded into the system. The structure was then activated in CaRI and pre-tested by registry staff to ensure understandability and ease of use. The advantage of this system is that the database will be updated as part of the annual *Call for Data* in which all registries participate, allowing continued currency of information. The Central Cancer Registry State Laws & Regulations section of the CaRI database will be available to the public using the following link: CaRI Database.

2. *Conduct expert interviews aimed at understanding the legal and regulatory processes that central registries follow and identifying best practices and success stories that improve registry operations. (Goals 3 and 4)*

Expert interviews were completed with 10 state registries with various levels of legislative and regulatory activity over the past 5 years: California, Colorado, Illinois, Louisiana, Kansas, Minnesota, Mississippi, New York, Oregon, and Tennessee. CCRs were chosen based on how often their laws and regulations were updated, geographical diversity, and whether they were located in government agencies or academic centers. Five states were identified as proactive based on the number of amendments to their laws or updates to their rules or administrative codes (two or more in past 5 years). Three were deemed as average in their legislative and regulatory activity (one update to either in past 5 years), and three were inactive (no updates in past 5 years). CCRs were offered a small stipend for participation.

A standard question set was developed based on input from central registry directors, operations staff, and NAACCR staff. In addition, an analysis of each state's laws and regulations was undertaken to identify any innovative elements that might be worth exploring, and individualized questions were designed to address these. General overarching topics included the legislative and regulatory processes in place within the state; major strengths and weaknesses of the state-specific laws and regulations; state funding and budgetary processes; approaches to fees, penalties, and reimbursements; partnerships with external partners; risks and benefits of using laws and regulations to improve registry reporting along with legal and regulatory factors that contributed to the overall success of central registry operations; and finally, threats that interfered with central registry effectiveness. Designated representatives were invited to participate using a Zoom meeting format. Qualitative/content analysis was then applied across all interview transcripts. Each offered insights into the processes required to amend laws or update administrative codes and regulatory rules, their attitudes toward and perceptions of the risks or benefits of amending laws or updating regulations, and what strategies they use to streamline or proactively approach using regulations and administrative codes to address the changing cancer surveillance field.

Findings and Results

Goal 1: Create a searchable database of central cancer registry laws and regulations.

The CaRI Database is complete with CCR state laws and regulations embedded for user-friendly search capability and is currently available to any interested party. It was updated by registry staff as part of the Call for Data in November 2020, and the process worked smoothly. Public access to the database is available using the link above.

Goal 2: Provide access to critical elements of the laws and regulations that support improved central cancer registry completeness and timeliness.

The research undertaken to create the searchable database for CaRI offers an opportunity to identify, analyze, and assess novel approaches, strategies, or language that states may adopt to either their laws or regulations. Registries or interested policymakers may use the database to see what other states are doing with the laws and regulations for major areas, such as reporting entities, reporting frequency and deadlines, required electronic reporting, required pathology reporting, and penalties or fees. Because the legal language is already in use within a

central registry, states interested in similar requirements or changes can be more confident that adapting model wording to their circumstances will reduce any risks of negative impact on operations or stakeholders.

Goal 3: Understand the legal and regulatory processes that central registries use to change laws and rules.

Each state varies in how laws are created, but most follow a similar process that, while not uniform, includes common steps. First, a bill requires a sponsor(s) who will introduce it for passage. It is assigned to one or more committees for intensive legislative review and public hearing where it needs to be approved by most of the committee members. During committee hearings, amendments or changes may be proposed. Once approved by all committees, it is then moved to the floor for a first reading, where legislators can again voice concerns or request amendments. A second reading is then completed, and the bill is posted for a vote. If approved, it then moves to the second house where the same procedures occur. Although the registry staff are not directly involved in most of this process, they nonetheless must deal with any consequences that might arise during it.

The process is complex, fraught with risks, and very time consuming. For example, a recent change to one registry law took more than 2 years to pass. Some health departments have strong policies that do not allow programs to initiate legislation. Advocates demanding more privacy and confidentiality protections have gained strength in recent years and argue tenaciously for stronger safeguards, proposing amendments that hinder access to data. Lobbyists for special interests can recommend language that might harm registry operations. Legislators might raise concerns about privacy or cancer clusters in their district or question the timeliness of registry data. One state does work with its law when changes are required, because the regulatory rules process is so long and tedious. However, the consensus of the CCR interviewees was that the risks were generally too high to make amending laws worthwhile.

Registry respondents were more open to using administrative codes and regulatory rules proactively to address reporting problems and maintain currency in a rapidly changing cancer surveillance field. Although variations exist among states in how regulations are updated, most follow similar processes. Some state registry rules expire and need renewal for a specific term. Most registries review rules annually but make changes on an as-needed basis. If a need is identified, the registry director usually works with his or her department's legislative services office to write the necessary language. It then is moved for review to the director/commissioner, attorney general's office, or other appropriate legal entity. It then undergoes a public comment period and/or public hearings. Negotiations may then occur in which problems are resolved, and a second public comment period may be required. Finally, the new codes or rules are either accepted or voted upon by the authorized body. In most instances, this process is less onerous than legislative change, but still takes 6–9 months and considerable work on behalf of the registry. One state does have a more time-consuming regulatory process, so it relies more on specificity in its law and amendments than on rules for any changes.

For registries housed in such nongovernmental organizations as universities, cancer centers, or freestanding health programs, the regulatory authority usually remains with its associated government partner, e.g., the department of health. This situation requires more communication and collaboration, but the overall process follows the same steps.

The state funding process varies depending on the state, but most registries are housed in or partner with a government agency, so an established appropriations process is followed. State budgets are proposed by the executive branch and submitted to the legislature for review and approval in the form of a law. Hearings are held and modifications either up or down to various programs may be occur. Special interests, advocacy groups, and lobbyists actively engage in promoting their cause. Because state budgets are under significant pressure, increases or new budget items usually need justification and receive serious scrutiny. A final budget is usually voted on very close to the end of the fiscal year. Of serious concern, many registries have faced stagnant or decreased state funding in recent years despite increasing costs, and many are forced to rely upon in-kind support for any federal matching requirements.

Goal 4: Identify practices to improve central cancer registry operations through legal and regulatory strategies.

Despite the challenges associated with legislative and regulatory changes, many registries work with their laws and rules to advance strategies to improve reporting and timeliness and keep registry operations current in a changing environment. In most instances, registry staff avoid amending laws and rely on updates to administrative codes and regulatory rules to move their agendas forward. Several overarching themes were identified through the interviews:

1. **Embrace the value of laws and regulations:** States that are most active in making changes to rules tend to have a positive attitude toward the regulatory process, having embraced a more proactive approach to updates. Registry directors in such states understood the regulatory process, developed strong relationships with their legislative liaisons, established timelines, and worked to meet any deadlines. They paid particular attention to the language used in the regulations and did background research to understand any barriers and opposition in advance. They laid the groundwork with stakeholders, explaining why changes were required and listening carefully to any concerns raised. Most were able to make changes successfully.

> ***"Laws and rules are the backbone of central registries, and we need to learn to be more comfortable working with them. Change is coming, and we cannot move forward if we are locked down by outdated laws."***
>
> Participating Registry Director

2. **Broad laws with authorization to the executive branch allow flexibility:** Broader laws that did not delineate requirements in detail are easier for registries to implement and allow much more flexibility in improving operations and reporting. Registries used their administrative codes and regulatory rules to lay out the exact language they wanted to work with reporters effectively, establish reporting schedules, and add new requirements as needed. One state has very specific laws and relies on its regulatory

codes less often because laws are easier to change than regulations. However, this still requires more time and energy than in states whose laws are broad.

> ***"Broad laws that empower the Executive Branch to promulgate regulations allow central registries to make changes as needed without opening the door to legislative scrutiny and unanticipated consequences."***
>
> Participating Registry Staff

3. **Non-cancer registry laws around hospital licensing and certificates of need may be helpful:** If language within the law require a hospital to follow all state laws and requirements to be eligible for a certificate of need or license, CCRs may use this to their advantage. Putting this language in correspondence or warning letters to reporters or hospital compliance officers is often enough to motivate improved reporting.

> **"*Our planning board laws include a requirement that hospitals not in compliance with all state laws could have their certificate of need held. It is a wonderful tool to motivate reporters."***
>
> Participating Registry Director

4. **The ability to use your administrative codes and regulatory rules proactively keeps you nimble:** CCRs can stay ahead of changes to the field using codes and rules strategically. Criteria most often included are requiring electronic reporting, allowing remote access to medical records, changing rapidly expanded data fields, and requiring electronic pathology reporting, to name a few. However, states must be strategic and thoughtful in how laws and regulations are written to produce ones that are not rigid but fluid. For example, genetic privacy is an emerging issue that may require changes to registry confidentiality laws. Respecting the interests of advocates while protecting access to data for research requires carefully crafted language and consensus building to be successful.

> ***"The modern cancer registry is so much more complex and clinically detailed than when our laws were passed. It becomes impossible to operate effectively using those old ways."***
>
> Participating Registry Director

5. **Stakeholder relationships are still critical for success:** Although registries use laws, codes, and regulations to strengthen their authority for reporting, nearly all participants pointed out that it was their strong relationship with stakeholders that is the most important tool in their success with reporting. To update a law requiring pathology reporting, one state needed to work with a consortium of stakeholders who served as arbitrators among different parties to come to consensus allowing an amendment to successfully pass. Many fees and penalties, although written into laws, may not be as useful as they appear. Interviewees reported that noncompliant reporters were rarely fined, and reimbursement costs were not retrieved. It was better to rely on good working relationships and provide support when needed; these approaches brought the most success when working with such challenging situations.

> ***"In the end, it is still your relationship with stakeholders that is most important to encourage better reporting. Laws and regulations can lay out expectations, provide clear and concise direction, and even offer some enforcement, but in the end, it all depends on strong relationships with all your stakeholders."***
>
> Participating Registry Director

Success Stories and Best Practices

Adding New Data Items

Using the regulations to allow frequent and continual updates for new data items is a top common strategy to improve reporting operations. For example, including language that allows registries to "publish a list of required data elements once a year" keeps data items current with changes that standard setters might make.

Reporting Timelines and Deadlines

Most states include reporting timelines and/or deadlines in either their laws or regulations. Deadlines vary, with the majority requiring reporting within 6 months, and timelines vary from monthly to annually, for example, "Each patient's cancer report form shall be sent within six months after the date of diagnosis or within four months after the date of discharge from the reporting facility, whichever is sooner. Reporting facilities shall report by letter to the Department, each year by July 1, the status of the completeness of reporting of cancer incidence cases diagnosed through December of the preceding year. All reporting facilities shall submit the report forms monthly.[2]" States may find using explicit language around timelines may improve reporting compliance.

Electronic Submissions

Several states have added a requirement for electronic reporting to their regulations, such as, "Health care entities shall report information concerning all patients diagnosed as having cancer

[2] TITLE 77: PUBLIC HEALTH CHAPTER I: **Section 840.110**
https://www.ilga.gov/commission/jcar/admincode/077/077008400B01100R.html

in a standard electronic format designated by the Department."[3] These changes were generally well received, reduced manual workloads, and improved operations significantly.

Access to Medical Records

Engaging in follow-up to find missing data is both time consuming and inefficient. Several interviewees included language in their regulations to permit remote access to reporters' medical records, allowing missing data to be retrieved quickly. For the most part, this approach has been successful, especially with smaller facilities, with compliance as high as 85 percent for one state. Some hospitals create onerous approvals prior to allowing access to medical data, but most readily comply. Health information exchanges (HIEs) are also useful in gaining access to medical records.

Increasing Fees or Penalties for Noncompliance

Several states decided to increase reimbursement rates for work that the registries undertook for noncompliant reporters. Generally, such fees had not been increased for many years and the increases reflected inflation and basic cost-of-living adjusted levels. It remains too early to determine whether this strategy will be successful, because collecting such fees often depends on the willingness of senior management to take appropriate action. One state tried to increase penalties through its regulations but experienced resistance from hospitals and physician groups, resulting in legislators' intervening on behalf of the opposition.

Collaborate with Health Care Facilities Regulators

Several states use a more innovative strategy—language offered in related laws from facilities oversight or licensing programs within the state departments of health allows registries to remind reporters that licenses or certificates of need could be in jeopardy in the event of late or incomplete reporting. For example, one state included the following in its administrative rules form Illinois:

> "The Certificate of Need approval is necessary in Illinois to establish a new category of service, allow a substantial increase in a facility's bed capacity, have a substantial change in the scope or functional operation of a facility, move forward with closure or change of ownership of a health care facility, or discontinue a category of health care service. Each Certificate of Need submitted to IDPH must be reviewed for cancer reporting compliance by the registry before it can proceed and be approved. This requirement is codified in the Administrative Rules (77 Illinois Administrative Code 1130) governing the Health Facilities and Services Review Board which states: Section 1130.620, c.1.H "all HFSRB requests and questionnaires for information or data for all Illinois facilities owned or operated by any applicant, such as but not limited to the Annual Hospital or Long-term Care Questionnaire (77 Ill. Adm. Code 1100.60 and 1100.70) **or Cancer Registry (77 Ill. Adm. Code 840.110(d) and 840.115(i)) have been received and are complete;[4]"**

[3]Department of Public Health and Environment, Regulations 6 CCR 1009-3: sec. III

[4] TITLE 77: PUBLIC HEALTH CHAPTERI I: Section 1130 C1:H http://www.ilga.gov/commission/jcar/admincode/077/077011300F06200R.html.

Legislative and Regulatory Challenges

High Political Risks When Amending Laws

Most interviewees reported great hesitancy to amend laws. The risks are considered very high because special interests or legislators who might not understand the complexities or value of population-based cancer registries could oppose changes or even introduce requirements that hinder the ability of central registries to function.

> **"I do not want to take the risk of opening that door!"**
>
> **"It would take an act of God before we would risk changing our law."**
>
> Participating Registry Directors

Time-Consuming Cumbersome Processes

Participating interviewees also pointed out that the process to change laws usually takes at least 2 years; some rural states may even take longer. Regulations can take 6 months to a year to update. Both processes are cumbersome, requiring multiple reviews by various legal entities, public hearings, or comment periods, and/or approval by various boards or committees.

Lack of Political Will to Enforce Penalties

Interviewees reported that even when penalties or fees were included in laws, implementation was almost never enacted. Senior leadership in most health departments is hesitant to damage relationships with health care facilities or make constituents angry by applying penalties or fees. Although the threat of action may be enough to motivate some reporters to respond, many simply ignore the threats.

Confidentiality and Privacy

A major concern of central registry directors involves confidentiality and privacy protections contained in laws and regulations. These often are subject to serious scrutiny and legal review that may curtail a registry's ability to share data across states or with researchers. In other instances, language creates patient notification requirements that are onerous for staff. More recently, laws dealing with data sharing and genetic privacy have gained momentum. Although these are not directly related to CCRs, language contained within them may affect the registry operations. Finally, privacy advocates have gained strong voices in recent years and are

> **"We have tried to introduce amendments to our laws to allow data sharing with other states, but it has not gained any momentum, and the privacy advocates are very politically connected."**
>
> Participating Registry Staff

applying political pressures that are difficult to negate. Finding a balance between protecting the privacy of individuals and supporting important research is a challenge that registries will increasingly have to deal with.

Funding and Budgetary Concerns

Another very serious concern for central registries is stagnant or reduced state funding. Most states have some funding to cover the CDC three-to-one matching requirement for states. These funds usually are included in state general appropriation budgets, which are submitted by departments that are often under pressure to cut costs. In some instances, line items specifically designating funds to registry programs may be included in budgets. However, funding has been stagnant for many CCRs, often not increasing since the program was created. In other instances, CCR state budgets have been cut significantly. Federal dollars are also static, and registries are being asked to do more with less. Little to no progress appears to have been made to overcome this problem that threatens the very existence of some registries.

> **"Very little of our match is covered by the State. Most comes from in-kind services."**
>
> **"We cannot hire staff anymore, our resources have not changed in years, and we are holding on by a thread."**
>
> Participating Registry Directors

Recommendations for Best Practices

1. State central registries can benefit from understanding the legislative and regulatory process in more depth. Establishing working relationships with legislative liaisons, legal departments, and other related programs can be useful when making necessary changes.

2. Administrative codes and regulatory rules offer opportunities for central registries to keep reporting requirements updated and stay current with the changing cancer surveillance field.

3. Adapting language and reporting requirements from other states to state laws or rules increases the likelihood of successful implementation because they are already field tested.

4. Central registries should consider working with managers in state health departments who regulate compliance and undertake oversight to identify ways to use licensing or certificate-of-need requirements to encourage timely reporting to the registry.

5. Central registries housed in universities or health care settings might benefit from working with their government relations offices to promote their needs to both state departments and legislators.

6. Advocacy remains critical to central registries. Although registry staff may be unable to speak for themselves in legislative settings, cancer advocates and organizations are often well positioned to take up the cause. Their voices are loud and effective.

7. Strong relationships with researchers, cancer control organizations, and public health professionals also can help legislators and policymakers understand and appreciate the value that central registries bring to the fight against cancer.

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[1] USLegal.com (https://definitions.uslegal.com/r/regulations/)
[2] *Identify and Implement Best Practices for Cancer Registry Operations,* NAACCR, August 2019

Automated Data Item Consolidation Best Practices Evaluation Project

February 2021

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Introduction

In January 2020 the Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR) initiated a project through the National Association of Chronic Disease Directors (NACDD) and the North American Association of Central Cancer Registries (NAACCR) to evaluate best practices in automated data consolidation within the Central Cancer Registry (CCR) setting and across several routinely collected cancer data items, comparing multiple automated consolidation methodologies. The goal of this effort was to undertake a systematic evaluation of multiple automated rules compared to manual consolidation for selected critical data items so that best practices could be identified based on real-world data. In so doing, a potential outcome included taking an initial step toward defining national standards for automated data item consolidation, which do not exist at this time.

Another potential outcome was the discovery that some data items do not lend themselves to automated consolidation, for example, because the items are new and require a better understanding prior to automation or are more challenging and require greater judgment.

Over the course of the project period, three CCRs—from Missouri (MO), North Carolina (NC), and Pennsylvania (PA)—were recruited to participate in the study, although one (PA) ended its participation prior to completion because of changing resource demands related to its response to the COVID-19 pandemic. The remaining two CCRs (MO and NC) completed the study; their results and experiences provide important advances in our understanding of the strengths and limitations for implementing automated data consolidation in the CCR setting.

Purpose and Goal

The purpose of the NPCR Automated Data Item Consolidation Evaluation project is to evaluate multiple automated consolidation methods across several registries to determine best practices for automated consolidation. This project will also allow the NPCR Registry Plus support team to assess whether the same consolidation method will be the optimal method for all participating registries.

The goal of this project is to determine the optimal automated consolidation methods using a data-driven approach to achieve the highest data quality for consolidated items reviewed in the evaluation. At the onset, we recognized that fully automated consolidation will never meet 100 percent accuracy. The goal is to determine the best value the majority of time, as well as the most optimal context for implementing automated consolidation to improve efficiencies and quality data.

Background

The goal of data item consolidation is the selection of the best value when multiple reporting sources report discrepant values for data items. The consolidated value becomes the value included in calls for data and used for analysis. Historically, the gold standard for consolidation has been manual review of coded values versus text by a trained cancer registrar performing best value selection. A trained registrar might have knowledge that is unknown to the computer system. However, many central registries find that manual consolidation is burdensome.

Many registries no longer have the resources to manually consolidate, given the volume of incoming cancer reports and increases in reporting sources. Automated decision-making can vary widely based on the registries' purposes, philosophies, operational procedures, and available resources. In 2015, NAACCR published a Data Item Consolidation Manual, but consensus on best practices was not achieved.

At the national level, many challenges have emerged in developing best practices for data item consolidation including the following considerations:

- New types of source records
- Operational issues
- Balancing data quality and efficiency
- Workflow processing
- Data quality issues

Because CDC's software CRS Plus contains tools for writing and applying rules for automated consolidation, we will use these tools for the study. A description of consolidation follows.

Summary of Current Process in CRS Plus

Consolidation in CRS Plus is flexible in that data item consolidation can be automated as much each CCR desires. Several data items currently have fully automated consolidation rules. Manual intervention was the previous consensus to achieve the best possible consolidated value by comparing coded values against text for tumor information and staging. Registries have been encouraged to provide consolidation logic changes to the Registry Plus team for assistance in modifying consolidation directives. Validation of automatically consolidated data against manually consolidated data has been encouraged to ensure quality of data, but this step has not been completed because of lack of resources, delays, etc. Automated consolidation works best when editing and visual review have occurred to ensure the source record data are accurate. Differences in visual review procedures across registries could impact consolidation results.

In CRS Plus, data from incoming source records are compared to determine the "best consolidated value." If at any point automated data item consolidation fails—i.e., a single value has not been selected by the algorithm—the incoming abstract is sent to a pending system for manual review. The thought process behind sending records to pending is that the records will be reviewed prior to adding to the database and fully disposing the records. This can be especially important if the data are used for research. Once the data are added to the database, registries may not have the resources to go back and review cases. Data item consolidation is becoming more and more burdensome and registries are seeking enhanced automation. Testing is necessary to validate automated decisions to produce high-quality and reliable consolidated data and to convince registries that automation is effective and sufficiently accurate.

In CRS Plus, a default set of consolidation rules is defined for each NPCR-required data item.

Registries have varying needs for automation, depending on caseload and staffing. The rules can be customized by the user to suit the needs of the registry. Some registries prefer to automate more than others because of several factors, including workload and availability of resources. The Tumor Linkage and Consolidation (TLC) module, TLC Plus, allows flexibility. Rules to fully automate consolidation of all consolidated items are possible in TLC Plus; however, it is highly encouraged that registries adequately test any changes to consolidation rules to ensure quality of consolidated data prior to implementation.

Methods

CCRs that have staff with extensive experience in data item consolidation were selected to participate in the consolidation evaluation project. Once the participating registries were identified and confirmed, the NPCR Registry Plus support team hosted a kickoff call to discuss expectations, methods, timelines, and final products for the project. The CCRs participating in the NPCR Data Item Consolidation Evaluation Project were from Missouri, North Carolina, and Pennsylvania. Because of changing resources as a result of responding to the COVID-19 pandemic and unexpected staff changes, the PA CCR ended its participation in the study the first week of May 2020, prior to running any cases through the finalized data consolidation rules. The MO and NC CCRs completed all project activities.

During the first few months of the project, the NPCR Registry Plus support team conducted regular calls with the CCRs and sought their feedback and input for specific aspects of the study. For example, participating CCRs helped with identifying the six data items most useful for testing automated data consolidation. Additionally, the NPCR Registry Plus support team developed a tool that was distributed to participating registries for the evaluation. Prior to finalizing the tool, the NPCR Registry Plus support team provided consolidation prototypes to registries participating in the evaluation project so that they could give input to help finalize the rules tested in the evaluation.

The final version of the tool used in the study applied multiple consolidation methods to existing central registry data by linking to the registry database. The results of the consolidation methods for a sample of records were written to an Excel file for viewing the results using the selected consolidation methods. The generated Excel file displayed the consolidation results for each consolidation method per patient and data item using the current abstract data, including real patient data, to determine consolidation best practices.

Selection of Data Items

When selecting the six data items for automated consolidation, multiple criteria were considered by participating CCRs and the NPCR Registry Plus support team. For example, some data items were considered inappropriate because CCRs would always want to complete a manual review of text when a discrepancy in the records emerged, because discrepancies are critical to understanding of the cancer case (e.g., primary site, laterality, behavior). The CCRs also reviewed sample cases to better understand the volume of discrepancies for given data items flagged for manual review evaluation to narrow down data items that would be strong candidates for study. The group discussed that it might be useful to target data items that have previously had less focus on automated consolidation to determine if they can be automated more easily than some of the data items that have already been consolidated less successfully.

The following six data items were **identified** for automated consolidation:

- ER Summary
- PSA Value
- Grade Clinical
- Histology Type ICDO3
- Rx Summ Surgery Primary Site
- SEER Summary Stage 2018

Selection of Cases for Evaluation

The MO registry used a simple convenience sample selection to determine which records would be included in the study, whereas the NC registry used case selection criteria to ensure its sample provided enough cases appropriate for the consolidation rules given the data items being evaluated. For example, NC oversampled prostate and female breast cancer cases to ensure there were enough to evaluate the Prostate Specific–Antigen (PSA) Value and Estrogen Receptor (ER) Summary automated consolidation rules, respectively. Additionally, only cases with more than one reporting source were considered by both participating CCRs.

Participating registries reviewed the subset of cases and performed manual consolidation to establish the gold standard value for each data item in the study for each record. The values determined by automated consolidation methods were then compared to the manually consolidated values to determine the method generating the highest quality.

Automated Data Consolidation Rules

All participating registries used the same consolidation method rules. When the same method for each item reviewed did not produce a similar result for a given case, differences were evaluated and documented. For the purposes of the automated data consolidation rules, “Silver Reporter” is defined as a reporting facility that is considered to have higher accuracy generally and is, therefore, given a higher degree of likelihood to provide the correct response for data items where there is a discrepancy between sources. For this automated data consolidation activity, CCRs were asked to identify the facilities to which they would like to assign Silver Reporter status, and they were not required to define Silver Reporters using the same criteria across CCRs, because no single criterion would be appropriate across CCRs nationally. The NC CCR used Commission on Cancer (CoC)-accredited facilities as a criterion for assigning Silver Reporter status, whereas the MO CCR asked the quality assurance staff to use their judgement to identify which facilities produced the highest quality data and assigned those facilities Silver Reporter status.

Five consolidation method rules were evaluated as follows:

- Rule 1 uses “the current method,” which employs a relatively small number of criteria to consolidate cases. Included in the rules are selecting known values over unknown values and selecting values from sources wherein other specific values are taken (such as Histology Type and Primary Site). Because several of the evaluated data items were new to the NAACCR record layout in version 18 and only basic edits were initially implemented, limited consolidation directives were initially applied, resulting in a higher

percentage of manual review when differing values were reported by multiple reporting sources.

- Rule 2 builds on many of the same criteria as Rule 1, with some important differences. Included in the rules for method 2 are selecting values from sources identified as Silver Reporter along with known values over unknown values.

- Rule 3 builds upon many of the same criteria as Rule 1, with some important differences. Included in the rules applied for method 3 are selecting values from sources identified as "Analytic Sources" over "Nonanalytic sources," along with known values over unknown values.

- Rule 4 builds on many of the criteria of Rule 2, with some important differences. Included in the rules applied for method 4 are selecting values from sources identified as Silver Reporter, values taken based on hierarchy of class of case, along with known values over unknown values.

- Rule 5 builds on many of the criteria of Rule 1, with some important differences. Included in the rules applied for method 5 are selecting values based on the hierarchy of class of case, along with known values over unknown values.

In summary, the automated consolidation for Rule 1 is the most basic and often results in the consolidated record's being sent for manual review, while Rules 2–5 factor in additional layers of criteria that allow comparisons of selecting values based on such criteria as Silver Reporter, class of case, and analytic versus nonanalytic case to evaluate consolidation results to determine if any method produces a higher data quality.

Results

North Carolina

- 1,190 records were selected for evaluation. The selection criteria specified—
    - Breast and prostate cancer site to ensure enough cases available to evaluate ER Summary and PSA Site-Specific Data Items (SSDI)
    - Lung, colon, bladder, melanoma, and hematopoietic, which are top sites or have known issues with coding grade and histology
    - Remaining 30 percent of records came from all other sites
    - 67 records eliminated based on link to pre-2018 cancer diagnosis
- Silver reporters limited to CoC Cancer Programs as defined by the registry.

- Quality control (QC) staff (Certified Tumor Registrars) reviewed the remaining 1,123 records and manually selected data items for each record based on text.

- QC staff met and discussed each case where values did not agree with any auto-consolidated value to ensure accurate coding of that record.

Findings (NC)

Data Item	# of records evaluated (1,123 total)	% agreement to Certified Tumor Registrar review				
		Rule 1	Rule 2	Rule 3	Rule 4	Rule 5
ERSummary	30	70%	80%	83%	80%	73%
GradeClin	226	63%	72%	67%	71%	47%
HistTypeICDO3	171	37%	58%	63%	65%	64%
PSAValue	44	41%	82%	77%	73%	66%
RxSumSurgPSite	400	40%	77%	82%	74%	68%
SS2018	252	22%	71%	80%	71%	65%

Table 1. Percent agreement between automated consolidation rules and CTR review (North Carolina).

- Rule 1 is the current rule (resulting in manual review the majority of the time thus not matching the value determined through the gold standard manual review).
- Cells marked in green reflect the rule giving the highest percent match to the preferred answer for each data item.

The NC team found that Rules 2, 3, and 4—which are based primarily on the Silver Reporter and/or class of case—had the highest accuracy. Rule 4 had the lowest overall accuracy but provided a significantly higher percentage of correct responses relative to the current rule. The NC team found that removing the hematopoietic cases from the evaluation did not improve the match percentage.

In 124 cases, manually coded correct values were not among the values selected by any of the automated data consolidation rule sets. A range of reasons explain why this occurred, including the following:

- 78 cases that had at least one abstract with the correct value, but none of the rules picked that value. This was especially true if the correct value was a 9 (e.g., grade,13 cases) or a lower code (e.g., surgery and SS2018, 23 cases). This creates some concern because at least one of the abstracts being consolidated contained the correct code, and none of the rules selected the code. Based on a manual review of the 78 cases, 13 had a correct code of “9 Unknown,” and the rules applied a preference for “Known” over “Unknown” logic. As a result, the rules worked as they should, but their logic resulted in an incorrect response recorded on automated consolidation because the unknown value was correct.

- 63 (2 PSA, 3 ER, 23 SS2018, 35 Grade) were related to new 2018 data items. As previously stated, new data items present some challenges for employing automated data consolidation rules. Most of the errors in this group were due to the incorrect use of new coding rules. There were also 16 records in which the correct choice was not selected because of new rules for Histology. The remaining records from this group included random issues, such as not coding the most specific code (e.g., 30 vs. 31 for surgery). Although not technically wrong, some of these selections were not the most specific, correct choice possible or the most specific, best code possible. Among these 124 cases, as abstractors become more proficient with new data items and rules, and as more robust edits are implemented, the automated data consolidation rules should work better.

In the analysis of the NC results that examines the accuracy of the selection based only on codes given in the abstract by dropping the 124 records discussed above wherein manually coded values were not among the values selected by the Rule Sets, Rules 2, 3, and 4 again had the most accurate selection, and the best rule for each data item did not change.

Data Item	# of records evaluated	Rule 1 # w/o NULL	Rule 1 % match	Rule 2 # w/o NULL	Rule 2 % match	Rule 3 # w/o NULL	Rule 3 % match	Rule 4 # w/o NULL	Rule 4 % match	Rule 5 # w/o NULL	Rule 5 % match
ERSummary	29	21	100%	28	86%	28	89%	28	86%	28	68%
GradeClin	225	197	73%	226	73%	197	77%	224	72%	225	47%
HistTypeICDO3	171	75	88%	148	68%	157	69%	168	67%	158	70%
PSAValue	44	18	100%	43	84%	43	79%	43	74%	43	67%
RxSumSurgPSite	400	200	79%	400	77%	400	83%	400	75%	400	69%
SS2018	252	73	78%	250	72%	252	81%	250	72%	252	65%

Table 2. Findings with NULL values removed (North Carolina)

- Cells marked in green reflect the rule giving the highest percent match to the preferred answer for each data item.

Although most of the current consolidation directives, especially for new data items, typically require manual review, it is also useful to see how each automated consolidation rule performs when no manual review is completed. When cases requiring manual review were included in the denominator, those cases counted as a non-match in the numerator because the rule was not able to determine the correct value. Including the nulls shows which rule gives the overall best match given all scenarios. However, when removing the nulls, some results were significantly different because the rule was not penalized for not being able to decide at all.

For example, for Histology, with the Nulls included, Rule 4 gave the highest percent match at 65 percent with the correct answer on 111/171 cases. When the nulls were removed, Rule 1 gave the highest percent match at 88 percent but only on 66/75 cases. Almost twice as many cases had the correct value with Rule 4, even though the overall percentage of accuracy is

lower. Surgery of Primary Site and SS2018 were very similar in both scenarios.

Missouri

- 1,818 records were selected for evaluation by the MO team using a simple sampling strategy that did not oversample a particular site or data item.
- Silver reporters were assigned based on the MO CCR QA staff's identifying which facilities they considered to provide the highest quality data.
- QC staff (Certified Tumor Registrars) reviewed the records and manually coded selected data items for each record based on text to compare against resulting automated data consolidation values.
- QC staff provided feedback for each case wherein values did not agree with any auto-consolidated value to ensure accurate coding of that record.

Findings (MO)

Data Item	# of records evaluated (1,818 total)	% agreement to Certified Tumor Registrars review				
		Rule 1	Rule 2	Rule 3	Rule 4	Rule 5
ERSummary	18	56%	89%	89%	94%	89%
GradeClin	379	57%	65%	56%	64%	55%
HistTypeICDO3	280	18%	44%	56%	55%	55%
PSAValue	75	20%	63%	56%	61%	61%
RxSumSurgPSite	578	34%	75%	80%	68%	66%
SS2018	488	7%	76%	78%	69%	69%

Table 3. Percent agreement between automated consolidation rules and CTR review (Missouri).

- Rule 1 is the current rule (resulting in manual review the majority of the time thus not matching the value determined through the gold standard manual review).
- Cells marked in green reflect the rule giving the highest percent match to the preferred answer for each data item.

The MO team found that Rule 3 produced the greatest percentage agreement with three of the six variables evaluated (Histology, Surgery Primary Site, and SEER Summary Stage 2018). For the ER Summary field, Rule 4 produced the greatest percent agreement with the Certified

Tumor Registrar (CTR) value and had the highest percent agreement for any of the fields evaluated. For Clinical Grade and PSA Value, Rule 2 produced the highest percent agreement with the value from the CTR. Rule 1, which is the current rule, did not have the highest percent agreement with the CTR value for any field. It actually was quite a bit lower in almost every field evaluated because the existing consolidation rules result in manual review for a range of reasons, including the fact that only basic edits were applied to new data items introduced in 2018. Rule 5 also did not produce the highest agreement with the CTR review for any of the fields reviewed, although it was relatively close to rules 2, 3, and 4 for most of the fields reviewed. For the specific fields reviewed, MO found the following overall trends when considering each of the rules used for automated data consolidation:

- For PSA value, none of the automated data consolidation rules were great at producing matches with what the CTR answered. Several reasons appeared to explain the differences, including rounding issues by abstractors. Additionally, a review of the cases determined that timing included in the text is the most important deciding factor when trying to resolve differences during consolidation, and that information was not factored into the automation rules.

- For ER Summary, the MO team determined that considering positive over negative could significantly improve the effectiveness of the automation. This might apply for other SSDIs, as well. Additionally, they found that Rules 4 and 5 prioritizing class 21 over class 00 produced errors with clinical findings.

- A few interesting findings emerged that may make it more difficult to fully automate consolidating clinical grade. For example, within breast cancer cases, the automated data consolidation rules missed some of the correct values based on not accounting for in situ biopsy, but invasive at resection, as well as non-hierarchical low, intermediate, and high nuclear grade for in situ. Also, in some instances, unknown grade is an acceptable answer, but some of the automated data consolidation rules still favor the incorrect known value.

- For histology fields consolidation, the MO team also found that the automated data consolidation rules that favor most frequent value listed sometimes resulted in errors, potentially because the registry had duplicate submissions. Overall, the MO team considered that histology might not be a good candidate for automated data consolidation because of its complexity and the importance of ensuring the correct value is entered because other fields (e.g., grade) depend on a correct coding of histology.

Findings with NULL Values Removed (MO)

Data Item	# of records evaluated	Rule 1 # w/o NULL	Rule 1 % match	Rule 2 # w/o NULL	Rule 2 % match	Rule 3 # w/o NULL	Rule 3 % match	Rule 4 # w/o NULL	Rule 4 % match	Rule 5 # w/o NULL	Rule 5 % match
ERSummary	18	10	100%	18	89%	18	89%	18	94%	18	89%
GradeClin	376	296	73%	376	65%	296	72%	365	67%	375	55%

HistTypeICDO3	279	56	88%	181	68%	250	63%	262	59%	254	61%
PSAValue	74	15	100%	74	64%	74	57%	74	62%	71	65%
RxSumSurgPSite	567	204	96%	567	76%	567	81%	567	69%	567	68%
SS2018	475	39	82%	475	78%	475	80%	475	71%	475	71%

Table 4. Findings with NULL values removed (Missouri)

- Cells marked in lighter green reflect the rule giving the highest percent match to the preferred answer for each data item, which was Rule 1 for each of the data items in this analysis. Additionally, to highlight which rules other than Rule 1 had relatively high matches compared to the other rules, the darker green shows the rule giving the second highest percent match.

The MO team completed an analysis of its data excluding the null cases, as described above in the NC analysis. When MO ran the analysis for each data item removing the null cases from the calculation where manual review was required, Rule 1 produced the highest percent agreement with what was considered the correct answer. Rule 1 also had the most cases dropped from the calculation given that it sends cases to manual review most often. However, as with the NC results, Rule 3 also performed quite well and gave the second-highest percent match and was quite close to Rule 1 for three of the data items.

Trade-Off: The Role of Manual Review and Achieving a Gold Standard

As standard setters and CCRs continue to evaluate their preferences for how much automation to include in the data consolidation process, a key consideration will be the trade-off between the often resource-intensive manual review and the ability of more automated methods to produce the preferred answer for a data item. The trade-off values will differ for data items, and CCRs will likely have different levels of tolerance for what they are willing to accept based on their resources and workload.

When the MO team looked at this specific issue, they found that Rule 1, which results in the most cases' going to manual review (on average 65% of cases going to manual review), also resulted in the preferred response much more often (between 73% and 100% of the time for the 6 data items tested) when a consolidated value could be determined by the consolidation rule. However, Rules 2–5 frequently came up with an automated response and less often sent a case to manual review (on average Rules 2–5 sent cases to manual review 5%, 6%, 2%, and 2%, respectively), but far less often result in a response that matched the preferred response. In fact, for the six data items tested the percentages of non-matches for Rule 2 were between 11 percent and 36 percent, Rule 3 were between 11 percent and 43 percent, Rule 4 were between 6 percent to 41 percent, and Rule 5 were between 11 percent to 45 percent. The trade-off for time saved by reducing manual review given the number of data items for which automated consolidation results in an incorrect answer will need to be carefully studied by CCRs and standard setters using "real world" data to ensure an informed decision is made when adopting automated data consolidation practices. The MO team has determined retaining

Rule 1 is preferred because it provides the most accurate results even though it results in manual review more often. This supports evaluation of data at some point, either through visual review and upon manual review of differing values reported from multiple sources upon processing or after the data are added to the database if consolidating via automated rules and running data quality checks to achieve a higher threshold for data quality.

Conclusion

Many lessons were learned by the Registry Plus support team and CCRs in working through the automated data consolidation activities, including the following:

- When differences across data items are being reviewed, including Primary Site, Class of Case, and Reporting Source to better understand the case at initial review can help determine which of the responses are most accurate. Differences in any of those items can shed light immediately regarding differences across other items.

- As we consider how best to enhance automated data item consolidation, thinking through the hierarchical logic of rules will be critical to ensure that all the information needed to evaluate makes it through the full logic of the tool.

Abstractors are learning lessons regarding what variables are best suited for automated consolidation. For instance, newer data items in which we do not yet have expertise for application of abstracting rules or robust edits and how they work in the field may not be as well positioned for inclusion in automated data consolidation. Partial automation may be best for initial implementation of a new data item until data quality improves and edits are identified to improve the quality of the new data items that are consolidated.

- CCRs are learning more about the role of reporting sources and reliability of responses that could be customized across states as a factor considered in automation.

- Reviewing data to determine the best value for Data Item Consolidation can help identify common errors in coding that could improve overall accuracy of auto consolidated values. For example, based on this project, both MO and NC are sending common errors to reporting facilities as part of an educational effort.

- Some factors seem to result consistently in issues that offer opportunities for improvement via edits, training, and/or education:

    - Grade for in situ breast: The priority code for breast differs based on behavior; the consolidation rules do not take this factor into consideration. This led to an incorrect decision when the abstractor did not apply the priority order for ductal carcinoma in situ (DCIS). They suggested potentially using edits or updated automated consolidation rules to apply this lesson.

    - For the surgery data items, the rules select 00 over 98, including for hematopoietic cases. But, if the edit is fixed to force a code of 98, automated data consolidation rules might work better.

    - The NC team suggested that a more in-depth evaluation looking at Histology for hematopoietic cases should be completed to better determine if these should be eliminated from the Histology consolidation rule.

- The MO and NC teams noted that on manual case review, class of case and reporting facility are key factors that help make coding decisions when there is no text. However, using different combinations of these factors with the automated data consolidation rules did not result in significant increases in the percent matches for correct values.

- The MO team found that when evaluating which rules work best for automated data consolidation activities, it may be important to consider which rules most often send the field to manual review, thus resulting in less automation.

- The MO and NC teams also used this study to guide them to the position that CCRs may fall into the habit of focusing too much on the red data items marked “For Review” in the CRS Plus software TLC window (manual decision required for consolidation). However, given that no rule can auto-consolidate at 100 percent, CCRs need to make sure the review process includes the green items as well (New value different from existing value—automated decision based on TLC Plus Directives).

- The MO team highlighted a few considerations that were unique to its CCR for this project but that could apply to more CCRs if automated data consolidation is rolled out on a more national scale. For example:

    - Missouri has the most border states and two major cities on borders, which results in many consolidations where one submission is a consolidated record without text from another CCR.

    - Additionally, Missouri has a large out-of-state NCI center with clinics on both sides of the border that reports to both the MO CCR and the other state’s CCR. This may result in duplicate values coming to the MO CCR under different facility codes for the same patient. This can impact the consolidation rules by giving the false impression that results taken from identical patient encounters look like separate encounters and therefore seem to produce the same value with increased frequency. The consolidation rules that favor frequency of same responses for a data item would misread these identical encounters as separate and give them greater weight.

    - Additionally, major cities sometimes have hospital systems that share abstracting software but send separate abstracts per facility. Thus, if they copy an existing abstract and do not apply adequate quality checks, the same hospital system may send duplicate erroneous values. This is an issue that the MO CCR has been working on with its hospital systems for some time and is an important consideration for automated consolidation.

- Some data items are considered so critical to the quality of the consolidated record that CCRs may feel reluctant to completely automate their consolidation and may insist that trained CTRs review any discrepancies to ensure the most correct choice is made for several reasons:

- Resolving discrepancies for the same primary cancer requires the highest degree of confirmation that the correct value is selected to ensure cancer counts are accurate. For this reason, CCRs will also prefer that trained CTRs review the discrepancy and make the final decision.
    - An incorrect Primary Site impacts the Schema ID and several data items including Grade, Stage, SSDIs, and Treatment. The preference is to manually review the Primary Site when differing codes are reported by multiple sources, because determining the correct primary site is critical for schema selection.
- For some conflicts, CCRs need CTRs to identify the case via manual review and follow back with facilities to provide education and training.
    - For example, Rules tying Grade to "Same as Histology" may not be advisable when there are misunderstandings of Histology and/or Grade rules, as seems to have been the case at this time point in 2018. Perhaps these fields are too complex for automation, or greater effort needs to be put into edits prior to these fields' coming to automated consolidation.
    - Also, Class of Case Hierarchy might need to be specific to a given use. Treatment items might benefit from a hierarchy that favors entries from a treating facility over a diagnosis-only facility.

The NC results demonstrated that CoC analytic cases do not necessarily hold a high enough level of accuracy that they can automatically be considered correct when discrepancies in codes exist. Although edits could be added to catch some obvious conflicts with the rules, every case may need to be evaluated to identify why there was a discrepancy, followed by review of the text to determine the final code. This became obvious when contrasted with the non-CoC data sources to which additional scrutiny is automatically applied. The study showed no consistencies within reporting source or Class of Case to assign priority that would guarantee that the most accurate and specific code was selected via an automated data consolidation process. As a result, although using Silver Reporter and Class of Case appears to get states closer to more cases being auto consolidated, there still are not enough consistencies in these factors to guarantee accuracy. For this reason, many CCRs might still expect to manually verify any decisions determined via automated consolidation directives.

Data quality issues were identified upon review that were unexpected, further stressing the importance of data evaluation to identify data quality checks and training needs. Another factor to consider is the existing variation among registries in the volume and level of visual review conducted on source data.

Many registries are hampered by resource issues and not able to invest the resources they would like into visual review, which can directly impact the quality of the data. Through working on this project, participating CCRs also discussed the existence of opportunities to use well-designed and tested automated data consolidation rules to better focus CTRs and QC staff on high-priority consolidation activities that require more manual review. For example, the NC QC staff outlined two areas, Patient Linkage and Tumor Linkage, wherein advances in CRS Plus automation resulted in efficiencies based on focusing limited staff resources in an area of increased importance for manual review. Additionally, the MO team noted that the project

activities were valuable for reinforcing that automated data consolidation rules can provide a more focused guide directing CTRs to what they should review, but they would not consider them a replacement for CTR evaluation.

The NC CCR indicated its preference is to leave resolving complex conflicts among data values (those that the current, basic consolidation rules cannot resolve) to the manual review by CTRs. Other areas are in Pending, where workload can be reduced to allow more time for manual consolidation of data item conflicts in TLC. For NC, data item consolidation between two records for the same primary cancer is the core of its Pending Review. NC wants to make every effort to ensure that the most accurate value is selected. It is also important to know where these conflicts exist so the CCR can identify the cause and follow back to facilities with education and training. The QC issues identified through this project are good examples. The NC CCR may not have realized the issues if CRS Plus had auto consolidated these data items.

- Patient Linkage: The NPCR Registry Plus support team has developed a Patient Linkage tool for use with CRS Plus to assist registries in evaluating and determining the best algorithm for weights assigned to data items to determine patient match with a reasonable number of cases requiring review for patient linkage. NC and MO have implemented the Patient Linkage tool and both registries have found the enhancement has significantly increased their efficiency in processing. Based on that improvement, they evaluated all components of the scoring system and reduced the number going to Pending, from 45 percent to 33 percent overall for NC, and from 65 percent to 29 percent in MO; and those going in as a Patient Linkage status from 15 percent to less than 5 percent for NC, and from 27 percent to 2 percent for MO. These changes made a significant difference in the efficiencies for CTR staff. An important component of this improvement is that the NC team has a routine process (“safety net”) for identifying missed patient matches outside of CRS Plus for the rare situations that have so many unknowns or discrepancies that a high enough score could not be assigned. This allows them to significantly reduce the patient non-matches in Pending but still have an effective means of identifying those rare situations.

  This example provides an opportunity for the registry community to work together to develop consensus on how much automated data consolidation for patient linkage should be conducted to reduce the Pending workload. On the other hand, different states have different thresholds that work for their patient populations, so a firm, consistent threshold across all states may not be possible.

- Tumor Linkage: The latest CRS Plus upgrade included automated logic for 10 additional primary sites based on the SEER Solid Tumor Rules, which automatically dispose of cases that are a separate primary or link records identified to be the same tumor. The NC team found this approach has reduced Pending work even further and addressed another area where the QC staff felt they could spend less time.

The value of the automated data consolidation rules seems to lie in the ability to improve the registry workflow, take advantage of efficiencies within the process, and give trained staff the ability to better focus their energy on the core work of confirming final data value decisions, especially among the most critical and/or newer data items. Based on the acknowledgement that it is not possible to set up automated data consolidation in a way that establishes 100 percent accuracy on every case, its value in making preliminary decisions and highlighting

important discrepancies is still quite valuable.

Before adopting any specific automated consolidation rules, it will be important that CCRs test the rules using actual registry data to determine which rule works best for specific data items. From this study, we have seen that the value of rules can differ from data item to data item, as well as CCR to CCR. We can build on this work to try to determine which items lend themselves more readily to automated data consolidation. For example, items that have been collected by CCRs longer with fewer rules changes may be better suited for automated data consolidation.

Over the course of working on this project, the CCRs also were able to identify QC improvements that could be completed to improve the quality of the records going into the automated data consolidation to improve the consolidated record output. For example, cases of Transrectal Biopsy (TRUS BX) were being coded in the Surgical Primary Site in error for prostate surgery, which could be addressed via an edit that looks for this issue. Based on what CCRs found in reviews during the automated data consolidation activities, they were able to add to their routine QC audits. Please see Appendix B *Supplement: The Role of Quality Control in Automated Data Consolidation* for more specific information related to the importance of QC in achieving optimal data consolidation results.

Clearly, this study highlights the critical role of routine QC checks and audits and shows that manual data item consolidation can provide another tool that highlights, by separating which cases require additional review, the areas wherein data items might benefit from additional edits and/or training to improve data quality. The lessons learned extend to other data items that have not been evaluated. The tool that was developed for this consolidation project can be used as a resource to CRS Plus users to evaluate other data items not considered for this project, and the consolidation methods and directives also can be modified and analyzed using registry production data by connecting to the CRS Plus database and generating comparison results for registries to review.

Additionally, different CCRs will have different preferences and acceptance of using automated data consolidation depending upon many factors. For example, higher volume CCRs may be more willing to adopt full automation rules while lower- to mid-volume CCRs may prefer more moderate levels of automated data consolidation that send more cases to be pending for final manual review.

Reducing manual review in the initial steps of data flow for Patient Linkage and Tumor Linkage in conjunction with a combination of automated and manual methods for consolidation has significantly reduced the volume of records requiring manual review, leaving the decisions to CTRs to determine the best value when multiple sources report differing values. Focusing on automating processes that can be completed by a computer algorithm effectively and efficiently allows registries to focus resources on consolidation decisions that cannot easily be made through automation.

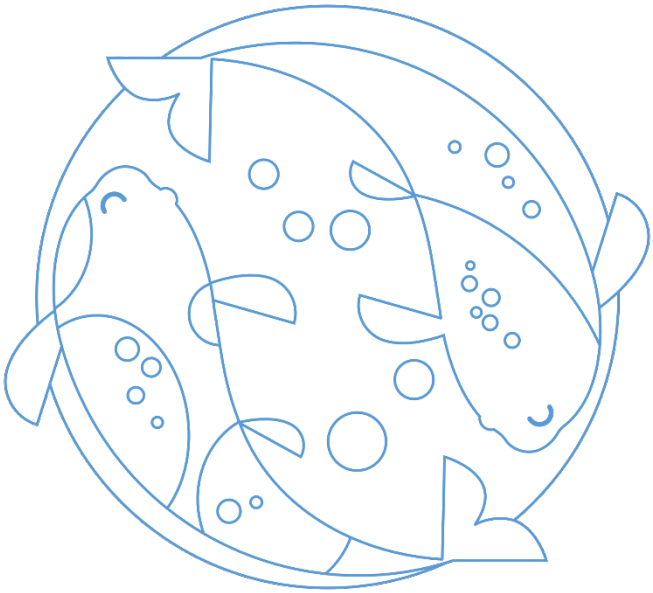
We would like to acknowledge the effort and valuable analysis provided by the Missouri Cancer Registry and Research Center and the North Carolina Central Cancer Registry. The thorough review by the participating registries identifies the need for consideration of data quality edits and checks as part of best practices for data item consolidation. Although identifying best practices for implementing fully automated data item consolidation was not the result of this project, this study did provide valuable information that needs to be considered as a first step by

identifying data quality audits, checks, and edits, with the goal of improving incoming source data to have the best source information available to be considered for consolidation. It is our hope that understanding the challenges and data quality issues will help inform the registry community to determine next steps in identifying data item consolidation best practices and to enhance existing consolidation directives.

Next Steps and Recommendations

Several important next steps are recommended to involve the wider cancer registry community in the process of evaluating the role that automated data consolidation can play with improving efficiencies and quality of cancer registry reporting. Among the steps CDC, NAACCR, and national partners in the registry community can take are the following:

- Present the project summary to the Registry Plus Users Group.
- Provide recommended data quality checks to the Registry Plus Users Group.
- Review potential edit recommendations to determine whether edits can be added to the NAACCR Edit Metafile.
- Consider evaluation of other data items (long-standing NAACCR data items that have more robust multifield edits) and try to identify registries with resources to evaluate data using the tool created for this project.
- Work with national partners toward a common goal of developing best practices for data item consolidation that will include recommendations for data quality checks or edits to improve the quality of incoming data.



A Summary of Interactive Best Practices Workshops Findings and Tools to Guide Registries to Improve Data Reporting and Registry Operations

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Interactive Workshops Designed to Identify Tools and Best Practices to Improve and Support Central Cancer Registries' Operations

Overview and Background

Based on the recommendations for next steps from the first year of the project, *Identifying and Implementing Best Practices for Cancer Registry Operations*, the North American Association of Central Cancer Registries (NAACCR) planned and implemented a series of virtual interactive workshops aimed at identifying best practices and tools to improve and support registry reporting and operations. Although the workshops all focused on different challenges within central registry operations, a common purpose focused on allowing registry staff to share experiences and knowledge around these topics and compare different registry operational approaches to learn which methods were the most effective in diverse settings. Workshops were virtual due to COVID 19 constraints, but they were developed to allow maximum engagement among participants. All National Program of Cancer Registries (NPCR)-supported registry staff were invited to participate in any and all of the workshops.

The purpose of this project was to plan and implement interactive workshops to facilitate discussion around best practices and tools for the following:

1. Developing and monitoring data management reports
2. Establishing strong communications and relationships with hospitals
3. Improving reporting from nonhospital sources
4. Managing best practices around the COVID-19 response

Because of COVID-19 and other time constraints, fully developed and vetted best practices could not be developed within the framework of this project. In NAACCR's experience, the development of best practices guidelines requires extended discussion and negotiation among a broad constituency. Consensus on best practices is often difficult to reach and not attainable within the framework of a brief virtual workshop. Nonetheless, these workshops produced substantial information on current and successful best practices used across NPCR registries. This information is summarized below, and tip sheets are offered containing ideas from registry directors. The summaries provided will serve as an excellent base to further develop these topics in the future.

A top salient benefit of these workshops was allowing the registries to exchange ideas freely on a selected topic. (See Appendix C, Workshop Evaluations.) Registries are always eager to share experiences, explain their approach to problems, and learn from others. In every breakout and workshop session creative ideas were shared, and registry directors heard about methods tried in other environments that might be useful in their own situation. We strongly recommend that the Centers for Disease Control and Prevention (CDC) continue to facilitate such opportunities for exchange of ideas among the registries.

Workshop I: Developing and Evaluating Management Reports

The first workshop addressed *Developing and Evaluating Management Reports* and was conducted during three sessions. During the first two sessions, participants were divided into three breakouts. Sessions One and Two addressed facility and central registry reporting, respectively, and Session Three focused on reaching consensus (Table 1). Participants were asked to attend all three sessions.

Table 1. Structure of Workshop I

Workshop Structure		
Session One - 8/13/2020	**Session Two - 8/13/2020**	**Session Three - 8/25/2020**
Breakout 1: Timeliness of Facility Reporting	Breakout 1: Timeliness of Central Registry Reporting	Polling for consensus of variables, benchmarks, and metrics for management reports
Breakout 2: Completeness of Facility Reporting	Breakout 2: Completeness of Central Registry Reporting	
Breakout 3: Quality of Facility Reporting	Breakout 3: Quality of Central Registry Reporting	

Workshop Objectives

1. Identify and assess the most important data management reports required to monitor completeness, timeliness, and quality of reporting facilities and central registries.

2. Establish metrics and benchmarks for the management reporting of facilities and central registries around completeness, timeliness, and quality.

3. Suggest new or improved management reporting practices that would enhance central registries' ability to meet completeness, timeliness, and quality goals.

Each breakout session identified the types of data management reports required to monitor and improve completeness, timeliness, and quality at both the central registry and facility level. The third session of this workshop was designed to reach consensus from all participants on what should be included in the recommended management reports. Polling through Zoom was used to achieve consensus. The most important data needs, benchmarks, and metrics were identified. Sample reports were also collected from the participating states and are provided in Appendix E

Registries in 28 states and Washington, D.C., participated (Table 2)

Table 2. Registries participating in Workshop I

Alaska	Louisiana	New Jersey	Tennessee
Arizona	Maine	New York	Texas
Arkansas	Maryland	North Carolina	Utah
Colorado	Massachusetts	North Dakota	Washington, D.C.

Florida	Minnesota	Ohio	West Virginia
Hawaii	Missouri	Oregon	
Idaho	Montana	Rhode Island	
Kentucky	Nevada	South Carolina	

Workshop Recommendations

Based on the results of the workshop, the following recommendations are made to CDC and to central registries for using management reports to monitor completeness, timeliness, and quality. Please refer to the full report for more details concerning these recommendations.

Recommendations for CDC

- Develop a dashboard and/or semiautomated on-demand reports within the central registry software that display the registry's progress toward 12- and 24-month submission benchmarks, including—
    - Completeness
    - Percent of cases missing age, sex, race, and county
    - Percent of cases from death certificates only
    - Percent of cases passing CDC-prescribed set of standards edits
- Develop a dashboard and/or semiautomated on-demand reports within the central registry software that display the following measures for each reporting hospital:
    - Timeliness of submissions—percent of cases that are received within the required time frame, with the ability for registries to choose the starting point (date of diagnosis or date of first contact) and time frame (in days or months)
    - Completeness of reporting—the number of cases received for the current reporting year as a proportion of the average of the number of cases reported in prior years
    - Percent of cases missing age, sex, race, and county
    - Percent of cases passing standard edits

Recommendations for central registries are threaded throughout this report. Please see Monitoring Timeliness, Completeness, and Quality Tip Sheets for specific registry-based recommendations.

Workshop Summary

Breakout 1: Timeliness

The participants reported that limited staff, increased workloads, and a lack of familiarity with or access to software packages were all barriers to generating reports to monitor timeliness.

Recommendation**:** The group reported that a real-time dashboard with the ability to provide timeliness metrics on demand would greatly reduce this burden. The metrics described below represent the final consensus of the group based on recommendations from the breakout participants.

Timeliness Monitoring of Reporting Facilities

Participants identified the need for metrics for two types of facility timeliness:

1. Timeliness of submission: Submission of cases according to a required or agreed-on schedule (monthly, quarterly, etc.)

    - Measure the proportion of cases that are reported to the central registry within the required time frame.
    - The required time frame varies somewhat between central registries, but in general it is 180 days or 6 months from the date of diagnosis or the date of first contact with the reporting facility.
    - Central registries that currently monitor timeliness of reporting are doing so using tools created outside of their registry software. This places a burden on staff that could be reduced or eliminated by building such reports into the cancer registry management software.
    - This report does not exist within CRS Plus.

    The full group consensus of workshop participants determined that a semiautomated, on-demand report should be built into central registry software programs and should include the following measures:

    - The percent of abstracts (source records) from each facility received within *X* days of [Start Date], where—
        - *X* is a user-selected number of days as determined by the registry.
        - Start Date is user-selected from either the Date of Diagnosis or the Date of First Contact.
    - The program should allow the user to select from the following parameters:
        - Diagnosis/Accession Year
        - Facility ID

- Primary Site
- NPCR Reportable Status
- Address at DX State
- Class of Case
- Type of Reporting Source

2. Timeliness of Reporting: The time from initiation of a case (date of diagnosis or first contact) to its submission to the central registry

- CRS Plus includes Cases Received by Facility but it does not have the level of detail outlined in the recommended data fields listed below.
- Monitor reporting facility adherence to required or agreed-on submission schedule.
- Monitor missed submissions in real time to help to identify facilities at risk of falling behind in reporting and take steps to avoid delinquency.
- All central registries indicated they track facility submissions, but for most registries this is a manual procedure that is done external to their registry software.

During the consensus gathering session the attendees voted and approved the recommended the following automated report specifications:

- Include the following fields:
  - Facility ID/Name
  - Date file Received.
  - File Name
  - Number of records in the file
    - Number in NAACCR Record type A (full case abstract)
    - Number in NAACCR Record Type M (modified record)
  - Number of Rejected files/cases
- Include nonhospital sources (physician offices, radiation therapy centers, cancer treatment center, ambulatory surgery centers, private pathology laboratories).
- Track by month (number of cases reported by each facility each month).
- Identify and flag facilities that did not report during the month (generate a report that lists all facilities that did not submit a report during a particular month).

- Provide comparisons to previous years (generate a report for each facility that compares what is being reported this year versus previous years; recommend comparing data from at least the previous 5 years).

Timeliness Monitoring of the Central Registry

The group discussed the degree to which timeliness and completeness are intertwined at the central registry level. Timeliness goals for central registries are meeting the 24- and 12-month call for data submission deadlines.

To that end, the group determined the best way to monitor central registry timeliness is to monitor the progress toward Call for Data tasks. The group documented steps necessary to meet Call for Data standards and developed a timeline for completion.

Several examples of Call for Data task lists and timelines are used by individual registries and could form a basis for a master timeline. The group agreed that a management tool containing all the tasks with a method to monitor progress and identify current priorities would be very helpful.

During the consensus-gathering session the attendees voted in favor of developing a process management tool to monitor the status of tasks. The tool should include tasks to be done throughout the year, as well as tasks that should not be started until after the file is 90–95 percent complete. The tool should achieve the following:

- Include each task listed below in the designated categories:
    - Throughout the year
    - When the file is 90–95 percent complete
- Allow the user to add, delete, and customize tasks.
- Allow registries to set due dates.
- Include a method to mark a task with an estimated percent complete, or as completed and the completion date.
- Mark past due tasks with a flag or warning.

The following tasks are to be performed throughout the year (in no particular order):

- Receive, import, process cases.
- Abstract and process paper pathology laboratory and other hard-copy nonhospital cases.
- Follow back for missing information—for example: percent missing follow up, by site.
- Deduplicate patients—run a deduplication report monthly.

- Undertake quality assurance runs; for example, cases with localized behavior but in situ stage, validating unusual site histology combinations, unknown birthdates, etc.
- Run EDITs at least monthly.
- Include geocoding; run a report to identify incorrect codes and missing codes monthly.
- Assess unknown values (race, sex, date of birth, county) monthly.
- Apply linkage to vital record death files; perform monthly or quarterly, as available—rematch the entire year when data are 95 percent complete.
- Run resolution of duplicate tumors quarterly.
- Run interstate data exchange twice a year and process cases.

The following tasks are to be performed when the file is 90–95 percent complete:

- Death Clearance
- IHS Linkage
- NDI Linkage
- SSDI linkage
- Resolution of duplicates should be an ongoing process, but it's not always possible to complete throughout the year; it must be done prior to call for data submission.

Breakout 2: Completeness

The participants again reported that limited staff, increased workloads, and a lack of familiarity with or access to software packages are all barriers to generating their own reports to monitor completeness. The group recommended a real-time dashboard with the ability to provide completeness metrics on demand to greatly reduce this burden. The metrics described below represent the final consensus of the group based on recommendations from the breakout participants.

Completeness Monitoring of Reporting Facilities

The group agreed that monitoring facility completeness is important to ensure complete capture of all cases. Like timeliness, completeness is being monitored in two ways:

- Completeness of case-finding: The facility identifies and abstracts all reportable cases.
- Completeness of submission: The facility transmits all reportable abstracted cases to the central registry.

Most registries reported that they are monitoring facility completeness; however, there is significant variability in the methods and tools employed for measuring completeness. Almost all

states were using software applied outside their registry database to perform the assessment (SAS, Excel, Access).

1. Completeness of Case-Finding

   The group agreed that completeness of case-finding involves the number of new cases (duplicates removed) submitted for the current reporting year in comparison to cases submitted in prior reporting years.

   Some states use a visual comparison (without calculation) to prior years, while most states reported calculating completeness by dividing the number of cases submitted for the current year (actual) by an average of the previous years' case counts (expected). States use 2–5 years of data to calculate the number of expected cases, and one state uses a weighted average with more recent years weighted more heavily.

   Some states track completeness by diagnosis year, while others use accession year (based on date of first contact). The difference primarily depended on whether the state collects non-analytic cases, which may be reported months or years after diagnosis, in which case tracking by accession year is more appropriate.

   Although some states assess facility completeness annually at the end of the reporting year, they all agreed it would be useful to monitor facility completeness more frequently (monthly or quarterly) to ensure facilities are on track to submit all cases by July 1.

   The development of a dashboard or report in the central registry software that provides the deduplicated number of cases submitted by each facility per year (diagnosis or accession), with a calculated completeness expressed as the percent of expected cases, is recommended. Registries should be able to define the number of years used to calculate average caseload. (Note: Although an automated report within the registry software would be useful, registries may choose to override the expected number of cases for a facility based on audit results or other external factors.)

2. Completeness of Submission

   The group recognized that reportable cases abstracted by a facility may not be in the central registry database for several reasons. To identify these missing cases, registries are using a variety of methods, including annual resubmission of all cases by each facility, annual comparison of case listings, and follow-back on gaps in sequentially assigned hospital sequence numbers. The group recommends the following:

   - Develop a report or flag in the central registry software that identifies missing facility accession numbers.

   - Develop a report in the central registry software that shows frequency of submissions/imports and number of cases by facility.

Completeness Monitoring of Central Registries

All participants agreed that the biggest barrier to monitoring central registry completeness and progress toward 12- and 24-month submission completeness goals is the lack of a transparent and consistent number of expected cases to use as the denominator. Although the group acknowledged that CDC and NAACCR are working on revising the methodology for calculating the denominator, they recommended that the number of expected cases used to estimate 12- and 24-month completeness should be the same.

The group recommends developing a dashboard report that shows real-time progress toward the 12- and 24-month completeness benchmark using a consistent denominator and numerator. The report should include the following:

- Expected number of cases for 12- and 24-month submissions based on historical data.
- Number of cases currently in the CCR database that will be counted toward completeness for the 12- and 24-month submissions.

It would be helpful if dashboard showed completeness broken down by the following:

- Primary site
- County (or other geographic region)
- Diagnostic confirmation

Breakout 3: Monitoring Quality

This group suggested an on-demand quality report that includes essential data items, benchmarks, exclusions, and accuracy calculations. Such a report would help provide consistent and timely feedback to reporters and central registry staff.

Quality Monitoring of Reporting Facilities

The group discussed how data quality feedback to reporting facilities is currently provided. Availability of resources and the number of reporting facilities are important factors in the central registries' ability to provide robust and consistent feedback to reporting facilities. There is substantial diversity in the frequency, approach, and methodology of providing feedback as well as the data quality indicators included.

Tools—Most central registries currently use software external to their database management system for generating facility data quality reports.

Frequency—Central registries vary in how frequently they provide data quality feedback to reporting facilities. Commonly, feedback is provided monthly, bimonthly (every 2 months), or quarterly.

Content—The number of data items reviewed and included for feedback also varied by central registries, but most indicated 6–10 data items.

The group reached consensus that registries should regularly evaluate the following data items from reporting facilities for accuracy and data quality control purposes and include them in data quality reports to reporting facilities:

Demographic Data

- Gender
- Race

Tumor Data

- Primary Site
- Histology
- Behavior
- Grade—Clinical (optional: Path and Post Therapy)
- Summary Stage 2018
- EOD—Primary Tumor, Reg Nodes, Mets
- Date of Diagnosis
- Laterality
- Lymph Nodes Pos/Examined
- Diagnostic Confirmation
- Hospital Sequence
- Site Specific Data Items (SSDIs)
- Lymph Vascular Invasion (LVI)

Treatment Data

- All first course of treatment for each treatment modality

To confirm data quality, central registries should strongly recommend that abstracts include text documentation to support codes for all the data items listed above.

Benchmark—The group discussed the accuracy rate for these data items. After much discussion, the group recommended a 95 percent accuracy rate as the benchmark.

Exclusions—Non-analytic cases, out-of-state cases, death certificate–only cases, pathology laboratory–only cases, autopsy-only cases, and nonhospital reporting sources.

Metric—The error rate is calculated by dividing the number of discrepancies by the total number of data items (or maximum possible number of discrepancies), multiplied by the number of abstracts reviewed. The accuracy rate would then be 1-the error rate (100). Each data item listed above is counted as a single item.

Other Issues Discussed

- The impact of the CoC RQRS requirements on central registries: How will the CoC requirement to frequently update a case impact central registries? Can central registries request that hospitals submit only completed cases? On the flipside, will this CoC requirement present an opportunity for central registries to obtain more real-time data as cases are updated more frequently?

- Data quality incentives: Having public recognition, certificates, or awards for achieving a specific data quality threshold based on a "report card" approach is recommended.

- Some hospital registries do not want feedback: A survey was conducted by one state registry to assess providing feedback to hospital registrars; concerns cited include having no time to update and correct the hospital registry database.

- Re-abstracting audits are also implemented by some central registries to evaluate data quality, but this is becoming more difficult to accomplish due to travel restrictions for on-site audits. Alternatively, conducting these audits remotely via access to hospital electronic medical records is often prohibited or a long and cumbersome process.

Quality Monitoring of the Central Registry

All participants agreed that central registries should monitor meeting NPCR National (24-month) and Advanced (12-month) Data Quality Standards. These standards are listed below. Central registries discussed the variety of tools and resources used to generate reports to monitor their data quality. Most use software external to their database management system. Some database management systems can create a dashboard for specific indicators. External tools used to generate reports include SAS, Crystal reports, Tableau, and Sequel queries. Some expertise is required to run these external programs, so having a standardized generated report that can be filtered as needed is the preferred approach.

It was noted CRS Plus has the *NPCR Incidence Completeness Report* that covers the items noted with an asterisk below.

NPCR National Data Quality Standard (24-month data):

- There are 3 percent or fewer death-certificate-only cases*

- There is a 1 per 1,000 or fewer unresolved duplicate rate.

- The maximum percentage missing for critical data elements are as follows:

    - 2 percent age

    - 2 percent sex

    - 3 percent race
    - 2 percent county
- 99 percent pass CDC-prescribed set of standard edits.

NPCR Advanced National Data Quality Standard (12-month data)

- There is a 2 per 1,000 or fewer unresolved duplicate rate.
- The maximum percentage missing for critical data elements are the following:
    - 3 percent age
    - 3 percent sex
    - 5 percent race
    - 3 percent county
- 97 percent pass CDC-prescribed set of standard edits.

The group also recommends adding the ability to include additional data items, such as the following:

- Unknown Primary Site: ≤10 percent
- Unknown Summary Stage: ≤10 percent

Other Issues Discussed

- Race is becoming more difficult and problematic to obtain, especially from nonhospital reporting sources.
- The number of pathology report–only cases is increasing, with little information to create a complete case, increasing the percentage of unknown values for many data items.
- Validating patient demographic information through investigative software, such as LexisNexis or Clear, is becoming more essential. In addition, having access to other state health information databases, vital records, and hospital discharge data is also important to complete or validate demographic data.
- Reaching out to participate in local physician workgroups, such as the Melanoma Workgroup in Arizona, helped to improve obtaining race information, as well as Clark's level.
- Reaching out to groups of independent oncology (medical and radiation) clinic databases to access their system for patient treatment information is helpful.
- Conducting the data linkages to obtain passive follow up information is important.

- Conducting various focused visual auditing data reviews several times a year can assist in identifying discrepancy trends and early corrective interventions.

Workshop Summary

This workshop provided central registries with a forum to discuss a range of management tools that would support more efficiency in monitoring progress toward timeliness, completeness, and quality in reporting. Cancer registry data management software is the most effective way to achieve these objectives; it is recommended that CDC focus on the development of a seamless software system that would help support this goal. The alternative of relying on registries to develop their own tools external to their data management systems continues the ad hoc approach to operations that results in inconsistencies in reporting procedures across central registries. A suite of tools and dashboards that could be used by all was conceptually defined and is included in the findings delineated above.

Workshop II: Establishing Communications and Relationships with Hospitals

The second in the series of workshops focused on *Establishing Communication and Relationships with Hospitals.* This workshop was held in two sessions on September 29, 2020, with breakout groups in Session One. The workshop agenda and schedule are outlined in Table 3.

Table 3. Structure of Workshop II

Establishing Communication and Relationships with Hospitals Workshop	
Session One - 9/29/2020	**Session Two - 9/29/2020**
Breakout 1: Feedback to Facilities	Review Summaries of the Breakout Sessions; Review Sample Tools; Recommendations
Breakout 2: Incentives: Pros and Cons	
Breakout 3: Relationship Building	
Breakout 4: Innovations in Communication	

Workshop Objectives

1. Identify and develop tools, strategies, and best practices to improve the quality, completeness, and timeliness of hospital reporting through—

    a. Feedback and Audits

    b. Incentives and Penalties

2. Examine and appraise successful strategies to improve relationships and connections between hospitals and central registries

3. Assess current communication practices among hospitals and central registries and explore innovative approaches and strategies aimed at improving such communications

Each breakout session focused on various components and methods to establish and strengthen communications and relationship building between hospitals and central registries. Session Two of this workshop reconvened all participants to share the summaries and recommendations from each of the breakout sessions. Communication tools were also discussed, as well as any communication barriers encountered.

Workshop II Attendance

Registries in 23 states and Washington, D.C., were represented (Table 4).

Table 4. Registries participating in Workshop II

Alaska	Kentucky	New Jersey	Rhode Island
Arizona	Louisiana	New York	South Carolina
Arkansas	Maryland	North Carolina	Texas
Colorado	Minnesota	North Dakota	Utah
Hawaii	Missouri	Ohio	Vermont
Idaho	Montana	Oregon	Washington, D.C.

Recommendations

Central registries may benefit from implementing the following tools and strategies:

Relationship-Building

- Designate a central registry point of contact for each reporting facility to provide one-on-one, personal communication.
- Establish a relationship with the state or regional cancer registrars' association by attending or cohosting events and providing speakers for educational sessions. The central registry should encourage staff to become members of the state or regional association and to participate in its governance and committees. The CCR Education and Training Coordinator may speak or provide training at association events.
- Attend hospital cancer conferences and/or cancer committee meetings.
- Invite hospital registry staff and/or administration to visit the CCR.
- Connect with cancer registry or health-information programs at local colleges and universities. Offer to speak at career events or invite students to spend time at the CCR. Offer cancer registrar training clinical hours for students preparing for the Certified Tumor Registrar (CTR) exam.
- Hold regular meetings with registry staff or administration at large facilities.
- Provide hospital registrars with resources to help them better perform their jobs. Resources may include no-cost training and education, follow-up or treatment information, counts of patients enrolled in institutional review board (IRB)–approved

studies, a list of available registry contractors, or letters of support to hospital administration.

- Communicate the results and outcomes of projects and studies that use cancer registry data or to which hospital registrars contributed.

Feedback to Facilities

- Central registries should develop a procedure for providing consistent positive and negative feedback on timeliness, quality, and completeness to reporting facilities. The procedure should address—
    - What information should be shared with the facility
    - How often and in what format feedback is given
    - The point of contact for feedback at each facility
    - Benchmarks or comparisons for quality, completeness, and timeliness measures
    - Recommendations or procedures for facilities to improve areas that do not meet expectations or standards (e.g., improvement plan or action plan)

Incentives

- Publish a list of compliant and/or noncompliant reporting facilities.
- Acknowledge hospitals meeting or exceeding cancer reporting standards with awards, certificates, and recognition.
- Make reports of follow-up or treatment information or counts of patients enrolled in IRB-approved studies available to compliant facilities.

Communications

- Provide monthly or quarterly communications via a newsletter or the state cancer registrars association. Topics may include education, abstracting tips, and central registry news and events.
- Use electronic surveys to obtain feedback and input from hospital registrars.
- Implement encrypted email or other secure data exchange tools to facilitate communication.

The CDC could consider the following recommendations:

- Develop the standardized timeliness, completeness, and quality reports identified in Workshop 1 to facilitate feedback to hospital reporting facilities.
- Develop a toolkit or best practice for engaging reporting facilities on an ongoing basis, based on this workshop, but drilling down further to include the following:

- Identifying the contact person(s)
- Relationship building
- Engagement frequency
- Engagement content

Summaries of Each Breakout Session

Relationship Building

Participants in this breakout discussed formal and informal strategies they have used to foster and maintain good relationships with reporting facilities to improve the completeness, timeliness, and quality of reporting.

Key Findings

- Fostering and maintaining strong relationships with reporting facilities can have intangible benefits for the central cancer registry and the hospital alike and can ultimately lead to improved reporting.
- Hospital registrars must understand how the central registry operates and what its goals and priorities are. This can help foster an understanding that hospital and central registries are working toward the same end.
- Designating a central registry representative for each hospital can help to build a personal connection.
- CCR staff involvement with state and regional cancer registrars' associations can improve relationships.
- Find opportunities for CCR staff to have face-to-face time with hospital registrars, such as by attending cancer conferences or cancer committee meetings and having regular meetings with staff at large facilities.
- CCRs can provide assistance to hospital registries in the form of the following:
    - Training
    - Providing follow-up/treatment information
    - Publishing a list of available contract registrars
    - Writing letters of support to hospital administration

Feedback to Facilities

This breakout session focused on current practices and strategies for providing feedback to hospital registries regarding compliance with reporting requirements, including completeness, timeliness, and quality.

Key Findings

- Depending on existing resources and facility caseload, all registries provide feedback to reporting hospitals at least quarterly; many communicate by telephone or email monthly.
- It is important to communicate with the appropriate contact at each facility to have the greatest impact.
- Personal one-on-one communications help build strong relationships and improve reporting.
- Facilities respond well to reminders of approaching deadlines.
- Establishing/maintaining strong working relationship with the state cancer registrars' association helps build collaboration and support for future mutually beneficial activities.
- Common topics during routine communications include the following:
    - Edit Results
    - Data Quality
        - Visual editing—identify coding errors, based on abstract documentation
        - Re-abstracting—identify coding errors, based on a review of the of the abstract codes against the source document (patient medical record)
    - Timeliness/Completeness
        - Monthly submissions—reflects the number of cases submitted for a given month
        - Expected case counts—reflects the expected number of cases submitted each month, based on the annual caseload divided by 12
        - Accession number/shipment receipt verification—issued to confirm the number of cases received per transmit file per month
        - Follow-up when submission deadlines are missed.
- Benchmarks are helpful for facilities to gauge their performance.
- Registries use ad hoc communications for missing values or discrepancies.
- Feedback sometimes needs to be adjusted for contracted staff.
- Registries find it useful to communicate via CCR and/or state association newsletters. Topics include—
    - Education tips
    - Listing compliant reporters

- Other strategies in use by central registries include—
    - Hospital staff perform re-abstracting of their own cases only using text they submitted.
    - Issue report cards for submissions/Data Quality Indicator reports
    - Give awards or recognition to high-performing facilities. Send notice of the award to hospital administration.
    - Conduct quarterly calls with reporting facility registrars.
    - When appropriate and feasible, schedule site visits to reporting facilities every 4–6 weeks to discuss cancer reporting status (timeliness and completeness), clarification of cancer reporting requirements, challenges facing the facility that impact cancer reporting, and opportunities for further collaboration and assistance from the central registry.

Incentives and Penalties

In this breakout session, participants discussed using positive and negative incentives to encourage timely and complete reporting from hospitals.

Key Findings

- Tracking hospital submissions—All registries reported tracking hospital submissions for timeliness either monthly or quarterly.
    - Some participants stated timeliness deadlines had been relaxed or altered because of delays with 2018 reporting and the COVID-19 pandemic.
    - If not on target, contact and request a remediation plan and/or send letters to hospital administration.
    - Send a monthly count and percent complete so hospitals know their status.
        - Hospitals can review counts and identify discrepancies with their records.
        - If they disagree, the hospital can send a case report listing showing submitted cases, which can be useful in identifying cases that were not transmitted.
    - Give some leeway to submit cases later to receive a complete abstract.
- Awards, certificates, or letters—All registries reported using awards, certificates, or letters to recognize hospitals meeting completeness and timeliness standards. Some registries indicated difficulty in continuing this practice because of the loss of staff, 2018 reporting delays, and COVID-19.
    - Awards, certificates, or letters often are handed out at state professional meetings.
    - Use “feel good awards” in light of 2018 reporting delays.

    - Send positive letters to hospital administration when a hospital registry is complete and timely or when the hospital registry successfully passes an audit.
    - Post a list of all hospitals meeting completeness or timeliness standards on the central registry web site or newsletter.
    - Acknowledge and thank hospital registrars for their efforts.
- Central registries can provide hospitals with access to helpful resources, such as—
    - Free coding training
        - Access to NAACCR webinars
        - Access to NCRA group educational webinars
    - Linkage or access to vital records data
    - Treatment and follow-up information if hospital reporting is current.
- Central registries can survey reporters to see what they might want as an incentive for timeliness or completeness (maybe paid registration for a meeting).
- Showcase registry data used for research.
    - Quarterly newsletters or email blasts
        - Highlighting a central registry research project—"Your Data at Work"
        - Sharing NAACCR/NPCR central registry awards
        - Talking about upcoming research projects or the current number of data requests
    - Rapid case ascertainment or patient contact studies
    - Fee for each case identified paid to the hospital registrar and funded by the researcher.
        - Continuing education for hospital registrars funded by the researcher.
- Penalties for non-reporting of cancer data can include:
    - Most participants indicated their law had no "teeth" to compel timely reporting or no case submission deadline in state law.
    - Some states were able to use the disincentive of withholding licensing or certificates of need.
    - Registries expressed hesitation to change reporting laws to include penalties.

Innovations in Communications

This breakout session focused on how central registries are using technological tools to facilitate communication with reporting facilities.

Key Findings

- In addition to telephone calls and email, central registries employ a variety of tools for communicating with reporting facilities.

- Central registries routinely use encryption when exchanging data with facilities and other data sources. Common tools in use by registries include the following:

    - **REDCap**—Research Electronic Data Capture, a web-based application developed at Vanderbilt University in 2004, to capture data for clinical research and create databases and projects. It is compliant with the Health Insurance Portability and Accountability Act, highly secure, and intuitive to use.

    - **Box**—A cloud content management platform that provides file sharing, collaborating, and other tools for working with files that are uploaded to its servers. Box uses Amazon Web Services (AWS).

    - **MOVEit**—A managed file transfer software that encrypts files and uses secure File Transfer Protocols to transfer data with automation, analytics, and failover options.

    - **GoAnywhere**—A managed file transfer software for multiple platforms, protocols, and encryption standards. Costs $1,600 annually.

- Other electronic communication methods included the use of electronic surveys to provide a mechanism for feedback and "finding the pulse" of the hospital constituents, as well as the use of an email marketing application to facilitate the communication distribution:

    - Electronic surveys identified and used

        - Survey Monkey—Costs $75 monthly ($900 annually)

        - Survey Gizmo

    - Constant Contact—Email marketing application. Costs $45 monthly ($540 annually)

        - Can be used to distribute non-confidential information, such as newsletters, announcements, broadcasts, or reporting advisories

        - Use of a portal or inquiry system for all abstracting and coding question to ensure standardized answers, less redundancy, and documented responses with tracking and search functions; fewer interruptions via telephone calls and emails regarding abstracting and coding questions

- Challenges to implementing some of these communication tools include—

- Resistance to adopting new technology and methods
- Lack of financial resources for purchasing software licensing
- Lack of IT support and other roadblocks (i.e., firewalls)
- Staffing resources to expand communication

Workshop Summary Conclusions: Establishing communications with key contacts at hospital reporting facilities is imperative to successfully maintain and improve cancer reporting. This workshop provided central registries with a forum to discuss various methods employed to effectively communicate with their hospital reporting facilities. The workshop breakout sessions focused on providing feedback to facilities, use incentives, techniques for relationship building, and innovations in communication. Participating registries exchanged communication challenges, tips, and ideas to improve communications with hospital reporting facilities. Several registries shared examples of tools they use for providing feedback to hospital registries (see Appendix F).

Workshop III: Improving Reporting from Nonhospital Sources

The third workshop was designed to identify tools, strategies, and best practices to improve the quality and timeliness of nonhospital reporting by sharing success stories. It was structured differently from the previous two workshops to facilitate exchange of information and generate strategic ideas through participant interaction (Table 5).

Table 5. Structure of Workshop III

Workshop Structure	
Session One - 10/14/2020	**Session Two 10/14/2020**
Abstract Plus Cancer Reporting for Non-Hospital Reporters—Oregon	Sharing Other Success Stories
Web Plus Focused Abstract Experience Demonstration—New Jersey	Discussing Challenges
Improving Melanoma Physician Reporting with the Help of a Task Force—Arizona	Identifying Strategies and Next Steps

The morning session featured presentations from three registries that had developed specific strategies for improving or facilitating nonhospital reporting, and the afternoon session was reserved for discussing challenges and opportunities. Recommendations to improve nonhospital reporting (tools or communication strategies) were discussed and tabulated during the afternoon session. Participants attended both sessions.

Registries in 24 states and Washington, D.C., participated (Table 6).

Table 6. Registries participating in Workshop III

Alaska	Minnesota	Rhode Island
Arizona	Missouri	South Carolina
Arkansas	Montana	Tennessee

Colorado	New Jersey	Texas
Hawaii	New York	Utah
Idaho	North Carolina	Vermont
Kentucky	North Dakota	Washington, D.C.
Louisiana	Ohio	
Maryland	Oregon	

Workshop Recommendations

Recommendations for CDC

- Build abbreviated, targeted abstracts, with corresponding edit sets in Web Plus and Abstract Plus for registries to implement with dermatologists, urologists, radiation oncologists, and hematology oncologists.
- Design the Web Plus and Abstract Plus user interface with intuitive field names and descriptive tool tip callouts.
- Provide up-to-date training materials and videos for using targeted abstracts in Web Plus and Abstract Plus.
- Develop tools for effective reportability screening.
- Enhance Web Plus with the ability to attach documents as PDF files.
- Develop strategies and best practices for central registries to identify nonhospital reporters.
- Hold a workshop on using linkages to enhance nonhospital sources.
- Conduct a cost-benefit analysis of the effort involved in increasing reporting from low-volume reporters.
- Provide registries with guidance on how to access health information exchanges.

Recommendations for Central Registries

- Contact state and local medical societies for opportunities to educate their members about cancer reporting requirements.
- Work with the state comprehensive cancer control program to build relationships with providers.
- Use pathology reports to identify physician offices that are not currently reporting.
- Partner with other programs within the health department that may have relationships and or access to providers.

- Process nonhospital reports after reporting from hospitals is complete or near complete.
- Consider regulatory changes to require electronic reporting from nonhospital facilities.

Session One

The first session involved presentations by three central cancer registries on their innovative best practices around improving reporting from nonhospital reporters.

Oregon State Cancer Registry

Refer to Appendix D for presentation slides.

The Oregon State Cancer Registry (OSCaR) decided to shift nonhospital reporters to electronic case submission and eliminate incoming paper reports. Registry staff collaborated with NPCR to develop a customized template using Abstract Plus software to capture the minimum information necessary for required cases. OSCaR implemented Abstract Plus on a Citrix server, rather than on an individual workstation. Although this allows a multiple-user environment, it also requires IT support. Because of the lack of IT staff supporting the registry, requested upgrades often take a year or more to implement once they are available from CDC. Overall, the rollout took 2 years. Of the 93 ambulatory sites approached, six are now reporting regularly using this method.

Benefits

- Reduce the number of paper reports received from ambulatory facilities.
- Receive physician reports in NAACCR format, which allows seamless integration with registry software and reduces the need for manual data entry and processing.
- Abstract Plus software is free for the central registry and the reporting physician.
- Abstract Plus has customizable templates to reduce the number of data items required from physicians.
- Software development is managed by CDC and is independent of OSCaR.
- Templates/Edits work well.
- The OSCaR Citrix server can be used to enable multiple users.
- Reduce the need for abstracting contractors to handle manual data entry.

Challenges

- Implementation took 2 years and required significant staff time.
- Templates/edits are not intuitive, and customization requires investment of staff time.

- Internal IT support is required to enable a multiuser environment.
- Some concepts can be hard to teach to reporters (i.e., exporting cases)
- Manuals and other materials available from CDC are outdated and do not apply to the most recent version of the software.
- Onboarding and training materials must be designed specifically for each state.
- A comprehensive outreach and communication plan is necessary to make providers aware of electronic reporting options.
- Adoption by ambulatory facilities is low, with only 6 out of 93 facilities having implemented reporting by Abstract Plus.

New Jersey State Cancer Registry

In 2019, the New Jersey State Cancer Registry (NJSCR) revised its cancer reporting regulations to require electronic reporting by nonhospital reporting facilities, including laboratories and physician practices. The NJSCR provides physician practices with Web Plus for electronic reporting. To reduce the time and effort required for reporting and to improve the quality and completeness of the data reported, NJSCR developed customized abstract layouts in Web Plus software to facilitate reporting from about 100 nonhospital sources. Customization includes layouts specific to radiation oncologists and hematology oncologists, as well as a general layout for all other providers. Each layout includes a limited required data set and edits. Data item names have been modified to be clear and descriptive, and tool tip call-out boxes provide detailed descriptions of each data item.

Key Takeaways

- Rename data items to be more intuitive to non-CTR reporters.
- Modify tool tip call out boxes for each field (including text fields) to provide detailed instructions.
- Provide a confirmation report to each facility, including date ranges for cases entered and the number of cases received.

Arizona State Cancer Registry

Refer to Appendix D for presentation slides.

National data revealed that in 2004 U.S. incidence rates of melanoma began to increase, while the rate in Arizona was declining. The Arizona Cancer Registry (ACR) was concerned melanoma cases were not being fully captured at the registry because of an increase in patients seen in outpatient settings. It was believed that nonhospital facilities may be underreporting to the ACR. Because there are no penalties within the Arizona law for physician reporting non-compliance, there is a need to work cooperatively with reporting sources. A pilot project to assess reporting at 15 dermatology practices in Tucson and Phoenix showed 71 percent underreporting of

melanoma. A task force was created to identify barriers and develop strategies to improve melanoma reporting by physicians in Arizona. The strategies identified included the following:

- A survey of physicians to identify barriers to reporting and create a database of physician email address.
- Presentations to dermatology societies on reporting to the central registry.
- Redesign of report form to make it melanoma specific.
- Dermatopathologists now include a statement on melanoma pathology reports regarding state reportability.
- A newsletter including physician names and number of cases reported distributed biannually.
- Development of a melanoma profile
- Data Quality Indicator Report for physician reporters (depth of lesion, most common sites of melanoma).

Task force efforts have resulted in a 147.5 percent increase in physicians reporting from 2009 to 2019. Most physician reported cases are paper case reports received through efax or email; however, in 2020 ACR changed regulations to require electronic reporting for any physician with more than 50 cases per year. ACR has developed a Web Plus melanoma module for physician reporting, along with electronic onboarding and user guides. The registry also has created four recorded training modules to assist in navigating Web Plus.

Session Two

The afternoon session focused on sharing other strategies and challenges registries encountered working with nonhospital reporting sources. Discussions were focused and used to identify recommendations for training, tools, and best practices.

Strategies

- Develop a video and materials to send to potential reporters to educate them about the registry and reporting process.
- Participate in the state cancer control plan to connect with cancer specialists from throughout the state.
- Use remote access to provider medical records to facilitate follow-back.
- Use pathology reports to identify physician offices that are not currently reporting.
- Partner with other programs within the health department that may have relationships and or access to providers.

- Develop relationships with the individuals who are reporting the cases for each practice.
- Modify Abstract Plus to collect a smaller number of variables.
- Hold nonhospital cases until most of the hospital treatment cases, then link that to the cases collected from the hospitals.

Challenges

- Cancer reporting rules and regulations do not always support enforcing reporting by nonhospital facilities.
- Maintaining a current list of practices required to report is challenging, given the frequency of changes.
- Education and outreach to nonhospital reporters requires staff and time.
- Physician offices often do not collect or report patient race and social security number.
- Monitoring physician reporting to identify when reporting stops or slows is important.

Workshop IV: Managing COVID-19 Response

The fourth in the series of workshops focused on Managing Best Practices around COVID Response. This workshop was held on January 27, 2021. The workshop agenda and schedule are outlined in Table 7.

Table 7. Structure of Workshop IV

Managing Best Practices around COVID Response Workshop	
Session One - 1/27/2021	**Session Two - 1/27/2021**
Breakout 1: Challenges in Human Resources	Unexpected positive outcomes from working remotely; challenges to working remotely; measures or changes identified to best accommodate the registries' current needs to be more agile or robust; preparing for the "new normal"
Breakout 2: Continuity of Operations Planning	
Breakout 3: Technical Challenges and Solutions	

Workshop Objectives

1. Review and assess how well disaster preparedness planning worked with the COVID-19 pandemic.
2. Examine the impact of COVID-19 on central registry operations with a special focus on human resources, continuity of operations, and technical challenges.
3. Identify the opportunities and challenges that the COVID-19 pandemic created for central registries.

4. Identify and develop tools, strategies. and best practices to prepare for the post-COVID-19 “new normal.”

Each breakout session in Session One, listed above, focused on various operational components impacted by the COVID-19 pandemic. Session Two of this workshop reconvened all participants to share the summaries and recommendations from each of the breakout sessions. The remainder of Session Two focused on discussing opportunities and challenges ahead, creating a culture of change, and preparing for the new normal.

Workshop IV Attendance

Registries in 28 states and Washington, D.C., were represented (Table 8).

Table 8. Registries Participating in Workshop IV

Alabama	**Idaho**	**Montana**	**South Carolina**
Alaska	Indiana	New Hampshire	Tennessee
Arizona	Kentucky	New Jersey	Texas
Arkansas	Louisiana	New York	Vermont
Colorado	Maryland	North Carolina	Washington, D.C.
Florida	Massachusetts	North Dakota	
Georgia	Minnesota	Ohio	
Hawaii	Missouri	Oregon	

Recommendations

Central registries may benefit from implementing tools and strategies in the following categories:

Challenges in Human Resources

- Don’t forget the “human” in human resources. It is critical to have open communication and be understanding and flexible.
- Focus on both mental and physical self-care. Encourage time off and daily screen breaks.
- Plan social activities to keep staff engaged and part of the team.
- Document teleworking policies.
- Document production expectations.
- Detail orientation plans for new staff.
- Continue to support education.

Continuity of Operations

- Continue to identify and institute cloud-based and other solutions that facilitate work from a dispersed workforce. Identify methods to improve bandwidth and connectivity; consider both hardware and software solutions.

- Develop robust work-from-home policies and productivity expectations. Develop a teleworking training video for staff. Include discussions of working from home in annual evaluations.

- Maintain team calendars that can be accessed by all staff to identify whether individuals are working from home or in the central office. Develop standardized work rotations to the office if feasible.

- Maintain an up-to-date inventory list. This will be helpful if staff need to take equipment home.

- Provide additional manuals for home use if desired by staff.

- Allow credit card purchases for office supplies and low-cost hardware (e.g., keyboards, mice). Provide some staff with credit cards or provide one for use by the unit in such emergencies for small purchases.

- Maintain an up-to-date staff list with emails and telephone numbers for emergency contacts. Consider establishing a telephone tree and running periodic drills.

- Consider purchases of software and hardware that make working from home more efficient as allowable costs on grants and cooperative agreements.

Technical Challenges and Solutions

- Review telecommuting agreements to ensure that they adequately cover security and confidentiality issues.

- Review and update disaster preparedness plans to ensure the transition to remote work is swift, with adequate equipment to facilitate potential long-term operational transition.

- Inventory equipment for potential long-term remote work, including computer workstations, telephones, and communication options.

- Ensure robust IT support to address software and hardware issues.

The CDC might consider the following recommendations:

- Assess budgetary needs for central registries and allow flexibility with expenditures that improve efficiencies in the home office environment.

- Consider purchases of software and hardware that make working from home more efficient as allowable costs on grants and cooperative agreements.

- Assess the impact of disasters on the central registry's ability to meet annual call for data standards and timelines.

Summaries of Each Breakout Session

Don't forget the HUMAN in Human Resources

Challenges in Human Relations

All the states participating in the Human Resource breakout session are teleworking either full-time or part-time. Some states had staff teleworking prior to the pandemic, but for most it was new and required a lot of coordination and adjustments. Several states reported that staff were reassigned to work on COVID-19 projects. One state reported that at one point 75 percent of its staff were reassigned.

Everyone reported that staff are happy working from home; concerns were raised about how to transition back to the office when the time arrives. Many registries are working with their human resource offices to implement a permanent teleworking policy.

Under the human resource umbrella, the group discussed the importance of self-care, being aware of other household challenges, maintaining production, and continuing education.

Key Findings:

- **Self-care:** Self-care is key to maintaining harmony between work and home life. Many states have programs that are offered through their health departments or universities that cover self-care. Everything from daily emails about mental and physical health to having a psychologist present at a staff meeting and being available for counseling was discussed. Many registries have been scheduling social activities, such as virtual happy hours, online games, holiday parties, etc. These social activities provide staff time to connect on a personal level with no discussions about work. Some attendees reported they have learned things about their staff that they never knew even when reporting to the office.

  Part of self-care is ensuring staff are taking time off and disconnecting from work. Suggestions include keeping the computer and other devices off, taking daily breaks from the screen, making sure you have lunch, taking walks, and stretching often. All participants reported that no restrictions were implemented to hinder the use of vacation time. Many are either re-assigned to COVID-19 activities or covering other staff that have been and are being stretched thin at work, not to mention the pandemic's impact on personal lives. Actually, staff are encouraged to use leave time because managers need to be aware of potential staff burnout.

- **Household Challenges:** Many staff have other family members also working from home, as well as children attending school online. As a result, it is important to maintain open communication to understand what staff are dealing with, so managers can provide

support and adjustments as required. Some states reported being able to offer flexible hours while teleworking. Some states allow staff to work for several hours in the morning, log off to care for children and assist with schoolwork, and then log back in later in the day to finish up workday. Other states require staff to keep normal work hours with little to no flexibility.

- **Maintaining Production:** While maintaining harmony and being aware of self-care, it is also important to make sure staff are remaining productive throughout the day. Most states reported staff complete daily or weekly production reports. Software-generated reports also are used to monitor production. All states reported that after the initial adjustment to teleworking, staff are as productive—if not more productive—working from home.

  Fortunately, most states did not have any difficult staff performance issues to deal with. A few had some staff not meeting production expectations; however, these were improved through the use of email reminders, and if necessary, telephone interventions. Some states reported staff using the excuse that "my internet is down" frequently. As a result, staff now have educational webinars and other activities saved on their desktop to ensure work productivity even if internet access is limited.

- **Education:** Teleworking has actually increased the ability for staff to attend national conferences when previously travel restrictions prevented multiple staff from participating. Some concerns were mentioned that when "normal" work routines return, states may have difficulty justifying travel to in-person conferences (e.g., NAACCR and NCRA) that were conducted virtually during the pandemic. In addition, many states participate in the NAACCR webinars and are using FLccSC to train their own staff and reporting facilities.

  Training new staff virtually takes a considerable planning and time. More follow-up and documentation are needed because of remote work status. It is particularly challenging to onboard a new staff member to make them feel a part of the team and offer the intensive training required for registry work.

Continuity of Operations

Maintaining continuity of operations during any crisis or disaster is a major priority for central registries, and the mandated office shutdowns of many state and university offices in March 2020 due to the emerging COVID-19 pandemic resulted in significant disruption to registry operations. Registries were forced to be agile and adjust very quickly without the benefit or any prior experience dealing with a similar situation.

Key Findings

- **Transition to Remote Work:** Registries had to arrange for staff to take computers (desktops), monitors, chairs and other equipment home and establish new offices. Some staff created makeshift workspaces (converting closets to maintain privacy and a secure environment), while others were able to establish more formal work areas. In general, all staff established workspaces conducive to working with confidential data and instituted policies consistent with strict privacy requirements.

Registries that had already instituted work-from-home policies, telecommuting, and electronic reporting had an easier transition to the new way of working with a distributed work force.

- **Positive Aspects of Working Remotely:** All registries now have at least some capacity for staff to work off site, and this has been beneficial. Working from home was cited as reducing turnover (fewer retirements due to long commutes, happier with work environment) and increased productivity (fewer distractions).

- **Negative Aspects of Working Remotely:** Working from home has also introduced some negative aspects into the workplace, such as decreasing the number of informal interactions that lead to innovation, creativity, and quick problem solving. Hiring and training new staff has become even more difficult due to the distributed workforce environment.

- **Workflow Impact:** Registries have proven themselves to be creative and resourceful in establishing solutions to the effects of the COVID-19 pandemic on the workforce. In addition, they have developed methods to maintain workflow and data processing to compensate for the traditional methods that are no longer available to them. Staff work through remote connections to the central database. Many registries reported that increased remote access to hospital data was a silver lining to the pandemic, with hospitals now allowing access via secure portals. Electronic auditing of reporting facilities has now completely replaced on-site audits.

  A few registry functions remain difficult to achieve in the new work environment, including death clearance, on-boarding physician offices and other facilities using electronic reporting, training of new staff, and team building. In addition, long-term changes in workflow and data processing may need to be considered. Many registries have not yet examined their processes to identify roadblocks and bottlenecks. They are still working in a temporary environment. However, these changes might remain in some form for many years to come, if not indefinitely. If so, we must all look at our data flow models to ensure timely, efficient, and accurate reporting of quality cancer data.

- **Future Considerations:** The registries are uncertain if they will ever return to a consolidated workforce in a single location. Most anticipate that at least some staff will work from home for the long term. Most registries anticipate making changes to their physical environments if they do return, including more space between cubicles, lower capacity thresholds, and staggered work hours. Some registries worry that staff who are now enjoying more flexible work hours and reduced commuting will not be pleased if these benefits are revoked. However, most registries are required to follow agency policy and may not have the autonomy to set their own work standards.

  Looking to the future, most registries are still seeking solutions to IT issues (improved connections, security measures, and software and hardware that make remote working more efficient).

  Registries anticipate the need to develop more formalized work-from-home policies and adapting other long-standing policies, including work hours, use of personal and work equipment, and home security.

Technical Challenges and Solutions

In this breakout session, participants discussed the technical challenges encountered with shifting to work remotely. This involved equipment, internet connectivity, and communication issues. This group also discussed security issues, as well as ongoing operational challenges.

Key Findings

- **Equipment and Software**
    - Registries with no previous remote-working staff were the least prepared and took the longest to restore operations.
    - Some registries had limited laptop computers for remote use and were ill prepared to provide equipment to all staff now working remotely, while other registries had some staff already working remotely and were able to obtain additional laptop computers from other programs.
    - Although many registries had laptop computers to continue minimal work efforts, a long-term equipment solution needed to be developed by most registries.
    - Although some registries had laptops, they had trouble with VPN range and needed to triple the VPN range.
    - Another registry allowed staff to come into the office to bring home their entire desktop workstation. This allowed access to all their electronic files on their local and network servers. Minimal work disruptions and down time were experienced with this approach.
    - Except for contractors, registry staff are not permitted to use their personal equipment to conduct business work.
    - **Internet connection:** Some registries reimbursed their staff internet connection. One registry provided its staff living in rural areas with hot spots. If staff required remote access to their workstations and the equipment was shutdown, remote access could not be established. Ethernet cables were provided for staff at some registries to connect to their router; however, this limited the home office setup, because cables needed to be near the router.
    - **Other connectivity issues cited:** Potential instability when the home has a high volume of users (work, distance learning, gaming, etc.) is a serious problem.
    - Wi-Fi adaptors and Wi-Fi extenders were cited as tools to improve connectivity. Issues that could impact connectivity included large mirrors and large metal objects between the computer station and the router, which can cause connectivity issues. Although the computer equipment may be the same, there was still much variation in equipment-related issues experienced while working from home; a strong IT support system is necessary to identify and improve individual remote work environments.

    - **Other equipment considerations:** Headsets (wireless or wired), cameras, portable standing desks, and office chairs were all issues. Most registries did not provide for staff to have printers while working remotely.
    - **Telephones:** Some registries purchased Magic Jack telephones for their staff. Others had a limited number of cell phones, and the manager was able to purchase additional cell phones for some staff. Some registries use a softphone application, such as ZoiPer, for VoIP calls over Wi-Fi. Zoiper runs on many different platforms.
    - Some registry staff use their personal cell phones to conduct business because of a lack of alternative telephone or communication options available, but unlike internet connections, personal cell phone use is usually not reimbursed by the registry.
    - **Other Communication Tools:** Use of Microsoft Teams, Skype, or Zoom was cited as a communication tool option.
- **Confidentiality and Security**
    - Most registries had teleworking agreements in place with specific requirements, but may have been enhanced (locked bags, description of office space, and equipment).
    - Very few staff had printers, decreasing the risk associated with paper documents.
    - Promoting best practices for telecommuting around security helped ensure compliance.
- **Operations That Did Not Translate Well to Remote Work**
    - Any paper-based operations (e.g., death clearance, faxes, mail-based processes)
    - Shift to more electronic approaches with more document scanning
    - Onboarding of new staff and staff terminations
    - No impact on hospital audits conducted remotely, unless hospital staff was unavailable (due to furloughs or temporary staff reductions)

Afternoon Session—Unexpected Positive Outcomes, Longer-Term Challenges, and Preparing for the New Normal

During the afternoon, the workshop moved into more forward-looking discussions seeking to anticipate some of the impact that the COVID-19 pandemic may have in the longer term for central cancer registries. Participants brainstormed together and focused on the following issues:

- Identifying any unexpected positive outcomes from dealing with the COVID-19 crisis.
- Assessing continuing or anticipated challenges that will need to be addressed.

- Examining the role of change management in dealing with COVID-19 by central registries.

- Preparing for the new normal as vaccination strategies are implemented and return to work is anticipated.

Unexpected Positive Outcomes from the COVID Crisis

Discussions revealed that overall, most central registries performed extremely well during the COVID crisis. Most programs were forced to shift from in-person offices to remote work in early March with many having less than a day or two to prepare. The challenges were demanding, as the morning breakout session discussions demonstrated. However, registries have clearly risen to face these arduous circumstances, and this success prompted an afternoon discussion of what unexpected positive outcomes might have arisen from the crisis that might have longer-lasting impact on registries. These included the following:

- **Remote work is working:** Most registries reported that the shift to remote work was very positive, establishing evidence that telecommuting and work from home options are a viable for longer-term operations. Programs were already feeling the pressure to offer flexible work hours prior to COVID-19 to recruit and retain younger staff who want more trackable working conditions. During the pandemic, registries demonstrated that flexible work hours offer such benefits as higher productivity, strong teamwork, and happier employees. During discussions, several participants urged central registry directors to document any higher productivity and employee satisfaction for senior management to encourage moving toward this new way of working.

- **Balancing the human needs with the business needs of the program:** During the pandemic, managers needed to be even more understanding and empathetic to staff while monitoring productivity and overall operations. Staff morale was higher when managers reached out regularly and were willing to help staff cope with the challenges of remote schooling, young children staying at home all day, competition for limited broadband among family members, and caregiving for elderly or sick family members. At the same time, it was critical to maintain registry operations to continue workflow and meet deadlines. Balancing the human needs of staff with the demands of strong management during the crisis was essential to success.

- **Teambuilding and communication:** Registries reported that staff all pitched in during the crisis to make things work for the program. Bonding among team members appeared stronger, collaborations intensified, and innovative problem solving increased. Managers worked to build teams by making sure employees felt heard and valued. Participants recognized that new technology such as Zoom, Microsoft Teams, and WebEx was critical to the successful transition to remote work. Weekly meetings were scheduled for staff, and time was included to share how things were going. Managers emphasized work-life balance and maintaining health and safety. Quick telephone calls, texts, and chats also contributed to success. Capturing this success over the long term will require reflection on the lessons learned during this experience and building these tactics into everyday operations.

Facing Longer-Term Challenges

Although registries coped extremely well with the crisis and dealt with numerous challenges, the concern that this success is only temporary and not permanent was voiced often. In addition, several barriers or problems either remain unsolved or are emerging as serious long-term problems. These include the following:

- **Staff mental health and wellness:** Employees often feel high levels of stress despite managers' efforts to be supportive. Many staff are juggling work with family or may be working in isolation with limited human contact. Worry about job security, furloughs, and the long-term impact of COVID-19 are common. Staff miss working together in person and the opportunity for informal conversations or personal interaction. The mental and behavioral health of employees is a priority that must be in the forefront for all managers. Employee assistance programs, work-life balance programs, and stress management may all help vulnerable staff, but managers must play a key role in identifying and monitoring the mental wellness of their staff. This is particularly challenging in remote settings.

- **New staff training and onboarding:** Because central registry staff must be highly trained in very technical and complex material, new staff training is intensive with mentoring and shadowing required for long periods during initial training. Remote learning platforms offer the fundamental information that new employees need, but quick advice, encouragement, clear information, and feedback require mentoring and strong relationships. During COVID-19, registries have struggled to onboard, mentor, and develop new employees. This issue is a serious concern with long-term impact on central registries already struggling with staff shortages.

- **Potential budget and resource reallocation:** Many registries lost staff who were reallocated to COVID-19 response initiatives; several were hired for higher salaries by those programs. Freezes are in place, and staff may not be replaced. Programs relying on general state funds faced cut, and budgets may be reduced even more if assistance is not offered to states at the federal level. Registries already facing very tight budgets are worried that they may not survive further reductions in funding. In addition, COVID-19 is adding extra work as registries are now tracking the pandemic's impact on cancers. Flexibility in budget allocation by federal funders to allow quick apportionment for emergency needs will be critical as programs transition back to worksites.

- **Security of confidential data and information:** The risk of security breaches or misuse of confidential data is higher in remote settings. Although such safeguards as use of VPNs, state- or program-owned equipment, and confidential data policies do offer some protections, more training and focus on the importance of staff's protecting confidential information in remote settings should be developed.

- **Equipment and software:** Remote work policies should delineate procedures regarding use of personal equipment, software requirements and updates, such shared resources as manuals, and cost allocations for use of private telephones and internet. If equipment and software is owned by the agency, then clear policies and procedures about its use and care are needed. Internet issues continue to plague programs with staff often having bandwidth problems requiring more modern routers, Wi-Fi enhancers, and repeaters.

Business telephone lines may be needed. Registries need to consider the possible costs incurred with hybrid systems wherein employees may be in the office a few days a week and home other days. These are all solvable problems, but they require attention if programs are to succeed into the future.

- **Outdated government infrastructures**: For registries housed in government agencies, the infrastructure may not be in place to support long-term needs around remote work or crisis management. Antiquated software systems, limited internet bandwidth, restricted desktop application, and outdated polices all hold back agility and success.

Preparing for the New Normal

Several specific concerns and opportunities were identified by participants as important to the successful transition to the new normal. These include the following:

- **Preparing a safe return to the workplace:** Any return to the workplace must ensure employee safety and wellness. Workspaces must be carefully organized to ensure physical distancing. Mask wearing will be required and congested locations closed or re-routed. This will likely result in less than half of the normal staff being in the office at any time. Monitoring for compliance and constant distraction from work activities may reduce productivity. A process for testing or monitoring employee's health must be in place, which involves technical and logistical strategies. Vaccination policies must be established and monitored. Will vaccination be required? If someone refuses to be vaccinated, how do we protect those in the office who may be vaccinated but could still be carriers if exposed? Complex procedures and policies will be required before staff can return to the workplace safely. Such a situation will mean shifts in scheduling or a hybrid approach to working. Planning is essential, and registry directors may have limited control over these decisions, making this more challenging.

- **Staff who want to stay remote:** As one participant pointed out, *it is very hard to take something back, once it is given*—so any attempt to bring back staff to the office on a full-time basis will be fraught with consequences. Although some staff may welcome a return, many have found convenience and comfort in working from home and wish to continue with remote working. According to a McKinsey survey, 80 percent of people report that they enjoy working from home, 41 percent report being more productive, and 28 percent say they are as productive.[3] Can these staff be forced back to the office? If so, what consequences will result? Will staff leave for positions where more flexibility exists? Will workers be unhappy to return and what will that do for productivity? How can we help staff with this transition, so it is smooth and seamless? All these issues will need to be addressed before we can return to the workplace.

- **Long-term impact of COVID-19 on staff:** It is not clear what the long-term impact of COVID will be on staff. Will health issues continue for those who were sick? Will there be emotional scarring or social concerns that will require extra support for staff? What type of sick leave policies will need to be in place for these circumstances? Will adequate employee assistance programs be available for staff facing these situations? These all need to be answered before we can go back into the workplace.

- **Impact of COVID on cancer reporting:** COVID-19 has created just as many challenges for reporters as the central registries themselves. Some hospitals have furloughed 40 percent of their staff, making any reporting by hospital registries almost impossible. Physician groups were closed except for emergency situations. Radiology, surgical centers, and ambulatory care centers have seen services slow significantly. Telehealth is becoming common, but will data be as accurate from such remote settings? Although central registries strive to maintain timeliness and quality, the future may be fraught with backlogs and catchup. Given the stress on central registries already, CDC, SEER, NAACCR, and other standard setters may want to prepare for more flexible policies to allow registries to recover from the impact of COVID-19.

Change Management and Agility

"*Change is the only constant for those of us working for central cancer registries,*" was a comment made by a registry director who pointed out that registry staff must be agile in dealing with not only COVID-19 but also the many changes required by standard setters in the cancer surveillance community. However, coping with the aftermath of COVID-19 and the new normal may require a transformational shift of previously unforeseen levels. New work processes, technological developments, and new organizational designs that may emerge in the post-COVID-19 period will be successful only if staff and stakeholders buy into these changes. Long-standing practices and cultural values may need to undergo serious assessment and eventual alterations. Will we start to live in silos? Will the registry community erode over time without physical interaction? Will collaborations diminish? Will there be less mentorship and staff development? Permanent change will require exceptional change-management skills and constant pivots based on how well the effort is working over time.[4] For all these reasons, increased attention to change management, including training and supportive services, will be necessary for future success of registries. The cancer surveillance community has long recognized that change is hard. There is no time when embracing agility and nimbleness will be more important than in the coming period as we continue to cope with the impact of the pandemic and transition into the post-COVID-19 era.

[3] https://www.mckinsey.com/business-functions/organization/our-insights/reimagining-the-office-and-work-life-after-covid-19#

[4] https://www.mckinsey.com/business-functions/organization/our-insights/reimagining-the-office-and-work-life-after-covid-19#

Tip Sheets

These tip sheets are based on shared discussions among registry directors and staff during the Best Practices Workshops:

a. Developing and Monitoring Data Management Reports
b. Establishing Strong Communications and Relationships with Hospitals
c. Improving Reporting from Nonhospital Sources
d. Managing Best Practices around the COVID-19 Response

They are not meant to lay out a specific methodology, but rather to serve as a starting point for more in-depth discussions, development of tools, and the establishment of new processes or practices within individual registries as appropriate.

Acknowledgment

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Tips to Monitor Central Registry Completeness & Timeliness

Although current registry software may not include on-demand reports for monitoring progress toward the 12- and 24-month submission standards, central registries can take some steps to monitor these on their own.

Ensure that at least 1–2 staff are trained in writing queries and reports within the software programs employed by the central registry, as well as in additional tools, such as SAS, Excel, and/or Access.

- Registries may wish to contact their software provider or their department- or university-wide IT support for training opportunities. Additional free training opportunities are available on the web.

Monitor the registry's progress toward the 12- and 24-month reporting standards on a monthly or quarterly basis.

- A rough estimate of completeness may be derived using the expected number of cases from the CDC Data Evaluation Reports from the previous few years.
- It may be helpful to monitor completeness by primary site, county, diagnostic confirmation, or other factors to assist in identifying where cases may be missing.
- Monitor the proportion of consolidated cases with unknown age at diagnosis, sex, race, and county at diagnosis.

Monitor reporting facility completeness and timeliness to ensure all cases have been received in a timely manner (refer to Tips to Monitor Facility Completeness and Timeliness).

Develop an annual schedule of cancer registry operations to be completed throughout the year to ensure key processes are performed in a timely fashion. The schedule might include the following:

- Processing pathology reports
- Conducting follow-back
- Quality control audits and activities
- Operational linkages (for vital status, follow-up, and demographics)
- Duplicate resolution
- Interstate data exchange
- Geocoding
- Death clearance
- Case-finding audits

Tips to Monitor Reporting Facility Completeness and Timeliness

Although current registry software may not include on-demand reports of reporting facility completeness and timeliness, central registries can take some steps to monitor these on their own.

Ensure that at least 1–2 central registry staff are trained in writing queries and reports within the software programs employed by the central registry, as well as in additional tools such as SAS, Excel, and/or Access.

- Registries may wish to contact their software provider or their department- or university-wide IT support for training opportunities. Additional free training opportunities are available on the web.

Maintain a log of submissions from each reporting facility. The log should include the following:

- Date of submission
- Number of cases in the submission
- Number of cases in the submission that do not pass required edits
- Number of cases in the submission that were rejected

Monitor the log monthly for missed submissions or submissions with an unusually low number of cases compared to prior submissions. These may indicate a problem with the reporting facility.

Provide feedback to each reporting facility on a monthly or quarterly basis with the status of their completeness and timeliness. The report could include the following:

- A list of submissions received from the facility with the submission date and number of cases in each submission
- The number of cases received from the facility for the current reporting year (excluding duplicates, rejected cases, or modified records)
- The total number of cases expected to be received from the facility based on prior reporting years or case-finding audits (excluding duplicates, rejected cases, or modified records)
- The proportion of cases submitted by the facility for the current reporting year that were received within the required time frame (i.e., within 6 months of diagnosis)
- An indicator of whether the facility is on track to being 100 percent complete by the required deadline

Tips to Monitor Reporting Facility Data Quality

Ensuring high-quality data from reporting facilities can help to reduce the burden on central registry consolidation staff, improve the reliability of auto-consolidation, and result in more timely central registry data. Providing facilities with feedback can help them improve the quality of their data.

Conduct quality audits of a selection of cases from each reporting facility and share the findings with the facility.

- Registries may choose to conduct targeted quality audits of one data item or a few related data items to reduce the burden on quality assurance staff.
- It may be helpful to have hospital registrars perform re-abstracting of their own cases using only the text submitted with the abstract.

Provide each facility with a report card or dashboard of the number and type of edits on incoming cases (based on standard edit sets) and/or the number and type of errors on incoming cases (based on visual editing).

- Calculate an accuracy rate by dividing the number of cases without errors by the total number of cases submitted and multiply by 100.

Monitor the proportion of cases from each facility that contain unknown or non-specific values in key data items. Show each facility how its data compare to data from all facilities combined.

- A registry may choose to exclude certain cases from review. These may include non-analytic cases, laboratory-only cases, or autopsy-only cases.

Registries may want to establish benchmarks or targets for data quality.

- An accuracy rate of 95 percent is recommended.

Provide reporting facilities with a mechanism for correcting and resubmitting cases to improve their accuracy rate and ensure the central registry has the most accurate information for each patient.

Tips to Build Strong Relationships with Hospital Registries

Fostering and maintaining strong relationships with reporting facilities can have intangible benefits for the central cancer registry and the hospital alike and can ultimately lead to improved reporting.

Develop procedures for providing consistent, ongoing feedback, both positive and constructive, to reporting facilities on their data completeness, timeliness, and quality. The procedure should address the following:

- Information to be shared with each facility
- Frequency and format of feedback
- The point of contact for feedback at each facility
- Benchmarks or comparisons for quality, completeness, and timeliness measures
- Recommendations or procedures for facilities to improve areas that do not meet expectations or standards (e.g., improvement plan or action plan)

Engage with hospital registrars by participating in the state or regional cancer registrars association.

Provide hospital registrars with access to no-cost training and education opportunities, such as the NAACCR Webinar Series.

Acknowledge hospitals meeting or exceeding reporting standards with awards, certificates, and/or recognition. Notify senior-level hospital administration and announce awards in a newsletter or on the website.

Offer CoC-accredited cancer programs reports of patient follow-up, treatment information, or counts of patients enrolled in IRB-approved studies to help them meet their accreditation standards.

When appropriate and feasible, schedule site visits to reporting facilities to discuss reporting status, clarify reporting requirements, learn about challenges, and explore opportunities for further collaboration and assistance.

- Poorly performing facilities or registries with high staff turnover or new registrars are a great opportunity for site visits.
- If possible, request to attend a cancer committee or performance improvement committee meeting to present on how cancer registry data are used.

Tips to Improve Reporting from Nonhospital Sources

Physician practices and other outpatient facilities rarely employ Certified Tumor Registrars; reporting to the central cancer registry often falls to office staff with little to no oncology training. It is important for central registries to provide them with tools to ensure data are as complete and accurate as possible.

Software Development

- Build abbreviated, targeted abstracts in Web Plus and Abstract Plus for dermatologists, urologists, radiation oncologists, and hematology oncologists.
- Modify field names and descriptions to be more intuitive for reporters.
- Develop training manuals and videos for nonhospital reporters.

Education and Outreach

- Contact state and local medical societies for opportunities to educate their members about cancer reporting requirements.
- Work with the state comprehensive cancer control program to build relationships with providers.
- Use pathology reports to identify physician offices that are not currently reporting.
- Partner with other programs within the health department that may have relationships and or access to providers.
- Provide data quality reports back to physician reporters.
- Survey physician practices to identify barriers to reporting.
- Maintain a contact list of nonhospital facilities and their reporting status.

Other

- Process nonhospital reports after reporting from hospitals is complete or near complete.
- Consider regulatory changes to require electronic reporting from nonhospital facilities.
- Request remote access to facility medical records to facilitate follow-back.

These tip sheets are not meant to lay out a specific methodology, but rather, are meant to serve as a starting point for more in-depth discussions, development of tools, and the establishment of new processes or practices within individual registries as appropriate.

Tips to Improve Communication with Hospital Registries

Effective two-way communication with hospital registries can help build strong relationships and improve reporting.

Develop a plan to communicate with hospital registrars on a regular basis.

- It may help to designate a single point of contact or liaison at the central registry for each facility to develop one-on-one personal connections.

Maintain an up-to-date list of key contacts at hospital registries, including on-site contacts for facilities with contracted staff.

Provide monthly or quarterly communications via a newsletter or the state cancer registrars association. Topics may include education, abstracting tips, central registry news and events, and approaching deadlines.

Hold quarterly or biannual town hall–style meetings with hospital registrars to cover important topics of interest and give registrars an opportunity to ask questions and share ideas among themselves.

Use electronic surveys to get feedback and input from hospital registrars.

Implement encrypted email or other secure data exchange tools to facilitate communication.

Implement use of a portal or inquiry system for all abstracting and coding questions to ensure standardized answers, less redundancy, and documented responses with tracking and search functions.

These tip sheets are not meant to lay out a specific methodology, but rather, are meant to serve as a starting point for more in-depth discussions, development of tools, and the establishment of new processes or practices within individual registries as appropriate.

Tips to Manage Staff and Technology During COVID-19

Discussions during the workshops resulted in the following recommendations.

Keep the focus on the HUMANS in human resource management during a disaster.

Tips for managing staff during the COVID-19 pandemic and beyond

- Encourage open communication; be understanding and flexible.
- Focus on self-care, both mentally and physically. Support staff's taking time off, as well as regular breaks from the screen.
- Plan social activities to keep staff engaged and feel part of the team.
- Document teleworking policies and production expectations.
- Provide detailed orientation plans for new staff.
- Continue to support education.

Tips for managing technology issues during the COVID-19 pandemic

- Review telecommuting agreements to ensure they adequately cover security and confidentiality issues.
- Review and update disaster preparedness plans to ensure a swift and comprehensive transition plan for staff to work remotely.
- Inventory equipment for potential long-term remote work, including computer workstations, telephones, and communication options.
- Ensure robust IT support to address software and hardware issues.

Tips to Ensure Continuity of Operations During COVID-19

Discussions during the workshops resulted in the following recommendations to guide you with your continuity of operations during COVID or a similar disaster.

Continue to identify and institute cloud-based and other solutions that facilitate work from a dispersed workforce. Identify methods to improve bandwidth and connectivity; consider hardware and software solutions.

Develop robust work-from-home policies and productivity expectations. Develop a teleworking training video for staff. Include discussions of working from home in annual evaluations.

Maintain team calendars that can be accessed by all staff to identify whether individuals are working from home or in the central office. Develop standardized work rotations to the office if feasible.

Maintain an up-to-date inventory list, in case staff need to take equipment home.

Provide additional manuals for home use if desired by staff.

Allow credit card purchases for office supplies, and low-cost hardware (e.g., keyboards, mice). Provide some staff with credit cards or provide one for use by the unit in such emergencies for small purchases.

Maintain an up-to-date staff list with emails and telephone numbers for emergency contacts. Consider establishing a telephone tree and running periodic drills.

Consider purchases of software and hardware that make working from home more efficient as allowable costs on grants and cooperative agreements.

Tips for Understanding the Legislative and Regulatory Process

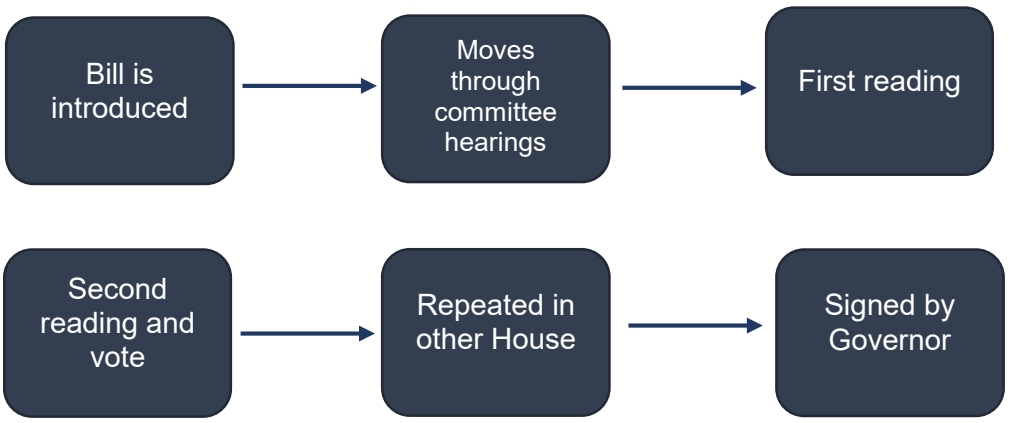
The legislative and regulatory procedures can be lengthy and complex, but it is important for registry directors to develop a basic understanding of these processes to ensure cancer registry requirements are appropriate and enforceable. Amendments to laws require specific actions. Regulatory rules need another set of steps. Learn about both.

Contact your department's office of legal and regulatory affairs or your legislative liaison to request training on procedures specific to your state.

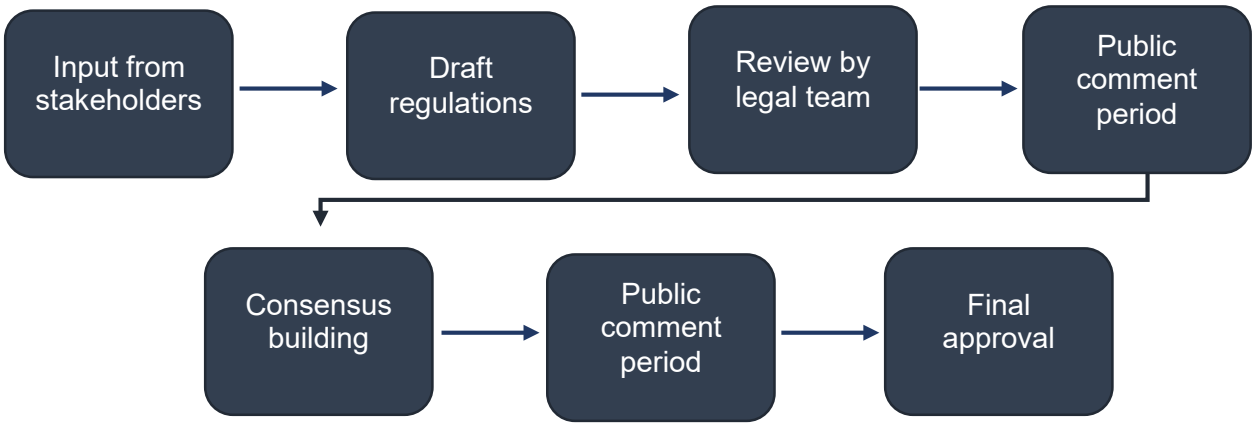
Registry staff may be prohibited from participating in the legislative process directly, but stakeholders or advocacy groups may act on the registry's behalf.

Work with stakeholders to review the CaRI database for language to include in the law.

How to Change a Law



How to Work with Regulations



Tips to Strengthen Central Cancer Registry Laws and Regulations

Discussions during interviews with registry directors resulted in the following tips to help you strengthen central cancer registry laws.

> *"Laws and rules are the backbone of central registries, and we need to learn to be more comfortable working with them. Change is coming, and we cannot move forward if we are locked down by outdated laws."* — **Participating Registry Director**

USE THE CaRI DATABASE: It allows registries to see what other states are doing with their laws and regulations. Because the legal language is already tested, you can be more confident when adapting model wording to your circumstances, reducing the risk of negative impact on operations or stakeholders.

PLAN STRATEGICALLY: Think carefully about the types of changes needed and how you will put them in place.

BE FLEXIBLE AND BROAD: Broad laws that provide regulatory power to the Executive Branch are best. Update and revise regulatory codes to improve operations and reporting.

CONSIDER LICENSING AND CERTIFICATE OF NEED REGULATIONS: Laws and regulations that require hospitals or health facilities to comply with all state requirements to be eligible for certificates of need or licenses may give you an opportunity to strengthen compliance. See if you can include registry reporting requirements under this umbrella.

WORK WITH YOUR STAKEHOLDERS: Strong relationships are critical to your success. Work with advocates and supporters. Listen to the opposition carefully. Build consensus and be willing to compromise. NACDD, ACS, and Komen are excellent sources for help with advocacy support.

SUCCESS STORIES: Registries have changed laws and regulations to simplify edits to reporting fields, require electronic reporting, improve access to medical records, require pathology reports, increase penalties or fees, and require CTRs.

Tips to Improve Electronic Pathology Reporting

Although software programs for processing electronic pathology reports differ, registries can implement some strategies to make the most efficient use of this important resource. Registries have reported that as much as 5 percent of the annual caseload may come from laboratories as the only reporting source.

Screening

- Screen for reportability and code electronic pathology reports as they are received
- Analyze the accuracy of automated screening and coding by cancer site; prioritize manual review of sites with the highest error rate from automated processes

Processing

- Wait to import pathology reports into the registry database until most hospital cases have been processed
- Work with vendor staff to make use of available auto-consolidation routines in the registry software
- If electronic pathology reports cannot be imported directly into the registry, use an external linking software, such as Link Plus or Match Pro to identify new cases

Follow-Back

- Review electronic pathology reports to identify referring physicians; contact these physicians to enroll them in electronic reporting using Web Plus or Abstract Plus
- Make use of linkages with hospital discharge data, health information exchanges, and other sources to supplement demographic data

These tip sheets are not meant to lay out a specific methodology, but rather, are meant to serve as a starting point for more in-depth discussions, development of tools, and the establishment of new processes or practices within individual registries as appropriate.

Overarching Recommendations

March 2021

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Overarching Recommendations

This comprehensive and multidimensional project offers a wide-ranging analysis of how to improve the compliance of cancer registries with National Program of Cancer Registries (NPCR) data standards and assesses many aspects of registry operations. Clearly, registries have made unparalleled strides in improving cancer surveillance in the United States with the support of the Centers for Disease Control and Prevention (CDC) NPCR program. The North American cancer surveillance system is the most advanced disease surveillance system in the world, and much credit is due to all those involved.

It is not possible to summarize all the recommendations here, and thus we stress the importance of studying each individual report to comprehend the breadth and depth of this work.

However, we offer some high-level, overarching recommendations:

1. **Information Sharing:** Share the individual project reports with the NPCR Registry program directors and NPCR staff. The individual reports contain a wealth of valuable information.

2. **Idea Exchange:** Continue to offer opportunities to NPCR registries to convene for a free exchange of ideas around specific topics and/or problems of mutual interest. The individual reports may serve as initial topics of discussion for the group.

3. **Completeness:** The Statistical Expert Panel recommends a three-pronged approach for states to evaluate completeness using external method(s)—current North American Association of Central Cancer Registries (NAACCR)/NPCR method and new logistic regression method; internal method(s)—Surveillance, Epidemiology, and End Results (SEER) and newly modified methods described herein; and secondary process methods. NAACCR will continue to work with NPCR to develop methods of distributing state-level results. After states have had the opportunity to evaluate these indicators in their own context, discussion should begin on the use and implementation of meaningful thresholds.

4. **Additional Completeness Recommendations:** The Statistical Expert Panel further recommends continued exploration to the completeness issue. For example, refinement of site-specific estimates, the use of a different scale, additional secondary process measures, and the setting of thresholds would be topics for further study. In addition, the development of tools to calculate completeness indicators at the registry level on an as-needed basis would greatly benefit the registries.

5. **Lean Evaluation:** Train NPCR registry staff in the Lean method to improve efficiency of operations. The Lean method was demonstrated to be an effective tool for analyzing cancer registry operations; however, the lack of standardized metrics hampered broad-based conclusions.

6. **Evaluation of Electronic Pathology Reporting in Four Registries—Lean Six Sigma (LSS) Project:** The LSS Project Team recommends enhancements to the CDC software systems, notably the output of HL7-readable messages that may be directly imported into CRS Plus, eliminating the NAACCR abstract creation step and building the capacity to capture process metrics within CRS Plus software. See the project report for more suggestions and specifications.

7. **State Laws and Regulations Database:** Use language that has been adopted in other states. The state laws and regulations database is designed to serve as a resource for states considering changes to their reporting requirements. States have made changes to regulations more often and more effectively than changes to legislation.

8. **Automated Data Item Consolidation:** The Automated Data Item Consolidation workgroup identified many important issues. The next steps focus on involving the wider cancer surveillance community in the process of evaluating the role of data item consolidation. Meanwhile, expansion of the NAACCR Edit MetaFile should be considered, as well as the development of data quality steps to improve the quality of data coming from reporting sources.

9. **Development and Evaluation of Management Reports:** Develop a customizable dashboard that would monitor the registry's progress toward 12- and 24-month completeness, timeliness, and data quality benchmarks. A comprehensive description of potential measures is included in the report. Further discussion with registries is warranted to fully develop the dashboard concept.

10. **Communications and Relationships with Hospitals:** Encourage registries to maintain regular contact with hospital and other reporting facilities and monitor the frequency and quality of incoming data. Several recommendations on how to provide effective feedback to facilities, including positive incentives are delineated in the report.

11. **Improvement of Reporting from Nonhospital Sources:** Build abbreviated targeted abstracts and corresponding edit sets in Web Plus and Abstract Plus for registries to implement with medical specialists. More details are provided in the report.

12. **Management of Best Practices Around COVID-19:** Consider certain costs as allowable as they are related to managing a dispersed workforce (see report for details). Many lessons have been learned from managing CCRs through the COVID-19 pandemic. Registries will want to continue successful adaptations to work practices and operations after the return to "normal," such as work from home allowances, remote auditing, access to hospital data, and other suggestions outlined in the report. In addition, data security concerns, human resource issues, and looming state budget reductions are issues of concern.

Additional Recommendations from Year 1 Findings: A few key findings from the analysis conducted in the first year of this project were not addressed during the second year. These include the following:

1. Establishing partnerships with colleges and universities to develop undergraduate education programs that offer concentrations or certifications in cancer registry operations.

2. Exploring strategies to launch a national marketing plan that focuses on careers in the cancer surveillance field similar to what the American Public Health Association and CDC did with their public health careers campaigns.

3. Consider steps to study the impact of changing or eliminating burdensome and costly data elements from the NPCR required data set.

Closing Remarks

> ***"This NAACCR/NACDD project has been incredibly helpful. We feel like our voices are being heard, and we are discovering so much about how we operate and function."***

The NPCR is well positioned to reshape the cancer registry terrain by giving careful consideration to the many findings from this project and the recommendations from the participating registries. Many of these concepts are worthy of further exploration and development beyond the scope of this project. The partnership among NPCR, National Association of Chronic Disease Directors (NACDD), and NAACCR has proven to be fruitful and productive, and these organizations are grateful for the opportunity to have contributed to not only this project, but the improvement of cancer surveillance nationwide.

This comprehensive and multidimensional project offered a wide-ranging analysis of the many challenges that cancer registries face when seeking to meet the NPCR standards, while ensuring complete, timely, and high-quality data. In the first year, the partnership conducted a written assessment, in-depth interviews, focus groups, and in-person summits to review findings. A Statistical Expert Panel was brought together and worked diligently to assess a range of completeness measures. Registry leaders collaborated to examine various processes within registry operations thought to influence timely reporting of cancer data, including software, staffing, reliance on electronic pathology reporting and a variety of other measures. The partnership held statistical and operations summits, at which in-depth analysis of the problems took place.

In the second year of effort, the Statistical Expert Panel continued its work assessing the completeness of case reporting to central cancer registries (CCRs) that drew on multiple independent measures. The panel recommended an amalgamation of different approaches that are more robust than the methods that have been used historically, while at the same time being more liberal, in the sense that incorporating a broader set of criteria makes it less likely that a registry will be incorrectly identified as having data that are insufficiently complete.

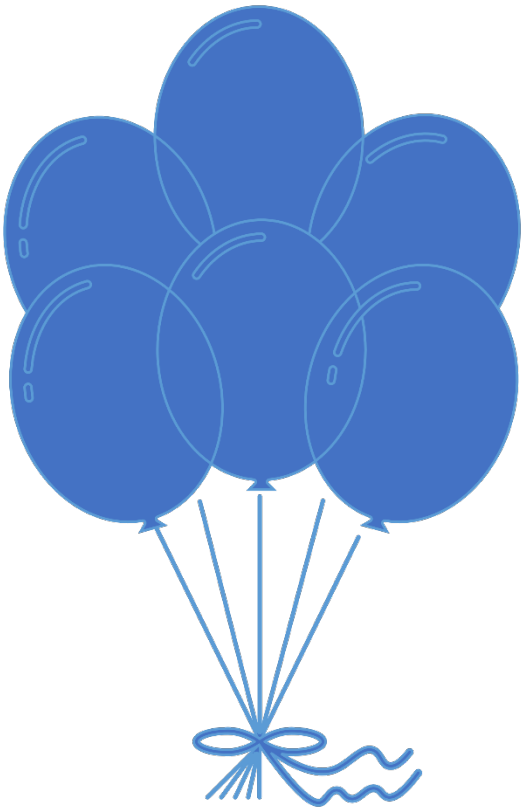
In addition, NAACCR undertook projects that were aimed at identifying best practices and providing guidelines to improve CCR completeness, timeliness, and quality of reporting. A Lean Six Sigma study of electronic pathology reporting in central registries was undertaken in collaboration with Rutgers University Lean Six Sigma Green Belt students. A database of state laws and regulations related to CCRs was developed and an analysis of best practices among state laws and regulations was conducted. The Automated Data Item Consolidation Best Practices Evaluation Project was completed with two states participating. Finally, a series of interactive workshops aimed at identifying best practices and capturing success stories among CCRs was sponsored, resulting in quick tip sheets created to guide and support registries around monitoring the reporting for central registries and facilities, improving communication with hospital and nonhospital reporters, and adapting to the challenges that the COVID-19 pandemic has brought to central registry operations.

This work has resulted in many forward-looking recommendations to help advance the completeness, timeliness, and quality of central registry reporting. Tools and best practices

were revealed to help registries improve their operations. This work also offered an opportunity for central registries to voice their views, share successes, and collaborate with one another on common concerns.

NAACCR would like to thank CDC (NPCR program) and NACDD for their generous support of and contributions to this project.

Finally, NAACCR would like to express deep gratitude to all the participants in this project for their dedication, diligence, and thoughtfulness. The participants demonstrated sensitivity, creativity, and honesty throughout the deliberations. Their significant contributions to this work were critical to its success. A list of contributors and participating registries may be found in the Attribution Section.



Attribution

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The North American Association of Central Cancer Registries would like to express its heartfelt appreciation to all of the participants, students and staff who supported this project over the last 2 years. Your generous support and dedication make this work possible.

State Participants in Project Components

Participating State or Province	State Expert Interviews	Operations Summit	Virtual Workshops	LEAN Project	Auto-consolidation	State Legislation & Rules
Alaska Cancer Registry	X	X	X			
Arizona Cancer Registry			X			
Arkansas Cancer Registry			X			
California Cancer Registry	X					X
Cancer Data Registry of Idaho	X		X			
Cancer Registry of Greater California		X				
Colorado Central Cancer Registry	X	X	X			
District of Columbia Cancer Registry			X			
Florida Cancer Data System	X	X	X			
Georgia Comprehensive Cancer Registry	X					
Hawaii Tumor Registry			X			
Illinois State Cancer Registry	X	X				X
Indiana State Cancer Registry			X			
Kansas Cancer Registry	X	X				

Participating State or Province	State Expert Interviews	Operations Summit	Virtual Workshops	LEAN Project	Auto-consolidation	State Legislation & Rules
Kentucky Cancer Registry	X	X	X			
Louisiana Tumor Registry	X	X	X			
Maine Cancer Registry	X		X			
Maryland Cancer Registry			X			
Massachusetts Cancer Registry	X		X			
Minnesota Cancer Surveillance System	X	X	X			
Missouri Cancer Registry			X		X	
Montana Central Tumor Registry			X			
Nevada Central Cancer Registry			X			
New Jersey State Cancer Registry	X	X	X	X		
New York State Cancer Registry	X	X	X			
North Carolina Central Cancer Registry			X		X	
North Dakota Statewide Cancer Registry	X		X			
Ohio Cancer Incidence Surveillance System	X	X	X	X		
Ontario Cancer Registry		X				

Participating State or Province	State Expert Interviews	Operations Summit	Virtual Workshops	LEAN Project	Auto-consolidation	State Legislation & Rules
Oregon State Cancer Registry	X		X			
Pennsylvania Cancer Registry	X	X			X	
Rhode Island Cancer Registry			X	X		
South Carolina Central Cancer Registry	X	X	X	X		
Tennessee Cancer Registry			X			
Texas Cancer Registry	X	X	X			
Utah Cancer Registry			X			
Vermont Cancer Registry			X			
Virginia Cancer Registry	X	X				
West Virginia Cancer Registry			X			

Statistical Summit Expert Panel—Completeness Method

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Identify and Implement Best Practices for Cancer Registry Operations

YEAR 2: Best Practices and Tools

Appendices

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Appendix A: Completeness Statistical Report

Appendix A.1 Internal Method

Case and Geography Definition. The internal method uses cases with International Classification of Diseases (ICD)-O-3 behavior codes of malignant, malignant only in ICD-O-3, and only malignant 2010+. The same behavior codes are used in the external method. The small differences in the two are because the external method requires age and sex to be known and excludes those cases with missing values for either of these variables. The cases on all cancer sites combined and 20 individual cancer sites are taken as input to the model described below. The Joinpoint model and delay adjustment are applied separately for all sites combined and for each of the individual sites. Unlike in the external model, we do not sum the completeness measures of individual sites to get the measure of all sites combined. Expected case counts are computed for all state registries, plus the District of Columbia, Detroit, Seattle, the three California substate registries, and Puerto Rico, for a total of 57.

Joinpoint. Joinpoint Trend Analysis Software (https://surveillance.cancer.gov/joinpoint/) is a statistical software developed by the National Cancer Institute that models time trends where several different line trends are connected at "joinpoints." This project has 16 input data points representing diagnosis years 2001 through 2016. We allow up to three time trends (two joinpoints) in these data, where the initial (starting in 2001) and final (ending in 2016) trends must contain at least three points and the middle trend must contain at least four time points. We used the last four years' (2013–2016) average annual percent change (AAPC) to project one year ahead to 2017. AAPC is a weighted average of the trend coefficients of the underlying joinpoint model, with weights proportional to the length of each trend segment. In the case of a sudden increase or drop during the last trend segment, using AAPC helps to alleviate the abrupt change and provides a smoother projected value.

Delay Adjustment. The expected number of cases is adjusted by the ratio of a registry's own delay factor to that of the nation. The motivation is to credit the registries with below-average delay factors for the timeliness of their case reporting. In 2017, the nationwide delay factor across all cancer sites was 1.04. Any registry with a delay factor of less than 1.04 will get a reduced expected count than that projected in Joinpoint, hence a higher completeness percent. The delay adjustment is applied for all sites combined and for each of the individual cancer sites. If a registry or a site does not have a specific delay factor, then the adjustment is not applied for the specific registry/site combination.

The projected count from Joinpoint is adjusted by the delay factors as follows:

$$\text{Delay-adjusted expected count} = \text{Joinpoint projected count} \times \text{Delay-adjustment factor},$$

$$\text{where Delay-adjustment factor} = \frac{\text{Registrydelayfactor}}{\text{Nationaldelayfactor}}$$

The completeness measure is then calculated as:

$$\text{Completeness} = \frac{\text{Observedcasecount}}{\text{Delay} - \text{adjustedexpectedcount}} \times 100$$

Evaluation of Completeness for the Current Year and Prior Years. The most recent cases were reported in 2019 for diagnosis years 2017 and before, with 2 years or longer in reporting delay. Every year, North American Association of Central Cancer Registries (NAACCR)

certificates the central registries based on data qualities, of which completeness is an important criterion. To evaluate the diagnosis (Dx) 2017 completeness, the case count from the 2019 submission was the observed count, and the expected count was modeled through joinpoint regression and adjusted for delay factors (described below) using all 2-year delay case counts from Dx 2001 (reported 2003) through Dx 2016 (reported 2018).

In the 2019 data submission, all prior years' data also are supplemented with new cases, and completeness measures are assessed for fit for use. Prior years' completeness measures are evaluated with previous reporting years' submissions, with longer reporting delays. For example, with the data submission in 2019 for Dx 2016 data, there is a 3-year reporting delay. All observed counts for Dx 2001 (report 2004 with a reporting delay of 3 years) through Dx 2015 (reported 2018) are put into the joinpoint model. The earliest completeness we can evaluate with this method is for Dx 2006, with a 13-year reporting delay. One less data point is put into the trend for each successive delay because the trends start with diagnosis year 2001. The maximum number of joinpoints is reduced in accordance with the default algorithms used in the Joinpoint software.

Uncertainty Measure. In addition to the point estimate of the completeness measure, we also estimate the variance of the completeness measure. Because completeness is the ratio of the observed to the expected counts, we need to consider the uncertainty measure in both the numerator and the denominator and apply the delta method to estimate the uncertainty in the ratio.

The numerator in the ratio —the observed count (O) — is assumed to follow a Poisson distribution with mean μ. The denominator — the delay-adjusted expected count (*W*) — is the joinpoint-projected count multiplied by the delay-adjustment factor described above. The variance estimate of the denominator is the square of the delay-adjustment factor multiplied by the variance of the joinpoint projection. Both the mean $E(W)$ and the variance $Var(W)$ of the projection are estimated by the Joinpoint software.

We then apply the delta method to estimate the variance of the ratio of the observed count over the delay-adjusted expected count as:

$$Var\left(\frac{O}{W}\right) = \frac{1}{[E(W)]^2} Var(O) + \frac{\mu^2}{[E(W)]^4} Var(W).$$

The variance of *W*, the joinpoint projected count, is calculated using the following procedure:

Let *Y = log(W),* so *Y* is the logarithm transformation of *W*.

Case 1: AAPC ≥ 0 and AAPC = last segment's annual percent change (APC)

$$Y = \hat{Y}_k$$

Notation: x = k-year ahead location. For example, x = 2017, the last segment starting from Dx 2010, ending at Dx 2016. Then $x_1, \ldots, x_7 = 2010, \ldots, 2016$, and $\bar{x} = 2013, n = 7$. Suppose the slope of the last segment is β, then

$$Var(Y) = \sigma^2 \left[1 + \frac{1}{n}\right] + Var(\beta)(x - \bar{x})^2,$$

where σ^2 estimated by mean squared error (MSE) and $Var(\beta)$ is estimated by $SE(\beta)^2$. Note that MSE and $SE(\beta)$ are found in the Joinpoint output, both based on the log-scale Y.

Case 2: AAPC ≥ 0 and AAPC ≠ last segment's APC

$$Y = \hat{Y}_k$$

The 4-year AAPC is between Dx 2013 and Dx 2016. Suppose the location at Dx 2013 is x_a and the location at Dx 2016 is x_b. The corresponding fitted values are $\hat{Y}_a$ and $\hat{Y}_b$, respectively. The variance of Y is then

$$Var(Y) = \sigma^2 + Var(\hat{Y}_b) + \frac{k^2}{9}\left[Var(\hat{Y}_b) + Var(\hat{Y}_a)\right] + \frac{2k}{3}Var(\hat{Y}_b)$$

$$Var(\hat{Y}_b) = \sigma^2\left[\frac{1}{n} + \frac{(x_b - \bar{x})^2}{\sum(x_i - \bar{x})^2}\right] = \frac{\sigma^2}{n} + Var(\beta_b)(x_b - \bar{x})^2$$
$$Var(\hat{Y}_a) = \sigma^2\left[\frac{1}{m} + \frac{(x_a - \bar{z})^2}{\sum(z_i - \bar{z})^2}\right] = \frac{\sigma^2}{m} + Var(\beta_a)(x_a - \bar{z})^2,$$

where $x_1, \ldots, x_n$ are the last segment; $z_1, \ldots z_m$ are the segment where x_a is located; β_b is the slope of the last segment; β_a is the slope of the segment, where x_a is located; and $\bar{x}$ is the mean of $x_1, \ldots, x_n$. $\bar{z}$ is the mean of $z_1, \ldots, z_m$.

Also, σ^2 is estimated by MSE. $Var(\beta_a)$ is estimated by $SE(\beta_a)^2$. $Var(\beta_b)$ is estimated by $SE(\beta_b)^2$. $E(\hat{Y}_a)$ is estimated by $\hat{Y}_a, E(\hat{Y}_b)$ is estimated by $\hat{Y}_b$.

Case 3: AAPC < 0, then $Y = \hat{Y}_0$.

To predict *x* = 2017. If the location at Dx 2016 is x_b,

$$Var(Y) = \sigma^2\left[1 + \frac{1}{n}\right] + Var(\beta)(x_b - \bar{x})^2,$$

where $x_1, \ldots, x_n$ are the last segment and $\bar{x}$ is the mean of $x_1, \ldots, x_n$.

Once the variance of *Y* is obtained, we then use the delta method to find the variance of *W* by

$$Var(W) \approx Var(Y) \times (exp(Y))^2.$$

Probability the Completeness is Greater Than a Cutoff Point. The completeness measure is assumed to follow a normal distribution. Once the point estimate and the variance estimate of the completeness measure are available, we can calculate the probability that the completeness measure of a registry exceeds a desired threshold value of 98 percent. Then, we are able to identify registries with low probabilities of exceeding the threshold, less than 0.2 or 0.4. This approach incorporates the higher variability in data from smaller registries and minimizes any bias in the completeness measure due to registry size.

Missing Data. Not all registry/year/site combinations are presented. In the following four situations, the data are not included as input:

1. For diagnosis year 2005, for all reporting years, Alabama, Louisiana, Mississippi, and Texas only reported about half of the cases due to hurricane Katrina and were excluded.

2. Some of the zeros were obviously wrong in the database; therefore, we removed all of the them. Some true zeros also were removed. The assumption is that they will be removed in the next step if not here.

3. Joinpoint was run if there were more than five data points and the mean number of observations was at least 50. If there were less than five data points or if the average count across years was less than 50, then there was no Joinpoint model estimate.

4. Some data points were detected as outliers and, hence, were excluded from the data input. In the case where the outlier exclusion resulted in less than five input points or less than 50 average counts, there was no Joinpoint model estimate. The details of outlier detection are described in the next section.

Outlier Detection. In reviewing the joinpoint trend plots of the case counts and expected counts, we found some registries had an "outlier" year during the 16-year period when the observed counts were either too high or too low relative to the joinpoint estimate. Because these outliers bias the overall time trends, we developed a metric to detect outliers and remove them from the trend calculations. The metric is a nonparametric version of the goodness-of-fit measure. Specifically, it is the ratio of the residual (the difference in the log-transformation between the observed and the estimated counts) over the median of the residual. This ratio has been shown to follow a standard normal distribution. Any data point with a ratio below -2 or above 2 was deemed to be an outlier and was removed from the input data. Joinpoint was then rerun after the removal of the outliers. If the last data point in the joinpoint model is removed as an outlier, then a 2-year projection is applied to get the projected count for the completeness calculation. The resulting joinpoint models thus are unbiased with respect to the outliers.

Appendix A.2 External method

Case and Geography Definition. The external method uses cases with ICD-O-3 behavior codes of malignant, malignant only in ICD-O-3, and only malignant 2010+. The same behavior codes are used in the internal method. The small differences in the two are because the external method requires age and sex to be known and excludes those cases with missing values for either of these variables. Expected case counts are computed for all state registries, plus the District of Columbia, Detroit, Seattle, and the three California sub-state registries, for a total of 56. Puerto Rico presently is not included in the external method because race information is missing; if all cases are taken to be Hispanic, then this can be computed, but this decision was not reached before the time of this report.

B1. Here, we offer the details on the regression approach. We build nearly 40 regression models. Specifically, we build separate regression models for each cancer type and gender pair (e.g., lung cancer in women). For building each model, we start with a data set that includes the cancer incidence and covariates for each combination of cancer registry, age group, race/ethnicity, reporting year, and calendar year. Because we have 56 registries, 10 age groups (0–4, 5–14, … 75–84, 85+); four race/ethnicity categories (White, Black, Hispanic, and other); five reporting years (2015–2019); and 13 calendar years prior to each reporting year, each data set has approximately 56 × 10 × 4 × 5 × 13 = 145,600 observations. This value may grow as we add additional registries. We then build a regression model to predict cancer incidence using this data set as described next.

Let *k* index the gender/cancer-type pairing and *i* index the 145,600 observations within that data set. Let Y_{ki} denote the number of cancers, $\lambda_{ki} = \mathrm{E}[Y_{ki}]$, n_{ki} denote the population size, $\{A_{ki2},\ldots,A_{ki10}\}$ denote age groups, $\{R_{ki2}\ R_{ki3},\ R_{ki4}\}$ denote race/ethnicity, $\{C_{ki2},\ldots,C_{ki5}\}$ denote calendar year, and $\{D_{ki2},\ \ldots,\ D_{ki13}\}$ denote reporting delay. Finally, let $\{M_{ki1},\ \ldots,\ M_{ki4}\}$ be a set of variables that represent log-mortality, which are derived using a natural spline with knots at the 20th, 50th, and 80th percentiles of the positive values. We then fit the following model using Poisson regression with a robust variance estimator.

$$\log(\lambda_{ki}) =$$

$$\beta_{ko} + \sum_{j=2}^{10} \beta_{kAj} A_{kij} + \sum_{j=2}^{4} \beta_{kRj} R_{kij} + \sum_{j=2}^{5} \beta_{kCj} C_{kij} + \sum_{j=2}^{13} \beta_{kDj} D_{kij} + \sum_{j=1}^{4} \beta_{kMj} M_{kij} + \log(n_{ki}) \quad (1)$$

To simplify the notation, we let *X* denote all 33 variables (intercept, age, race, etc.) and rewrite equation (1) as

$$\log(\lambda_{ki}) = \sum_{j=1}^{33} \beta_{kj} X_{kij} + \log(n_{ki}) = \beta_k X_{ki} + \log(n_{ki}) \quad (2)$$

After fitting equation (2) separately for each of the approximately 40 data sets, we then can estimate the expected cancer rates for a given registry, calendar year, and delay period by $\hat{Y} = \sum_k \sum_{i\in\Omega} \hat{\lambda}_{ki} = \sum_k \sum_{i\in\Omega} n_i exp(\hat{\beta}_k X_{ki})$, where Ω indexes the relevant observations. Letting $Y = \sum_k \sum_{i\in\Omega} Y_{ki}$ denote the total number of observed cases, we estimate completeness as $\hat{C} = 100 \times Y/\hat{Y}$. We can calculate the standard error (SE) using the delta method (Appendix A.2). Therefore, we report the 95 percent confidence interval as $\hat{C} \pm 1.96SE$ and the probability of exceeding a prespecified threshold, $\underline{c}$, by $P(Z > c)$, where $Z \sim N(\hat{C}, SE^2)$.

We considered two modifications to model 2. First, we considered including additional covariates (e.g., smoking rates, poverty levels, obesity rates),

$$\log(\lambda_{ki}) = \sum_{j=1}^{33} \beta_{kj} X_{kij} + \sum_{l=1}^{p} \alpha_{kl} W_{kil} \quad (3)$$

where $\{W_{ki1},\ldots,W_{kip}\}$ are the *p* additional variables relevant for the k[th] gender and cancer pair (i.e., not all 33 variables will be relevant for each cancer type). Second, we considered using county-level data. The data sets now would include cancer incidence for each combination of county (as opposed to cancer registry), age group, race/ethnicity, reporting year, and delay year. Given that approximately 3,000 counties are in the United States, each data set includes approximately 3,000 × 10 × 4 × 5 × 13 = 7,800,000 observations.

B2. We can obtain the SE for the external estimate of completeness $\hat{C}$. Referring to equation 2, we assume that $\sqrt{N}(\hat{\beta}_k - \beta_k) \sim N(0, \Sigma_k)$, let $\hat{\Sigma}_k$ be the robust variance estimator, and denote the needed derivatives by

$$\dot{g}_k^T = [\sum_{i\in\Omega} X_{ki1} n_i exp(\hat{\beta}_k X_{ki}), \ldots, \sum_{i\in\Omega} X_{ki33} n_i exp(\hat{\beta}_k X_{ki})].$$

Then, by the delta method, we assume

$$(\sum_{i\in\Omega} n_{ki} \exp(\hat{\beta}_k X_{ki}) - \sum_{i\in\Omega} n_{ki} \exp(\beta_k X_{ki})) \sim N(0, \dot{g}_k^T \hat{\Sigma}_k \dot{g}_k) \equiv N(0, \hat{\sigma}_{kE}^2).$$

Moreover, letting $\hat{\sigma}_{kV}^2 = \sum_{i\in\Omega} Y_{ki}$, $\hat{\lambda}_k = \sum_{i\in\Omega} n_i exp(\hat{\beta}_k X_{ki})$, $\hat{\lambda} = \sum_k \hat{\lambda}_k$, $\hat{\sigma}_E^2 = \sum_k \hat{\sigma}_{kE}^2$, and $\hat{\sigma}_V^2 = \sum_k \hat{\sigma}_{kV}^2$, we estimate the distribution of completeness by

$$(\hat{C} - C) \sim N(0, (\hat{C}^2 \hat{\sigma}_E^2 + \hat{\sigma}_V^2)/\hat{\lambda}^2) \equiv N(0, \hat{\sigma}_C^2).$$

Appendix A.3. List of Additional Variables Considered for External Method

Age and Sex
Percentage of persons under 18 years of age
Percentage of persons 65 years and over
Percentage of female-headed households

Education
Percentage of persons 25 years and over with at least a bachelor's degree
Percentage of persons 25 years and over with less than 9th grade education

Employment
Percentage of persons 16 years and over who are unemployed
Percentage of white collar workers

Income
Median household income
Percentage of families below poverty
Percentage of persons below poverty

Geography
Land area in square miles
Population density
Percentage of persons in rural areas
Percent migrating between states

Housing
Percentage of households with more than one person per room

Language
Percentage of households that is isolated linguistically

Race/Ethnicity/National Origin
Percent Hispanic
Percent foreign born
Percent non-Hispanic American Indian and Alaska Native alone
Percent non-Hispanic Black alone
Percent non-Hispanic White alone

Cancer Outcomes
Relative survival

Health Behaviors
Percentage of adults with a body mass index greater than 25
Percentage of females who ever smoked
Percentage of males who ever smoked

Health Insurance
Percentage of females less than 65 years without insurance
Percentage of males less than 65 years without insurance

Medical Care and Screening
Hospitals per 1,000 population
Doctors per 1,000 population
Percentage of individuals meeting age-appropriate colorectal cancer-screening guidelines
Percentage of women meeting age-appropriate breast cancer-screening guidelines
Percentage of women meeting age-appropriate cervical cancer-screening guidelines
Percentage of men over age 50 years receiving a prostate-specific antigen test in the past year

Appendix A.4 Potential Use of January (12-month) NAACCR Submissions for Reporting National Cancer Statistics

The data submitted to NAACCR in November is used to report cancer statistics for cases diagnosed through 2 years earlier. For example, the November 2020 submission will be used to produce statistics diagnosed through the end of 2018. This data submission also is known as 24-month data because the time between the submission and 2 years earlier is 24 months. Since 2013, NPCR-funded registries have made a second submission to produce the first report on cases diagnosed through the previous year. This submission is due in January, but many registries submit it at the same time because their other submission is due in November. This is known as 12-month data, although given the range of submission times, it is technically 11- to 13-month data. With an interest in making population-based cancer registry reporting more timely, a natural question is whether the 12-month data are complete enough for the reporting of national cancer statistics.

To answer this question, it is useful to look at the experience of SEER registries. Since 2011, SEER registries have been making their second submission in February, one month later than NPCR registries, effectively making it 14-month data, although it often is referred to as 12-month data as well. After the first four such submissions, an article was published titled “Early estimates of SEER cancer incidence for 2012: approaches, opportunities, and cautions for obtaining preliminary estimates of cancer incidence” (*Cancer* 2015; 121(12): 2053-2062). This paper found that although fewer cases were reported in the February submissions than in the subsequent November submissions, the amount of under-reporting was not that large and was fairly consistent over time. This allowed the authors to adjust for the under-reporting of rates from the February submissions by extending the reporting delay model, which had been previously used for November submissions.

Reporting delay factors represent a multiplier by which rates should be adjusted to account for additional cases that will come in eventually. For example, a factor of 1.05 means that the rates should be adjusted upward by 5 percent. For SEER November submissions, reporting delay factors range from about 1.025 to 1.15 depending on the cancer site, with the largest factors for leukemia, lymphoma, and myeloma. For the SEER February submissions, the factors are usually about twice as large, ranging from about 1.05 to 1.30. They also found that Joinpoint trends estimated using the February submission were very close to trends estimated using the subsequent November submission. This analysis provided confidence that preliminary estimates of rates and trends could be released earlier than the typical delay of 28 months (23 months for reporting and then an additional 5 months for processing before being released in April. National Cancer Institute published preliminary rates and trends in the journal *Cancer* for the next 3 years (122(10): 1579-1587, 123(13): 2524-2534, 124(10): 2192-2204) and on the SEER website in 2019 (https://seer.cancer.gov/statistics/preliminary-estimates/).

For these estimates to be valid, there must be consistency in the under-reporting over time because the delay model uses the history of reporting delays to predict future delays. For example, the February 2020 submission, including cases diagnosed through 2018, was thought to be more under-reported than prior February submissions due to delays in the release of updated coding software to registries. Consequently, no preliminary estimates were published this year.

To evaluate the potential of using NAACCR submissions to produce preliminary rates and trends, we computed the ratio of cancer counts by registry for the January to subsequent

November submissions for selected cancer sites for submissions in 2013, 2014, 2015, and 2016. They are displayed for all sites, colon and rectum, female breast, lung, and prostate cancers in Figures 12 through 16. Each of the 69 registries that submitted data to NAACCR, including Canadian registries, is displayed in a column with a dot for each of the four ratios, sorted by the 2013 ratio. Registries were assigned random reference codes to prevent identification. The figures allow one to view the average level of the ratios for each registry, as well as their variability, which as previously described is a key to estimating delay factors with reasonable predictive ability. Missing data points indicate missing 12-month submissions and/or subsequent 24-month submissions that did not meet minimum NAACCR certification standards. We chose a ratio of 0.8 as an ad hoc cut point for ratios sufficiently high for delay modeling, requiring that registries met this threshold in at least 3 of the 4 years. Thirty-three registries met this threshold for all sites combined, and 36 met this threshold for colorectal and breast cancers, but only 24 reached the threshold for lung and bronchus cancer and 23 for prostate cancer. The reasoning behind the choice of 0.8 is as follows: Assume that these each of these cancers had an average reporting delay factor of 1.05 based on the subsequent November submission, making the ratio of the cases from that submission to the final count years later $1 \div 1.05 = 0.95$. Then, a 12- to 24-month ratio of 0.8 translates to a delay factor of $1 \div (0.8 \times 0.95) = 1.3$, which is among the largest delay factors for the SEER February submissions. Note that delay factors for cancers beyond these most common sites may be substantially larger.

Further evaluation would be necessary to determine whether the rates or trends from the 12-month NPCR submission could be utilized reliably. The ratios in Figures 12 through 16 should be updated to include data for 2017–2020. The delay model then could be run for registries where a majority of the ratios are greater than 80 percent. Similar to what was done with the SEER registries, evaluations should be conducted to determine how well the 12-month delay-adjusted rates and joinpoint trends track the 24-month delay-adjusted rates and joinpoint trends. Depending on these results, a stricter registry inclusion threshold than 0.8 may be necessary. These preliminary results show some promise for early reporting but only for roughly half of all registries.

Appendix A.5 Completeness Estimates

All Sites Completeness Estimates

Submission Year = 2019; Diagnosis Year = 2017

	Internal				External			
Registry	Observed	Predicted (Delay Adjusted)	Completeness (95%CI)	P(Completeness>98)	Observed	Predicted	Completeness (95%CI)	P(Completeness>92)
Alabama	27084	27348	99.0 (96.6, 101.4)	0.80	27084	28100	96.4 (95.1, 97.7)	>0.99
Alaska	2917	2824	103.3 (93.0, 113.6)	0.84	2917	3001	97.2 (93.6, 100.8)	>0.99
Arizona	32424	33295	97.4 (93.2, 101.5)	0.39	32424	36512	88.8 (87.7, 89.9)	<0.01
Arkansas	17474	17630	99.1 (94.8, 103.4)	0.70	17474	17263	101.2 (99.6, 102.8)	>0.99
California	170786	165864	103.0 (100.7, 105.3)	>0.99	170784	173792	98.3 (97.5, 99.0)	>0.99
Colorado	24226	23401	103.5 (99.8, 107.3)	>0.99	24226	25897	93.5 (92.2, 94.8)	0.99
Connecticut	21297	20704	102.9 (100.0, 105.8)	>0.99	21297	19686	108.2 (106.6, 109.8)	>0.99
Delaware	5617	6088	92.3 (87.6, 96.9)	0.01	5617	5716	98.3 (95.6, 100.9)	>0.99
Detroit	23009	22567	102.0 (98.4, 105.5)	0.99	23009	21640	106.3 (104.8, 107.8)	>0.99
District of Columbia	2907	2562	113.5 (102.8, 124.1)	>0.99	2907	2888	100.7 (96.9, 104.4)	>0.99
Florida	124804	126573	98.6 (94.7, 102.5)	0.62	124804	126932	98.3 (97.5, 99.1)	>0.99
Georgia	52690	52522	100.3 (96.1, 104.5)	0.86	52690	50744	103.8 (102.8, 104.9)	>0.99
Greater Bay	33523	31841	105.3 (101.5, 109.1)	>0.99	33523	32644	102.7 (101.4, 103.9)	>0.99
Greater California	97280	93882	103.6 (99.4, 107.8)	>0.99	97278	99502	97.8 (96.9, 98.6)	>0.99
Hawaii	7561	7183	105.3 (100.8, 109.7)	>0.99	7561	6382	118.5 (115.6, 121.3)	>0.99
Idaho	8624	8769	98.4 (92.9, 103.8)	0.55	8624	8791	98.1 (96.0, 100.3)	>0.99

	Internal				External			
Registry	Observed	Predicted (Delay Adjusted)	Completeness (95%CI)	P(Completeness>98)	Observed	Predicted	Completeness (95%CI)	P(Completeness>92)
Illinois	69222	68393	101.2 (97.9, 104.5)	0.97	69222	66994	103.3 (102.4, 104.3)	>0.99
Indiana	34318	35605	96.4 (93.5, 99.3)	0.14	34318	36643	93.7 (92.5, 94.8)	>0.99
Iowa	18600	18081	102.9 (100.3, 105.4)	>0.99	18600	17795	104.5 (102.9, 106.1)	>0.99
Kansas	15303	15210	100.6 (98.0, 103.3)	0.97	15303	15394	99.4 (97.7, 101.1)	>0.99
Kentucky	27714	27540	100.6 (98.4, 102.9)	0.99	27714	26067	106.3 (104.9, 107.7)	>0.99
Los Angeles	40003	39888	100.3 (97.5, 103.1)	0.94	40003	42239	94.7 (93.6, 95.8)	>0.99
Louisiana	26114	25290	103.3 (101.1, 105.4)	>0.99	26114	25216	103.6 (102.2, 104.9)	>0.99
Maine	9061	8756	103.5 (99.4, 107.5)	>0.99	9061	9001	100.7 (98.5, 102.8)	>0.99
Maryland	31735	31972	99.3 (95.1, 103.4)	0.73	31735	31297	101.4 (100.1, 102.7)	>0.99
Massachusetts	37769	36452	103.6 (100.0, 107.3)	>0.99	37769	37138	101.7 (100.5, 102.9)	>0.99
Michigan	54674	54169	100.9 (96.8, 105.1)	0.92	54673	57573	95.0 (94.0, 95.9)	>0.99
Minnesota	31152	30666	101.6 (96.9, 106.3)	0.93	31152	29300	106.3 (105.0, 107.6)	>0.99
Mississippi	16548	16168	102.4 (97.5, 107.2)	0.96	16548	16633	99.5 (97.9, 101.1)	>0.99
Missouri	34380	34166	100.6 (97.1, 104.1)	0.93	34379	35271	97.5 (96.3, 98.6)	>0.99
Montana	6426	6278	102.4 (94.5, 110.2)	0.86	6426	6096	105.4 (102.8, 108.1)	>0.99
Nebraska	10411	10359	100.5 (97.2, 103.8)	0.93	10411	9992	104.2 (102.1, 106.3)	>0.99
Nevada	12963	13184	98.3 (87.2, 109.5)	0.52	12963	15026	86.3 (84.7, 87.8)	<0.01
New Hampshire	8532	8466	100.8 (96.8, 104.7)	0.92	8532	8128	105.0 (102.7, 107.3)	>0.99
New Jersey	52654	50531	104.2 (99.7, 108.7)	>0.99	52654	46614	113.0 (111.8, 114.1)	>0.99
New Mexico	9263	9127	101.5 (96.9, 106.1)	0.93	9261	10312	89.8 (87.9, 91.7)	0.01
New York	115010	111292	103.3 (100.2, 106.5)	>0.99	115007	101751	113.0 (112.1, 113.9)	>0.99

	Internal				External			
Registry	Observed	Predicted (Delay Adjusted)	Completeness (95%CI)	P(Completeness>98)	Observed	Predicted	Completeness (95%CI)	P(Completeness>92)
North Carolina	57041	56633	100.7 (95.7, 105.8)	0.85	57038	55844	102.1 (101.1, 103.2)	>0.99
North Dakota	3878	3853	100.6 (95.0, 106.3)	0.82	3878	3775	102.7 (99.4, 106.0)	>0.99
Ohio	67167	67152	100.0 (96.2, 103.9)	0.85	67167	68366	98.2 (97.3, 99.2)	>0.99
Oklahoma	19807	20297	97.6 (94.6, 100.5)	0.39	19807	21064	94.0 (92.6, 95.4)	>0.99
Oregon	21528	21236	101.4 (95.5, 107.3)	0.87	21528	23081	93.3 (91.9, 94.6)	0.97
Pennsylvania	79341	79522	99.8 (96.9, 102.6)	0.89	79340	76769	103.3 (102.4, 104.3)	>0.99
Puerto Rico	14367	16939	84.8 (74.4, 95.2)	0.01	Data not available	Data not available	Data not available	Data not available
Rhode Island	5761	6036	95.4 (90.2, 100.7)	0.17	5761	5939	97.0 (94.4, 99.6)	>0.99
Seattle	27537	27022	101.9 (98.7, 105.1)	0.99	27537	25304	108.8 (107.4, 110.2)	>0.99
South Carolina	27762	28379	97.8 (93.3, 102.3)	0.47	27762	28894	96.1 (94.8, 97.3)	>0.99
South Dakota	4739	4848	97.8 (90.7, 104.9)	0.47	4739	4738	100.0 (97.1, 102.9)	>0.99
Tennessee	37623	36567	102.9 (98.3, 107.5)	0.98	37623	38190	98.5 (97.4, 99.7)	>0.99
Texas	114402	112266	101.9 (97.9, 105.9)	0.97	114402	120363	95.0 (94.3, 95.8)	>0.99
Utah	10942	10556	103.7 (99.6, 107.7)	>0.99	10942	11397	96.0 (94.1, 97.9)	>0.99
Vermont	3901	3670	106.3 (101.1, 111.6)	>0.99	3901	3933	99.2 (96.0, 102.3)	>0.99
Virginia	39840	40167	99.2 (93.0, 105.3)	0.65	39839	43874	90.8 (89.8, 91.8)	0.01
Washington	37522	37131	101.1 (98.4, 103.7)	0.99	37522	37464	100.2 (99.0, 101.3)	>0.99
West Virginia	12143	11836	102.6 (97.1, 108.1)	0.95	12143	12011	101.1 (99.2, 103.0)	>0.99
Wisconsin	32655	33091	98.7 (93.6, 103.7)	0.60	32655	32512	100.4 (99.2, 101.7)	>0.99
Wyoming	2874	2732	105.2 (96.6, 113.8)	0.95	2874	3016	95.3 (91.8, 98.8)	0.97
Utah	10942	10556	103.7 (99.6, 107.7)	>0.99	10942	11397	96.0 (94.1, 97.9)	>0.99

Appendix A.6 Sample Individual State Reports

Full reports for all states can be found here.

Table 1. Illinois All Sites Completeness Estimates

Submission Year = 2019; Diagnosis Year = 2017

Internal				External			
Observed	Predicted (Delay Adjusted)	Completeness (95%CI)	P(Completeness>98)	Observed	Predicted	Completeness (95%CI)	P(Completeness>92)
69222	68393	101.2 (97.9, 104.5)	0.97	69222	66994	103.3 (102.4, 104.3)	>0.99

Table 2. Illinois Completeness Estimates by Site

Submission Year = 2019; Diagnosis Year = 2017

	Internal			External		
Site	Observed	Predicted (Delay Adjusted)	Completeness	Observed	Predicted	Completeness
All Sites	69222	68393	101.2	69222	66994	103.3
Brain and ONS	869	894	97.2	869	876	99.2
Breast (Female)	10332	10558	97.9	10332	9909	104.3
Cervix	514	507	101.3	514	500	102.7
Colon and Rectum	6073	6387	95.1	6073	5706	106.4
Corpus and Uterus NO	2517	2563	98.2	2517	2289	110.0
Esophagus	693	738	93.9	693	702	98.7
Kidney and RP	2646	2722	97.2	2646	2565	103.2
Leukemia	1933	1757	110.0	1933	1950	99.1
Liver and IBD	1207	1309	92.2	1207	1234	97.8
Lung and Bronchus	9438	9469	99.7	9438	8938	105.6
Lymphoma	3199	3175	100.7	3199	3072	104.1
Melanoma of the Skin	3288	3048	107.9	3288	3295	99.8
Myeloma	1003	951	105.4	1003	1048	95.7
Oral Cavity and Phar	1913	1895	100.9	1913	1816	105.4
Ovary	812	840	96.7	812	815	99.7
Pancreas	2184	2040	107.1	2184	2014	108.4
Prostate	8313	7148	116.3	8313	8081	102.9
Stomach	1070	1023	104.6	1070	974	109.8
Urinary Bladder	3064	3057	100.2	3064	2901	105.6
Other Sites	8154	8718	93.5	8154	8310	98.1

Table 3. Illinois Completeness Estimates by Site and Diagnosis Year

Submission Year = 2019

	Internal												External											
	Diagnosis Year												Diagnosis Year											
Site	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
All Sites	103	103	103	98	96	100	97	101	103	102	101	101	102	101	103	103	102	102	101	101	102	102	103	103
Brain and ONS	106	94	102	93	101	101	91	94	100	101	98	97	103	96	102	94	102	104	94	94	99	101	100	99
Breast (Female)	108	105	106	105	98	101	97	101	102	101	100	98	104	101	101	101	104	103	100	103	105	104	106	104
Cervix	102	99	115	96	96	104	91	99	113	97	111	101	108	104	115	103	99	106	95	101	108	93	106	103
Colon and Rectum	100	97	97	93	100	103	97	100	101	103	107	95	109	107	106	104	108	112	108	107	107	105	111	106
Corpus and Uterus NO	.	98	100	107	102	100	98	101	99	99	101	98	112	106	107	109	109	108	104	109	105	105	106	110
Esophagus	.	103	102	101	91	104	103	94	100	102	93	94	107	105	103	104	100	110	112	101	104	108	99	99
Kidney and RP	101	95	98	98	90	105	101	100	104	102	100	97	109	106	105	108	103	108	106	105	108	106	104	103
Leukemia	102	93	106	101	105	107	110	97	95	98	100	110	103	95	102	94	96	97	95	92	91	93	93	99
Liver and IBD	.	102	96	108	108	95	100	95	101	101	99	92	95	101	92	100	100	93	98	90	93	95	95	98
Lung and Bronchus	102	101	100	102	97	98	98	96	105	100	99	100	105	103	103	106	104	105	103	101	105	105	103	106
Lymphoma	95	99	103	99	102	97	95	99	104	103	99	101	99	100	102	99	103	100	98	98	102	101	102	104
Melanoma of the Skin	99	100	102	97	92	97	97	91	104	109	109	108	86	87	91	89	89	91	92	84	87	91	98	100
Myeloma	102	94	111	109	101	107	106	100	104	105	107	105	102	95	102	100	94	96	96	90	91	94	96	96
Oral Cavity and Phar	99	106	105	101	98	105	100	99	98	101	99	101	100	103	102	104	103	106	103	102	100	103	100	105
Ovary	.	95	94	98	103	97	94	100	100	106	95	97	106	103	99	101	105	101	98	98	99	103	101	100
Pancreas	94	99	102	105	98	98	99	102	102	104	100	107	102	105	104	109	104	101	103	104	102	105	101	108
Prostate	.	115	106	90	89	95	85	95	100	109	108	116	98	100	106	107	99	100	103	102	105	104	102	103
Stomach	98	103	102	104	99	108	102	109	104	105	102	105	104	107	107	105	101	106	101	109	106	109	108	110
Urinary Bladder	91	98	104	103	96	98	97	106	101	105	100	100	103	104	107	108	104	104	101	109	104	108	106	106
Other Sites	102	104	100	98	96	97	100	99	99	98	98	94	98	99	98	97	97	95	97	96	98	99	99	98

Table 3. Illinois Completeness Estimates by Site and Diagnosis Year

Submission Year = 2019

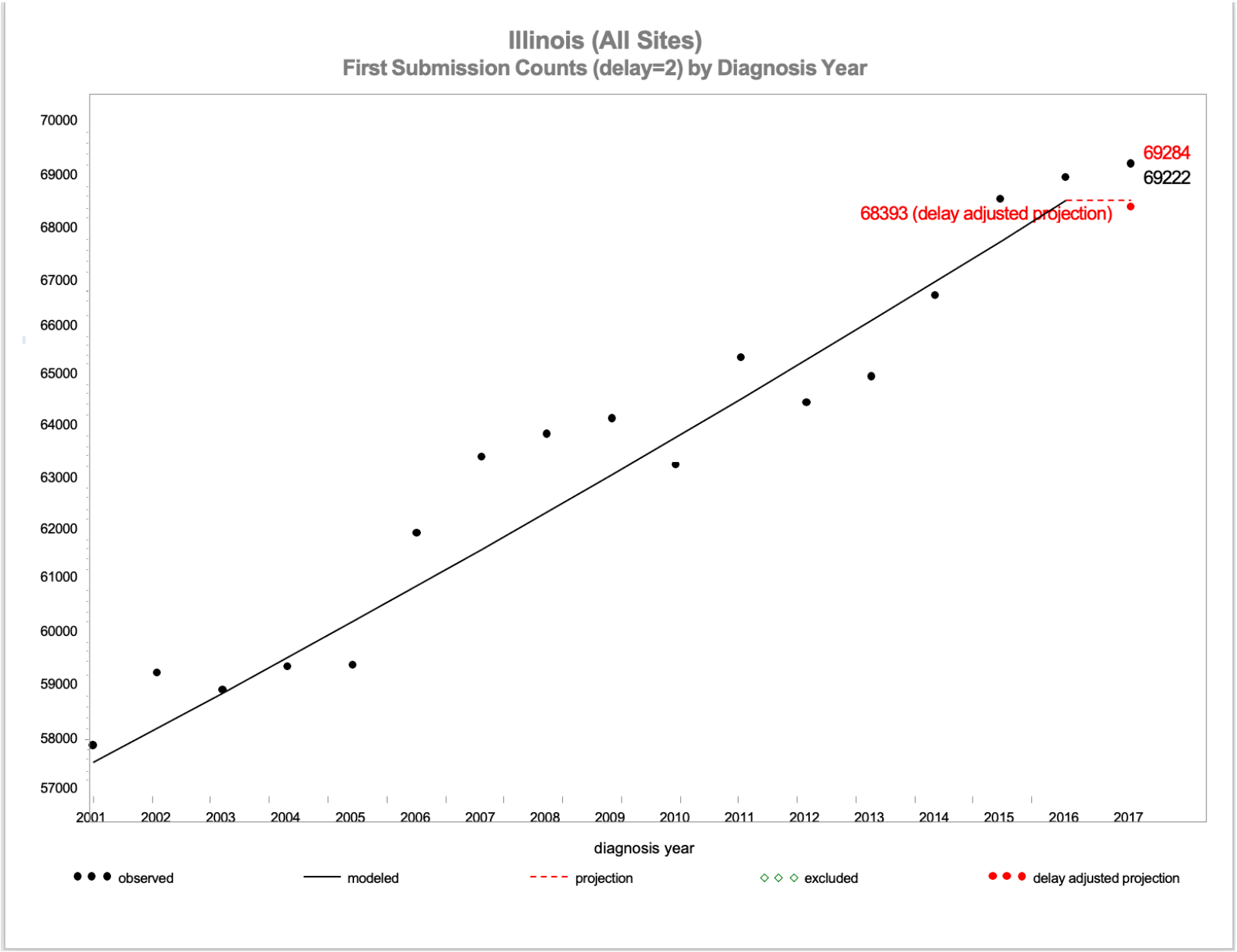


Table 3. Illinois Completeness Estimates by Site and Diagnosis Year

Submission Year = 2019

Figure 2. Percentage of DCO Cases

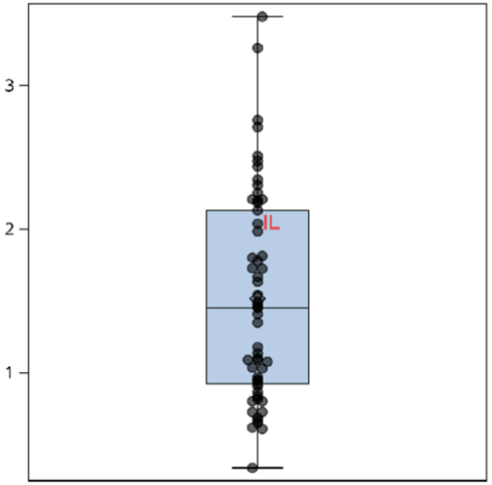


Figure 3. Percentage of Cases with III-defined Site

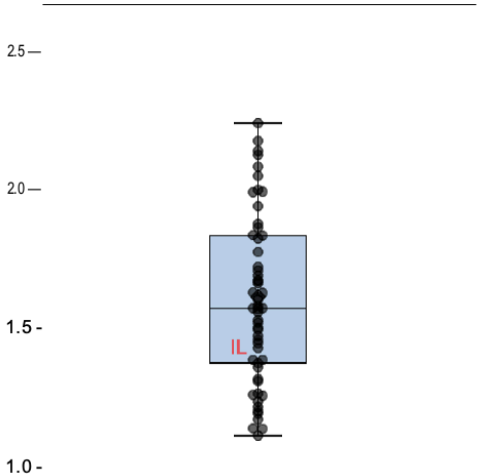


Figure 4. Percentage of Tumors Microscopically Confirmed

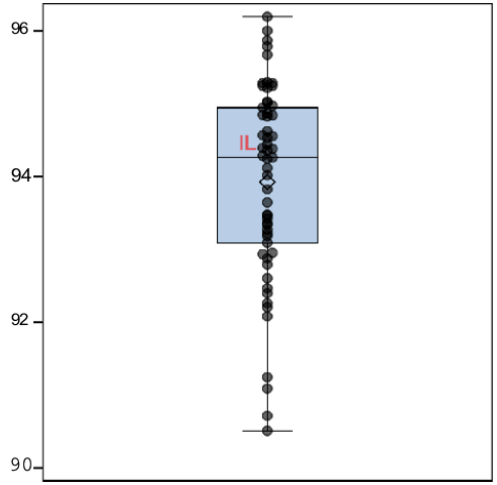


Figure S. Percentage of Leukemia and Myeloma Cases

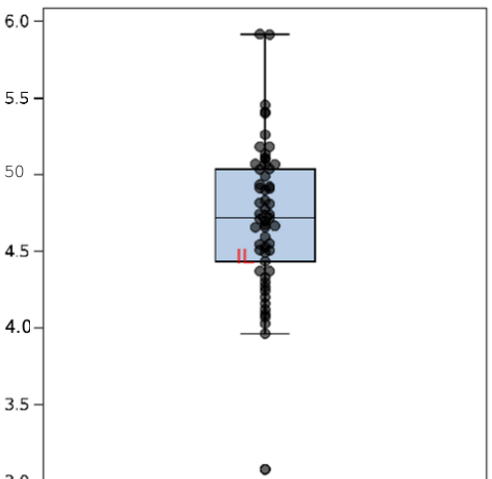


Figure 6. Percentage of Brain Tumors That Are Benign

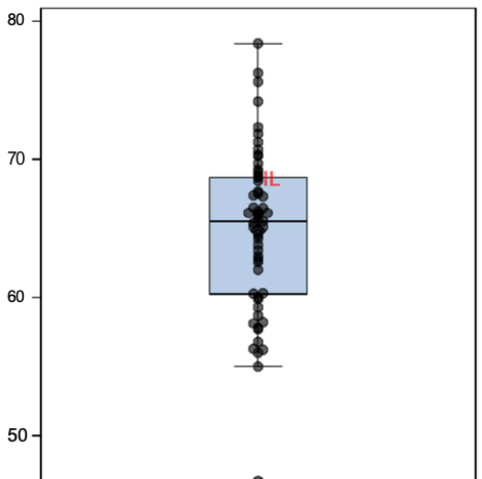


Table 1. Pennsylvania All Sites Completeness Estimates

Submission Year = 2019; Diagnosis Year = 2017

Internal				External			
Observed	Predicted (Delay Adjusted)	Completeness (95%CI)	P(Completeness>98)	Observed	Predicted	Completeness (95%CI)	P(Completeness>92)
79341	79522	99.8 (96.9, 102.6)	0.89	79340	76769	103.3 (102.4, 104.3)	>0.99

Table 2. Pennsylvania Completeness Estimates by Site

Submission Year = 2019; Diagnosis Year = 2017

	Internal			External		
Site	Observed	Predicted (Delay Adjusted)	Completeness	Observed	Predicted	Completeness
All Sites	79341	79522	99.8	79340	76769	103.3
Brain and ONS	1089	1070	101.7	1089	1000	108.9
Breast (Female)	11213	11372	98.6	11213	11153	100.5
Cervix	503	507	99.3	503	486	103.6
Colon and Rectum	6579	6716	98.0	6579	6383	103.1
Corpus and Uterus NO	2933	3045	96.3	2933	2706	108.4
Esophagus	906	891	101.6	906	837	108.3
Kidney and RP	2971	2900	102.4	2971	2844	104.5
Leukemia	2404	2399	100.2	2404	2247	107.0
Liver and IBD	1552	1627	95.4	1551	1408	110.1
Lung and Bronchus	10930	10712	102.0	10930	10325	105.9
Lymphoma	3701	3908	94.7	3701	3541	104.5
Melanoma of the Skin	3475	3708	93.7	3475	4219	82.4
Myeloma	1193	1161	102.8	1193	1140	104.6
Oral Cavity and Phar	2086	2092	99.7	2086	2059	101.3
Ovary	986	990	99.6	986	912	108.1
Pancreas	2587	2501	103.4	2587	2388	108.3
Prostate	8747	8212	106.5	8747	9121	95.9
Stomach	976	1021	95.6	976	978	99.8
Urinary Bladder	3990	4053	98.5	3990	3575	111.6
Other Sites	10520	10511	100.1	10520	9449	111.3

Table 3. Pennsylvania Completeness Estimates by Site and Diagnosis Year

Submission Year = 2019

	Internal												External											
	Diagnosis Year												Diagnosis Year											
Site	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
All Sites	104	103	98	98	99	101	96	100	99	102	100	100	103	103	103	103	105	106	103	105	103	104	104	103
Brain and ONS	100	102	98	93	98	96	98	100	95	95	100	102	105	107	106	99	105	105	106	107	104	102	106	109
Breast (Female)	104	102	104	102	98	101	100	102	101	99	100	99	100	97	100	100	100	100	101	102	102	100	101	101
Cervix	.	107	100	100	88	106	98	96	90	103	106	99	99	110	104	105	101	111	107	105	93	102	105	104
Colon and Rectum	99	97	96	98	94	100	99	102	99	104	100	98	107	106	103	105	102	107	104	105	102	104	103	103
Corpus and Uterus NO	101	107	.	97	102	102	97	101	98	99	101	96	113	114	121	112	115	119	114	115	108	110	114	108
Esophagus	97	98	104	97	93	99	98	102	102	105	109	102	101	101	106	98	101	102	102	104	102	104	110	108
Kidney and RP	104	97	101	94	93	101	104	107	103	104	103	102	108	105	108	101	103	102	101	105	103	104	103	104
Leukemia	103	98	98	105	112	101	89	97	108	106	101	100	101	98	96	101	105	105	99	98	102	102	103	107
Liver and IBD	101	104	102	104	98	98	97	99	98	101	93	95	108	106	107	108	108	112	104	110	107	113	108	110
Lung and Bronchus	100	101	99	100	97	99	97	100	100	101	101	102	101	102	100	102	102	103	100	103	103	103	104	106
Lymphoma	101	97	103	105	94	104	101	98	103	98	98	95	105	101	105	110	105	109	109	106	110	106	107	105
Melanoma of the Skin	98	93	101	112	109	96	93	112	104	97	85	94	84	78	81	88	93	92	93	102	103	100	90	82
Myeloma	.	109	104	111	110	94	95	103	108	102	97	103	96	104	97	104	104	101	97	100	105	103	99	105
Oral Cavity and Phar	105	104	104	99	101	104	99	99	98	96	106	100	96	96	95	94	97	101	102	99	97	95	99	101
Ovary	95	109	102	100	100	97	96	96	101	97	102	100	98	106	104	103	108	106	102	101	103	100	111	108
Pancreas	.	.	100	96	105	104	94	99	104	106	101	103	102	102	103	101	107	107	102	105	106	110	106	108
Prostate	117	115	85	96	99	103	82	86	82	117	105	107	105	103	99	98	103	105	99	100	95	102	101	96
Stomach	103	100	.	97	111	99	93	94	105	96	102	96	113	109	120	110	115	110	102	102	110	103	107	100
Urinary Bladder	101	102	101	99	101	103	99	103	97	98	96	98	111	111	112	110	114	116	112	117	111	112	111	112
Other Sites	100	.	103	101	101	97	97	96	93	99	101	100	110	113	112	112	114	112	112	110	108	108	109	111

Appendix B: Automated Data Item Consolidation Best Practices Evaluation Project Final Report Supplement

The Role of Quality Control in Automated Data Consolidation

The critical role that quality control plays in decisions related to the use of automated data consolidation was again reinforced by the work that the Missouri and North Carolina central cancer registries (CCRs) completed on this project. Both CCRs provided feedback and specific examples of ways in which improved quality control on data items could change their decision on the appropriateness of using automated data consolidation. For example, through this project, there were examples in which the following activities done before automated data consolidation likely would have improved matches with the correct value:

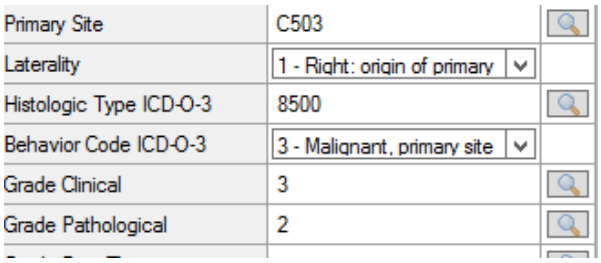
- Increased training for Certified Tumor Registrars (CTRs) on new data items or abstraction rules so that the quality of the records brought into the automated data consolidation process more often contained the correct value
- Improved edits on data fields prior to their processing via automated data consolidation so that incorrect values are weeded out
- Improved record process flow to CCRs from in-state health systems and bordering states to minimize the duplicate patient records found within the CCR database

Additionally, we received specific feedback from the CCRs regarding updates to edits or rules on data items or primary cancer sites that might result in improved matching with correct values during the automated data consolidation process. It is important that as the cancer community considers the optimal role for automated data consolidation at CCRs, the necessary steps be taken to increase the likelihood that the highest quality records are being brought into the consolidation process. It is only when high-quality individual records are used for input that a high-quality consolidated record can be the output.

Data Item and Cancer Site Edits To Consider

Data Item: Grade

- The highest grade is being coded in Clinical Grade without taking into consideration the timeframe allowed, especially for prostate bx vs trans-urethral resection of the prostate (TURP).
- (EDIT OPPORTUNITY) Pathological grade was less than clinical grade. Many records do not reflect the grade rule change for 2018 in circumstances when the clinical grade is higher than the pathological grade.



Note 1: Pathological grade must not be blank.

Note 2: Assign the highest grade from the primary tumor. If clinical grade is highest grade identified, use grade that was identified during the clinical timeframe for both clinical grade and pathological grade. This follows the American Joint Committee on Cancer (AJCC) rule that pathological timeframe includes all of the clinical timeframe plus information from the resected specimen.

- If a resection is done of a primary tumor and there is no grade documented from the surgical resection, use the grade from clinical workup.
- If a resection is done of a primary tumor and there is no residual cancer, use the grade from clinical workup.
    - The correct codes for in situ cases and applying the priority order are not being used. For example, for breast, the grade for ductal carcinoma in situ (DCIS) incorrectly used codes for numerical grades 1-3 instead of L, M, and H.“High grade” DCIS = H, not 3.

Rationale from the Surveillance, Epidemiology, and End Results (SEER)*Educate Breast case scenarios: Codes 1-3 are the preferred grading system codes for invasive cancers and **do not apply to in situ cancers**.

Grade Coding Instructions and Tables manual (page 71), Note 3 states the priority order for the breast:

- Invasive cancers: codes 1-3 take priority over A-D.
- In situ cancers: codes L, M, H take priority over A-D

How to code various references to grade (grade 2/3, Grade 1 [NG 5]), etc.

- (EDIT OPPORTUNITY) **Prostate:** Most errors occurred when there was a Gleason Score 7. The pattern equation has to be according to the table. IE 3+4 and 4+3.
- **Colon:** Grade from polypectomy is pathologic grade only.
- (AUDIT) Just a biopsy of LN or distant site. Often, grade from these is used to code clinical grade. Run report where stage is not local and there was surgery of a site other than the primary. Check text to verify clinical grade is not coded from other than primary site.

(EDIT OPPORTUNITY) Melanoma: C44.9 and grade not 9.

Data Item: SEER Summary Stage 2018

- **Prostate:** Coded as 9-unknown when it could've been coded more definitively according to the text fields and review of the Summary Stage 2018 manual. Review of film studies and path text was usually able to determine summary stage.

- **Prostate:** Ext to perivesical soft tissue + regional LN but no metastasis. Code 4, not 3 or 7.

- **Lung:** Incorrectly coded to 3 - Regional to Lymph nodes when Supraclavicular Nodes were positive. Supraclavicular node involvement should be coded to 7 - Distant. Supraclavicular LN involvement is staged differently for TNM. It is considered a regional node and coded as N3.

For Supraclavicular nodes specifically, these are considered "regional" as far as coding the FNA/biopsy in the treatment fields of abstract.

Data Item: Surgery

- **Melanoma:** Need overall review of surgical codes. Margins from path report not being included in text. STORE manual pg. 466 CCARM pgs. 294–298. "Shave/punch bx followed by re-excision" and margins for re-exc.

- **Breast:** "Partial mastectomy" versus "lumpectomy"; it appears that some abstractors use these terms and codes interchangeably, but the STORE Appendix B has clear definitions for both.

- **Breast:** Modified radical mastectomy codes require LN surgery code beyond SLN.

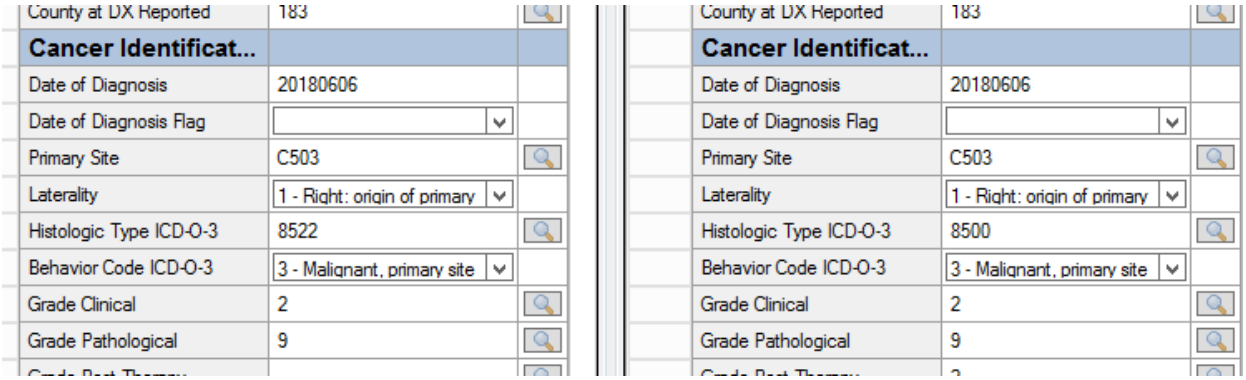
- (EDIT OPPORTUNITY—Reported to the North American Association of Central Cancer Registries [NAACCR] **Hemat:** Site code C421. Surg Prim Site MUST be 98. No edit! Same with Scope Reg LN.

- (AUDIT) **Regional lymph node biopsies:** FNA and/or biopsy of regional nodes should be coded in the Scope of Regional LN Surgery data item as a code 1. It is not coded in the Diagnostic and/or Staging Procedure. Run report on stage and these two surgery data items.

Data Item: Histology

- **Melanoma:** When Lentigo maligna melanoma is used with a different specific term, use the other term, STR H7.

- **Breast:** Although some breast cases have involved histology details, we still get varying histology codesfor more common text. For example, both abstracts have the exact same text that states, "Ductal Carcinoma w/lobular features." Reviewing STR for both DCIS and Invasive primaries would be beneficial.



County at DX Reported	183
Cancer Identificat...	
Date of Diagnosis	20180606
Date of Diagnosis Flag	
Primary Site	C503
Laterality	1 - Right: origin of primary
Histologic Type ICD-O-3	8522
Behavior Code ICD-O-3	3 - Malignant, primary site
Grade Clinical	2
Grade Pathological	9

County at DX Reported	183
Cancer Identificat...	
Date of Diagnosis	20180606
Date of Diagnosis Flag	
Primary Site	C503
Laterality	1 - Right: origin of primary
Histologic Type ICD-O-3	8500
Behavior Code ICD-O-3	3 - Malignant, primary site
Grade Clinical	2
Grade Pathological	9

Another histology check might be the use of code 8522 for invasive duct and lobular cases. The College of American Pathologists statement may have changed or been updated but it is definitely a rule in the 2018 STR—because it uses the word "features," abstractors may be still using the 8500 code. There have been a few cases withthe text exactly stating "invasive carcinoma w/ductal and lobular features."

Rule H23 Code **8522** when carcinoma NST and lobular are present in multiple tumors.

- DCIS and in situ lobular **8522/2**
- Carcinoma NST/duct carcinoma and invasive lobular **8522/3**

Note 1: CAP uses the term Invasive carcinoma with ductal and lobular features ("mixed type carcinoma") as a synonym for duct carcinoma/carcinoma NST AND invasive lobular carcinoma 8522/3.

- **Lung:** Non-Small Cell Carcinoma (NSCLC) was incorrectly coded to 8010/3 (Carcinoma, NOS) insteadof 8046/3 so that the case was eligible for AJCC TNM staging.

SEER inquiry System #20180112 states, "You should not change a histology to assign TNM to the case; AJCC does not determine histology coding. And while pathologists are not encouraged to use NSCLC,the code is not obsolete and should be used if there is no other specific histology."

The 2018 Solid Tumor Rules for Lung, Rule H3 state:

Rule H3 Code the specific histology when the diagnosis is **non-small cell lung carcinoma** (NSCLC) **consistent with** (or any other ambiguous term) **a specific carcinoma** (such as adenocarcinoma, squamous cell carcinoma, etc.) when:

- The histology is clinically confirmed by a physician (attending, pathologist, oncologist, pulmonologist, etc.)
- The patient is treated for the histology described by an ambiguous term
- The case is accessioned (added to your database) based on a single histology described by ambiguous terminology and no other histology information is available/documented

Note: If the case does not meet the criteria in the first two bullets, code non-small cell lung cancer (NSCLC) **8046**.

Primary Site: Bladder

- **Behavior:** There was no mention of involvement or invasion of tissues in the text, but the behavior was coded as invasive. Referred back to the SEER Training Bladder Module Abstracting Keys and the general instructions in the SS2018 (Bladder Schema page 8–12 and the Notes 3–6) to determine whether the tumor was in situ or invasive. This information had to be corrected/investigated before being able to appropriately code the summary stage. “No stromal invasion” is common.

Primary Site: Prostate

- **PSA Site-Specific Data Items (SSDI)**
    - **Rounding:** If 0–4, round down. If 5–9, round up. Record to the nearest tenth in ng/mm.

      Incorrect rounding could affect the stage group. Be sure to review the General Rules for Entering Lab Values at the beginning on the SSDI Manual (page 18).

    - Use the LAST PSA value prior to biopsy. Old rules used the highest value. NEW RULES SAY USE THE LAST!

      Be sure text includes DATE AND VALUE. Without the date, it is difficult to validate that this was the LAST PSA prior to diagnostic biopsy or treatment.

Primary Site: Head and Neck: HPV Positive

Check sites of C100-C109; C090-C099; C111 with histology coded to 8070/3. Is there information in the text about human papilloma virus (HPV) (virus) +/- where the histology could be recoded to 8085 or 8086? In this audit, there were cases where histology was coded to 8070/3 and the text had information about HPV.

Appendix C: Workshop Evaluations

Workshop 1
Best Practices for Developing and Evaluating Data Management Reports
Evaluation Responses

1. Please rate the overall workshop including sessions I, II, and III on the following parameters.

	Very Satisfied	Somewhat Satisfied	Neutral	Somewhat Dissatisfied	Very Dissatisfied	Responses
Ease of registration	30	0	0	0	0	30
Row %	100 .0 %	0 .0 %	0 .0 %	0 .0 %	0 .0 %	
Workshop organization	25	3	1	0	0	29
Row %	86.2%	10 .3%	3.4%	0 .0 %	0 .0 %	
Objectives of the workshop were well defined	21	7	2	0	0	30
Row %	70 .0 %	23.3%	6.7%	0 .0 %	0 .0 %	
Overall content	22	8	0	0	0	30
Row %	73.3%	26.7%	0 .0 %	0 .0 %	0 .0 %	
Time allocated for discussions	24	4	1	1	0	30
Row %	80 .0 %	13.3%	3.3%	3.3%	0 .0 %	
Adequate opportunities to share your ideas and opinions	27	2	0	1	0	30
Row %	90 .0 %	6.7%	0 .0 %	3.3%	0 .0 %	
Overall workshop experience	25	5	0	0	0	30
Row %	83.3%	16.7%	0 .0 %	0 .0 %	0 .0 %	
Total						30

2. Please rate the Breakout session you attended on the following parameters.

	Very Satisfied	Somewhat Satisfied	Neutral	Somewhat Dissatisfied	Very Dissatisfied	Responses
Quality of the Facilitator	28	2	0	0	0	30
Row %	93.3%	6.7%	0 .0 %	0 .0 %	0 .0 %	
Identified Topics	27	2	1	0	0	30
Row %	90 .0 %	6.7%	3.3%	0 .0 %	0 .0 %	
Duration of the Session	25	4	0	1	0	30
Row %	83.3%	13.3%	0 .0 %	3.3%	0 .0 %	
Topic Coverage and Relevance	23	5	0	0	1	29
Row %	79.3%	17.2%	0 .0 %	0 .0 %	3.4%	
Adequate Adequate opportunities to share your ideas and opinions	26	3	1	0	0	30
Row %	86.7%	10 .0 %	3.3%	0 .0 %	0 .0 %	
Total						30

3. **What did you like best about the workshop?**
   - Interactive workshop!
   - I believe that idea of the workshop is fantastic. These reports have needed to be done and added to all software for ease of use.
   - I got some good ideas about procedures that other central registries were doing for timeliness. I also received some good ideas about ongoing processes that other registries do throughout the year for the Call for Data.
   - The topics covered
   - back-and-forth discussion was excellent
   - I thought it was very nice, thank you for doing it. The first day with the breakouts was especially nice. It was a lot of time but well spent.
   - Hearing the perspective and experiences of other states
   - This workshop was extremely informative being that I am new to the Central Registry and looking for ways to make our processes more efficient
   - I liked the format of the sessions - identifying the top topics and breaking out the sessions which allowed for more participation with smaller groups.
   - Good exchange of ideas and solicitation of written materials prior to sessions.
   - Everything
   - Information from other states
   - I liked the way Wendy let the group into the breakout sessions. It was a very smooth transition. The participation in the breakout sessions was great! Initially I was nervous, but it ended up being very helpful hearing the other participants' comments and input.
   - Topics covered. Ability to share ideas freely. Looking forward to seeing what proposed reports will look like.
   - The breakout sessions that gave us a chance to work in smaller groups so we could all add ideas and opinions.
   - Ideas from other registries.
   - N/A
   - Different points of view from cancer registries. Those struggling and those with best practices to share.
   - no travel involved, more states and staff could participate
   - Breakout sessions with a followup the next session was a great idea.
   - Provided a forum for cancer registries to share their ideas and experience.
   - Ability to have "real" conversations with other registries rather than listening to presentations

4. **How might we improve future workshops?**
    - No suggestions. I thought this workshop was very informative.
    - The focus was all over the board. I thought we were there to come up with management reports. We spent too much time on methods, CCR data management system functions.
    - technical issues made parts of workshop difficult.
    - It might have been helpful if the facilitator shared some of the examples in the review session and not just a list. I realize a lot of great work was done in the breakout sessions, but I was a little surprised that there was so much consensus at the review. Were you?
    - n/a
    - This was a great format.
    - Not sure.
    - This was a great workshop. We should have these on a quarterly basis.
    - I thought this was a great workshop that ran very smoothly. I like the polling system in the final workshop and the presentations and asking for further feedback. You all did an excellent job!
    - I was satisfied with the whole process.
    - I know time is tight, but it would be great to have more time for discussions. Some topics could have been discussed into further detail but because we were only given so much time it felt like we were only able to brush the top.
    - N/A
    - Invite guest speakers and walk-through real scenarios to encourage critical thinking and problem solving.
    - I think this was a great format and it worked well.

Workshop 2: Report for Best Practices in Establishing Strong Communication and Relationships with Hospitals

Evaluation Responses

1. Please rate the overall workshop including sessions I and II on the following parameters.

	Very Satisfied	Somewhat Satisfied	Neutral	Somewhat Dissatisfied	Very Dissatisfied	Responses
Ease of registration	26	1	1	0	0	28
Row %	92.9%	3.6%	3.6%	0 .0 %	0 .0 %	
Workshop organization	25	1	1	0	0	27
Row %	92.6%	3.7%	3.7%	0 .0 %	0 .0 %	
Objectives of the workshop were well defined	23	3	1	0	0	27
Row %	85.2%	11.1%	3.7%	0 .0 %	0 .0 %	
Overall content	23	3	1	0	0	27
Row %	85.2%	11.1%	3.7%	0 .0 %	0 .0 %	
Time allocated for discussions	24	2	1	0	0	27
Row %	88.9%	7.4%	3.7%	0 .0 %	0 .0 %	
Adequate opportunities to share your ideas and opinions	26	1	0	0	0	27
Row %	96.3%	3.7%	0 .0 %	0 .0 %	0 .0 %	
Overall workshop experience	23	3	1	0	0	27
Row %	85.2%	11.1%	3.7%	0 .0 %	0 .0 %	
Total						28

2. Please rate the Breakout session you attended on the following parameters:

	Very Satisfied	Somewhat Satisfied	Neutral	Somewhat Dissatisfied	Very Dissatisfied	Responses
Quality of the Facilitator	27	1	0	0	0	28
Row %	96.4%	3.6%	0 .0 %	0 .0 %	0 .0 %	
Identified Topics	24	3	0	0	0	27
Row %	88.9%	11.1%	0 .0 %	0 .0 %	0 .0 %	
Duration of the Session	23	3	1	0	0	27
Row %	85.2%	11.1%	3.7%	0 .0 %	0 .0 %	
Topic Coverage and Relevance	24	1	2	0	0	27
Row %	88.9%	3.7%	7.4%	0 .0 %	0 .0 %	
Adequate opportunities to share your ideas and opinions	25	1	1	0	0	27
Row %	92.6%	3.7%	3.7%	0 .0 %	0 .0 %	
Total						28

3. What did you like best about the workshop?

- the collaboration
- Sharing of ideas and solutions to common problems
- Love hearing new ideas from different registries
- Hearing from different central registries and their practices

- It was nice to hear confirmation that other states do some of the same things we do to encourage timely reporting.
- The ability to discuss and listen to other ideas that could be implemented at your registry
- Sharing of experiences
- Sharing (potentially helping) and learning.
- I liked the smaller breakout groups. It gave you an opportunity to speak up about a topic.
- Sharing ideas. Some were new to me and others were what we had done or were doing currently.
- Great summary on each breakout section.
- The breakout sessions. Learning from others what works and what doesn't work
- Great way to learn from other registries.
- I love hearing how other registries approach challenges. This gives me ideas to improve processes in my registry.
- The experiences shared during the breakout session are very helpful.
- Interacting opposed to just listening to someone speak.
- Hearing how other states operate with the topics that were presented.
- Breakout session/interaction.
- Being able to hear ideas from other registries and seeing how those ideas could be adjusted and used for our registry.
- Breakout sessions.
- Breakout sessions
- The coming together of registries to share their individual practices was excellent. It was a great opportunity to learn more about each other and take away some good ideas.
- Getting together with other states and hearing their ideas or processes
- I like the breakout session (small groups). It was great to learn from peers and to hear what other registries are doing.

4. How might we improve future workshops?

- I do not have anything to say. Keep up the great work!
- Signing on was difficult for me...but other than that not recommendations.
- I wanted more new ideas to try.
- They are great.
- NA
- Maybe do a follow-up white paper or something more easily referenced that recordings or slides. The resources and ideas were great. Having a written summary for reference would be great.
- I thought the workshop went well and would like to participate in another one.
- Have specific questions to address along with open discussion and sharing of ideas.
- More involvement of the participants through these breakout sessions is a great opportunity to continue.
- I think 1.5 hours would be adequate for each session. 2 hours per session was a bit long.
- allow more participants to join.
- Having more participants in a group at a time to engage more participation or having more than one topic covered during the session. There was a bit of overlap between the main topics, and it may have reduced the redundancy in final thoughts/reports.
- I feel like the breakout sessions was a little longer than it needed to be. It allowed for things to be discussed that were not on the workshop topic.
- Breakout sessions
- The format of the workshop was not what I had expected. While it provided some great insight, I thought it was going to be more structured with tools/information or guidance for improving communication from NAACCR and working together through scenarios using individual registry techniques and those tools. Instead, it was almost two hours of what

does your registry do. There was a lot of overlap of information presented from all the breakout sessions during the second two hours. For future, perhaps structure some working exercises, send out questions in advance so that participants can be better prepared to share more effectively and/or shorten the sessions.

Report for Workshop 3: Best Practices in Improved Reporting from Non-Hospital Sources Post Workshop Survey

1. Please rate the overall workshop including sessions I and II on the following parameters.

	Very Satisfied	Somewhat Satisfied	Neutral	Somewhat Dissatisfied	Very Dissatisfied	Responses
Ease of registration	24	1	0	0	1	26
Row %	92.3%	3.8%	0 .0 %	0 .0 %	3.8%	
Workshop organization	25	0	0	0	1	26
Row %	96.2%	0 .0 %	0 .0 %	0 .0 %	3.8%	
Objectives of the workshop were well defined	20	4	1	0	1	26
Row %	76.9%	15.4%	3.8%	0 .0 %	3.8%	
Overall content	21	3	1	0	1	26
Row %	80 .8%	11.5%	3.8%	0 .0 %	3.8%	
Time allocated For discussions	22	3	0	0	1	26
Row %	84.6%	11.5%	0 .0 %	0 .0 %	3.8%	
Adequate opportunities to share your ideas and opinions	22	2	1	0	1	26
Row %	84.6%	7.7%	3.8%	0 .0 %	3.8%	
Overall workshop experience	22	3	0	0	1	26
Row %	84.6%	11.5%	0 .0 %	0 .0 %	3.8%	
Total						26

Report for Workshop 3: Best Practices in Improved Reporting from Non-Hospital Sources Post Workshop Survey

4. Please rate the overall workshop including sessions I and II on the following parameters.

	Very Satisfied	Somewhat Satisfied	Neutral	Somewhat Dissatisfied	Very Dissatisfied	Responses
Ease of registration	24	1	0	0	1	26
Row %	92.3%	3.8%	0 .0 %	0 .0 %	3.8%	
Workshop organization	25	0	0	0	1	26
Row %	96.2%	0 .0 %	0 .0 %	0 .0 %	3.8%	
Objectives of the workshop were well defined	20	4	1	0	1	26
Row %	76.9%	15.4%	3.8%	0 .0 %	3.8%	
Overall content	21	3	1	0	1	26
Row %	80 .8%	11.5%	3.8%	0 .0 %	3.8%	
Time allocated For discussions	22	3	0	0	1	26
Row %	84.6%	11.5%	0 .0 %	0 .0 %	3.8%	
Adequate opportunities to share your ideas and opinions	22	2	1	0	1	26
Row %	84.6%	7.7%	3.8%	0 .0 %	3.8%	
Overall workshop experience	22	3	0	0	1	26
Row %	84.6%	11.5%	0 .0 %	0 .0 %	3.8%	
Total						26

5. What did you like best about the workshop?

- Sharing of processes
- It was helpful to hear from other states about how they were dealing with non-hospital reporting sources.
- I really enjoyed hearing from other states
- Ability to share
- We shared a lot of useful information for a variety of registry situations, which was great. Strangely, just as important to me was hearing from other, larger, more plentifully staffed states that they are struggling with some of the exact same issues I am -- I'm not just bad at this! Validation that you cannot get anywhere else....
- Exchange of ideas from other registries
- Presentation and exchange of information
- Meeting with other state registries to hear how they are operating and using different tools to gather non-hospital data. It is always great to see how other states are working and helps to get ideas for improving processes.
- Hearing that many are having the same problems
- Opportunity for discussion and examples of how states are working with non-hospital sources.
- Plenty of time for discussion and the sharing of information.
- The presentations and the discussion were excellent!
- There were registries willing to give insight from their own experiences
- Getting new ideas
- I like the overall layout. Brainstorming in the AM and then summarization/action plan in the afternoon.
- Hearing how other states reach out to get non-hospital reporting
- Great information was shared from several different perspectives.
- Hearing what other states are doing to identify and bring cases into their registry by making use of Web Plus and other resources.
- Hearing how states handle with non hospital reporting, and their different processes
- I liked the discussions the group had on non-hospital reporting. However, I think it would have been better if there were small-group discussion on specific topics (i.e. increasing non-hospital reporters, engaging non-hospitals, etc.)

6. How might we improve future workshops?

- It would be helpful to have a copy of the slides outlining discussions and recommendations. It would not be the final set of guidelines. It would be helpful for me to be able to discuss with my manager.
- Continue to incorporate states into presentations
- none
- This was a very long workshop, and beforehand I worried it might drag a bit. It absolutely did not! Nice long break in the middle, and I was engaged throughout. If anything, a (shorter? maybe?) follow-up session might be nice at some point in the future, to discuss anything we've learned or tried out in the interim.
- NA
- Can NAACCR do something at the national level like talking to the AMA or at ASCO? Other physician organizations?
- Solicit presenters to share processes and documentation in advance for audience review.

- More presentations from registries with details of how they are engaging with non- hospital reporters. It doesn't have to be a success story. Hearing about challenges helps me with the situations in my own State.
- Maybe do a proceedings doc afterwards that has info (not just ppt slides)
- give more new ideas on how to get ambulatory facilities to report electronically.
- I liked this format and content-- no suggestions for improvement.
- I thought the format worked well and holding the conference virtually allowed more people to attend. Continue with virtual workshops.
- Not having it so close to State file submission time
- I think hearing from 3 different registries is a great idea but it seems like this is done every year.

Report for Workshop 4: Managing Best Practices around COVID Response

1. Please rate the overall workshop including sessions I and II on the following parameters.

	Very Satisfied	Somewhat Satisfied	Neutral	Somewhat Dissatisfied	Very Dissatisfied	Responses
Ease of registration	25	0	0	0	0	25
Row %	100.0%	0.0%	0.0%	0.0%	0.0%	
Workshop organization	25	0	0	0	0	25
Row %	100.0%	0.0%	0.0%	0.0%	0.0%	
Objectives of the workshop were well defined	18	6	1	0	0	25
Row %	72.0%	24 .0%	4 .0%	0.0%	0.0%	
Overall content	19	5	0	0	0	24
Row %	79.2%	20.8%	0.0%	0.0%	0.0%	
Time allocated for discussions	24	1	0	0	0	25
Row %	96.0%	4 .0%	0.0%	0.0%	0.0%	
Adequate opportunities to share your ideas and opinions	25	0	0	0	0	25
Row %	100.0%	0.0%	0.0%	0.0%	0.0%	
Overall workshop experience	24	1	0	0	0	25
Row %	96.0%	4 .0%	0.0%	0.0%	0.0%	
Total						25

2. Please rate the Breakout session you attended on the following parameters:

	Very Satisfied	Somewhat Satisfied	Neutral	Somewhat Dissatisfied	Very Dissatisfied	Responses
Quality of the Facilitator	24	1	0	0	0	25
Row %	96.0%	4 .0%	0.0%	0.0%	0.0%	
Identified Topics	21	4	0	0	0	25
Row %	84 .0%	16.0%	0.0%	0.0%	0.0%	
Duration of the Session	23	2	0	0	0	25
Row %	92.0%	8.0%	0.0%	0.0%	0.0%	
Topic Coverage And Relevance	22	3	0	0	0	25
Row %	88.0%	12.0%	0.0%	0.0%	0.0%	
Adequate opportunities to share your ideas and opinions	25	0	0	0	0	25
Row %	100.0%	0.0%	0.0%	0.0%	0.0%	
Total						25

3. What did you like best about the workshop?

- A good opportunity to hear how other registries coped with the pandemic.
- I really like the break-out session format followed by a break and then a group format that covers the break-out sessions. I have truly enjoyed this entire series and gotten many useful ideas from each instance I attended.
- Hearing from other registries
- Break out sessions and ease of interactions with other members.
- Ability for states to share their Covid experiences.
- The opportunity to listen to others experience on this topic and how they resolved some of the problems identified.
- opportunity to hear others workings
- topics were good
- The open exchange of thoughts and ideas

- I really liked hearing about how other registries were sent home and how they had to accommodate to make it possible to work. I am hoping that as a result of the discussion that there will be a list of suggestions that registries can do in the future to be better prepared.
- The breakout group structure is very nice.
- I enjoy the smaller breakout sessions so that you can give input easily
- Opportunity to hear what other states experiences were and their resilience in dealing with the pandemic.
- To collaborate with other registries and hear the way they were dealing with the pandemic.
- Facilitator I had was great keeping the conversation flowing.

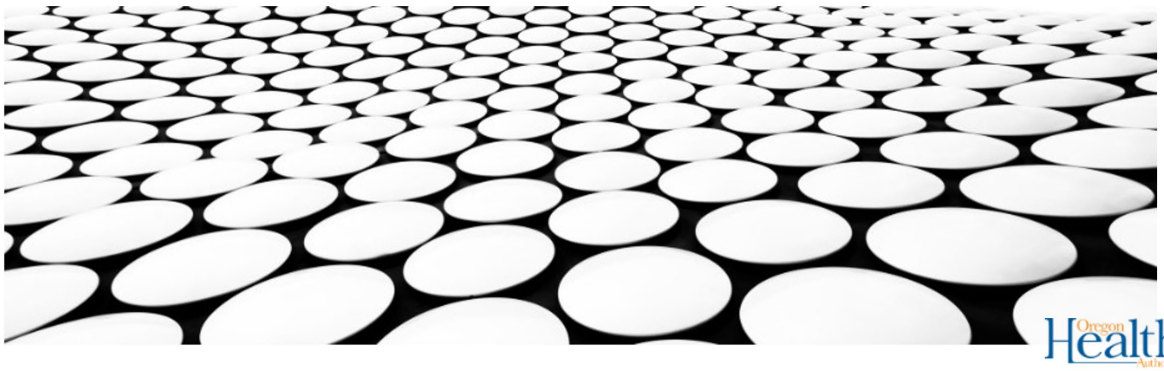
4. How might we improve future workshops?

- More, please.
- I thought there would be actual coverage and discussion of the disaster plans themselves. More focused and not so much sharing about overall COVID experiences as they relate to different aspects of our work.
- Encourage more video presence from all participants.
- I think this format was very good.
- Some of what we discussed in this workshops had been discussed in other forums -- so this seemed a bit redundant. The most important thing is putting together the main discussion points so that it can be shared and used by registries that did not participate.
- Continue doing the same
- Notification of the change in topic came rather late.

Appendix D: Workshop 3: State Presentation Slides

THE OREGON STATE CANCER REGISTRY (OSCAR)

ABSTRACT PLUS CANCER REPORTING FOR NON -HOSPITAL REPORTERS OCTOBER 2020



OSCAR'S DECISION TO MOVE NON-HOSPITAL REPORTERS TO ELECTRONIC REPORTING WITH ABSTRACT PLUS

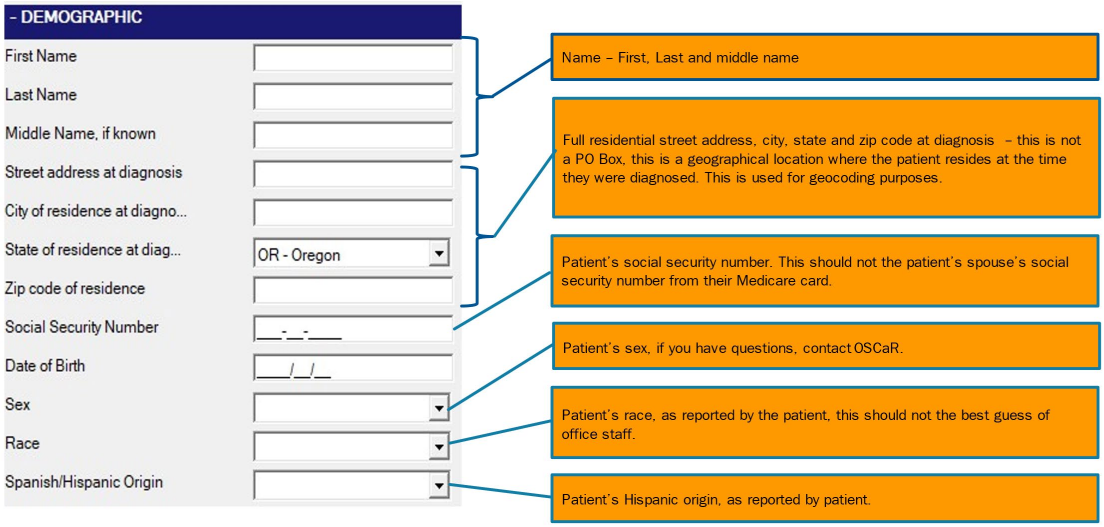
Pros:

- Reduce the number of paper reports
- Receive reports in NAACCR format
- Software is free
- Software has customizable templates
- Software is independent of OSCaR
- Templates/Edits work well
- OSCaR Citrix server to enable multiple users
- Reduced need for abstracting contractors

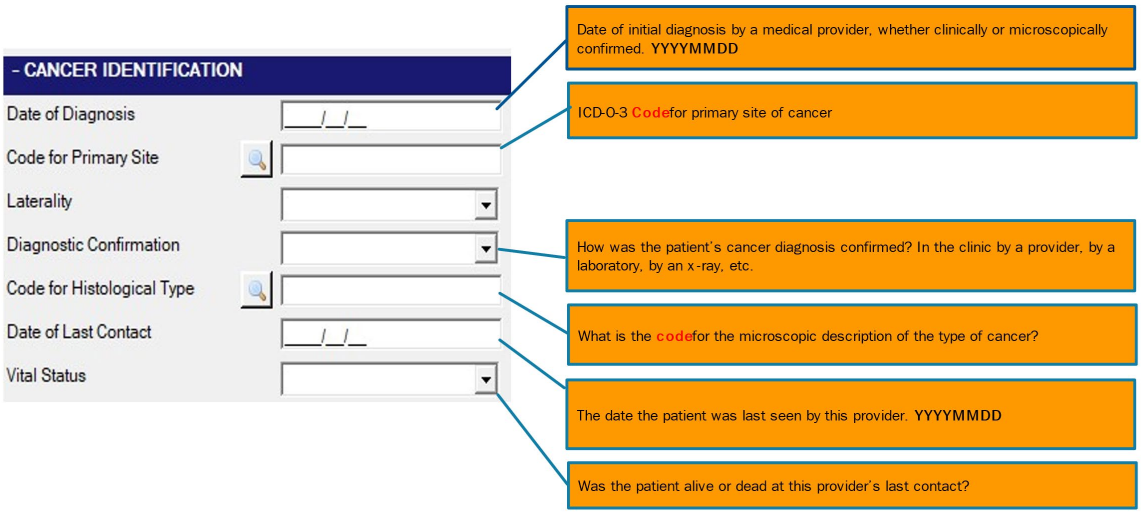
Cons:

- Templates/edits are not intuitive
- IT support is required for a multi -user environment.
- Some concepts can be hard to teach (exporting cases)
- Onboarding & Training materials must be designed for your State (v16 available from CDC)
- Comprehensive outreach and communication plan

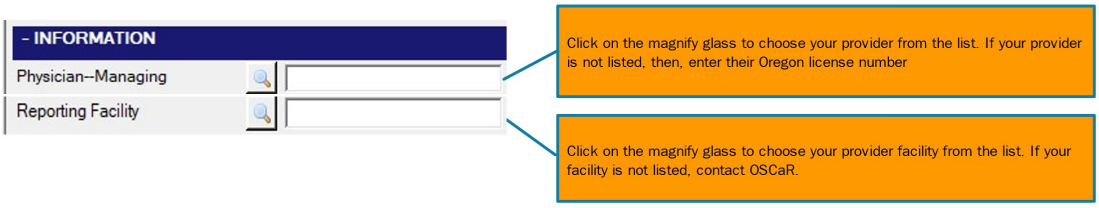
ABSTRACT CONTENT - DEMOGRAPHICS



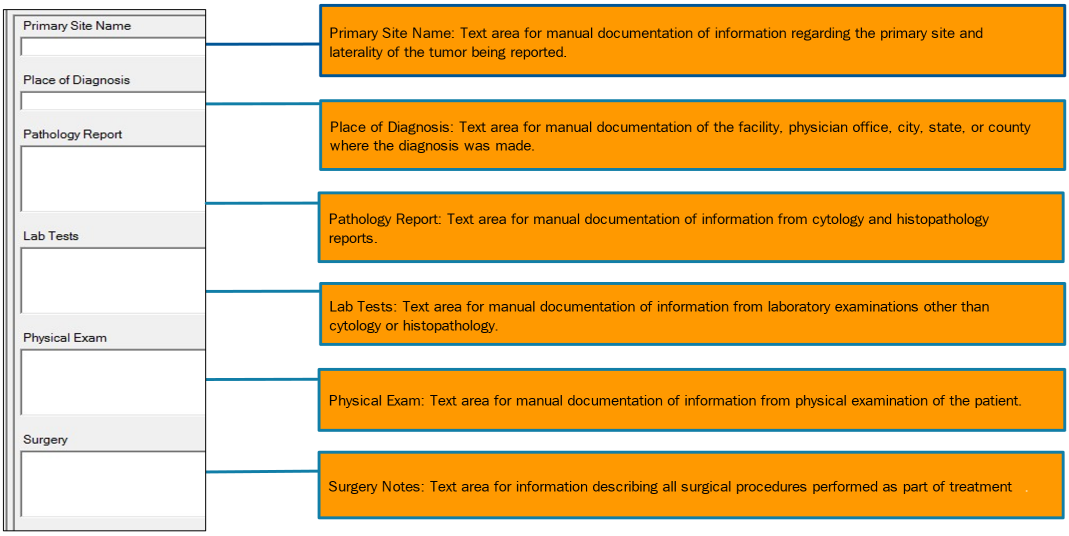
ABSTRACT CONTENT – CANCER IDENTIFICATION



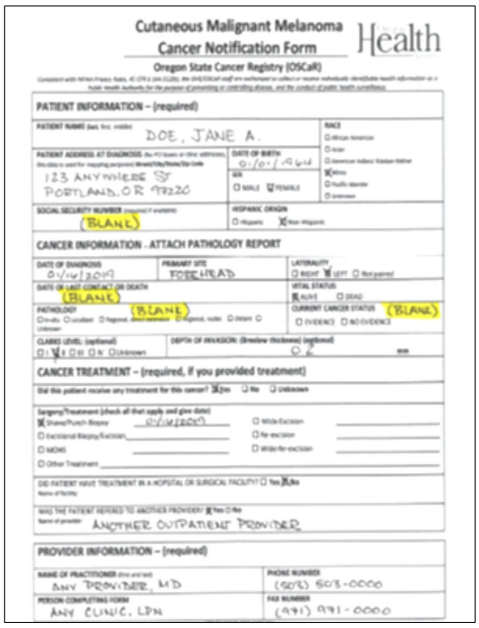
ABSTRACT CONTENT – INFORMATION



ABSTRACT CONTENT – TEXT FIELDS



OSCAR'S ORIGINAL MELANOMA PAPER REPORTING FORM



Cutaneous Malignant Melanoma
Cancer Notification Form
Oregon State Cancer Registry (OSCaR)

Health

PATIENT INFORMATION – (required)

DOE, JANE A.

123 ANYWHERE ST
PORTLAND, OR 99220

(BLANK)

CANCER INFORMATION – ATTACH PATHOLOGY REPORT

FOREHEAD

(BLANK)

(BLANK)

(BLANK)

CANCER TREATMENT – (required, if you provided treatment)

ANOTHER OUTPATIENT PROVIDER

PROVIDER INFORMATION – (required)

ANY PROVIDER, MD

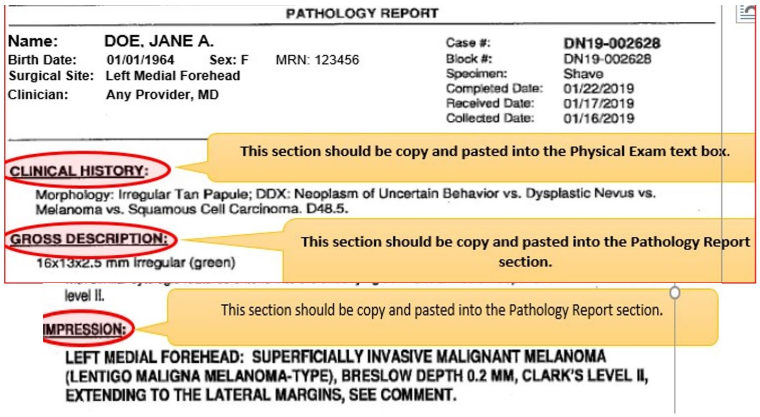
(503) 503-0000

ANY CLINIC, LPN

(971) 991-0000

Oregon Health Authority

PAPER MELANOMA PATHOLOGY REPORT



PATHOLOGY REPORT

Name: DOE, JANE A.
Birth Date: 01/01/1964 **Sex:** F MRN: 123456
Surgical Site: Left Medial Forehead
Clinician: Any Provider, MD

Case #: DN19-002628
Block #: DN19-002628
Specimen: Shave
Completed Date: 01/22/2019
Received Date: 01/17/2019
Collected Date: 01/16/2019

CLINICAL HISTORY:

This section should be copy and pasted into the Physical Exam text box.

Morphology: Irregular Tan Papule; DDX: Neoplasm of Uncertain Behavior vs. Dysplastic Nevus vs. Melanoma vs. Squamous Cell Carcinoma. D48.5.

GROSS DESCRIPTION:

This section should be copy and pasted into the Pathology Report section.

16x13x2.5 mm irregular (green)

level II.

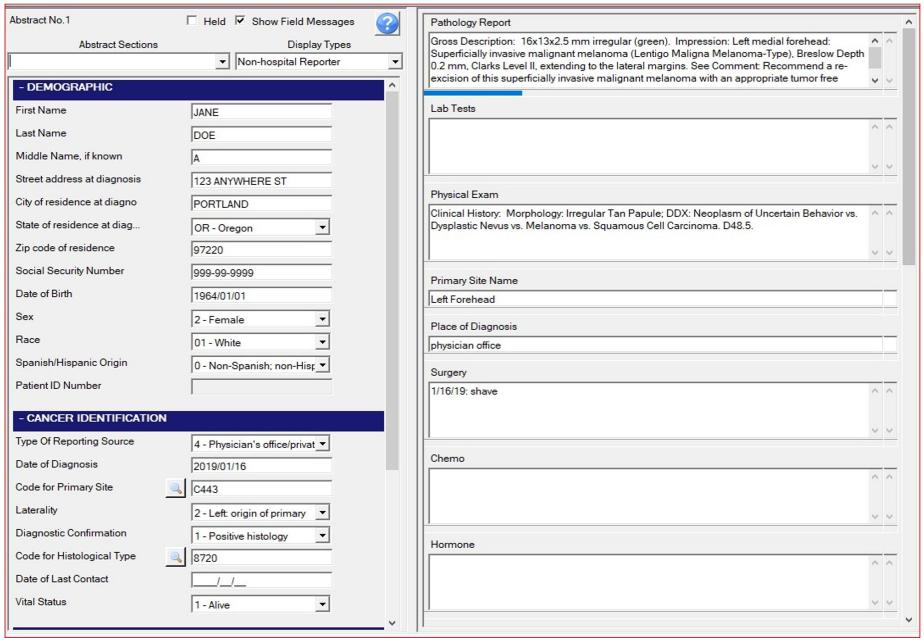
IMPRESSION:

This section should be copy and pasted into the Pathology Report section.

LEFT MEDIAL FOREHEAD: SUPERFICIALLY INVASIVE MALIGNANT MELANOMA (LENTIGO MALIGNA MELANOMA-TYPE), BRESLOW DEPTH 0.2 MM, CLARK'S LEVEL II, EXTENDING TO THE LATERAL MARGINS, SEE COMMENT.

Oregon Health Authority

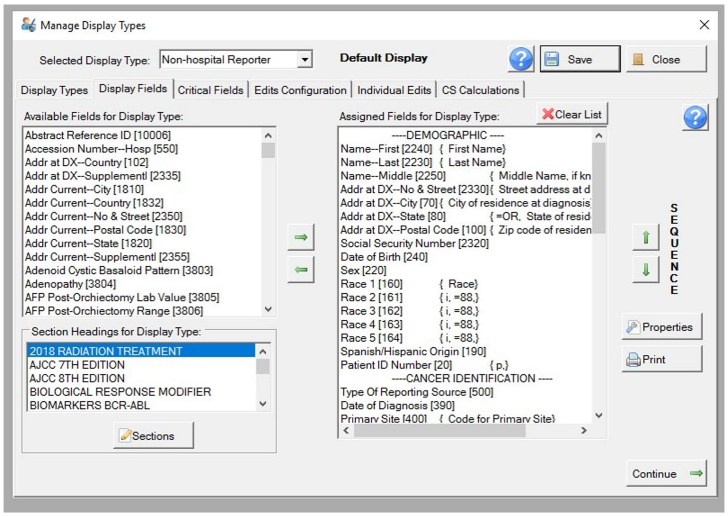
OSCAR'S ABSTRACT PLUS MELANOMA REPORTING FORM



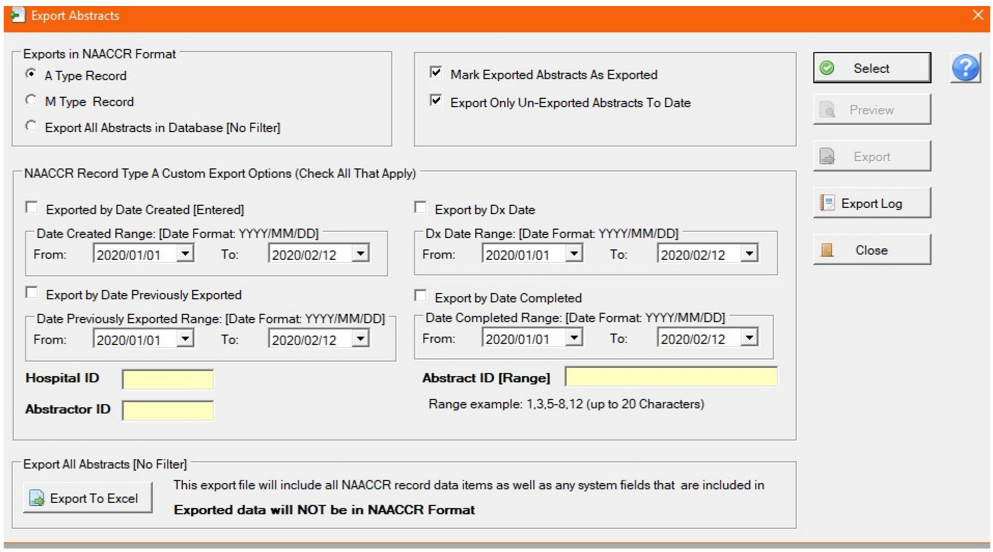
OPPORTUNITIES TO IMPROVE THE USER EXPERIENCE

- The Abstract Plus application downloads onto individual workstations multi-user environments require IT assistance.
- In's and Out's of building reporting templates
- Preparing and exporting case file bundles is confusing and can be difficult to teach.
- Basic onboarding and training materials
- Explaining the difference between Abstract Plus and Web Plus can be challenging.

OPPORTUNITIES FOR IMPROVEMENT – TEMPLATES/EDITS



OPPORTUNITIES FOR IMPROVEMENT - EXPORTING ABSTRACTS



OSCAR'S **ABSTRACT PLUS** TRAINING AND ONBOARDING MATERIALS

INFORMATIONAL OUTREACH LETTER TO AMBULATORY SURGERY CENTERS

10/6/2018

To Whom It May Concern:

Every year, thousands of Oregonians are diagnosed with cancer. The Oregon State Cancer Registry (OSCaR) was established in August 1995, after the Oregon Legislature unanimously passed legislation making cancer a reportable disease.

Under Oregon Revised Statute, all cases of cancer diagnosed on or after January 1, 1996, must be reported to the Oregon State Cancer Registry (OSCaR). Completeness in reporting requires the participation of many reporting sources including hospitals, ambulatory surgical centers (ASC), physicians/practitioners, pathology labs, and other cancer treatment centers.

Cancer is under-reported in Oregon. In an effort to reach cancer reporters who may not be aware of reporting requirements or understand how to report to OSCaR, we are directly contacting ambulatory surgical centers, physicians/practitioners, pathology labs and other cancer treatment centers we have identified with possible reporting obligations.

Ambulatory surgical centers and Cancer treatment centers :

- must report to OSCaR each case of reportable cancer or reportable non-malignant condition, in patients admitted for diagnosis or any part of the first course of treatment for that cancer.
- must report cases of reportable cancer or reportable non-malignant conditions to OSCaR within 180 days of the date the case first receives cancer diagnostic or treatment services at the facility.
- may elect to contract with a private vendor or contractor to report cases of reportable cancer and reportable non-malignant conditions to OSCaR.
- may report to a health system cancer registry, discharging their reporting responsibilities provided that the health system registry reports those cases to OSCaR according to the requirements for health care facilities.

Please find text and links to the applicable Oregon statutes and administrative rules, attached. OSCaR maintains a website which explains the cancer incidence reporting process, reportable diagnosis list, and case finding lists. https://www.oregon.gov/oha/PH/DISEASESCONDITIONS/CHRONICDISEASE/CANCER/OSCAR/Pages/index.aspx

If you have any questions about Abstract Plus and/or your Cancer reporting obligation please do not hesitate to contact Shannon Evangelista at 971-673-0986 or by email at SHANNON.D.EVANGELISTA@dhsoha.state.or.us.

Oregon Health Authority

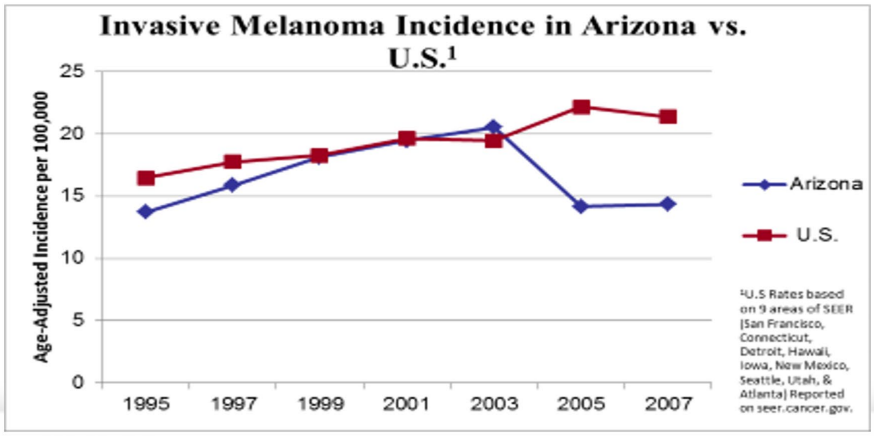
Increasing Physician Melanoma Reporting with the Help of a Task Force

Arizona Cancer Registry
NAACCR Best Practices Workshop
Improving Non-Hospital Reporting
October 2020

ARIZONA DEPARTMENT OF HEALTH SERVICES
Health and Wellness for all Arizonans

Challenges

Melanoma – Decreasing or Under-reported?



ARIZONA DEPARTMENT OF HEALTH SERVICES
Health and Wellness for all Arizonans

Challenges

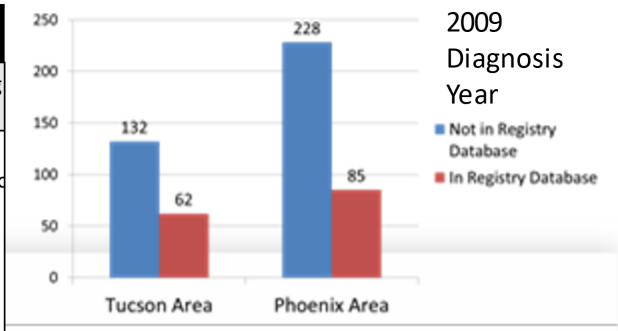
- Patients seen in outpatient settings increasing
- CDC NPCR Standards
    - Annually increase case reporting by urologists, dermatologists, and gastroenterologists, medical oncologists, radiation oncologists, and hematologists
    - For non-hospital facilities reporting to the CCR, increase percentage reporting electronically every year
- Internal challenges
    - Staffing/budgetary constraints
    - Arizona regulations
- Assumption – Arizona has the highest rates of melanoma

ARIZONA DEPARTMENT OF HEALTH SERVICES
Health and Wellness for all Arizonans

Process Development

- Assumption – Arizona has the highest rates of melanoma
- First meeting with researchers and physicians
    - **To address: Declining rates of melanoma / under -reporting by physician offices**
    - **Pilot Project: To assess reporting**

Melanoma Task Force Members Multiple Disciplines	
AZ Cancer Registry	Dermatologists/Dermatopatholog
Arizona SunWise Cancer Prevention Program	University: College of Public Health/Skin Canc Institute Dermatologist Epidemiologist Graduate Student

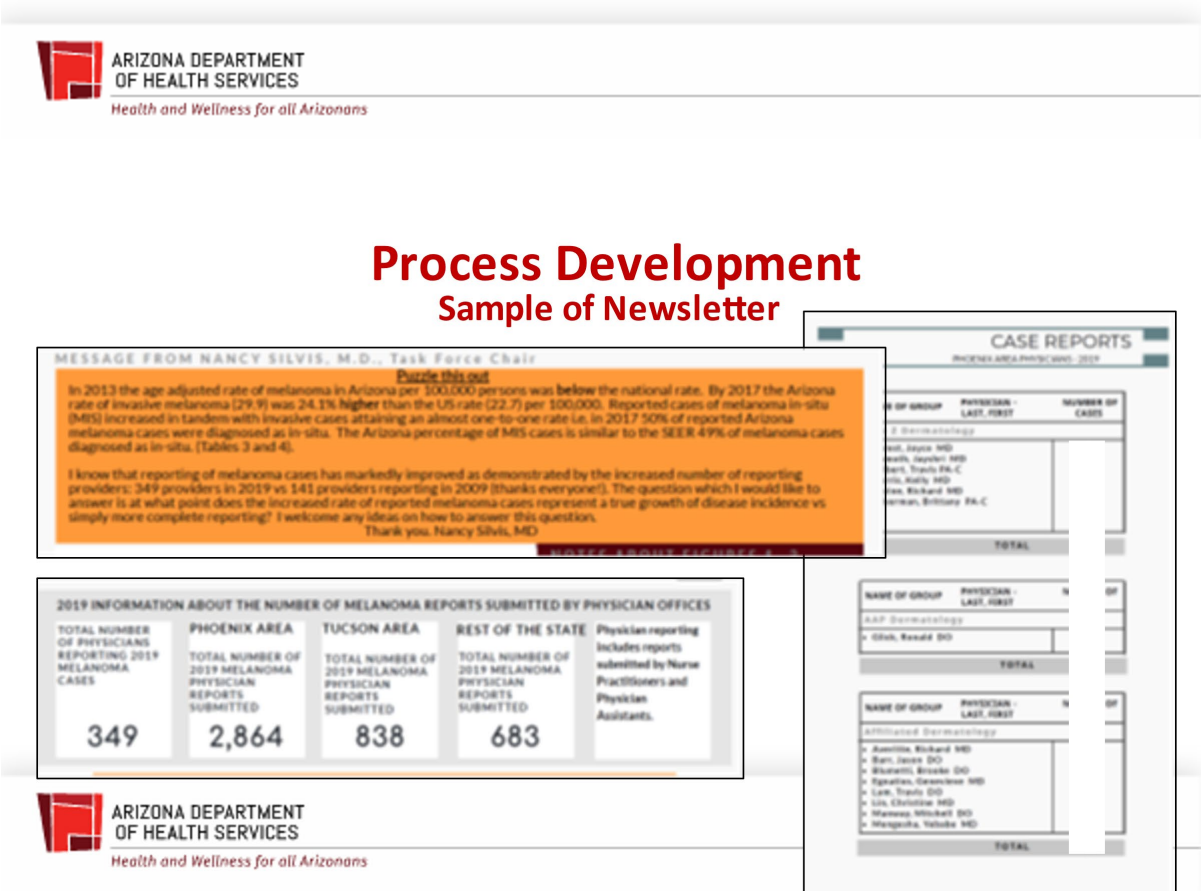


Process Development

- Worked with University to survey physicians to identify barriers to reporting / create a database of physician email addresses
- Educational presentations to dermatology societies
- Redesign of report form
- Dermatopathologists include statement on melanoma pathology reports
- Newsletter (physician names)
- Melanoma Profile
- Data Quality Indicator Report

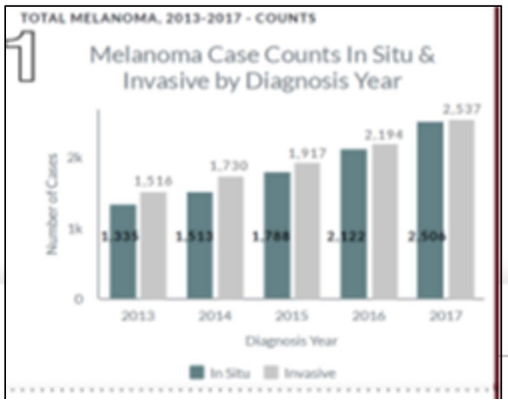
Process Development

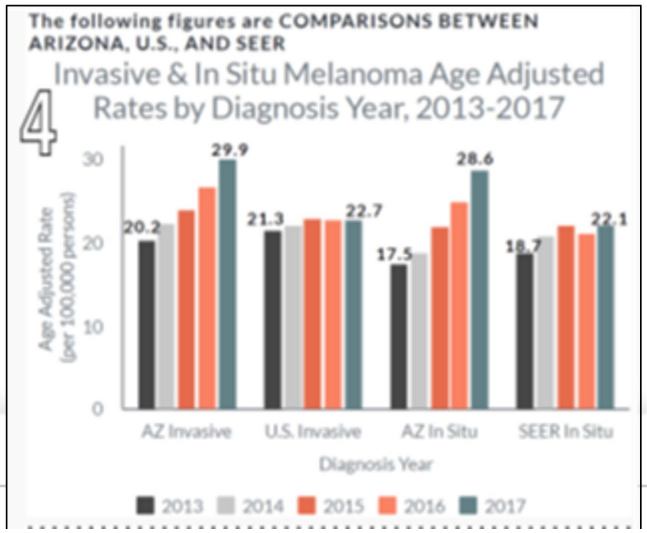
Sample of Newsletter



Impact of Registry Operations

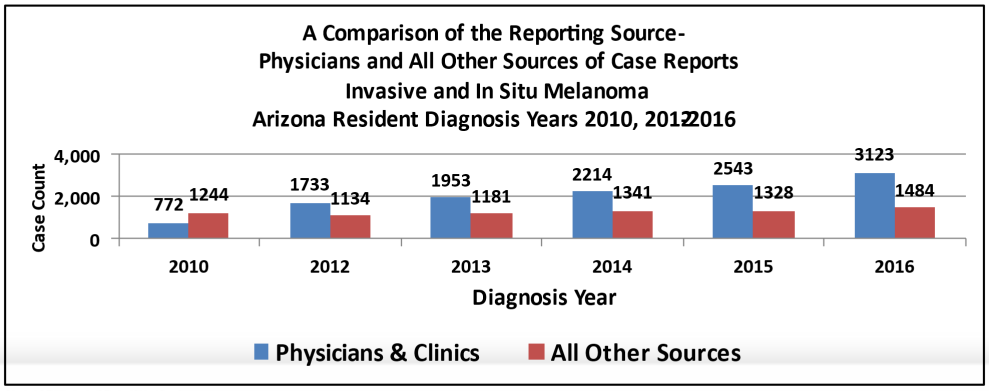
- Number of physicians reporting
  - 2019 Diagnosis Year = 349
  - 2009 Diagnosis Year = 141





Impact of Registry Operations

- Most physician reported cases are paper case reports received through efax or mail.



ARIZONA DEPARTMENT OF HEALTH SERVICES
Health and Wellness for all Arizonans

Training, feedback and Communication with Users

- New Challenges
  - How does the registry keep up with melanoma reporting but also engage other physician specialties in cancer reporting
  - Continue engagement of physician reporting
  - How do we know we have all the melanoma cases?
- ACR Regulations
- Continue activities described (newsletter/periodic reports/direct physician reports)
- Arizona Cancer Plan – Melanoma Task Force involvement
- Development of a Web Plus melanoma module for physician reporting
  - Many documents created: Onboarding, user guides, etc.
  - How to engage physician reporting during a pandemic: Created 4 recorded modules to assist in navigating Web Plus

THANK YOU!

Georgia Yee | Office Chief
Georgia.Yee@azdhs.gov | 602 -542-7308

azhealth.gov@azdhs

facebook.com/azdhs

The Centers for Disease Control and Prevention provide support for enhancement to the registry under cooperative agreement NU58DP006341. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

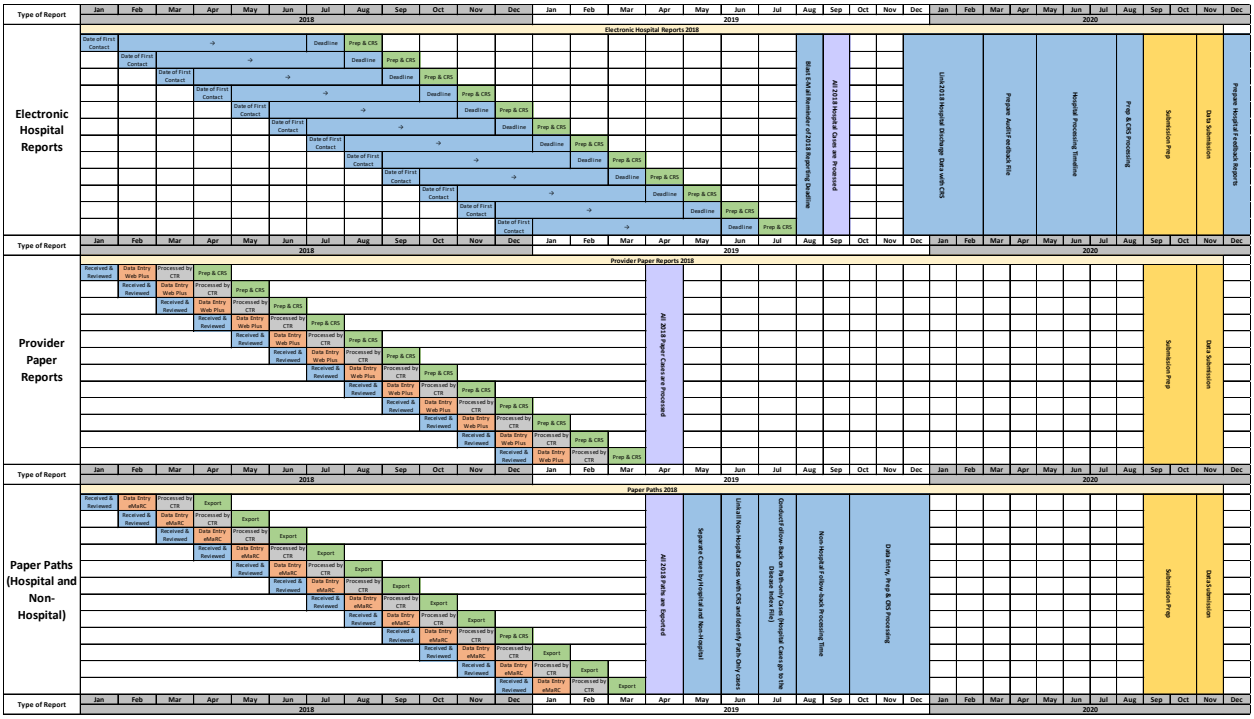
Appendix E: Sample Management Reports Submitted by States

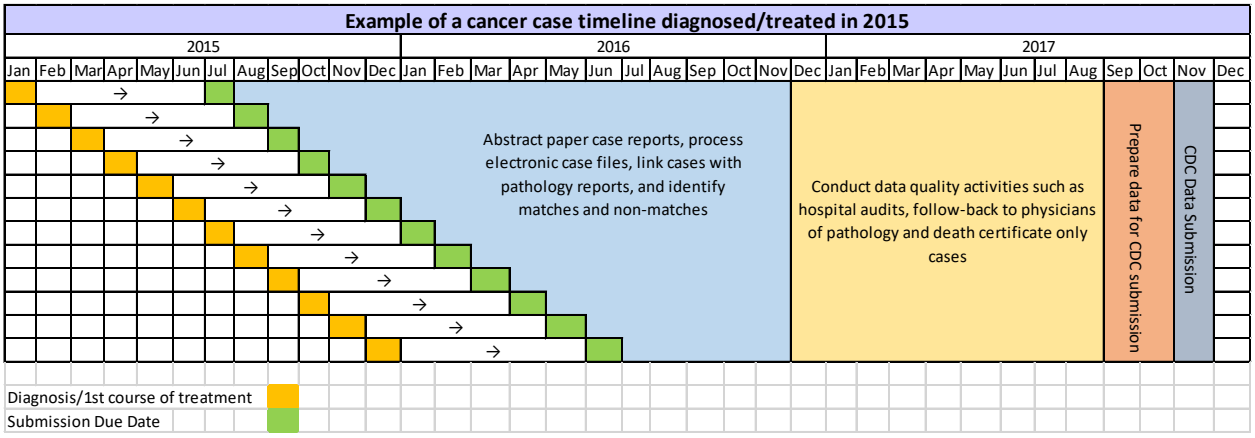
Colorado Sample Central Registry Timeliness Form													
2020 NAACCR / NPCR Submission Summary			**Submission Deadline 12/1/2020**										
Data Quality Completeness:	Total Cases												
2020 Submission: 1995 - 2018			**2018**	**95 %**			**2019**	**90 %**					
2019 Submission: 1995 - 2017	499 500		**2017**	95 %	27537		**2018**	90 %	22249				
Status Update-		7/5/2020		8/5/2020		9/5/2020		10/5/2020		11/5/2020		12/1/2020	
(Run querry on specified dates/ Ck Frequencies)		#	%	#	%	#	%	#	%	#	%	#	%
Total Cases Dx Year 1995-2018													
Completeness 2018													
Completeness 2019													
Data Quality Measures/ Accuracy Rates Tracking	**Goal**	**7/5/2020**		**8/5/2020**		**9/5/2020**		**10/5/2020**		**11/5/2020**		**12/1/2020**	
2018 CASES		#	%	#	%	#	%	#	%	#	%	#	%
Death Cert Only	< 3%												
Unknown Race	< 3%												
Unknown County	< 3%												
Unknown Age	< 2%												

Unknown Gender	< 2%												
Duplicate Case Reports - NAACCR Protocol	< 1%												
% Passing Edits	100 %												
Inter-Record Edits Clear	100 %												

DATA REVIEW TASKS
Review Insitu Breast
Review Insitu Colon
Review Insitu Melanoma
Review Breslow's Depth of Invasion- Invasive tumors
Unknown Age
. Review Odd Ages (>105)
. Review Odd Ages (> = 000)
Unknown Sex
First Name Sex Check
Review Unknown Dx Date
Review Unknown Site (C80.9)
Review Vague Histology (8000-8010)
Review Unknown Stage
Review Dx dates with blank day, 01,15,30

Nevada Sample Central Registry Timeliness Form





Sample Central Registry Calendar from Nevada

CCR Calendar				
PROCESSES	**EMPLOYEE**	**WHEN**	**MONTH STARTED**	**COMMENTS**
Surveillance Activities				
Reportable List	Staff	updated annually		
Data Dictionary	Staff	updated annually		
Standards Revisions				
Determine required data elements	Staff	as needed		
Publish requirements	Staff	as needed		
Monitor compliance	Staff	as needed		
Convert registry data	Staff	as needed		
Casefinding				
Casefinding source reports	Staff	quarterly		
Generate	Staff	quarterly		
Review/monitor	PD/PM	quarterly		
Data Management/Case reporting				
Pathology reports	Staff	ongoing		
Paper (review, followback, abstract)	Staff	ongoing		
Electronic	Staff	ongoing		
Review/Monitor	Staff	ongoing		
Physician reporting	Staff	ongoing		
Paper (review, followback, abstract)	Staff	ongoing		
Electronic	Staff	ongoing		
Monitoring	PD/PM	quarterly		
Health Care Facilities	Staff	ongoing		
Paper	Staff	ongoing		
Electronic	Staff	ongoing		
Monitoring	Staff	ongoing		
Follow-up, correction, deletions	Staff	ongoing		
Data submission reports	Staff	ongoing		
Generate	Staff	monthly		
Review/monitor	PD/PM	monthly		
Delinquent reporting management reports	Staff	monthly		
Generate	Staff	monthly		
Review/monitor	PD/PM	monthly		
Plan to assist delinquent reporting sources	PD/PM	ongoing		
Develop/Revise	PD/PM	annually		

Implement	Staff	monthly		
Process interstate records	Staff	annually		
Receive resident cases	Staff	annually		
Transmit non-resident cases	Staff	annually		
Record consolidation	Staff	ongoing		
Patient linkage	Staff	ongoing		
Tumor linkage	Staff	ongoing		
Follow back to reporters as needed	Staff	ongoing		
Geocoding	Geo-Staff or Co.	ongoing		
Death Clearance	Staff	ongoing		
Linkage	TBD*	annually ?		
Follow Back	TBD*	ongoing		
Linkages with external files	TBD*	as needed		
Rapid reporting management	TBD*	as needed		
Feasibility/IRB approval	TBD*	as needed		
Budget	TBD*	as needed		
Software needs	TBD*	as needed		
Procedures	TBD*	as needed		
Data Quality		annually		
Data quality audit plan	PD/PM	annually		
Develop/Revise	PD/PM	annually		
Implement	Staff	monthly		
Monitor	PD/PM	monthly		
Automated edits	Staff	ongoing		
Visual review/editing	Staff	ongoing		
Data accuracy and completeness	Staff	ongoing		
Compliance with new standards	Staff	ongoing		
Data appears in the correct fields	Staff	ongoing		
Duplicate record check	PD/PM	quarterly		
Data accuracy report to reporters		as required		Reports results of any QC activity and may include comparison reports
Generate/distribute	Staff	TBD		
Review/monitor	PD/PM	quarterly		
Special edit reports	Staff	quarterly		
Communications Activities				
Reporting sources				
Correspond with reporting facilities	TBD*	as needed		
Update reporting facility list	TBD*	as needed		
Reporting facility manual				

Develop/Revise	PD/PM	annually		
Distribute	Staff	annually		
Training				
Review reports to determine needs	PD/PM	quarterly		
Develop/Revise	TBD*	quarterly		
Conduct training sessions	TBD*	TBD		
New reporting requirements	TBD*			
Changes/additions in standards	TBD*			
Funding sources				
Grant proposals	PD/PM	as needed		
Grant activity reports	PD/PM			
Regulatory bodies				
Legislation/rules	PD/PM			
Develop/Revise	PD/PM	as needed		
Monitor	PD/PM	annually		
Interjurisdictional				
Interstate data exchange agreements	PD/PM	annually		
Advisory committee	PD/PM	TBD		
Professional organizations/groups	TDB*	as needed		
Public	TDB*	as needed		
Media	PD/EPI	as needed		
Data Use Activities				
Reports				
Prepare reports	PD/PM	annually		
Prepare articles	PD/PM	as needed		
Prepare newsletters	TBD*	TBD		
Annual Report	PD/EPI	annually		
National Data submission				
Extracting data files	Staff	annually		
Final edits	Staff	annually		
Revising/correcting edits	Staff	annually		
Submission of data	Staff	annually		
Studies				
Cluster evaluation	PD/EPI	as needed		
Screening/intervention programs	PD/EPI	as needed		
Data Requests	PD/EPI	as needed		
General	PD/EPI	as needed		
Special Studies	PD/EPI	as needed		
IRB Processes	PD/EPI	as needed		
Communication with researchers	PD/EPI	as needed		
Technology Management Activities				
Hardware/software requirements	IT Staff	as needed		
Review hardware/software capabilities	IT Staff	annually		
Correspond with IS/vendor	IT Staff	as needed		

System maintenance/programming	IT Staff	as needed		
Web site updates	IT Staff	as needed		
Processing data submissions from facilities	TBD*	as required		
New submissions	TBD*	as required		
Followup	Staff	as needed		
Corrections	Staff	as needed		
Deletions	Staff	as needed		
Backup/security	PD/PM	ongoing		
Administrative/Management Activities				
Financial/Budgeting/Accounting	PD/PM	as needed		
Contract management	PD/PM	as needed		
Resource allocation	PD/PM	as needed		
Policy/procedure manuals	PD/PM	annually		
Privacy policy				
Write privacy policy	PD/PM	as needed		
Conduct staff training	PD/PM	annually		
Maintain signed agreements for staff	PD/PM	annually		
Management reports	PD/PM	monthly		
Review workload status	PD/PM	quarterly	TBD	
Student/intern supervision	TBD*	as needed		
Staff supervision				
Assign job duties	PD/PM	as needed		
Develop/Revise job descriptions	PD/PM	as needed		
Conduct regular staff meetings	PD/PM	as needed		
Review/monitor monthly productivity reports	PD/PM	monthly		
Conduct annual staff performance evaluations	PD/PM	annually		
Interview/recommend hire potential employees	PD/PM	as needed		
Maintain staff contact list with emergency contact numbers	PD/PM	ongoing		
Clerical responsibilities	Staff	ongoing		
Update physician contacts for DC	Staff	ongoing		
PD/PM = Program Director or Program Manager				
PD/EPI = Program Director or Epidemiologist				
Staff = Central Cancer Registry Staff				

TBD = To Be Determined				
TBD* = Processes could be managed by PD/PM/EPI/Staff based on registry size and needs				
Date Revised 12/8/2005				

Ohio Cancer Incidence Surveillance System
HOSPITAL CLOSE OUT REPORT FORM
Diagnosis Year 2018

Part I:

1. Hospital Name, City:

_____

2. OCISS Reporting Source ID: _____

3. List other facilities/physicians for which you did cancer reporting for diagnosis year 2018 under this same Reporting Source ID:

_____

_____

_____

_____

Part II:

1. To the best of my knowledge, we have identified and reported all cancer cases **DIAGNOSED** between January 1, 2018 and December 31, 2018. _____YES
   _____NO

2. Number of cancer cases reported with a **diagnosis date from January 1-December 31, 2018**.

   Total number cases reported:

_____

3. Please explain any increase or decrease in cancer case reports over the previous year:

_____

_____

_____

_____

4. If you have not yet reported all your 2018 cases, when do you anticipate doing so?

   Date when all 2018 data will be reported to OCISS:

_____

SIGNATURE:

_____

NAME:

_____

___

TITLE: _____ DATE:

_____

PLEASE RETURN TO OCISS BY February 28, 2020.

Return by email to OCISS @odh.ohio.gov or by FAX to 614-644-8028

New Jersey Sample Central Registry Completeness Pivot Table Report

2014	2015	2016	2017	2018	2019	(blank)	Grand Total
1180	1237	1083	1235	1161	637		6533
443	547	535	402	418	310		2655
320	359	358	366	364	394		2161
436	414	401	521	480	124		2376
1223	1172	1038	1000	1161	767		6361
1056	1081	1051	1063	973	1037		6261
750	731	849	853	749	506		4438
434	477	445	364	375	184		2279
834	738	622	582	638	2		3416
1590	1491	1623	1564	1612	1678		9558
155	150	141	82	132	14		674
107	96	76	129	140	29		577
1340	1375	1355	1447	1367	1276		8160
			1				1
4177	4477	4786	5119	4867	3332		26758
225	235	279	280	383	180		1582
193	201	197	188	178	64		1021
1012	1157	1088	1262	1194	493		6206
					1		1
63	57	46	24	43	11		244
166	159	191	306	277	127		1226
557	542	565	678	621	289		3252
647	660	731	750	791	355		3934
1047	986	1123	1097	996	700		5949
513	496	586	517	583	537		3232
465	444	429	615	619	544		3116
1443	1528	1649	1913	1601	1772		9906

1018	1003	1049	1026	868	337	5301
1060	1314	1039	1130	1402	1408	7353
3631	4358	4867	4733	4468	1585	23642
1012	1117	1136	1254	1245	1160	6924
140	124	140	137	116	97	754
1299	1249	1271	1210	1121	1093	7243
292	312	304	343	455	449	2155
3602	3938	4504	4776	5136	1435	23391
91	86	104	62	50	11	404
887	850	760	848	829	733	4907
602	579	625	570	615	465	3456
2838	2900	2967	2892	2796	1980	16373
236	273	279	424	276	317	1805
804	704	550	487	507	5	3057
1193	1213	1433	1322	1370	1604	8135
4605	4674	4773	4785	4982	4553	28372
649	608	695	770	728	83	3533
751	722	680	616	586	633	3988
581	554	688	625	564	412	3424
909	949	916	868	818	451	4911
402	438	528	714	597	512	3191
908	952	875	790	720	592	4837
2448	2550	2768	2753	2856	2780	16155
229	234	210	181	115	83	1052
752	851	737	838	245	389	3812
283	288	240	274	260	164	1509
439	367	395	322	364	10	1897
446	433	447	414	379	164	2283
1541	1510	1527	1448	1367	736	8129
565	578	523	531	475	356	3028
1251	1226	1235	1309	1232	659	6912
1028	1318	1313	1180	1143	765	6747
2408	2483	2448	2389	2491	1903	14122
667	650	663	683	614	575	3852
351	320	346	463	382	309	2171
3560	3419	3296	3206	3290	3103	19874
171	177	131	159	66	132	836
64025	**66131**	**67709**	**68890**	**67251**	**47406**	**381412**

	2014	2015	2016	2017	2018	AVG	2019	% Complete	Grand Total
Hospital A	1180	1237	1083	1235	1161	1180	637	54%	6533
Hospital B	443	547	535	402	418	433	310	72%	2655
Hospital C	320	359	358	366	364	362	394	109%	2161
Grand Total	######`	######	######	######	######	######	######	######	######

New Jersey's Unsaved Modification of Completeness Sample Form

display_id	accession_number_hosp	sequence_number_hospital	date_of_1st_contact_yyyy
FAC-11304	201700957	0	2017
FAC-11104	201600034	0	2016
FAC-10301	200701087	3	2016
FAC-12005	201600041	0	2016
FAC-11303	201700388	0	2017
FAC-10402	201504361	0	2015
FAC-12006	201600135	0	2016
FAC-11505	201800833	0	2018
FAC-10301	201800557	0	2018
FAC-11502	200701769	2	2018
FAC-11202	201702402	0	2017
FAC-10211	201701562	2	2017
FAC-11305	201801245	0	2018
FAC-11205	200400893	2	2016
FAC-11104	201700417	0	2017
FAC-10204	201600122	0	2016
FAC-10710	201300877	2	2016
FAC-10710	201700007	2	2017
FAC-11305	201800116	0	2018
FAC-10101	201701494	60	2017
FAC-11605	201500788	0	2015
FAC-11802	201600815	0	2016
FAC-11103	201800159	0	2018
FAC-10303	201900020	0	2019

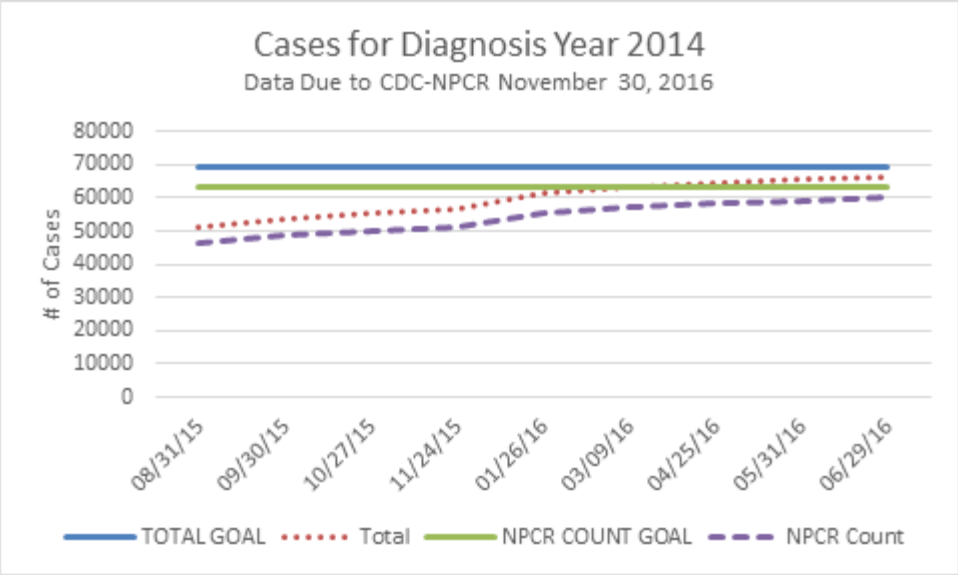
FAC-11301	201800359	0	2018
FAC-10710	201900348	0	2019
FAC-24745	201700274	2	2017
FAC-10204	201802263	0	2018
FAC-10702	201600159	3	2016
FAC-10204	201600695	0	2016
FAC-11201	201400899	60	2014
FAC-11104	201400008	0	2014
FAC-10902	201700019	0	2017
FAC-10204	201600111	0	2016
FAC-10403	201700298	2	2017
FAC-10905	201800175	0	2018
FAC-11203	201500411	2	2015
FAC-10202	201500582	2	2015
FAC-12002	201800001	0	2018

Ohio Central Registry Completeness Sample Form

OCISS Monthly Report, end of June 2016

Ohio Cancer Incidence Surveillance System (OCISS): OCISS is currently working on submission of 2014 data to CDC's National Program of Cancer Registries (NPCR), which are due November 30, 2016. Data are evaluated for completeness and data quality. Data that meet CDC's criteria for completeness and data quality are included in national cancer publications.

The chart below shows the number of incident cancer cases for 2014, by month. NPCR calculates completeness based on an algorithm that compares cancer incidence to cancer mortality. OCISS uses a more simplified approach, comparing incident cancer cases to a numerical goal derived from previous years' data submissions. This allows OCISS to monitor the volume of incident cases and approximate the number not yet reported.



*NPCR Total includes malignant cancers and in situ bladder. Total includes NPCR Total plus in situ cancers other than bladder plus benign brain.

Action Steps and Timelines:

OCISS staff is working with a number of cancer reporters to obtain all 2014 data in order to meet completeness goals. We anticipate an increase of 2000-3000 cancer cases as a result of the following:

- OCISS contacted the Veterans Affair (VA) Central Cancer Registry to obtain reports for 2014. They let OCISS know that a new contract is needed since the current contract was executed 3 years ago. A new contract was developed and sent to the VA for signature in late June. We anticipate 500-1000 additional cancer reports.
- OCISS has not yet received a data file from Department of Defense (DoD). OCISS will contact DoD to learn when data will be submitted. We anticipate 50-100 cases.
- OCISS has not yet processed electronic pathology reports for 2014. This will be started now that the new OCISS Data Administration Manager has been hired. We anticipate 500 additional cancer reports.
- OCISS is working on death clearance for 2014. We identified almost 4000 potential cancer cases and anticipate 2000 will result in new cancer cases after review.
- OCISS is working to resolve missing data issues. Cancer reporters that submitted cases with unknown race were contacted for this information; race was reported to OCISS for 68% of the cases.
- OCISS continues to review cancer cases with an unknown primary site, as they are not counted when completeness is calculated.

Georgia Sample Facilities Completeness Reports

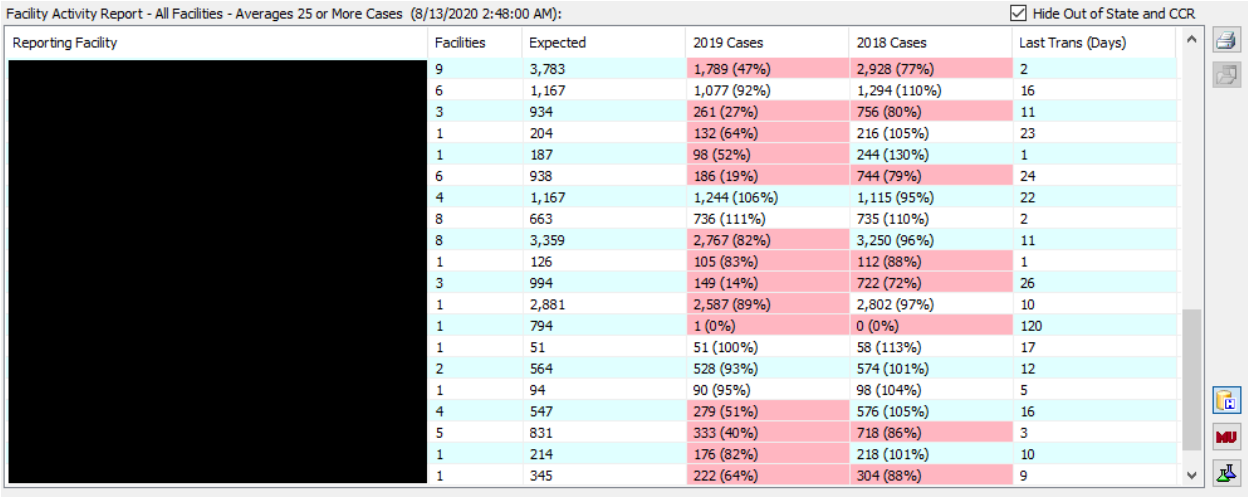
Coordinator	FACILITY	ANALYTIC	NON ANALYTIC	Out of State	PENDING	SUSPENSE	TOTAL
3		24	0	10	0	0	34
3		9	0	0	0	0	9
3		1075	1	577	14	70	1737
3		1	0	0	0	0	1
3		514	0	2	22	21	559
3		37	0	1	0	9	47
3		102	0	2	2	13	119
3		707	2	1330	27	26	2092
3		759	0	154	33	34	980
3		21	0	2	0	0	23
3		0	0	0	0	0	0
3		0	0	0	0	0	0
3		4	0	0	0	0	4
3		0	0	0	0	0	0
3		0	0	0	0	0	0
3		145	0	1	15	12	173
3		8	0	0	0	4	12
3		1545	1	15	53	33	1647
3		23	0	0	1	4	28
3		1	0	0	0	0	1
3		3	0	0	1	0	4
3		225	1	0	8	1	235
3		25	0	0	1	2	28
3		1441	0	11	12	14	1478
3		104	0	1	6	2	113
3		206	0	72	10	2	290
3		1470	0	21	24	57	1572
3		1285	3	17	32	62	1399
3		881	0	69	8	40	998
3		35	0	0	1	13	49
3		1	0	0	0	0	1
3		485	1	147	35	1	669
3		1	0	0	0	0	1
3		0	0	0	0	0	0
3		9	0	0	0	5	14
3		296	0	4	6	0	306

3		699	0	57	6	28	790
3		1255	0	408	19	5	1687
3		140	0	3	4	6	153
3		65	0	1	0	6	72
3		1	0	0	0	0	1
3		343	0	3	10	16	372
3		353	0	56	1	6	416
3		0	0	0	0	0	0
2		1818	437	0	0	143	2398
2		13	0	0	5	1	19
2		58	0	0	0	64	122
2		421	0	17	8	2	448
2		517	2	3	4	8	534
2		1437	0	80	24	41	1582
2		392	0	5	12	31	440
2		926	0	28	27	35	1016
2		2448	0	129	78	69	2724
2		6468	3	555	265	205	7496
2		3817	1	208	94	104	4224
2		1837	827	40	0	144	2848
2		1301	5	23	5	27	1361
2		393	1	3	42	66	505
2		0	0	0	0	0	0
2		0	0	0	0	0	0
2		7	0	0	0	1	8
2		1709	2	8	80	17	1816
2		12708	7	388	163	114	13380
2		0	0	0	0	0	0
2		2956	4	70	17	59	3106
2		100	0	1	3	5	109
2		0	0	0	0	0	0
2		24	0	0	3	0	27
2		39	0	0	0	13	52
2		1	0	0	0	0	1
2		344	0	7	5	20	376
2		151	0	4	1	10	166
2		2	0	0	0	1	3
2		4243	1	93	32	62	4431

Colorado Facility Completeness Sample Form

COLORADO CENTRAL CANCER REGISTRY																
COMPLETENESS REPORT (BY SOURCE TYPE)																
June 5, 2020																Gold Status
								2017		2018		2019				Silver Status
Standard - Statewide Completeness Percentage								100%		100%		100%				Behind in Reporting
Current - Statewide Completeness Percentage								100.3%		92.2%		55.7%				
History - Statewide Completeness Percentage (12 Months Prior)								98.9%		99.0%		XX.X%				
			Case Counts (Date First Seen)													
Hos #	Hos Name	CCCR Tech Staff	2014	2015	2016	2017	2018	2019	15 - 16 Avg # Cases	2017 Comp %	16 - 17 Avg # Cases	2018 Comp %	18 - 19 Avg # Cases	2019 Comp %	Number of cases needed for 100% for 2019	Comments on Hospital Status
Reported by Hospital																
H1	Facility A	T1	3292	3336	3614	4004	3664	3033	3475	115.2%	3809	96.2%	3349	90.6%	316	
H2	Facility B	T2	1385	1364	1434	1473	1660	1595	1399	105.3%	1454	114.2%	1567	101.8%	29	
H3	Facility C	T1	625	581	632	651	629	294	607	107.3%	642	98.1%	640	45.9%	346	Why the drop in cases in 2018?
H4	Facility D	T3	103	99	77	84	152	146	88	95.5%	81	188.8%	118	123.7%	28	
H5	Facility E	T3	531	574	577	553	547	14	576	96.1%	565	96.8%	550	0.0%	536	Requesting 2019 records from hosp
H6	Facility F	T1	996	1041	1097	1122	1224	1130	1069	105.0%	1110	110.3%	1173	96.3%	43	
H7	Facility G	T2	33	49	43	45	41	40	46	97.8%	44	93.2%	43	93.0%	3	
H8	Facility H	T2	227	202	218	265	266	4	210	126.2%	242	110.1%	266	1.5%	262	
H9	Facility I	T4	100	113	119	126	151	141	116	108.6%	123	123.3%	139	101.8%	3	

Arkansas Facility Completeness Sample Form

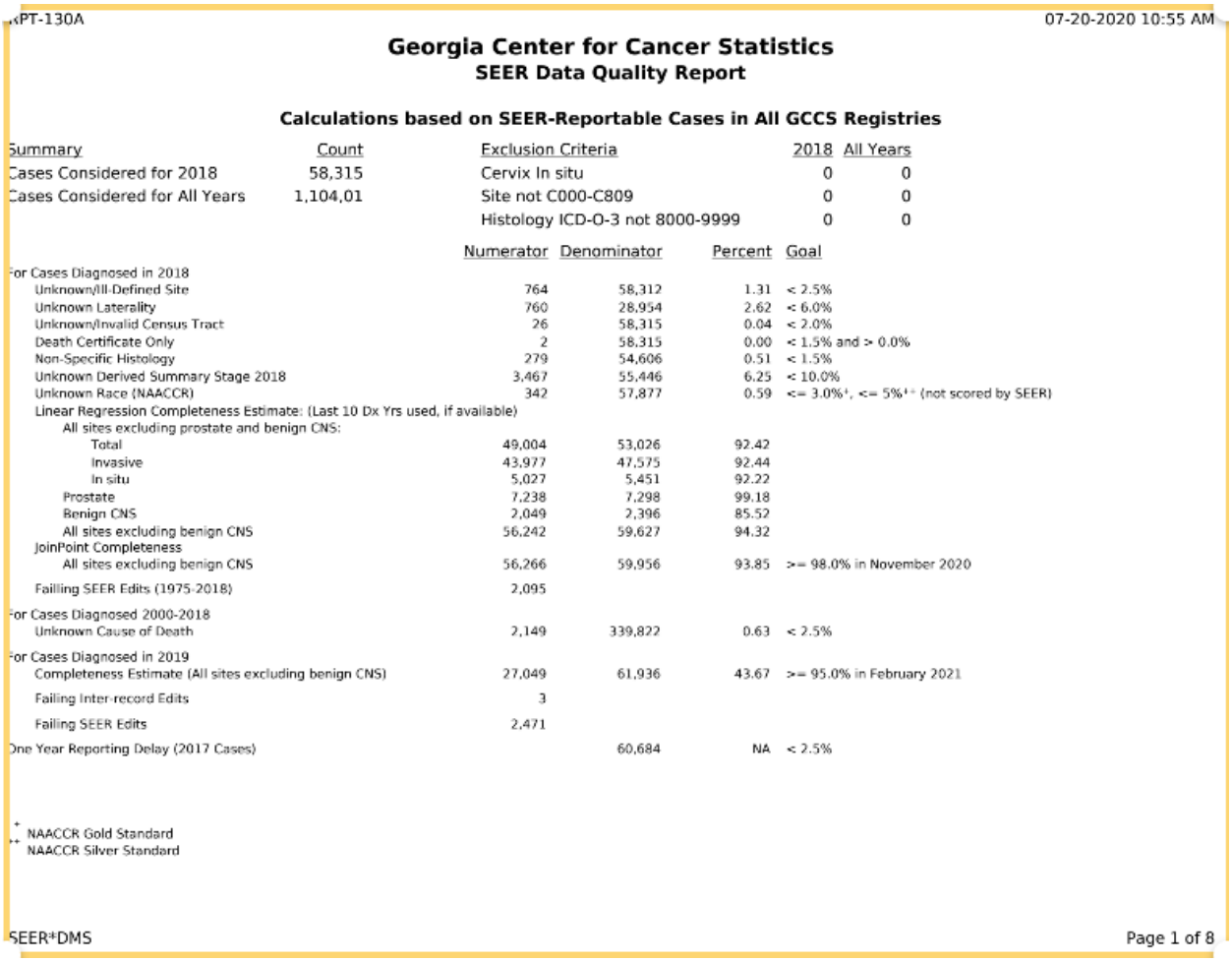


Facility Activity Report - All Facilities - Averages 25 or More Cases (8/13/2020 2:48:00 AM):

Hide Out of State and CCR

Reporting Facility	Facilities	Expected	2019 Cases	2018 Cases	Last Trans (Days)
[redacted]	9	3,783	1,789 (47%)	2,928 (77%)	2
	6	1,167	1,077 (92%)	1,294 (110%)	16
	3	934	261 (27%)	756 (80%)	11
	1	204	132 (64%)	216 (105%)	23
	1	187	98 (52%)	244 (130%)	1
	6	938	186 (19%)	744 (79%)	24
	4	1,167	1,244 (106%)	1,115 (95%)	22
	8	663	736 (111%)	735 (110%)	2
	8	3,359	2,767 (82%)	3,250 (96%)	11
	1	126	105 (83%)	112 (88%)	1
	3	994	149 (14%)	722 (72%)	26
	1	2,881	2,587 (89%)	2,802 (97%)	10
	1	794	1 (0%)	0 (0%)	120
	1	51	51 (100%)	58 (113%)	17
	2	564	528 (93%)	574 (101%)	12
	1	94	90 (95%)	98 (104%)	5
	4	547	279 (51%)	576 (105%)	16
	5	831	333 (40%)	718 (86%)	3
	1	214	176 (82%)	218 (101%)	10
	1	345	222 (64%)	304 (88%)	9

Georgia Central Registry Quality Sample Form



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Georgia Center for Cancer Statistics
SEER Data Quality Report

Calculations based on SEER-Reportable Cases in All GCCS Registries

Summary	Count
Cases Considered for 2018	58,315
Cases Considered for All Years	1,104,01

Exclusion Criteria	2018	All Years
Cervix In situ	0	0
Site not C000-C809	0	0
Histology ICD-O-3 not 8000-9999	0	0

	Numerator	Denominator	Percent	Goal
For Cases Diagnosed in 2018				
Unknown/Ill-Defined Site	764	58,312	1.31	< 2.5%
Unknown Laterality	760	28,954	2.62	< 6.0%
Unknown/Invalid Census Tract	26	58,315	0.04	< 2.0%
Death Certificate Only	2	58,315	0.00	< 1.5% and > 0.0%
Non-Specific Histology	279	54,606	0.51	< 1.5%
Unknown Derived Summary Stage 2018	3,467	55,446	6.25	< 10.0%
Unknown Race (NAACCR)	342	57,877	0.59	<= 3.0%+, <= 5%++ (not scored by SEER)
Linear Regression Completeness Estimate: (Last 10 Dx Yrs used, if available)				
All sites excluding prostate and benign CNS:				
Total	49,004	53,026	92.42	
Invasive	43,977	47,575	92.44	
In situ	5,027	5,451	92.22	
Prostate	7,238	7,298	99.18	
Benign CNS	2,049	2,396	85.52	
All sites excluding benign CNS	56,242	59,627	94.32	
JoinPoint Completeness				
All sites excluding benign CNS	56,266	59,956	93.85	>= 98.0% in November 2020
Failling SEER Edits (1975-2018)	2,095			
For Cases Diagnosed 2000-2018				
Unknown Cause of Death	2,149	339,822	0.63	< 2.5%
For Cases Diagnosed in 2019				
Completeness Estimate (All sites excluding benign CNS)	27,049	61,936	43.67	>= 95.0% in February 2021
Failing Inter-record Edits	3			
Failing SEER Edits	2,471			
One Year Reporting Delay (2017 Cases)		60,684	NA	< 2.5%

+ NAACCR Gold Standard
++ NAACCR Silver Standard

SEER*DMS Page 1 of 8

Georgia Center for Cancer Statistics
SEER Data Quality Report

Calculations based on SEER-Reportable Cases in All GCCS Registries

Summary	Count
Cases Considered for 2018	58,315
Cases Considered for All Years	1,104,01

Exclusion Criteria	2018	All Years
Cervix In situ	0	0
Site not C000-C809	0	0
Histology ICD-O-3 not 8000-9999	0	0

	Numerator	Denominator	Percent	Goal
For Cases Diagnosed in 2018				
Unknown/Ill-Defined Site	764	58,312	1.31	< 2.5%
Unknown Laterality	760	28,954	2.62	< 6.0%
Unknown/Invalid Census Tract	26	58,315	0.04	< 2.0%
Death Certificate Only	2	58,315	0.00	< 1.5% and > 0.0%
Non-Specific Histology	279	54,606	0.51	< 1.5%
Unknown Derived Summary Stage 2018	3,467	55,446	6.25	< 10.0%
Unknown Race (NAACCR)	342	57,877	0.59	<= 3.0%[+], <= 5%[++] (not scored by SEER)
Linear Regression Completeness Estimate: (Last 10 Dx Yrs used, if available)				
All sites excluding prostate and benign CNS:				
Total	49,004	53,026	92.42	
Invasive	43,977	47,575	92.44	
In situ	5,027	5,451	92.22	
Prostate	7,238	7,298	99.18	
Benign CNS	2,049	2,396	85.52	
All sites excluding benign CNS	56,242	59,627	94.32	
JoinPoint Completeness				
All sites excluding benign CNS	56,266	59,956	93.85	>= 98.0% in November 2020
Failling SEER Edits (1975-2018)	2,095			
For Cases Diagnosed 2000-2018				
Unknown Cause of Death	2,149	339,822	0.63	< 2.5%
For Cases Diagnosed in 2019				
Completeness Estimate (All sites excluding benign CNS)	27,049	61,936	43.67	>= 95.0% in February 2021
Failing Inter-record Edits	3			
Failing SEER Edits	2,471			
One Year Reporting Delay (2017 Cases)		60,684	NA	< 2.5%

[+] NAACCR Gold Standard
[++] NAACCR Silver Standard

Georgia Center for Cancer Statistics
SEER Data Quality Report

Calculations based on SEER-Reportable Cases in the SEER Metropolitan Atlanta Registry

Summary	Count
Cases Considered for 2018	18,910
Cases Considered for All Years	465,312

Exclusion Criteria	2018	All Years
Cervix In situ	0	0
Site not C000-C809	0	0
Histology ICD-O-3 not 8000-9999	0	0

	Numerator	Denominator	Percent	Goal
Unknown/Ill-Defined Site	188	18,909	0.99	< 2.5%
Unknown Laterality	182	9,283	1.96	< 6.0%
Unknown/Invalid Census Tract	4	18,910	0.02	< 2.0%
Death Certificate Only	0	18,910	0.00	< 1.5% and > 0.0%
Non-Specific Histology	72	17,679	0.41	< 1.5%
Unknown Derived Summary Stage 2018	919	17,875	5.14	< 10.0%
Unknown Race (NAACCR)	83	18,692	0.44	<= 3.0%+, <= 5%++ (not scored by SEER)
Linear Regression Completeness Estimate: (Last 10 Dx Yrs used, if available)				
All sites excluding prostate and benign CNS:				
Total	15,429	16,617	92.85	
Invasive	13,752	14,771	93.10	
In situ	1,677	1,846	90.85	
Prostate	2,630	2,523	104.24	
Benign CNS	837	937	89.33	
All sites excluding benign CNS	18,059	18,911	95.49	
JoinPoint Completeness				
All sites excluding benign CNS	18,073	19,463	92.86	>= 98.0% in November 2020
Failling SEER Edits (1975-2018)	560			
For Cases Diagnosed 2000-2018				
Unknown Cause of Death	746	90,948	0.82	< 2.5%
For Cases Diagnosed in 2019				
Completeness Estimate (All sites excluding benign CNS)	9,581	20,319	47.15	>= 95.0% in February 2021
Failing Inter-record Edits	2			
Failing SEER Edits	715			
One Year Reporting Delay (2017 Cases)		19,596	NA	< 2.5%

+ NAACCR Gold Standard
++ NAACCR Silver Standard

Georgia Center for Cancer Statistics
SEER Data Quality Report

Calculations based on SEER-Reportable Cases in the SEER Metropolitan Atlanta Registry

Summary	Count
Cases Considered for 2018	18,910
Cases Considered for All Years	465,312

Exclusion Criteria	2018	All Years
Cervix In situ	0	0
Site not C000-C809	0	0
Histology ICD-O-3 not 8000-9999	0	0

	Numerator	Denominator	Percent	Goal
For Cases Diagnosed 2000-2017 and Followed into 2018				
Percent Followed (Invasive):				
Age < 20	2,675	2,804	95.40	>= 90*, >= 80**
Age 20-64	108,112	112,951	95.72	>= 90*, >= 80**
Age 65+	79,068	80,499	98.22	>= 95*, >= 90**
All Ages	189,855	196,254	96.74	
Percent Followed (In situ)	17,331	17,979	96.40	>= 90*, >= 80**
For Cases Diagnosed 2000-2017 and Followed into 2019				
Percent Followed (Invasive):				
Age < 20	2,588	2,804	92.30	
Age 20-64	105,005	112,951	92.97	
Age 65+	78,334	80,499	97.31	
All Ages	185,927	196,254	94.74	
Percent Followed (In situ)	16,394	17,979	91.18	
For Cases Diagnosed 1975-2017 and Followed into 2018				
Percent Followed (Invasive):				
Age < 20	4,712	4,927	95.64	
Age 20-64	185,820	192,362	96.60	
Age 65+	146,107	147,722	98.91	
All Ages	336,639	345,013	97.57	
Percent Followed (In situ)	24,789	25,660	96.61	
For Cases Diagnosed 1975-2017 and Followed into 2019				
Percent Followed (Invasive):				
Age < 20	4,566	4,927	92.67	
Age 20-64	182,133	192,362	94.68	
Age 65+	145,351	147,722	98.39	
All Ages	332,050	345,013	96.24	
Percent Followed (In situ)	23,717	25,660	92.43	

* Contractual standard
** Minimum acceptable

Georgia Center for Cancer Statistics
SEER Data Quality Report

Calculations based on SEER-Reportable Cases in the SEER Rural Georgia Registry

Summary	Count
Cases Considered for 2018	910
Cases Considered for All Years	24,503

Exclusion Criteria	2018	All Years
Cervix In situ	0	0
Site not C000-C809	0	0
Histology ICD-O-3 not 8000-9999	0	0

	Numerator	Denominator	Percent	Goal
Unknown/Ill-Defined Site	7	910	0.77	< 2.5%
Unknown Laterality	12	447	2.68	< 6.0%
Unknown/Invalid Census Tract	0	910	0.00	< 2.0%
Death Certificate Only	0	910	0.00	< 1.5% and > 0.0%
Non-Specific Histology	4	837	0.48	< 1.5%
Unknown Derived Summary Stage 2018	55	862	6.38	< 10.0%
Unknown Race (NAACCR)	1	908	0.11	<= 3.0%⁺, <= 5%⁺⁺ (not scored by SEER)
Linear Regression Completeness Estimate: (Last 10 Dx Yrs used, if available)				
All sites excluding prostate and benign CNS:				
Total	776	885	87.68	
Invasive	711	808	88.00	
In situ	65	77	84.42	
Prostate	97	124	78.23	
Benign CNS	37	24	154.17	
All sites excluding benign CNS	873	1,002	87.13	
JoinPoint Completeness				
All sites excluding benign CNS	873	992	88.00	>= 98.0% in November 2020
Failling SEER Edits (1978-2018)	44			
For Cases Diagnosed 2000-2018				
Unknown Cause of Death	32	6,358	0.50	< 2.5%
For Cases Diagnosed in 2019				
Completeness Estimate (All sites excluding benign CNS)	457	1,023	44.67	>= 95.0% in February 2021
Failing Inter-record Edits	0			
Failing SEER Edits	71			
One Year Reporting Delay (2017 Cases)		985	NA	< 2.5%

⁺ NAACCR Gold Standard
⁺⁺ NAACCR Silver Standard

Georgia Center for Cancer Statistics
SEER Data Quality Report

Calculations based on SEER-Reportable Cases in the SEER Rural Georgia Registry

Summary	Count
Cases Considered for 2018	910
Cases Considered for All Years	24,503

Exclusion Criteria	2018	All Years
Cervix In situ	0	0
Site not C000-C809	0	0
Histology ICD-O-3 not 8000-9999	0	0

	Numerator	Denominator	Percent	Goal
For Cases Diagnosed 2000-2017 and Followed into 2018				
Percent Followed (Invasive):				
Age < 20	81	81	100.00	>= 90*, >= 80**
Age 20-64	5,166	5,298	97.51	>= 90*, >= 80**
Age 65+	5,664	5,704	99.30	>= 95*, >= 90**
All Ages	10,911	11,083	98.45	
Percent Followed (In situ)	661	674	98.07	>= 90*, >= 80**
For Cases Diagnosed 2000-2017 and Followed into 2019				
Percent Followed (Invasive):				
Age < 20	74	81	91.36	
Age 20-64	5,103	5,298	96.32	
Age 65+	5,631	5,704	98.72	
All Ages	10,808	11,083	97.52	
Percent Followed (In situ)	632	674	93.77	
For Cases Diagnosed 1978-2017 and Followed into 2018				
Percent Followed (Invasive):				
Age < 20	161	161	100.00	
Age 20-64	8,342	8,503	98.11	
Age 65+	10,305	10,352	99.55	
All Ages	18,808	19,016	98.91	
Percent Followed (In situ)	845	858	98.48	
For Cases Diagnosed 1978-2017 and Followed into 2019				
Percent Followed (Invasive):				
Age < 20	152	161	94.41	
Age 20-64	8,262	8,503	97.17	
Age 65+	10,272	10,352	99.23	
All Ages	18,686	19,016	98.26	
Percent Followed (In situ)	810	858	94.41	

* Contractual standard
** Minimum acceptable

Georgia Center for Cancer Statistics
SEER Data Quality Report

Calculations based on SEER-Reportable Cases in the SEER Rural Georgia Registry

Summary	Count
Cases Considered for 2018	910
Cases Considered for All Years	24,503

Exclusion Criteria	2018	All Years
Cervix In situ	0	0
Site not C000-C809	0	0
Histology ICD-O-3 not 8000-9999	0	0

	Numerator	Denominator	Percent	Goal
For Cases Diagnosed 2000-2017 and Followed into 2018				
Percent Followed (Invasive):				
Age < 20	81	81	100.00	>= 90*, >= 80**
Age 20-64	5,166	5,298	97.51	>= 90*, >= 80**
Age 65+	5,664	5,704	99.30	>= 95*, >= 90**
All Ages	10,911	11,083	98.45	
Percent Followed (In situ)	661	674	98.07	>= 90*, >= 80**
For Cases Diagnosed 2000-2017 and Followed into 2019				
Percent Followed (Invasive):				
Age < 20	74	81	91.36	
Age 20-64	5,103	5,298	96.32	
Age 65+	5,631	5,704	98.72	
All Ages	10,808	11,083	97.52	
Percent Followed (In situ)	632	674	93.77	
For Cases Diagnosed 1978-2017 and Followed into 2018				
Percent Followed (Invasive):				
Age < 20	161	161	100.00	
Age 20-64	8,342	8,503	98.11	
Age 65+	10,305	10,352	99.55	
All Ages	18,808	19,016	98.91	
Percent Followed (In situ)	845	858	98.48	
For Cases Diagnosed 1978-2017 and Followed into 2019				
Percent Followed (Invasive):				
Age < 20	152	161	94.41	
Age 20-64	8,262	8,503	97.17	
Age 65+	10,272	10,352	99.23	
All Ages	18,686	19,016	98.26	
Percent Followed (In situ)	810	858	94.41	

* Contractual standard
** Minimum acceptable

Georgia Center for Cancer Statistics
SEER Data Quality Report

Calculations based on SEER-Reportable Cases in the SEER Greater Georgia Registry

Summary	Count
Cases Considered for 2018	38,495
Cases Considered for All Years	614,196

Exclusion Criteria	2018	All Years
Cervix In situ	0	0
Site not C000-C809	0	0
Histology ICD-O-3 not 8000-9999	0	0

	Numerator	Denominator	Percent	Goal
For Cases Diagnosed 2000-2017 and Followed into 2018				
Percent Followed (Invasive):				
Age < 20	4,908	5,104	96.16	>= 90*, >= 80**
Age 20-64	209,909	217,256	96.62	>= 90*, >= 80**
Age 65+	210,876	213,122	98.95	>= 95*, >= 90**
All Ages	425,693	435,482	97.75	
Percent Followed (In situ)	30,745	31,960	96.20	>= 90*, >= 80**
For Cases Diagnosed 2000-2017 and Followed into 2019				
Percent Followed (Invasive):				
Age < 20	4,713	5,104	92.34	
Age 20-64	206,314	217,256	94.96	
Age 65+	209,629	213,122	98.36	
All Ages	420,656	435,482	96.60	
Percent Followed (In situ)	29,758	31,960	93.11	

NEW JERSEY STATE CANCER REGISTRY

QUARTERLY HOSPITAL QUALITY AND COMPLETENESS REPORT

FOR

Hospital Name

PREPARED ON Date

The New Jersey State Cancer Registry (NJSCR) is dedicated to compiling complete, current, and high quality data on cancer in the State of NJ. The Registry is an important source of information for health care providers, public health officials, and administrators. This information is widely used by clinicians, scientists, and researchers. Data on cancer patterns in the population can be very useful for preventing and controlling cancer

and improving treatment and patient care. The data are used to respond to New Jersey residents on cancer issues and concerns. Also, the incidence rates in New Jersey are shared and compared with other states and the nation. The data collected by the NJSCR can be useful for describing cancer patterns in the population, discovering causes of cancer, planning programs for people affected with cancer, and other related research. Early detection programs, such as for cervical, breast, and colon cancers, use these data to plan screening services. Early detection is more likely to improve survival. Health care providers use these data for planning, and researchers use these data for studying ways to increase survival and identify risk factors.

Beginning with accession year 2014, the New Jersey State Cancer Registry has developed new criteria for the Award for Excellence in Timely and Complete Cancer Reporting. Only hospitals that meet these criteria will be eligible for the Award. There will be three levels of awards: Gold, Silver and Bronze. Each level requires that the facility meet the benchmark for each of the three criteria categories: completeness, timeliness, and quality. The benchmarks are:

	Completeness	Timeliness	Quality
Bronze	90%	90%	**
Silver	95%	95%	**
Gold	98%	98%	**

**See page 3 for quality benchmarks for bronze, silver, and gold awards.

Awards will be given in October of each year. Recipients will be recognized at the annual meeting of the Oncology Registrars Association of New Jersey. In order to assist each facility in assessing its progress toward the benchmarks, NJSCR will provide each facility with a quarterly report of its completeness, timeliness and quality.

This report represents the final analysis of the 2017 accession year. It includes all cases and updates submitted prior to July 1, 2018.

For details on how these measures are calculated, please see the Data Dictionary on page 4 of this report.

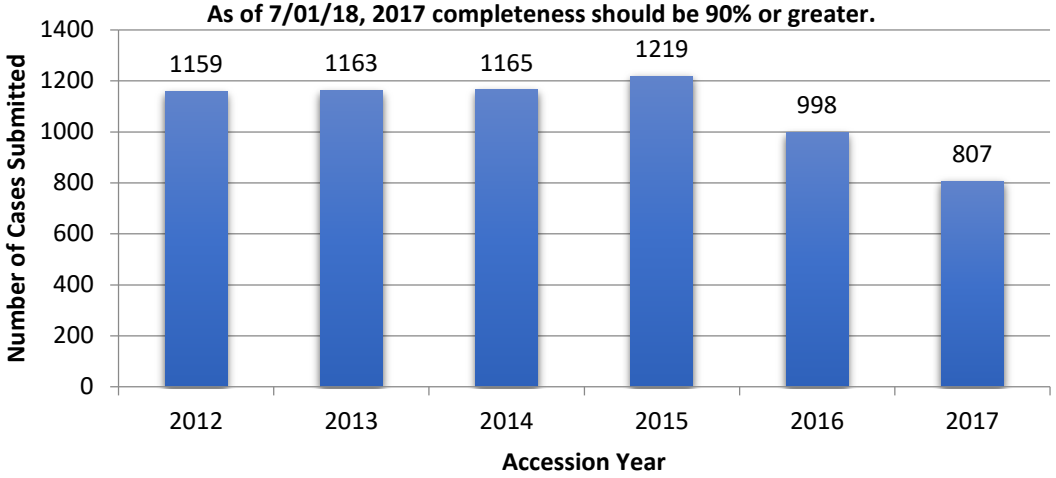
This report is a summary of data submitted by HOSPITAL NAME and is meant to be used as a quality improvement tool by your facility's Cancer Registry, Cancer Committee and administration. Use the data contained herein to gauge your progress toward achieving the Award for Excellence. Please contact your NJSCR representative, REP's Name at 609-633-XXXX with questions about the data contained in this report.

COMPLETENESS & TIMELINESS

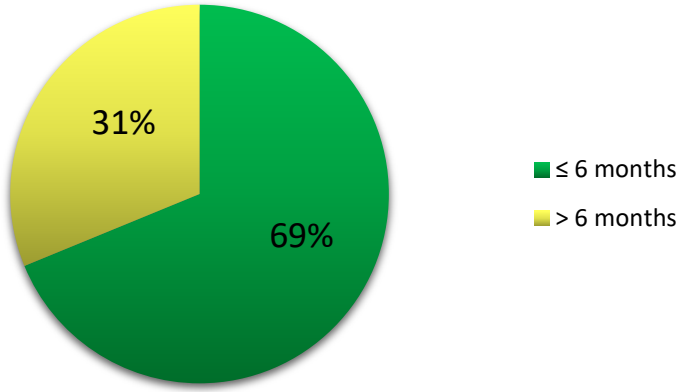
1. Number of Cases Submitted to NJSCR by Accession Year

(2012-2016 Weighted Average =1,097.3; 2017 Completeness = 73.5%)

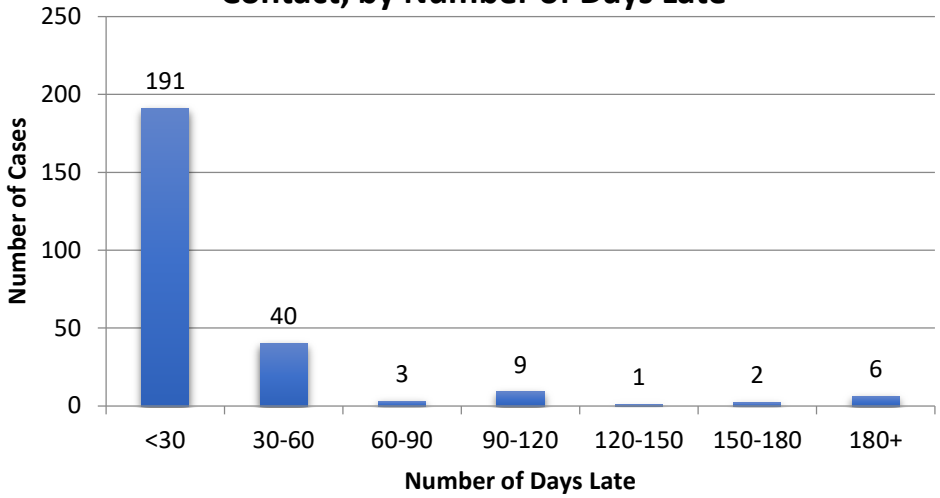
As of 7/01/18, 2017 completeness should be 90% or greater.



2. Percent of 2017 Accession Year Cases Submitted Within 6 Months of Date of 1st Contact



3. Cases Reported >6 Months After Date of 1st Contact, by Number of Days Late



4. DATA QUALITY MEASURES

Measure	My Facility					All NJ Facilities	Benchmarks*,¥		
	Percent	90% Confidence Interval€			Numerator	Denominator		Bronze	Silver	Gold
Unknown Social Security Number	2.5%	1.5%	-	3.5%	16	634	7.8%	<3%	<2%	<1%
Unknown Year of Diagnosis	0.0%	0.0%	-	0.0%	0	634	0.2%	<1.5%	<1%	<0.5%
Unknown/Other Race (99, 98)	2.7%	1.6%	-	3.7%	17	634	2.8%	<5%	<4%	<3%
Unknown/Other Hispanic Ethnicity (9, 8)	3.8%	2.5%	-	5.0%	24	634	1.8%	<5%	<4%	<3%
Unknown Class of Case (99)	0.0%	0.0%	-	0.0%	0	807	0.2%	<1%	<0.5%	<0.1%
Unknown Gender	0.0%	0.0%	-	0.0%	0	634	0.0%	<3%	<2%	<1%
Unknown/Ill-defined Primary Site (C76, C80)	2.4%	1.4%	-	3.4%	15	634	1.6%	<2.5%	<2%	<1.5%
Unknown Laterality	1.5%	0.4%	-	2.7%	5	325	2.6%	<6%	<4%	<2%
Non-Specific Histology (8000, 8001)	0.5%	0.0%	-	1.0%	3	609	0.3%	<3%	<2.5%	<2%
Unknown County at Diagnosis	0.0%	0.0%	-	0.0%	0	634	0.2%	<3%	<2%	<1%

*Benchmarks are derived from standards of the North American Association of Central Cancer Registries and the Surveillance, Epidemiology and End Results Program of the National Cancer Institute.

¥ In order to receive the Award for Excellence in one of the three categories, your facility must achieve that category for all measures listed in the table, in addition to the completeness and timeliness measures listed on the previous page.

€Credit is given for the highest benchmark included within the 90% Confidence Interval for each measure.

Measure	Definition	Numerator	Denominator	Notes
Completeness	The percent of cases (analytic and non-analytic) expected to be submitted by your facility for a given timeframe which have actually been submitted.	Number of cases submitted by your facility for the diagnosis year.	Weighted average of the number of cases submitted by your facility for the previous five diagnosis years.	Facilities that fall below 90% completeness may be subject to audit by NJSCR. Un-reported cases are subject to penalties pursuant to N.J.S.A 26:2-104 through 109.
Timeliness	The percent of cases (analytic and non-analytic) first submitted by your facility for the accession year that were submitted within 6 months of the date of first contact (as defined in FORDS 2013, page 115).	Number of cases submitted by your facility for the accession year that were submitted within 6 months of the date of first contact (as defined in FORDS 2013, page 115).	Total number of cases submitted by your facility for the accession year.	**Please note:** While this report measures timeliness based on date of **first contact**, N.J.S.A 26:2-104 through 109 requires hospitals to report cases to NJSCR within 6 months of the date of **diagnosis**, or within 3 months of **discharge**, whichever is sooner. Therefore, the timeliness measures reflected in this report do not indicate a facility is compliant with NJ State Law.
Unknown Social Security Number	The percent of analytic cases submitted by your facility for the accession year with a social security number coded as 999-99-9999.	The number of cases submitted by your facility for the diagnosis year with a social security number coded as 999-99-9999.	Total number of cases submitted by your facility for the diagnosis year.	A Social Security Number is important for identifying patients with similar names and for matching records received from multiple reporting facilities for the same patient.
Unknown Year of Diagnosis	The percent of analytic cases submitted by your facility for the accession year with a diagnosis year coded as 9999.	The number of cases submitted by your facility for the accession year with a	Total number of cases submitted by your facility for the accession year.	According to the SEER Program Coding and Staging Manual (SPCSM) "Year of diagnosis **cannot be blank or unknown**." If date of diagnosis is not known and cannot be

Measure	Definition	Numerator	Denominator	Notes
		year of diagnosis coded as 9999.		estimated, **use the date of admission** as the date of diagnosis. (SPCSM 2011, pp. 49-50)
Unknown/Other Race (99, 98)	The percent of analytic cases submitted by your facility for the accession year with race coded as 99 or 98.	The number of cases submitted by your facility for the accession year with race coded as 99 or 98.	Total number of cases submitted by your facility for the accession year.	Race is an important element in the analysis and utilization of cancer registry data. See FORDS 2013, page 63 for instructions on coding race.
Unknown/Other Hispanic Ethnicity (9, 8)	The percent of analytic cases submitted by your facility for the accession year with Hispanic ethnicity coded as 9 or 8.	The number of cases submitted by your facility for the accession year with Hispanic ethnicity coded as 9 or 8.	Total number of cases submitted by your facility for the accession year.	Ethnicity is an important element in the analysis and utilization of cancer registry data. See FORDS 2013, page 69 for instructions on coding ethnicity.
Unknown Class of Case (99)	The percent of cases (analytic and non-analytic) submitted by your facility for the accession year with class of case coded as 99.	The number of cases submitted by your facility for the diagnosis year with class of case coded as 99.	Total number of cases submitted by your facility for the accession year.	See FORDS 2013, page 110 for instructions on coding class of case.
Unknown Gender	The percent of analytic cases submitted by your facility for the accession year with sex coded as 9.	Number of cases submitted by your facility for the accession year with sex coded as 9.	Total number of cases submitted by your facility for the accession year.	See FORDS 2013, page 70 for instructions on coding gender.
Unknown/Ill-defined Primary Site (C76, C80)	The percent of analytic cases submitted by your facility for the accession	Number of cases submitted by your facility for the accession year with	Total number of cases submitted by your facility for the accession year.	It is expected that a small percent of cases will have no identified primary site. In these cases the use of codes C76 and C80 may be justified.

Measure	Definition	Numerator	Denominator	Notes
	year with primary site coded as C76 or C80.	primary site coded as C76 or C80.		However, a more specific code should always be used when available.
Unknown Laterality	The percent of analytic cases of paired sites submitted by your facility for the accession year with laterality coded as 9 or 3.	Number of cases of paired sites submitted by your facility for the accession year with laterality coded as 9 or 3.	Total number of cases of paired sites submitted by your facility for the accession year.	See FORDS 2013, pages 8-9 for a list of paired sites.
Non-Specific Histology (8000, 8001)	The percent of histologically or cytologically confirmed analytic cases submitted by your facility for the accession year with histology coded as 8000 or 8001.	Number of histologically or cytologically confirmed cases submitted by your facility for the accession year with histology coded as 8000 or 8001.	Total number of histologically or cytologically confirmed cases submitted by your facility for the accession year.	The most specific histology should always be used. See FORDS 2013, page 120 for instructions on coding histology. Refer to the Multiple Primary and Histology Coding Rules for instructions on choosing the most appropriate histology.
Unknown County at Diagnosis	The percent of analytic cases submitted by your facility for the accession year with County at Diagnosis coded as 999.	Number of cases submitted by your facility for the accession year with County at Diagnosis coded as 999.	Total number of cases submitted by your facility for the accession year.	Address at diagnosis is essential to researchers using cancer registry data to assess geographic patterns of cancer. See FORDS 2013, pages 42-49 for instructions for coding address at diagnosis, including county at diagnosis.

DC Facility Quality Sample Report Form

DC | HEALTH
GOVERNMENT OF THE DISTRICT OF COLUMBIA

DISTRICT OF COLUMBIA CANCER REGISTRY
DATA SUBMISSION STATUS REPORT

Facility Name: _____ Facility ID# _____

Data Submission Year: _____

DC Cancer Reporting Regulations

In accordance to DC Law CDCR 22.215, "each health care provider and health care facility shall report within six (6) months of diagnosis or first contact, any person diagnosed with or treated for benign tumors of the brain or central nervous system or any malignant cancers, or for whom cancer treatment planning was performed but the patient opted no treatment or who expired with cancer as a cause of death.

DC Cancer Registry requires data submission from reporting facilities every other month (during even months), on the 15th day of the month.

If your facility is an American College of Surgeons, Commission on Cancer (ACoS/CoC) approved facility, 2016 Cancer Program Standard 1.6 requires *each year the cancer committee establishes and implements a plan to annually evaluate the quality of cancer registry data and activity. The plan includes procedures to monitor and evaluate each required control plan component, which includes abstracting timeliness, accuracy and completeness of abstracted data. Quality control must be performed prior to data submissions and a copy of the QA summary provided with each submission.*

A copy of this report will be sent to Cancer Registry Manager, Cancer Registry Manager's Director, Cancer Committee Chair (if applicable) & Hospital Administration.

Data Submission Requirements

This report is used as a preliminary indication of the completeness, timeliness, and quality of data in your cancer registry. Data submissions must meet all reporting requirements to be in compliance. If data does not meet all requirements, the submission file will be rejected. Your facility will have five (5) business days to correct and resubmit to DCCR. Please ensure that the corrected submission file has the same number of cases as rejected submission file.

- Data is 100% error-free (Edits must be performed using DC v18c metafile. Edits can also be performed using DC metafile in GenEdits Plus v5.)
- Data received within 6 months of first contact/diagnosis
- No duplicate cases identified in submission
- Data submission meets frequency requirements (75% of cases submitted for reporting month)
- Data passes 98% visual edits (25 randomly sampled cases)
- DCCR text requirements are utilized

Facility Quality_DC.pdf

DISTRICT OF COLUMBIA CANCER REGISTRY
DATA SUBMISSION STATUS REPORT

Summary of Data Submission

Submission Timeframe

Submission Due Date _____

Date Submission Received _____

Data Submission Results

Total number of cases submitted _____

Percentage of cases passing defined edits on submission _____

Total number of deleted cases within file _____

(Cases deleted due to duplicate record submission; suspense/incomplete cases, cases that do not meet the DCCR reporting requirements (non-reportable cases), and cases diagnosed prior to the DCCR 1996 reference date

Data Submission Criteria (all requirements must be met to obtain compliance)

____ Data is 100% error-free (file will be returned if <100%)

____ Data received within 6 months of first contact/diagnosis (timeliness)

____ No duplicate cases identified in submission (file will be returned if duplicates exist)

____ Data submission meets frequency requirements (75% of cases submitted for reporting timeframe)

____ Data passes 98% visual edits (25 randomly sampled cases)

____ DCCR text requirements are utilized (visual edits review)

Current Status of Your Cancer Registry

____ Compliant

____ Non-Compliant (File rejected/returned to facility for corrections)

899 North Capitol Street NE, 3rd Fl | Washington, DC 20002 | P 202-442-5925 | F 202-442-4947 | dchealth.dc.gov

DISTRICT OF COLUMBIA CANCER REGISTRY
DATA SUBMISSION STATUS REPORT

DCCR COMMENTS

Please review this report in detail. If you have any questions or would like additional information please contact Maria Leuchert at (202) 442-5873 or maria.leuchert@dc.gov. Thank you for your cooperation in providing timely and quality data to the District of Columbia Cancer Registry (DCCR).

DCCR Cancer Registry Data Submission Report Card

Facility Name: **Facility ID:** **Diagnosis Year:** **Submission Year:**

Reporting Criteria	Data Submission Months						Yearly Total by Criteria
	February	April	June	August	October	December	
Data is 100% error-free	0	1	1	1	1	1	**5**
Data received within 6 months of first contact/diagnosis	1	0	0	1	0	1	**3**
No duplicate cases identified in submission	1	1	0	1	0	1	**4**
Data submission meets frequency requirements	0	1	0	1	1	1	**4**
Data passes 98% visual edits	1	1	1	1	1	1	**6**
DCCR text requirement utilization	1	1	1	1	0	0	**4**
Monthly Submission Points	**4**	**5**	**3**	**6**	**3**	**5**	**26**
Monthly Submission Grade	**C**	**B**	**D**	**A**	**D**	**B**	**4**
Total Annual Grade							**C**

Criteria Not Met = 0
Criteria Met = 1

Facilities with an overall annual grade of "A" will be recognized by the DCCR.

Grading Scale
6/6 points = A
5/6 points = B
4/6 points = C
3/6 points = D
< 3/6 points = F

899 North Capitol Street NE, 3rd Fl | Washington, DC 20002 | P 202-442-5925 | F 202-442-4947 | dchealth.dc.gov

Appendix F: Sample Communication Tools Submitted by Registries

1. Please complete this form electronically and save the file
2. Use two forms if more space is needed
3. Email the completed form as an attachment to: wroshala@crgc-cancer.org

Cancer Registry of Greater California
Public Health Institute

Note: Effective June 1, 2019, the CRGC office location is:
1750 Howe Avenue, Suite 550
Sacramento, CA 95825
916-779-0300

Reporting Facility Abstractor Information Form

Facility Name:	
Facility Street Address:	
Contact Name:	
Phone:	
Fax:	
E-Mail:	
Cancer Reporting Software Used:	

Number of Abstractors:

Abstractor Name	Initials*	Indicate whether Employee or Vendor		If a Vendor, provide name of agency or service	CTR Status		If Non-CTR, indicate if CTR eligible		If CTR, please provide CTR #**	If working remotely, enter physical location (i.e. City, State, Country)
		Employee	Vendor		CTR	Non-CTR	Yes	No		

*Include all initials and/or numbers the named abstractor uses in cancer reporting software.

**The CTR number begins with the last 2 digits of the year the CTR exam was successfully taken.

Revised June 2019

CRGC
CANCER REGISTRY OF GREATER CALIFORNIA

Completeness of Reportable Cancer Cases for Year 2019

Complete one form for each reporting facility

This is to attest that (Enter the Name of the Reporting Facility and Reporting Facility Number**), has completed submitting reportable cancer cases for year 2019.** Please email the completed form to: wroshala@crgc-cancer.org

_____

Print Name of Person Completing the Form

_____

Position/Title

_____

Date

If complete, confirm the total number of cases submitted for year 2019: _____

If not complete, provide an estimated date for when all 2019 cases will be completed:

_____

1750 HOWE AVENUE • SUITE 550 • SACRAMENTO, CA 95825 916-779-0300 916-779-0264 CRGC-CANCER.ORG

Note from registry: The intent is to have the Registry attest to the fact they are completed with casefinding and abstracting for the specified year and to provide the total number of cases they accessioned for that year. The form asks the Registry to provide current staff, Registry Managers, Hospital CEO and the Cancer Committee chair. The form gives the Registry a chance to tell us about any significant changes in staffing, physicians or program changes that may impact their case counts for the year. Once we receive the report we compare their numbers with what we have in our database. If a hospital has more cases in their registry, we will ask them to resend the full year of cases so we can add the missing cases. The form is then stored as a reference in the hospital file.

Colorado Central Cancer Registry - Hospital Year End Summary

Hospital Affiliation	
Hospital Name	

Please provide a summary of the work completed by your facility for the 2018 reporting period.

Total number of cases first admitted to your facility in 2018 and reported to the CCCR.

Total Number of Cases:	
- Number of Analytic Cases	
- Number of Non-Analytic Cases	

Did you have any changes at your hospital or in your registry in the past year (i.e. number of beds, physician changes, hospital services, registry staffing changes, etc.)

CERTIFICATION:

☐ I hereby certify that all casefinding and abstracting of reportable cancer cases for the year 2018 is complete.

☐ Abstracting for 2018 is not complete, we will contact our Registry Liaison to create a reporting plan.

Registry Manager: _____ Date: _____

Please provide the Current Status of 2019 Cases: _____

Does your hospital report any cases as requested by your Cancer Committee such as high grade intraepithelial neoplasia, Gr III of the colon? Please state which cases you are reporting by Cancer Committee agreement and the year you started collecting these cases:

Please provide your current hospital contact information: (Include name, phone number and email of all applicable individuals)

	Name	Email or Phone
CEO		
Cancer Committee Chair		

Cancer Registry Staff	Name	Phone	Email
Registry Manager			
Registry Supervisor			
Registrars:			

Louisiana Tumor Registry - Facility Data Quality Indicator Report (DQIR)

XXX MEDICAL CENTER

Year Reported - 3rd/4th Qtr 2018 & 1st/2nd Qtr 2019

	Benchmark***	2019 Qtr3	2019 Qtr4	2020 Qtr1	2020 Qtr2	Total
Cases						
Total Cases		763	353	436	338	1890
% Analytic Cases		76.9%	83.9%	92.9%	97.3%	85.6%
% Non-Analytic Cases		23.1%	16.1%	7.1%	2.7%	14.4%
Not Reported to LTR within 6 months*	<10.0%	0.0%	0.0%	0.00%	3.0%	3.0%
Demographics**						
Sex Unknown (9 or blank)	<1.0%	0.0%	0.0%	0.0%	0.0%	0.0%
Race Unknown (98,99, or blank)	<2.0%	1.0%	1.0%	0.2%	0.6%	0.7%
Ethnicity Unknown (9 or blank)	<3.0%	1.4%	1.7%	0.2%	1.2%	1.1%
Birth Date Unknown (99/99/9999)	<1.0%	0.0%	0.0%	0.0%	0.0%	0.0%
Marital Status Unknown (9 or blank)	<10.0%	6.1%	1.7%	3.0%	2.4%	3.8%
Addr at Dx - PO Box	<5.0%	2.2%	0.3%	0.2%	0.0%	0.9%
Addr at Dx Street Unknown	<2.0%	0.0%	0.0%	0.0%	0.0%	0.0%
Addr at Dx City Unknown	<2.0%	0.0%	0.0%	0.0%	0.0%	0.0%
Addr at Dx Zipcode Unknown (99999 or blank)	<2.0%	0.0%	0.0%	0.0%	0.0%	0.0%
County at Dx Unknown (999 or blank)	<1.0%	0.0%	0.0%	0.0%	0.0%	0.0%
Tumor Characteristics**						
Other/Ill-Defined Sites (C76.x)	<2.5%	0.0%	0.0%	0.0%	0.0%	0.0%
Unknown Primary Site (C80.9)	<2.5%	0.9%	1.7%	0.0%	1.1%	0.9%
Laterality (codes 3, 9, blank)	<5.0%	1.2%	0.0%	1.8%	0.0%	0.9%
Morphology Non-specific (8000-8005)	<2.5%	0.2%	0.0%	1.6%	1.2%	0.7%
Dx Method Unknown (9 or blank)	<1.5%	0.0%	0.0%	0.0%	0.0%	0.0%
Primary Payer Unknown (99 or blank)	<5.0%	0.2%	0.3%	0.5%	0.0%	0.2%
Clin & Path Stage Group Unknown (99 or blank)	<10.0%	6.9%	4.4%	7.7%	9.1%	7.1%
Summary Stage 2018 -Unknown (9 or blank)	<10.0%	2.9%	4.2%	2.7%	2.8%	3.1%
EOD--Primary Tumor-Unknown (999 or blank)	<8.0%	4.7%	3.8%	3.5%	1.8%	3.6%
EOD--Regional Nodes-Unknown (999 or blank)	<6.0%	2.3%	2.4%	1.5%	1.5%	2.0%
EOD--Mets-Unknown (99 or blank)	<1.0%	0.0%	0.3%	0.0%	0.0%	0.1%
Prostate Pathological Extension-Unknown (999 or blank	<10.0%	0.0%	0.0%	1.5%	0.0%	0.4%

* Timeliness is a comparison of the the date of first contact/date of admission and date the case was received by central registry. A one month grace period is given for those cases awaiting complete treatment information. Only cases dx'd 2018+ are considered for Timeliness.

** DQI measures for Demographics and Tumor Characteristics are only calculated on Analytic Cases (Class of Case 00,10,11, 12,13,14,20,21,22) Exception - Morphology and Staging indicators exclude Class of Case 00.

*** Benchmarks for Demographics and tumor characteristics are based on SEER, NPCR, and NAACCR with modification when average unknown percentage in LTR is much lower than the benchmark of SEER, NPCR, or NAACCR. For the data items (Ethnicity, Marital status, Address PO Box, diagnosis confirmation, and primary payer) that are not in the SEER, NPCR, or NAACCR data quality report, the average of unknown percentage based on previous two years cases combined is used as a benchmark.

Report Run Date - 7/23/2020

DQI	Benchmark	Award Certificate Gold	Sliver	Bronze
Cases				
Total Cases				
% Analytic Cases				
% Non-Analytic Cases				
Not Reported to LTR within 6 months*	<10.0%	<10.0%	<15.0%	<20.0%
Demographics**		Met all 10	Met 9 at least	Met 8 at least
Sex Unknown (9 or blank)	<1.0%			
Race Unknown (98,99, or blank)	<2.0%			
Ethnicity Unknown (9 or blank)	<3.0%			
Birth Date Unknown (99/99/9999)	<1.0%			
Marital Status Unknown (9 or blank)	<10.0%			
Addr at Dx - PO Box	<5.0%			
Addr at Dx Street Unknown	<2.0%			
Addr at Dx City Unknown	<2.0%			
Addr at Dx Zipcode Unknown (99999 or blank)	<2.0%			
County at Dx Unknown (999 or blank)	<1.0%			
Tumor Characteristics**		Met all 12	Met 10 at leas	Met 9 at least
Other/Ill-Defined Sites (C76x)	<2.5%			
Unknown Primary Site (C80.9)	<2.5%			
Laterality (codes 3, 9, blank)	<5.0%			
Morphology Non-specific (8000-8005)	<2.5%			
Dx Method Unknown (9 or blank)	<1.5%			
Primary Payer Unknown (99 or blank)	<5.0%			
Clin & Path Stage Group Unknown (99 or blank)	<10.0%			
SEER Summary Stage 2000 Unknown (99 or blank)	<6.0%			
EOD--Primary Tumor-Unknown (999 or blank)	<8.0%			
EOD--Regional Nodes-Unknown (999 or blank)	<6.0%			
EOD--Mets-Unknown (99 or blank)	<1.0%			
Prostate Pathological Extension-Unknown (999 or bl	<10.0%			
Variables not scored***				
Tumor Size Summary-Unknown (999 or blank)				
Tumor Size Clinical-Unknown (999 or blank)				
Tumor Size Pathologic-Unknown (999 or blank)				

* Timeliness is a comparison of the the date of first contact/date of admission and date the case was received by central registry.
A one month grace period is given for those cases awaiting complete treatment information. Only cases dx'd 2018+ are considered for Timeliness.

** DQI measures for Demographics and Tumor Characteristics are only calculated on Analytic Cases (Class of Case 00,10,11, 12,13,14,20,21,22)
Exception - Morphology and Staging indicators exclude Class of Case 00.

*** Data items related to the tumor size were not scored for now. We are waiting for SEER to release a list of cancer sites that are required to code tumor size.

Note: Benchmarks for Demographics and tumor characteristics are based on SEER, NPCR, and NAACCR with modification when average unknown percentage in LTR is much lower than the benchmark of SEER, NPCR, or NAACCR. For the data items (Ethnicity, Marital status, Address PO Box, diagnosis confirmation, and primary payer) that are not in the SEER, NPCR, or NAACCR data quality report, the average of unknown percentage based on previous two years cases combined is use