

# **Identify and Implement Best Practices for Cancer Registry Operations**

August 2019

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## Executive Summary

In 2018, the National Program of Cancer Registries (NPCR) initiated a major assessment aimed at enhancing the capacity of states to meet 12-month reporting standards for cancer reporting and improving central cancer registry operations overall. The work was considered important because high-quality and timely data are essential to cancer surveillance, public health, and policy development. At that time, there appeared to be variability in the capacity of NPCR cancer registries to meet NPCR's established standards for the completeness and timeliness of cancer registry data at 12 months following diagnosis.

A key component of this work involved identifying and implementing best practices for registry operations that would increase the compliance of cancer registries with NPCR's 12-month data standard. NPCR contracted with the National Association of Chronic Disease Directors (NACDD) to provide administrative oversight for the project, which was largely carried out by the North American Association of Central Cancer Registries (NAACCR). The project built upon an earlier study conducted by NAACCR's Assessment of Central Cancer Registry Timeliness and Reporting Standards Task Force entitled [\*NAACCR Assessment of Central Registry Timeliness and Reporting Standards \(ACCR TRS TF\)\*](#) (NAACCR 2018).

The first factor to consider is the method by which completeness is measured. NPCR sets a benchmark of having 90% of cases diagnosed within the past 12 months reported to the central cancer registry. How do we know that 90% of the cases have been counted when we do not know the final tally of cases for a given year? This is a complex problem that has been under discussion for quite some time. NPCR has been using a method to calculate completeness that relies on the ratio of newly diagnosed cases to the number of deaths in the same area. This method is similar to the one used by NAACCR but different from the method utilized by the Surveillance, Epidemiology, and End Results (SEER) program.

While the NPCR/NAACCR method has proven to be useful, it is known to have several drawbacks. In addition, the applicability of applying this measure to the 12-month data has never been demonstrated; it was designed to measure 24-month data. For these reasons, one arm of this investigation was to analyze the statistical methods used to measure cancer registry completeness and determine which measure(s) are most effective at the 12-month and 24-month time periods.

The second factor involved evaluating the operational methods in use by states that usually or always met the NPCR 12-month data standard and comparing these operational methods to states that sometimes or rarely met the standard. The intent of this aspect of the project was to identify best practices in use by the registries that usually/always met the standard and share them with registries that have been unable to consistently meet this goal.

This report discusses the findings from each arm of the project: Statistical Approach to Evaluating Completeness and Examination of Registry Operations and Best Practices. In addition, NPCR requested the collection of other information related to registry operations and NPCR services. This report also includes thorough discussions of these topics in the section Other Information from Assessments and Interviews.

To address the first goal, a Statistical Expert Panel was organized to assess the major methods used in North America to estimate cancer registry completeness and make recommendations for an objective, unified, and accurate metric. An expert panel was convened that included representatives chosen for their experience in statistical modeling and demonstrated authority in the field. Representation from all major cancer surveillance organizations was recruited, including Centers for Disease Control and Prevention (CDC), NACDD, NAACCR, and SEER, as well as expert consultants in the field (see Expert Panel List in Appendix B). The project required carefully evaluating the pros and cons of various methods for measuring registry completeness and then selecting the most promising of these methods for more rigorous analysis.

Throughout the project period, the Expert Panel met via Zoom meetings biweekly and then convened in Gaithersburg, Maryland, in early April 2019, for a Summit where members conducted an intensive review of the pros and cons of all models. Two models were identified for additional study: the incidence-to-mortality rate ratio method; and a modeling approach that estimates expected case counts for each registry based on population demographics, smoking and other behaviors, and screening rates and other characteristics of health care systems. The panel then met in Vancouver, Canada to review the preliminary analysis of the models and define a more robust assessment for the models. Because of the complexity found in the initial review, the project requires much more analysis than originally forecast. While the analysis is presently underway, more study will continue until June 2020 when the analysis should be complete and a best model identified.

As part of the operations study, we undertook comprehensive evaluations of eight NPCR registries that always or usually met the NPCR 12-month 90% completeness measure in recent years, five that sometimes met the measure, and nine that rarely or never met the measure. The registries were chosen to represent a geographical cross-section of the country, different funding streams, and a range of population sizes. An extensive analysis was conducted, including a quantitative assessment of critical registry practices, guided expert interviews, focus groups, and several special studies of workflow procedures. All of these data were then collated and presented at an in-person Summit with the participating registries and operations experts. The Summit was held in Atlanta, Georgia, on May 6–8, 2019, to review findings, formulate guidelines for best practices, and set priorities for moving forward. The group deliberated thoughtfully over the next 2.5 days, considering all aspects of the issues and examining the pros and cons of various best practices for meeting 12-month reporting standards, as well as reviewing the barriers and opportunities for such critical registry needs as staffing and

education, software and IT, auto-consolidation, operational workflows, external reporting bottlenecks, and technical assistance improvements. Viable solutions were identified, priorities were set, and recommendations were developed. The participating registries then stepped back to carefully review and discuss the findings of the Summit with their staff and stakeholders within their state. The group reconvened in Vancouver, Canada, in June 2019, to further deliberate and reach a final consensus for the recommendations presented in this report.

## **Statistical Conclusion and Recommendations**

The Statistical Expert Panel carefully evaluated several models for estimating completeness of cancer reporting by central cancer registries. All of the methods considered had disadvantages, and significant biases were uncovered that relate to nature of the measures themselves. Nevertheless, the Statistical Expert Panel has developed plans to refine these measures to create a more accurate measure. In short, no single method emerged as a satisfactory measure. The Panel wishes to continue working on this problem and conduct further analysis and modeling with the intent of improving the methods currently in use.

In addition, the Panel believes that it is possible to produce reliable cancer incidence rates for the nation and states by applying statistical modeling to the data collected by registries at 12–13 months after diagnosis. The Panel would like to work to demonstrate the feasibility of this concept during the next project period.

## **Operations Conclusion and Recommendations**

This project generated a sweeping view of registry operations in 22 states. All of the Registries are able to conform to a 24-month completeness data standard, but only 14% of our sample were able to consistently meet the 12-month data standard. Some of the reasons for this may lie in the biases inherent in the completeness measures being used. Those states that meet the 12-month standard, whether consistently or not, often expressed concerns that meeting the standard required unorthodox methods that could compromise data quality and bias the results. Many barriers to achieving completeness were identified, including difficulty completing the first course of treatment, a lack of qualified staff at both the hospital and central cancer registry level, funding issues, burgeoning workload, a lack of technology to assist in auto-consolidation, insufficient IT support, difficulty with ePath applications, weak state laws, and trying to manage reporting from multiple nonhospital sources.

On the other hand, Registries had clear ideas about the methods they use to overcome some of the barriers, including developing and managing strong relationships with reporting facilities, tools to monitor timely reporting, incentives, and strengthening regulations. Interestingly, a number of factors thought to be associated with timely reporting were not found to be influential in our sample, although this may be due to classification problems, and we will be reexamining this once more detailed information on state specific completeness scores becomes available.

In addition, many broad themes emerged from the study that could improve overall registry operations and ultimately timely reporting. The Registries identified software improvements and a need for auto-consolidation routines to improve the processing of the growing number of records received each year. More timely software releases are needed, and developing a standardized timeline for such releases would be beneficial. More training and education are definitely needed, and creative solutions such as supporting academic programs would be helpful to increase the trained professionals needed to staff the Registries now and into the future. Registries also asked for guidance in recruiting and retaining staff, work-from-home policies, and standardized educational opportunities for on the job training. Workflow processes vary among states, and no standard procedures or best practices exist for most reporting. Efficient methods would help workflow and improve overall timeliness of registries. The technical assistance needs—focused around software improvements and training, Veterans Affairs (VA) reporting, change management, help with improving facility reporting—were all also recommended.

## Recommendations for Next Steps

The Statistical Expert Panel recommends the following:

- Further analysis of the modeling approach to measuring completeness of cancer reporting, although it is likely that the modeling approach will provide the most accurate estimate of completeness
- Developing and refining statistical methods to use the data submitted at 12 months to accurately project incidence rates for the nation

The following steps were recommended for developing operations best practices for meeting 12-month timeliness standards:

- Develop guidelines for best practices to be used across all NPCR-funded states to help in meeting the 12-month timeliness standard. Suggested topics include:
  - Best-practice tools to monitor central registry and facility timely reporting progress
  - Best-practices tool to develop and promote good relationships with reporting facilities
  - Best practices to develop facility specific displays or record formats for case reporting
  - Best-practice tool to establish a standard timeline for biannual updates to cancer-reporting software
  - Developing and implementing procedures to effectively handle ePath volume

- Best-practices guidelines to “Grow a CTR” program
- Best-practices guidelines to strengthen state-reporting regulations
- Pilot test guidelines in states that almost never and sometimes meet NPCR 12-month timeliness standards.
- Develop and test new strategies, methods, and tools designed to help all states meet timeliness standards
- Plan and implement follow up meetings among participating states to review and refine best practices

The following next steps were recommended to move forward to address operations infrastructure and broad changes:

- Conduct pilot projects with one or two 4-year colleges and universities to develop concentrations or certifications in cancer registry operations that would provide core courses for certified tumor registrar (CTR) training for public health, biology, informatics, Health Information Management (HIM), and other related majors.
- Establish standard timeline for biannual updates to cancer reporting and central registry software. Analyze the timing and order of processing the different types of source records to elicit efficiencies that could be adopted by all registries.
- Develop a promotional campaign designed to encourage students to pursue careers in cancer surveillance.
- Develop a basic CTR-training program to provide the core skills needed to educate new staff and reduce the burden on current staff who have other job responsibilities.
- Design and produce training materials and modules for hospital and non-hospital reporters to handle the complexities of their work.
- Evaluate the importance of collecting certain data items such as treatment and detailed stage information.
- Develop statistical solutions to producing reliable incidence rates based on 12-month data from 80% of the population.
- Evaluate existing auto-consolidation routines to form a foundation for automatically consolidating information at the tumor and report level.

## Project Overview

### Background and Significance

The American cancer surveillance systems 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) has collected population-based cancer incidence data in the United States since 1995; today, NPCR 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. These data represent 97% of the U.S. population.

This coverage enables researchers, clinicians, policymakers, public health professionals, and members of the public to monitor the burden of cancer, evaluate the successes of programs, and identify additional needs for cancer prevention and control efforts at national, state, and local levels. Public health professionals, researchers, the medical community, and policymakers need information about newly diagnosed cancer cases to understand and address the nation's cancer burden, and the NPCR provides the foundation for all of the data needs.

In order to maximize the utility of these data, it is critical that information be available in a timely manner. Currently, national cancer surveillance organizations require complete reporting of cancer data within 23 months of diagnosis; thus, there is a 2-year lag between diagnosis and the reporting of cancer statistics to the CDC. This delay is due in part to delays in collecting complete information on the first course of treatment, which may extend for many months after the initiation of treatment. Other factors known to cause reporting delays include weak state laws covering the reporting of cancer, the need to consolidate multiple reports from various institutions that see any one cancer case, and a shortage of specially trained staff to do this work. CDC has also introduced a requirement to reduce the reporting delay to within 12 months of diagnosis, but the majority of the registries fail to meet this standard on a consistent basis.

In the interest of reducing this reporting delay, the CDC contracted with the National Association of Chronic Disease Directors (NACDD) to conduct an extensive analysis focusing on methods to improve the compliance of cancer registries with the CDC's NPCR 12-month data standard. In turn, NACDD subcontracted with the North American Association of Central Cancer Registries (NAACCR), a collaborative umbrella organization for cancer registries, governmental agencies, professional associations, and private groups in North America interested in enhancing the quality and use of cancer registry data.

Two expert panels were convened: 1) to examine the statistical validity of completeness/timeliness measures in use by CDC and cancer surveillance groups; and 2) to evaluate best practices for collecting and processing cancer incidence data within 12 months of diagnosis. The NPCR program provided information on compliance with



their 12-month data standard, and central cancer registries that met, did not meet, and sometimes met the NPCR 12-month data standard were identified to participate in the project. The project initiated with registries completing written assessments and participating in in-depth interviews and focus groups, followed by two in-person summits (one for the statistical part and one for the operational part of the project).

High-quality and timely data are essential to cancer surveillance, public health, and policy development. There is variability among NPCR cancer registries in meeting NPCR's established standards for the completeness and timeliness of cancer registry data at 12 months following diagnosis, hence the request by NPCR for an in-depth study. A comprehensive assessment of workflow across registries was proposed to determine gaps or challenges hampering timeliness. The intent was to identify evidence-based strategies to enable NPCR registries to collect and process cancer incidence data in a timely manner, while making data available for evidence-based informed decision making regarding public health priorities. It is anticipated that, as a result of this project, cancer registries in the NPCR program will be better equipped to collect and process cancer incidence data in a timely manner and make such data available for informed decision making regarding public health priorities.

## General Approach

There are two important factors to consider when evaluating 12-month cancer data for public health purposes. NPCR sets a benchmark of having 90% of cases diagnosed within the past 12 months reported to the central cancer registry. The first factor to consider is the method by which completeness is measured. How do we know that 90% of the cases have been counted when we do not know the final tally of cases for a given year? This is a complex problem that has been under discussion for quite some time. NPCR has been using a method to calculate completeness that relies on the ratio of newly diagnosed cases to the number of deaths in the same area. This method is similar to the method used by NAACCR but different from the method utilized by the SEER program. (These methods will be discussed in detail below.) While the NPCR method has proven to be useful, it is known to have several drawbacks. In addition, the applicability of applying this measure to 12-month data has never been demonstrated; it was designed as a measure for 24-month data. For these reasons, one arm of this investigation was to analyze the statistical methods used to measure cancer registry completeness and determine which measure(s) are most effective at the 12-month and 24-month time periods.

Secondly, this project evaluated operational methods in use by states that usually or always met the NPCR 12-month data standard and compared these operational methods to states that sometimes or rarely met the standard. The intent of this aspect of the project was to identify best practices in use by the registries that usually/always met the standard and share them with registries that have been unable to consistently meet this goal.

This report discusses the findings from each arm of the project:

- Statistical Approach to Evaluating Completeness
- Examination of Registry Operations and Best Practices

In addition, NPCR requested the collection of other information related to registry operations and NPCR services. This report also includes thorough discussions of these topics in the section Other Information from Assessments and Interview.

## How States Were Chosen

CDC's NPCR annually evaluated data for quality, completeness, and timeliness. Data evaluated for the 12-month standard must meet the following criteria:

- 90% complete based on observed-to-expected cases
- 2 per 1,000 or fewer unresolved duplicate rates
- Maximum percent missing critical data elements
  - 3% age
  - 3% sex
  - 5% race
  - 3% county
- 97% pass CDC-prescribed set of standard edits

The registries selected for inclusion in the project were chosen based on their performance in meeting the NPCR 12-month data completeness standard in recent years. At the onset of the project, NPCR provided a spreadsheet showing each registry's performance in meeting this standard for diagnosis in years 2010 through 2016. Those that met the standard at least at six of the 7 years were categorized as "usually or always" meeting the standard. Those that met the standard 4 or 5 times were categorized as "sometimes" meeting the standard, and those that met the standard two or fewer times were categorized as "rarely or never" meeting the standard. Registries that met the standard five of seven times were elevated to the "usually or always" group if they met the standard in each of the four most recent years. There were no registries that met the standard exactly three times. Note that we were provided with compliance data as a dichotomous variable (met or did not meet the standard by year), and having completeness scores may have provided a better basis of classification.

Sixteen registries were classified in the "usually or always" category. Of these registries, eight were selected to participate in the assessment, interviews, focus groups, and other project activities. These eight were chosen to provide geographic and demographic diversity from among the 16.

Twenty-six registries were classified in the “rarely or never” category. Of these, nine were selected to participate in the assessment, focus groups, and other project activities. These nine were chosen to provide geographic and demographic diversity.

There were just five registries in the “sometimes” category. All of them were selected for participation in the wider project. It was thought that registries that changed their completeness status from year to year might have particular insight into what practices did and did not work. Of course, it is also possible that these registries conducted the same practices from year to year and that their efforts always placed them near the cut point for meeting the standard.

Please note that state-specific compliance information was provided by NPCR and that the classification was conducted in conjunction with NPCR. State-specific classification results are not presented here to preserve the confidentiality of registries in regard to their performance on these measures. Data available on request to NPCR staff.

# Statistical Approach to Evaluating Completeness

## Establishment and Composition of Statistical Expert Panel

The Statistical Expert Panel includes representatives from CDC, NACDD, NAACCR, SEER, Information Management Services, Inc. (IMS), individual registries, and outside consultants. Participants were invited based on their expertise in quantitative aspects of cancer surveillance, particularly past involvement with defining and refining completeness measures for North American registries.

- Dr. Kevin Ward of the Georgia Comprehensive Cancer Registry has served as the primary curator of the existing NAACCR completeness method and has chaired a work group designed to address some of its shortcomings.
- Dr. Hannah Weir of the CDC has served on this work group and was the co-chair of the group that initially developed the NAACCR method. She brings a historical background to the group.
- Drs. Eric Feuer, Li Zhu, and Huann-Sheng Chen of the National Cancer Institute's SEER program have led the development of the modeling approach and internal methods for measuring completeness, as well as the implementation of delay adjustment for a variety of cancer surveillance purposes.
- Dr. Barnali Das of the National Center for Health Statistics (NCHS) previously worked on the modeling approach when she was at SEER.
- Dr. Robert Anderson from NCHS is a national expert on mortality data and frequently collaborates with the cancer surveillance community.
- Dr. Charles Wiggins is the director of the New Mexico Tumor Registry and past president of NAACCR. He has been outspoken about the implications of the constant incidence-to-mortality ratio assumption. New Mexico has consistently appeared to be underestimated using the NAACCR method.
- Dr. Lihua Liu, representing the Los Angeles Cancer Surveillance Program, is a national expert on demographics and cancer, particularly among minority populations. The Los Angeles Cancer Surveillance Program also has frequently appeared to be underestimated for completeness using the NAACCR method.
- Dr. Francis Boscoe of Pumphandle is a national cancer surveillance expert with nearly 20 years' experience at the New York State Cancer Registry.
- NAACCR was represented by Betsy Kohler, the Executive Director, and Lori Havener provided logistical support at the in-person meetings.
- The CDC additionally was represented by Drs. Paul Sutton, Trevor Thompson, and Manxia Wu. Dr. Paulette Valliere represented NACDD.

- Andy Lake, Rick Firth, Don Green, and Joe Zou variously represented IMS in the role of providing programming and IT support and access to NAACCR databases.
- Kathy Huamani of SCG served as notetaker during both the conference calls and in-person meetings.

## Description of Completeness Models Considered

### Incidence to Mortality Rate Ratio Method

#### Measuring Completeness

Cancer surveillance relies on complete, unduplicated case capture within a defined catchment area and during a defined time period to accurately enumerate incident cancer cases and calculate age-adjusted cancer incidence rates. Any disease surveillance system requires complete case capture to accurately measure disease burden within a defined population. However, it is often difficult to estimate how many cases go undetected and, thus, not enumerated. Cancer is distinguished by having relatively clear diagnostic criteria, generally microscopic confirmation of malignant cells, and sometimes diagnoses are made based on other clinical findings. Yet still, cases may remain unidentified by the healthcare system. In order to estimate the accuracy with which cancer registries are able to identify all cases within their catchment areas, several completeness estimates have been developed and evaluated. These estimates form the foundation by which compliance the NPCR 12-month data standard is measured. Yet, it is understood that the measures currently in use are not ideal; thus, this project evaluated the existing methods to determine if the measures could be improved or replaced with a more accurate measure.

#### Description of Completeness Measures Considered

The Expert Panel considered several different approaches for measuring completeness. The methods considered were those that have been in use by cancer surveillance organizations in the United States and also in other parts of the world. They represent all of the most commonly used methods to measure completeness of cancer registry reporting. Each of the methods is discussed in detail below. The Expert Panel recommends that two of these methods be considered for continued development and assessment—one not to be further considered and one to be considered to the extent that it informs the delay-adjustment methodology.

More information on the deliberations of the Statistical Expert Panel may be found in Appendix C.

## **Incidence-to-Mortality Ratio Method**

This is the method currently used by NAACCR and NPCR to measure registry completeness. There are minor differences between the methods used by the respective organizations; a recent comparison found that the estimate differed by more than 1% for only five registries and by more than 2% for just one registry. This summary considers only the NAACCR version of the method.

The method defines completeness as the ratio of observed-to-expected incidence rates for a registry. As is characteristic of such ratios, the average value across all registries is 1, or 100%; values are distributed around this average so that roughly half of registries have values above 1, and roughly half have values below 1. The observed incidence rate is calculated by summing age-adjusted rates stratified by sex, race, and cancer site. Many race and site classifications have been assessed. Currently, the method considers 18 sites for men and 15 for women, including nearly all of the most common sites but excluding the two most common sites—the breast and prostate. Currently, race comprises whites and blacks, but Hispanics and “other” categories also have been proposed for inclusion. For minority race groups, a rule of thumb has been that such groups must comprise at least 10% of the population in a registry to be included in a calculation.

The expected number of cases is obtained by multiplying the registry’s mortality rate by the national incidence-to-mortality rate ratio (IMRR), again stratified by sex, race, and cancer site. Thus, if the national IMRR is 1.5 for white male bladder cancer, for example, then the incidence rate of white male bladder cancer in that state would be expected to be 1.5 times the mortality rate. In order to achieve a more stable measure, the IMRR makes use of 5 years of data, and the registry’s mortality rate uses 2 years of data (3 years for small registries with fewer than 500,000 people). National IMRRs use national mortality but incidence from 11 SEER registries (See Glossary for explanation). (The NPCR method uses incidence data from all NPCR registries instead of restricting to the SEER 11 registries.)

The core assumption of this method is that incidence tracks mortality in a constant and universal manner by sex, race, and cancer site. This is not the case, of course, and indeed much of cancer surveillance is concerned with showing how this relationship is not constant insofar as it is driven by factors such as screening, healthcare access, and quality of care. One way of correcting for this issue has been to introduce an adjustment term to the method that increases the weight that each registry gives to its own data, effectively smoothing the calculated IMRRs toward 100%, raising them for registries with low-measured completeness and lowering them for registries with high-measured completeness. At the extreme, raising the adjustment term to its maximum value would mean that every registry was using only itself as a reference, and all registries would be 100% complete. The appropriateness of such an adjustment term is unknown, and it lacks any empirical basis.

The Statistical Expert Panel discussed this measure at length and identified advantages and disadvantages to the method. The primary advantages are its long tenure and familiarity within the registry community and its transparency; it is a simple matter to independently verify the calculation using routine surveillance data. In addition, a spreadsheet is available that allows any registry or researcher to assess the implications of varying parameters such as sex, race, and site stratification and the adjustment term.

The primary disadvantages include the constant IMRR assumption, instability of the measure for small registries, exclusion of the most common cancer sites, and a seeming systematic underestimation of completeness in areas with heavily Hispanic populations.

This measure has been used as a criterion in NAACCR certification for more than 30 years. Registries that achieve 95% completeness (and meet other criteria) are certified at the gold level. In recent years, nearly all NAACCR registries have been certified gold. For cases diagnosed in 2015, for example, 49 U.S. registries were certified gold, six were silver, and two were uncertified. The registries certified silver or uncertified most often in recent years have included Nevada, Arizona, New Mexico, Los Angeles, and Minnesota. (Minnesota's status was never attributed to completeness.) Four of these five are in the Southwest, and each of these four has a large Hispanic population, representing the registries with the first, second, sixth, and seventh largest percentages of Hispanics in the country. However, adding a Hispanic stratum into the method does not improve the completeness of these registries substantially, and this issue has not seemed to affect Texas with the third highest Hispanic population.

Another limitation is that a registry's completeness estimate can be sensitive to whether and how sex, race, and site are stratified and which adjustment term is chosen. At the second in-person meeting in Vancouver, Canada, there was a demonstration of how one registry (Arizona) could have fallen into any of these three categories depending on what assumptions were made. Other registries straddled two categories. Prior work by one member of the Expert Panel showed that this characteristic is not only a property of parameter selections but of sampling variability (Das et al., 2008). The Vancouver presentation was limited to four registries, all of which have had difficulty meeting the NAACCR completeness standard consistently (New Mexico, Arizona, Nevada, Los Angeles). Members of the Expert Panel agreed that it would be useful to expand this analysis to all registries to see if the conclusions are broadly applicable or confined to these negative outliers.

Recall that under the IMRR method, the average completeness value across all registries is 100%; values are distributed around this average so that roughly half of them have values above 100% and roughly half have values below 100%. In fact, the distribution of values appears to closely approximate a normal distribution or bell-shaped curve, with most of the values clustered around 100% and fewer values farther from 100%. In recent years, the range of values has been from about 85% to about

115%. Let us focus momentarily on states at the high end of this range. There are only three possible ways that a state can have a score this high. One is that they truly have found more cases than actually exist. This could happen if there are a large number of duplicates or if nonreportable cases are being counted. We are confident that between the duplicate protocol, edits, and well-defined rules for counting invasive tumors, this is not a likely explanation, certainly not at the grand scale that a score of 115% implies. A second is random error. Even if every state were to capture its cases to the exact same degree, there would still be some variation in the measurement stemming from the collective imprecision of all of the various inputs into the method (population age, sex and race composition, mortality rate, and so on). It is hard to know the exact size of this error, but members of the Statistical Expert Panel do not feel this is a major source of variation—at most a few percentage points.

That leaves an unexplained variation as the dominant explanation. There must be factors other than the incidence-to-mortality ratio that account for variation in completeness. If a state is coming in at 115%, it is because its expected count is artificially low. Why this is important is because of what happens when states on the other side of the distribution are considered. If three states can have a score of 115% for reasons have nothing to do with registry quality, then on these same grounds we would expect three states to have a score of 87% (the reciprocal) for reasons having nothing to do with registry quality. We currently assume that such state has too many unreported cases when in fact the chances are quite good that it is due to methodological imprecision.

## **Modeling Method**

The modeling method is adapted from the method used to predict current cancer counts for the nation that was jointly developed by the National Cancer Institute and the American Cancer Society (Pickle et al., 2007; Das et al., 2008; Zhu et al., 2012). This method uses a hierarchical Poisson regression model, which includes spatial and temporal random effects across counties, and years of diagnosis. Using county-level cancer incidence counts from the Cancer in North America (CiNA) Deluxe file—stratified by age, sex, race, and diagnosis year as an input, it models incidence as a function of cancer mortality, sociodemographic variables for each county (urban/rural status, household characteristics, income, education, medical resources), and behavioral risk factors (smoking, obesity, health care coverage, cancer screening).

Completeness is then taken to be the ratio of the observed counts submitted by registries to the expected counts from the model. Like the IMRR method, this method is a relative method that implicitly assumes that completeness is 100% for the reference population, which is this case in the entire nation. Half of the population will belong to registries with completeness below 100%, and half will belong to registries with completeness above 100%.



Preliminary results for cases diagnosed in 2015—using 2015 as the reference year—were presented at the in-person meeting in Vancouver and revealed a moderate correlation with the IMRR method and a moderately narrower range of estimates, as indicated in **Table 1**. Since the method uses data from CiNA Deluxe, registries that did not meet the standards for inclusion in this volume or that opted not to have their data included are not reflected in the table. Additionally, states with multiple registries (California, Washington, Michigan) were grouped.

**Table 1. Completeness score comparison, IMRR and Modeling Methods, 2015 diagnosis year.**

Completeness Score	Incidence to Mortality Rate Ratio Method (NAACCR Version)	Modeling Method
90.0–94.9%	3	4
95.0–104.9%	25	30
105.0%–109.9%	15	11
110.0%–114.9%	—	1
<b>Total</b>	<b>46</b>	<b>46</b>

A major advantage of this method is that all cases are counted equally, regardless of site or race. This would presumably remove the temptation for registries to delay the processing of some cases intentionally because they do not count toward completeness. It also does not depend on the problematic assumption that incidence and mortality are perfectly correlated but instead incorporates factors known to influence cancer rates for which data are available, including demographic, behavioral and institutional data.

The major disadvantage is that the model is complex and is not transparent, and at present, its expected case counts are not independently reproducible by the registries. A spreadsheet similar to that developed for the IMRR method could be developed to potentially ameliorate this problem. Another issue is that deriving both observed and expected counts from the same year of data means that changes in absolute case counts cannot be captured. This will likely be an issue when estimating completeness of 2018 data, where reporting reductions of more than 5% are anticipated. The modeling method will assign an average completeness of 100% to the nation, with individual registries mainly distributed between 95% and 105%, as if nothing had changed. One potential way of addressing this problem would be to use an internal method (see Section C.5 below) as an additional validity check.

The modeling approach has the same limitation that was seen with the IMRR method; the values are normally distributed around 100%. If values well above 100% are seen,

they must be largely due to unmodeled variation, which means that values well below 100% can also be attributed to unmodeled variation, with equal probability. Based on preliminary analyses, modeled estimates are falling within the range of 90–110%, a narrower range than seen with the IMRR method. However, the values at the low end of the range are still close to current quality and certification standards. A realistic goal might be to reduce model uncertainty to the point where no states exceed 105% estimated completeness, which would mean that scores below 95% would more likely be related to incompleteness than to modeling imprecision. This could be achieved by incorporating additional covariates such as interstate migration, foreign-born composition, survival, and environmental variables. There will always be some variation that will not lend itself to being modeled, because the necessary data do not exist and there are no adequate proxies.

### Flow Method

The flow method is a method for measuring completeness that was developed in Great Britain about 20 years ago and was subsequently adopted by several European registries (Bullard et al., 2000). The term “flow” comes from the way that the computation draws upon the flow of cases through a registry as part of its routine operation. It categorizes all cancer cases into one of seven different categories. Five of them are easily counted:

- Patients alive at the time of interest and registered
- Patients deceased at the time of interest and registered, with cancer recorded on the death certificate
- Patients deceased at the time of interest and registered, with cancer not recorded on the death certificate
- Patients deceased at the time of interest but not registered, with cancer recorded on the death certificate and with cancer information obtained through follow-back (“death certificate-initiated” cases)
- Patients deceased at the time of interest but not registered, with cancer recorded on the death certificate, but without cancer information obtained through follow-back (“death certificate only” cases)

The remaining two cannot be counted and must be estimated:

- Patients alive at the time of interest and not registered (“missing” cases)
- Patients with cancer deceased at the time of diagnosis, with cancer not recorded on the death certificate, and not registered (“lost” cases)

Estimating the missing and lost patients is accomplished by estimating the probability that a patient is registered while alive, the probability that cancer is accurately mentioned on a death certificate, and the expected patient survival.

The Expert Panel discussed several drawbacks with this method. It assumes that the survival of missing and lost cases matches those of recorded cases, when they would be expected to be quite different (Tervonen et al., 2017). It also requires that death certificates are timely and of high quality. Because, in general, U.S. death records require more than a year for acquisition, linkage, and processing, it would be impossible to use the flow method to estimate completeness for periods of 1 year or less, a crucial consideration for this project. The method also requires registries to identify “death certificate initiated” cases, which is not a property that U.S. registries routinely record. The Expert Panel felt that while some registries could likely deduce this information, others would find it difficult or impossible. On the positive side, completeness obtained from the flow method is intuitive—what you have is an estimate of the ratio of recorded cases to total cases, with an upper limit of 100%.

### Capture-Recapture Method

The Expert Panel also discussed the capture-recapture<sup>1</sup> method, whereby completeness is ascertained by comparing reporting to different entities (Brenner et al., 1995). In its simplest form, it involves comparing cases reported to a central registry and cases reported on a death certificate. Assuming the two are independent, the number of cases not reported to either location (D) can be derived algebraically as

$$D = (ABC + B^2C + BC^2) / (A^2 + AB + AC),$$

where variables A through D correspond as illustrated in **Table 2**:

**Table 2. Variables in the Equation to Calculate the Number of Cases Not Reported to Death Certificates or Cancer Registry**

		Reported on Death Certificate	
		Yes	No
Reported to Cancer Registry	Yes	A	B
	No	C	D

Completeness is then simply 1 minus D.

A test of this approach on a past NAACCR data submission revealed immediate problems. One state reported zero death certificate-only (DCO) cases (cell C), implying a completeness of 100%. Another registry reported very few cancer deaths (cell B), implying poor completeness. In both instances, the limiting factor was not the cancer registry data but the timeliness and accuracy of the mortality data. Whether that was

<sup>1</sup> We note that the term “capture-recapture” was not actually used during the summit—no one in attendance made the connection to the 1990s work of Hermann Brenner and others—and the notes from the meeting refer to this as the “naïve method,” because the assumption that central cancer registries and vital records were independent and that the vital records data was error-free seemed naïve.

because the mortality data were incomplete or in error in its original form or because the registry did not process them correctly is not known. In any case, “completeness” as measured this way ends up being a hybrid measure of both incidence and mortality completeness that is not interpretable.

Any method that relies heavily on death certificate-only rate is also subject to the problem that as the rate diminishes toward zero—as has been the general trend in North American cancer registries in recent years—the proportion of cases that are not true DCOs increases. Cause of death coding, while extremely good, is not perfect, and an unpublished study conducted by one registry found that a significant share of the DCOs actually died of other causes, the miscoding occurring sometimes through what appeared to be simple typographical errors.

When capture-recapture is expanded to include more sources (for example, hospitals, outpatient cancer centers, labs, physician offices, and so on), the interactions between these source types result in a loss of precision and accuracy. The capture-recapture method requires sources to be independent and equally likely to be reported, and it is easy to see how these requirements are grossly violated in the cancer data collected in the United States. The mix of source types depends on the patient’s age, the survivability of the cancer, whether the cancer is screen-detectable, the availability of laboratory tests to identify molecular subtypes, and so on. In a test case, the capture-recapture method was applied to data from a state that has had consistently highly complete data and it suggested completeness was actually low but with wide confidence intervals.

## Internal Method

The internal method refers to the practice of using registries’ past case counts as the sole input to predict future case counts and assess the completeness of current counts. The advantage of this method is that it is straightforward to calculate and does not depend on external demographic or mortality data. SEER uses it to estimate completeness in its internal February (14-month) data submission. Many other registries do this implicitly when they provide mid-year progress reports back to facilities. For example, if a facility is told that they had 93 cases reported at this time last year but 76 cases this year, there is an implication that this number may be too low, that they may be behind in their submissions, because this year’s number is expected to be equal or greater.

The disadvantage is that it can be thought of as more of a measure of consistency than quality. As a simple example, imagine a national registry in a developing country where there are 10 hospitals, only 2 of which report to the registry. As long as this year’s case counts are similar to or greater than last year’s case counts, which will be true as long as the same two hospitals continue to report, completeness will appear high. The method implicitly assumes that a registry was virtually complete at least one time in the past. This may be a reasonable assumption for U.S. registries, but it is difficult to prove.

A registry that has been consistently 90% complete over its entire existence has the same issue as in the previous example.

### Other Topics Considered—Using Delay Adjustment to Develop National Rates from 12-Month Data

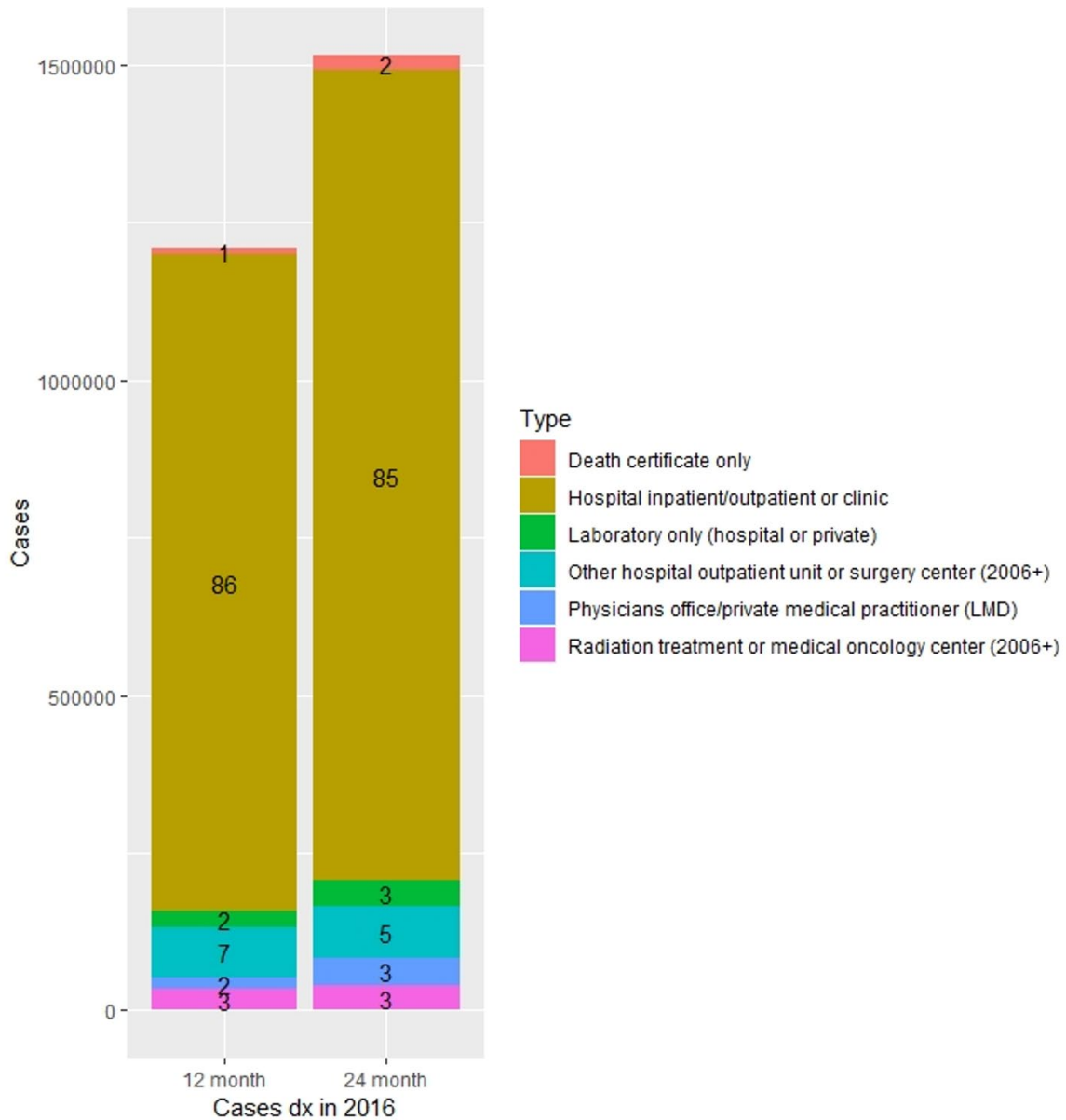
During the course of their deliberations, the Expert Panel considered options to utilize existing data to produce national cancer incidence rates at 12 months following diagnosis. Knowing that the data available at that time will be incomplete to some degree, the Panel considered statistical solutions that could account for this “missingness” and still produce robust and reliable rates for public health purposes.

The Expert Panel finds that it is feasible to use data from existing 12-month data submissions to project national cancer rates. This can be accomplished by utilizing the cases reported in the 12-month submissions and projecting the data to the anticipated final counts using the delay-adjustment methodology already in widespread use in U.S. cancer surveillance (Lewis et al., 2018). Delay-adjustment uses the ratios of current to past case counts to anticipate cases still to be reported. The method developed by SEER statisticians considers 11 years of data, although in practice virtually all the cases are received within 3 years. **Table 3** below shows a typical matrix of case counts, where the 24-month data are inflated by 3.2% and previous years are inflated by smaller amounts.

**Table 3. Matrix of Case Counts: 24-Month Data Inflated by 3.2% and Previous Years by Smaller Amounts**

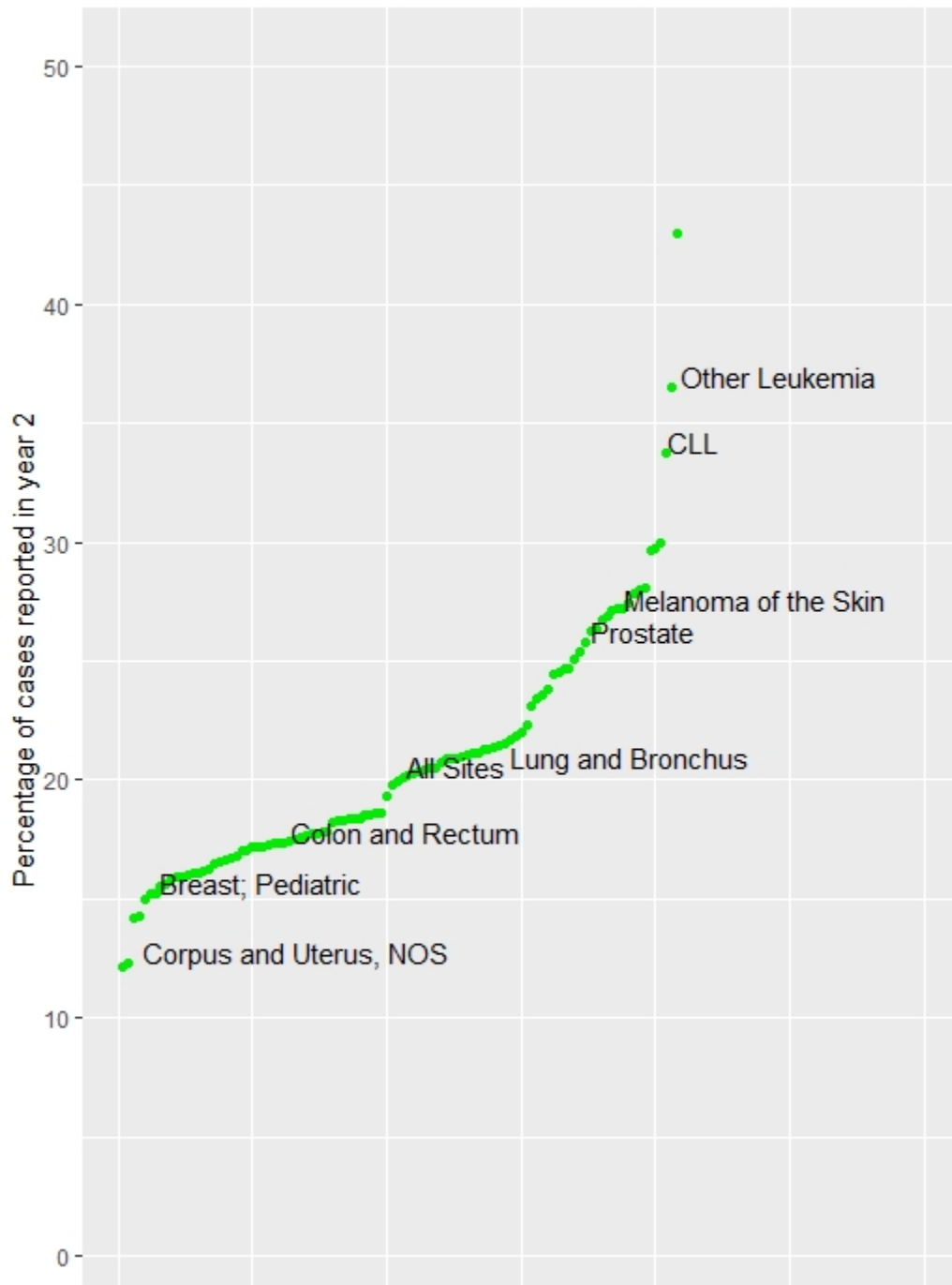
Diagnosis Year	Submission Year										Delay Factors	Expected Count After 11 Years
	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017		
2006	17,083	17,422	17,603	17,638	17,725	17,754	17,763	17,765	17,780	17,787	1.000	17,787
2007	—	17,262	17,621	17,701	17,885	17,901	17,940	17,996	18,015	18,027	1.000	18,027
2008	—	—	18,076	18,255	18,482	18,522	18,561	18,568	18,583	18,596	1.000	18,596
2009	—	—	—	18,137	18,782	18,856	18,908	18,940	18,971	18,990	1.000	18,990
2010	—	—	—	—	19,440	19,802	19,886	19,923	20,383	20,409	1.001	20,429
2011	—	—	—	—	—	19,882	20,113	20,161	20,600	20,643	1.002	20,684
2012	—	—	—	—	—	—	20,673	20,828	21,216	21,278	1.003	21,342
2013	—	—	—	—	—	—	—	20,294	20,939	21,059	1.005	21,164
2014	—	—	—	—	—	—	—	—	21,149	21,356	1.014	21,655
2015	—	—	—	—	—	—	—	—	—	21,251	1.032	21,931

With 24-month data, delay factors are typically under 5%, although this varies by cancer site and registry. If we were to apply this methodology to 12-month data, delay factors would likely be closer to 20%. Nationwide, in the most recent NAACCR data submission, about 80% of the cases reported in the 24-month data submission were also present in the 12-month submission (see **Figure A**). We chose to stratify the counts by type of reporting source to illustrate that the distribution of source types between the 2 years does not change dramatically—the hypothesis that the second-year submissions are fundamentally different from the first-year submissions and thus a source of bias is not supported by the evidence in the NAACCR file. While there are more death certificate-only cases after the second year, and proportionally fewer cases from free-standing surgery and other hospital outpatient centers, these are small shares of the total. It may be true that individual registries may exhibit bias, but the goal here is to estimate rates for the nation, not individual registries, so the influence of any individual registry is diluted. Furthermore, registries with highly incomplete data will be excluded from this calculation, as will be explained shortly.



**Figure A**

The ratio of 12-month case counts to 24-month case counts varies by cancer site (see **Figure B**). Ignoring a few rare sites, the range is seen to extend from about 67% for chronic lymphocytic leukemia to 88% for uterine cancer (these figures were obtained by subtracting the value on the y-axis from 1). For certain sites such as CLL and possibly melanoma and prostate, the projection of national rates may be less feasible given higher uncertainty. Knowing which cancer sites may be projected and under which circumstances will require further analysis.



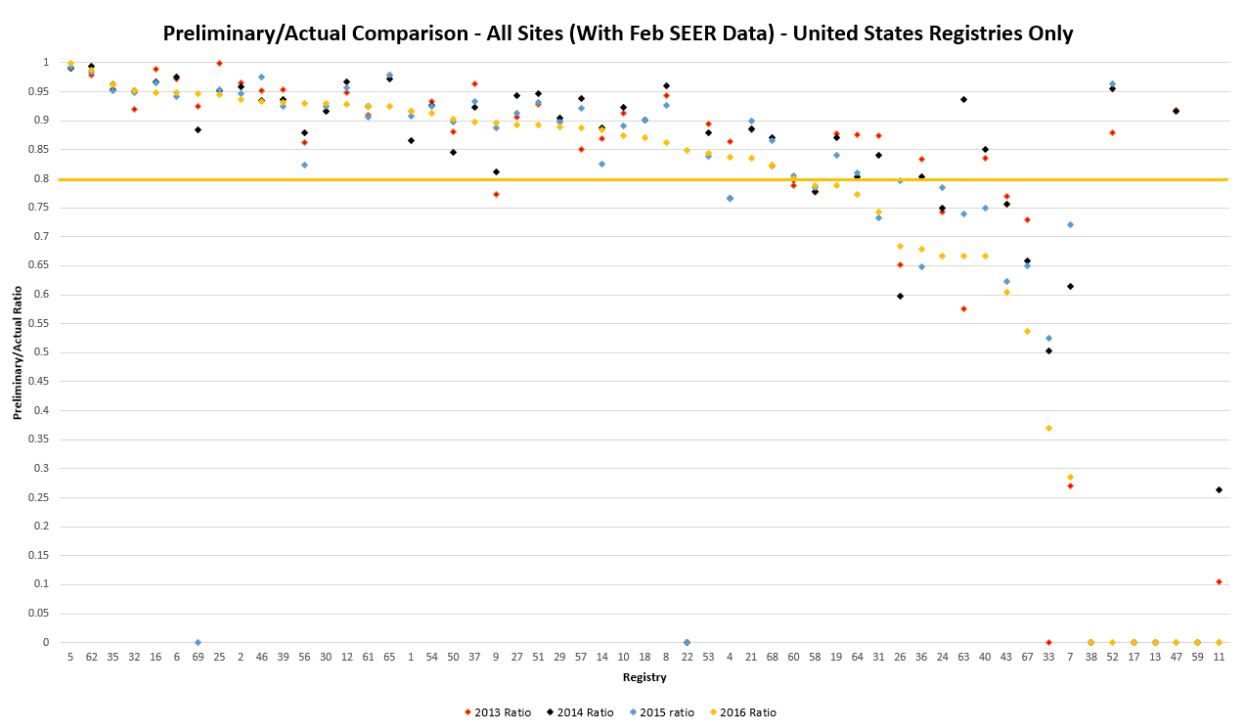
**Figure B**

The above figures made use of all data available to the Expert Panel—specifically, data for cases diagnosed in 2016 submitted to NAACCR between November 2017 and January 2018 (what we will henceforth refer to as 12-month or one-year data, even though technically it ranged between 11 and 13 months), and data for cases diagnosed in 2016 submitted to NAACCR in November 2018 (what we will call 24-month or 2-year data, even though technically it was 23-month data). However, the picture is better than



this if registries with an unusually poor 12-month reporting performance are excluded. Drawing upon prior analysis among SEER registries, the Expert Panel is proposing to limit the basis for national projections to only those registries that had a 12-month case count to 24-month case count ratio of at least 0.8 in at least three of the four most recent diagnosis years and to those registries that were certified gold or silver in all four of these years.

Applying these criteria to the NAACCR data submissions for cases diagnosed between 2013 and 2016, 36 registries would meet these criteria (see **Figure C**). These are the registries with at least three points above the horizontal yellow line, representing years in which at least 80% of the 24-month data was reported within 12 months. We anticipate that the picture would improve still further if NPCR rather than NAACCR and SEER submissions were used for the analysis. For many registries the submissions are the same, but some registries separately submit 12-month data to NAACCR in November and then again to NPCR in January. In one state, the difference between these submissions is substantial —typically below 80% complete in the first submission and above 90% complete in the second. In addition, there are several states that only submit their 12-month data to NPCR and not to NAACCR. The total number of states included in the generation of national rates could potentially be raised to at least 40.



**Figure C**

We note that if 12-month data are to be used going forward to generate national incidence rates, there are obvious advantages to placing all registries on the same calendar. Based on the 22-registry sample used in our in-depth assessment, 11 registries responded that they typically report 12-month data to NAACCR in January, 10

registries report in November, and one registry does either. Whether the registries that report in November make a separate submission in January to NPCR was not assessed. While it is possible to continue to analyze a mixture of 11-, 13-, and 14-month data, it complicates the analysis and delays the eventual release of the data by 3 months.

## Summary of Statistical Expert Panel Findings

The Statistical Expert Panel carefully evaluated several models for estimating completeness of cancer reporting by central cancer registries. All of the methods considered had disadvantages. In addition to the disadvantages described above, there appear to be some aspects of the measures that systematically disadvantage some registries, making it difficult to achieve acceptable completeness scores because of factors beyond their control (See Factors Related to the Completeness Measure that Influence Compliance with the 12-Month Data Standard). In short, no single method has emerged as a satisfactory measure. However, the group wishes to continue working on this problem and conduct further analysis and modeling, with the intent of improving the methods currently in use.

In addition, the Panel believes that it is possible to produce reliable cancer incidence rates for the nation and states by applying statistical modeling to data collected by registries at 12–13 months after diagnosis.

## Recommendations and Next Steps

The Statistical Expert Panel recommends further analysis of the modeling approach to measuring the completeness of cancer reporting. The Panel thinks that the modeling approach will provide the most accurate estimate of completeness, because it takes into account many local factors that influence cancer rates such as behavioral risk factors, socioeconomic status measures, etc. The model behaves and performs like the existing IMRR method, but with reduced variance, which will reduce the likelihood of a “false negative”—that a registry will be deemed not to have met a quality standard when, in fact, it has. The reduction in variance is a consequence of including information on demographics, health care systems, and behavioral risk factors absent from the IMRR approach. The modeling approach needs further refinement as described below.

Regarding the existing incidence to mortality rate ratio method, the Panel intends to compute completeness measures using this method for all registries over multiple years with a wide range of parameters. This exercise was completed for several states and presented at the Vancouver in-person meeting, and it showed that at least for some registries, completeness scores varied widely when minor parameter adjustments were made. The results of this sensitivity analysis will be useful in illustrating why the modeling approach is the preferred method. In addition, comparing these results with those from the modeling approach is of interest to see how completeness scores might have changed in the past or will change in the future.

The flow and capture-recapture methods studied are not recommended for further analysis at this time due to significant problems uncovered with these methods. The internal method is being kept in the conversation only insofar as it may prove useful in evaluating 2018 data should there be evidence of reduced completeness on the nationwide basis. The modeling approach scales the national completeness level to 100%, but the internal method makes use of year-to-year comparisons.

The Panel also recommends developing and refining methods to use the data submitted at 12 months to accurately project incidence rates for the nation. Using data from NPCR states that are at least 80% complete and representing approximately 70% of the population, the group believes that reasonably accurate incidence rates could be derived for the nation and states for public health purposes. Using appropriate statistical techniques, the data from the sample would be adjusted to account for the cases not yet reported. These techniques would be based on what has been learned through delay adjustment modeling conducted by NCI, CDC, and NAACCR over the past several years.

1. Short-term plans for improving the completeness estimate are as follows:
  - Generate historic completeness estimates for diagnosis years 2013 through 2016 using the modeling approach and compare these with existing completeness estimates.
  - Seek ways to reduce residuals in the model through the inclusion of other covariate terms. This may include variables that capture interstate migration, international migration, survival, and environmental variables.
  - Consider the implications of the false-negative rate for certification that is implied by the distribution of model residuals. That is, making reasonable assumptions about the shape of the distribution of completeness estimates around 100% implies that some states should be in the lower range of completeness estimates (under the IMRR method and, to a lesser degree, in the modeling method as it currently exists) for reasons entirely beyond the control of the registries.
  - Ascertain which states, if any, tend to be systematically overpredicted or underpredicted.
  - Discuss the development of communication materials around the modeling approach so that NAACCR members will have a clear understanding of how it works.
  - Expand the presentation showing the sensitivity of the IMRR method to varying parameters to include all registries.
2. Long-term plans for developing incidence projections from 12-month data submissions are as follows:

- Further develop and refine the delay adjustment-based method for projecting 12-month data into national incidence rates. Thus far, we have demonstrated that by using a lower completeness threshold of 80%, data from a large majority of registries would be included. The resulting over-80% sample that the 12-month data represents has many properties in common with the 24-month data, including similar site and reporting source distribution.

# Examination of Registry Operations and Best Practices

## Operations Overview and Methods

A comprehensive evaluation of registry operations in central cancer registries participating in the NPCR program was conducted. First, an evaluation of eight NPCR registries that meet the NPCR 12-month data criteria, five that sometimes meet the criteria and eight NPCR registries that do not meet them, was conducted. NPCR criteria for 12-month data were evaluated to identify best practices for collecting and processing cancer incidence data within 12 months of diagnosis.

Second, at the request of NPCR, the project was expanded to include a broader assessment of overarching issues surrounding cancer registry operations. The evaluations included, but were not limited to, suggested enhancements to the CDC suite of software Registry Plus, technical assistance needs, educational and training needs, staffing, external funding, and ePath reporting.

## Assumptions

The original design of comparing registry operations of eight registries that met the NPCR 12-month completeness standard to eight registries that did not meet the standard was defined by the NPCR program. This methodology presumed that registries that always met the NPCR 12-month data criteria did so because they used procedures or practices that influenced their success rates and that the states that rarely or never met the standard did not use these best practices.

## Selection of Participating Registries

The registries selected for inclusion in the project were chosen based on their performance in meeting the NPCR 12-month data completeness standard in recent years. At the onset of the project, NAACCR was provided with a spreadsheet showing each registry's performance in meeting this standard for diagnosis years 2010 through 2016. Information was provided dichotomously (i.e., "met" or "did not meet" the standard in a given year). Those that met the standard at least six of the 7 years were categorized as "usually or always" meeting the standard. Those that met the standard four or five times were categorized as "sometimes" meeting the standard, and those that met the standard two or fewer times were categorized as "rarely or never" meeting the standard. Registries that met the standard five of seven times were elevated to the "usually or always" group if they met the standard in each of the four most recent years. There were no registries that met the standard exactly three times. Note that we were unable to distinguish between states that just missed the standard and those that fell well short of meeting the standard, and it is possible that these registries differ in meaningful ways that we were unable to assess.

Sixteen registries (34%) were classified in the "usually or always" category. Of these registries, eight were selected to participate in the assessment, interviews, focus

groups, and other project activities. These eight were chosen to provide geographic and demographic diversity from among the 16.

Twenty-six (55%) registries were classified in the “rarely or never” category. Of these registries, nine were selected to participate in the assessment, focus groups, and other project activities. These nine were chosen to provide geographic and demographic diversity.

There were just five (11%) registries in the “sometimes” category: All of these registries were selected for participation in the wider project. It was thought that registries that changed their completeness status from year to year might have particular insight into what practices did and did not work. Of course, it is also possible that these registries conducted the same practices from year to year and their efforts always placed them near the cut point for meeting the standard.

Please note that state-specific compliance information was provided by NPCR, and the classification was conducted in conjunction with NPCR. State-specific classification results are not presented here in order to preserve the confidentiality of registries in regard to their performance on these measures. Specific data are available on request to NPCR staff.

## **Tools and Instruments**

The following tools were used as part of this work.

*Quantitative Assessment:* A total of 27 multiple choice and open-ended questions were developed, with input from NPCR, NAACCR, NACDD, and outside consultants with expertise in survey development. The questions focused on both 12-month completeness standards and broader overarching topics of interest to NPCR. A pretest of the questionnaire was conducted prior to full implementation, with modifications completed based on feedback. See Appendix E for the Assessment Report.

*Expert-guided Interviews:* Thirteen open-ended questions were developed, with input from NPCR, NAACCR, and NACDD that were designed to explore critical areas in more depth. The interviews were conducted by NAACCR consultants who had many years of expertise in central cancer registry operations. This approach was used to assure that registry respondents would be trustful and open in providing responses. All consultants were trained to follow standard procedures for conducting the interviews. A pretest of the questionnaire was conducted prior to full implementation, with modifications completed based on feedback. See Appendix F for the Interview Report.

*Focus Group Process:* A facilitator’s guide and script were developed based on input from NPCR staff, central registry directors, operational staff, and NAACCR staff. After feedback on the initial guide, the scope of the script was expanded to include a broader range of key topics of interest to NPCR. See Appendix G for the Focus Group Report.

## Data Collection and Analysis

Evaluation processes included quantitative assessments of all 22 registries, individual-guided interviews by consultants with operations expertise with participating registries, focus groups, and an in-person Operations Summit meeting with representatives from the 22 registries and other experts. Specific methodologies for each were as follow:

*Quantitative Assessment:* Twenty-two state registries were asked to complete a 27-question assessment of their registry operations (100% response rate). The registries were chosen to represent a geographical cross-section of the country and a range of 12-month completeness estimates for cases diagnosed between 2010 and 2016 as submitted to NPCR. Eight of the registries met the 90% completeness standard at least five of the 7 years and were classified as “usually or always” meeting the standard, nine met the standard two or fewer times and were classified as “rarely or never” meeting the standard, and five met the standard four or five times and were classified as “sometimes” meeting the standard.<sup>1</sup> None of the registries had difficulty meeting the 24-month NAACCR standard—20 were certified gold and 2 were certified silver for cases diagnosed in 2016. The questions in the assessment, developed in consultation with NPCR and NACDD, covered case volume, source types, software, electronic reporting, staffing, data use, and relevant state laws. A primary aim of the assessment was to see whether any of the responses to the questions correlated with 12-month completeness.

*Expert-guided Interviews:* Twenty-two states were asked to and participated in individual interviews conducted by project consultants over a 3-week time period. A 100% response rate was achieved. All states were provided with the same 13 interview questions in advance, and each interview lasted anywhere from 30 to 60 minutes. States were categorized by how consistently they met the 12-month NPCR standard of 90% case completeness with eight states usually or always meeting; nine states rarely or never meeting and five states sometimes meeting the standard. Registry interview responses were transcribed by project consultants and recorded. Results were tabulated and aggregated.

*Focus Groups:* Three focus groups were held over a 1-week period using registries who met the NPCR 12-month data criteria, sometimes met the 12-month data criteria, and never met the 12-month data criteria. Three states—Idaho, Maine, and North Dakota—were not available to participate (86% response rate). A facilitator’s guide was developed based on input from NPCR staff, central registry directors, operational consultants, and NAACCR staff. After feedback on the initial guide, the scope of the script was expanded to include overarching questions related to central cancer registry operations, in general, and then 12-month data criteria specifically. General overarching topics included staffing and training; resources; IT and software needs; automation and electronic reporting; technical assistance, particularly around NPCR services; data usage; factors that contributed to the overall success of central registry operations; and finally, barriers and threats that interfered with central registry effectiveness. A second layer of questions focused specifically on factors causing delays in reporting of 12-

month data and model strategies that might be adapted across all central registries leading to improvement and more success in reaching 12-month criteria.

A script was prepared for use across all focus groups, and members were invited to participate using a 1.5-hour Zoom meeting format that allowed for recording and transcription of results. Qualitative analysis processes were then applied across all focus groups. The numbers of participants in each focus group were as follows:

- Participants from States that meet 12-month standards regularly (n = 4)
- Participants from States that sometime meet 12-month standards (n = 7)
- Participants that rarely meet 12-month standards (n = 10)

### **Operations Summit**

Findings from the quantitative assessment, guided expert interviews, and focus groups were reviewed by expert operations consultants and the meeting facilitator to develop a Summit agenda designed to address critical issues identified in the assessment. All states that participated in the assessments, interviews, and focus groups were encouraged to participate in the summit. Funding was provided by this contracting mechanism to cover travel and per diem for participants. Representatives from NACDD and NPCR were also invited to observe proceedings. A reporter was present to take notes and prepare minutes.

Day 1 included a review of the findings from the *Assessment of Central Registry Timeliness and Reporting Standards* (NAACCR 2018), and then the quantitative assessment, guided expert interview, and focus group results were presented to lay the groundwork for the rest of the summit. Over the next 2 days, a combination of brainstorming sessions, group discussions, and consensus-building activities were planned to examine the pros and cons of various best practices for meeting 12-month reporting standards, as well as reviewing the barriers and opportunities for such critical registry needs as staffing and education, software and IT, auto-consolidation, operational workflows, external reporting bottlenecks, and technical assistance improvements. Once viable solutions were identified, priorities were set, and recommendations were developed, the participating states were asked to step back to carefully review and discuss the findings of the Summit with their staff and stakeholders within their state. Then the participants reconvened at the NAACCR Annual Meeting in Vancouver to further deliberate and reach final consensus for the recommendations to be presented in this report.

### **Special Studies**

As part of the analysis, we also undertook several special studies. They included estimating a cost per case, calculating the number of cases per FTE and per CTR to see if they were correlated with achieving the 12-month completeness estimates. We also looked for evidence of bias within the 12-month data submitted to NAACCR based



on reported operational practices of some registries that were uncovered at the Operational Summit.

## **Achieving 12-Month Data Standard**

### **How Do Registries Achieve 12-Month Completeness Standards?**

On average, according to NPCR, 21 of 47 (45%) registries achieve the 12-month data standard by January 31 following the diagnosis year (at 13 months). The registries that are able to meet this standard annually vary from year to year, with only seven (15%) meeting it each of the last 7 years. (Data provided by NPCR program January 2018.)

Our analysis indicates that there are several factors at work that influence a state's ability to meet the 12-month standard. Some of these factors are inherent in the completeness measure itself. Certain characteristics of the measure cause some states to be consistently at an advantage for achieving the standard, while others are consistently disadvantaged. In addition, some states have adopted practices that maximize their potential for meeting this criterion, but these practices may result in biased data.

In this section, we discuss some of the important factors that influence the achievement of the 12-month data standard.

### **Factors Related to the Completeness Measure That Influence Compliance with the 12-Month Standard**

#### **Demographic issues and population size**

With the existing incidence-to-mortality ratio method used to estimate completeness, states with low cancer mortality rates are at an advantage when it comes to the completeness measure, for reasons largely independent of registry quality. One of the large states in our sample, for example, that meets the 12-month standard every year and that typically has a NAACCR 24-month completeness score that well exceeds 100% also has one of the lowest cancer mortality rates in the nation. The reasons for this are not entirely understood. It could be the influence of a city making up over 40% of this state's population that contains a very large foreign-born population representing all parts of the globe. The dramatically low cancer mortality rates in this population are not well captured by the coarse "race" and "ethnicity" categories that the IMRR method employs to smooth over some of the differences between states. It could also be the influence of significant emigration of older residents upon retirement, leading to the counting of incidence and mortality in different registries.

Additional possibilities include aspects of the local health care system, high screening rates, biased mortality reporting, or competing causes of death. Regardless of which of these hypotheses are true, the fact is that this state does not have to undertake any special effort to meet the 90% 12-month completeness standard. In fact, the registry

could have many unreported cases and still achieve a score comfortably over 95%. The state may realize that they have been under-reporting because the completeness estimate is habitually well over 100%; however, it still makes the mark of 95% and appears complete.

The IMRR method for measuring completeness also favors larger states. Recall that the method is a relative one, so that the total number of expected cases equals the total number of observed cases and that the completeness for the nation as a whole (or in the case of NPCR for the NPCR-funded states as a whole) is 100%. Roughly half of the states will be above 100%, and half will be below 100%. States contribute to the total measurement in proportion to their size, so that a large portion of the NPCR-wide expected cases are contributed by such states as California and New York and Florida, and a small portion from such states as Alaska, Wyoming, and Vermont. If states served as their own standard—if their expected cases were determined by their observed cases—then each state would have a completeness score of 100%. In the national calculation, this is what is happening in part with the large states. California comprises 13% of the population in the national calculation; its data are self-weighted by this amount. Vermont, meanwhile, has only 0.2% of the population. California is 66 times closer to a score of 100% before a single case is processed.

### **Bias in completeness estimate may make it easier to some state to achieve**

As discussed in the previous section, some registries have a much easier time of achieving completeness for reasons beyond the registry's control—the age structure of the population, its migration patterns, its ethnic composition, and its health care delivery patterns. To use statistical language, these are unaccounted for covariates in a model. There are aspects of the current completeness measure related to unmodeled variation that systematically cause some states to achieve completeness standards easily while others may never obtain them. The Statistical Expert Panel will strive to reduce this bias in their work to produce a more robust completeness measure.

### **Factors Related to Registry Operations That Influence Compliance with the 12-Month Standard**

In this research conducted with 22 NPCR registries, we learned that meeting the 12-month data standard comes at a significant cost to other operations and may be achieved only by incorporating unorthodox methodologies. Many registries reported setting specific work priorities to process cases that were included in the completeness calculations, while setting aside other cases in order to make the benchmark. For example—

- Not processing prostate and breast cancer cases (not included in completeness calculations)
- Selectively processing only cancer sites used in the calculation (only 16 sites included)

- Selectively processing only white and black cases (other races/ethnicities not included in completeness calculations)
- Not de-duplicating the file (results in overcounting cases)
- Not editing the file (inaccurate data)
- Many cases lack treatment and stage information (these data items take a long time to collect, so filled in as unknown)
- DCO cases are included without resolution (no DCO limit for 12-month data)
- Cases from other states are not processed or exchanged (not included in completeness calculations)

While these practices may not be incorporated by all registries, it is our understanding that at least some of these practices are used by many if not most registries. Several registries reported that using these tactics was the only way that they could achieve the current standard. Registries tended to believe that 12-month data were not being actively utilized by CDC, and the benchmark was used to track progress rather than produce accurate rates. As a result, registries have tended to focus on quantity over quality and may have submitted subpar data to NPCR on this file, knowing that it would not be used for generating rates. The registries correct the data in the subsequent 11 months, creating a clean file for the 23/24-month data submission. Some registries submit a 24-month file that is essentially a complete replacement of the file submitted at 12 months.

This discovery was unexpected and has generated concern at the pervasiveness of these practices. We cannot in good faith recommend the methods (described above) utilized by registries to hit the benchmark as “best practices,” because they would seriously affect the quality and accuracy of the data and introduce bias into the resulting statistics. Any use of data collected using this circuitous approach would be highly susceptible to inaccuracies and errors.

### **Factors That Do Not Influence Compliance with the 12-Month Standard**

In this section, we consider factors that have been hypothesized to be related to 12-month completeness. These factors were included in the assessments, interviews, and focus group sessions as potential influencers of timely reporting. However, virtually all have been found to show no correlation. These include Commission on Cancer (CoC) reporting, ability to produce modified or updated records, electronic reporting, physician and non-hospital reporting, paper reporting, use of ePath, submission time (December or January), and presence of missing treatment data. Outsourcing and contracting were external factors that appeared to correlate with completeness but in the opposite direction, as might be expected; registries generally not meeting the standard tended to find it beneficial, while those generally meeting the standard found it detrimental. It seems that each registry has developed its own workflow practices that

are informed by a unique mix of experience, working relationships with reporting facilities, and selective use of technological assistance that allow them to reach a the 24-month data standard, if not necessarily the same 12-month endpoint. It does not appear that registry metrics can predict the quality or completeness of a 12-month data submission.

### Commission on Cancer reporting

It might be hypothesized that having a higher proportion of cases reported from Commission on Cancer-approved facilities would correlate with higher 12-month completeness, because these cases are generally thought to be of higher quality and are reported more rapidly. However, registries with the highest proportion of CoC cases, the middle range of CoC cases, and the least number of CoC cases were all equally likely to have met or not met the standard (**Table 4**).

**Table 4. Number of Registries by Percentage of Reports from CoC Hospitals**

Met 12-Month Completeness Standard	60%–67%	70%–82%	89%–98%
Never or Rarely	2	4	2
Sometimes	1	4	0
Usually or Always	2	5	1
<b>TOTAL</b>	<b>5</b>	<b>13</b>	<b>3</b>

### Ability to process modified or updated records

It might be expected that the ability to process modified or updated records to existing cases is an asset for complete reporting. Having this capability would facilitate the processing of multiple records per case and partial records, but of the five registries that responded that they lacked this capability, two were in the “rarely or never” group, one was in the “sometimes” group, and two were in the “usually or always” group (**Table 5**).

**Table 5. Ability to Process Modified Records**

Met 12-Month Completeness Standard	Registries That Can Process Modified Records	Registries That Cannot Process Modified Records	Don’t Know
Never or Rarely	6	2	1
Sometimes	4	1	0
Usually or Always	6	2	0

Met 12-Month Completeness Standard	Registries That Can Process Modified Records	Registries That Cannot Process Modified Records	Don't Know
<b>TOTAL</b>	<b>16</b>	<b>5</b>	<b>1</b>

## Electronic reporting

Registries were asked the percentage of reports from hospitals, pathology labs, physician offices, and non-hospital facilities that were submitted electronically. Hospital reports were nearly all electronic across the board, with only two registries reporting values below 98%. Pathology reports, in contrast, varied widely, with half the registries receiving at least 90% of their pathology reports electronically and five others receiving almost no electronic pathology reports. This was uncorrelated with completeness; the 11 registries with at least 90% electronic pathology reporting were evenly drawn from the three completeness categories (**Table 6**), and two registries managed high 12-month completeness despite negligible electronic pathology reporting.

**Table 6. Number of Registries by Percentage of Cases with ePath Reports**

Met 12-Month Completeness Standard	0%–2%	20%–50%	70%–82%	90% and above
Never or Rarely	3	1	1	4
Sometimes	0	0	1	4
Usually or Always	2	2	1	3
<b>TOTAL</b>	<b>5</b>	<b>3</b>	<b>3</b>	<b>11</b>

In eight of the registries, at least 90% of the reporting from physicians and non-hospital sources were electronic. In 11 others, electronic reporting was below 5%, with just three registries falling in between (**Tables 7 and 8**). There was no correlation with completeness.

**Table 7. Number of Registries by Percentage of Physician Reports Received Electronically**

Met 12-Month Completeness Standard	0%–5%	25%–63%	90%–100%
Never or Rarely	4	1	4

Met 12-Month Completeness Standard	0%–5%	25%–63%	90%–100%
Sometimes	1	2	2
Usually or Always	6	0	2
<b>TOTAL</b>	<b>11</b>	<b>3</b>	<b>8</b>

**Table 8. Number of Registries by Percentage of Non-Hospital Reports Received Electronically**

Met 12-Month Completeness Standard	0%–3%	30%–80%	90%–100%
Never or Rarely	4	0	5
Sometimes	0	1	4
Usually or Always	5	1	2
<b>TOTAL</b>	<b>9</b>	<b>2</b>	<b>11</b>

### Paper reporting

Most registries see occasional paper reports (**Table 9**), but the level of paper reporting showed no correlation with completeness.

**Table 9. Number of Registries by Percentage of Source Records Received on Paper**

Met 12-Month Completeness Standard	0%	1%–6%	10%–18%
Never or Rarely	3	5	1
Sometimes	1	3	1
Usually or Always	3	2	3
<b>TOTAL</b>	<b>7</b>	<b>10</b>	<b>5</b>

*Note: No registry reported receiving more than 18% of the source records on paper.*

## Reporting date

Equal numbers of registries responded that they report their 12-month data in November or January. While it might seem that the January reporters would benefit from the additional 2 months of processing time, there was no correlation between this and the 12-month completeness.

## Missing treatment

We examined whether the level of missing treatment information in the 12-month data was related to completeness. One hypothesis is that there would be more missing information in registries that were complete, because this is one of the tradeoffs a registry would make in order to be complete; it would add a larger share of low-quality reports to its database in the first year.

This was a quantity that we were available to evaluate using data available to us in the NAACCR submission files, and it was not limited to the 22 registries included in the assessment, interviews, and focus groups. We used data from the diagnosis year 2016 to perform this analysis.

There was, in fact, no significant difference between registries that did and did not meet the NPCR 12-month completeness standard for cases diagnosed in 2016. Of the 38 states for which we had data (some states elect not to send their 12-month data to NAACCR, hence the lower number), states that met the 12-month standard ( $n = 14$ ) averaged 3% of unknown radiation, while states that did not meet the standard ( $n = 24$ ) averaged 5% of unknown radiation, as measured by the RX Summ—Radiation variable.

There were examples of registries above 10% missing and below 1% missing in both those that met and those that did not meet the standard.

Chemotherapy yielded the identical result as radiation; registries not meeting the standard had 5% missing, and those meeting the standard had 3% missing—a nonsignificant difference.

## External forces that influence timeliness

Registries were asked if there were any external forces that influenced timeliness of reporting, either positively or negatively. Specifically, they were asked about the Rapid Quality Reporting System (RQRS), laws and rules, fines and penalties, outsourcing and contracting, and interstate data exchange. The results are summarized in **Table 10** below. Overall, registries found laws and rules to positively influence timeliness, with a weaker positive sentiment for most of the other categories. The results for outsourcing and contracting are interesting, because not only was opinion divided, it was mainly divided along completeness lines. Registries rarely or never meeting the 12-month completeness standard found that outsourcing and contracting exerted a positive influence, while those usually or always meeting the standard found it to exert a negative influence. It appears that for the incomplete registries, the sentiment was that

they would have fared even worse were it not for the outsourcing, while for the complete registries, the sentiment seemed to be that outsourcing tended to slow down their operations.

**Table 10. External Forces Influencing the Timeliness of Registry Reporting**

	Positive	Negative	Both Positive and Negative	No Response
RQRS	7	3	0	10
Laws and rules	17	2	1	2
Fines and penalties	7	4	0	11
Outsourcing and contracting	6	7	2	7
Interstate data exchange	9	2	0	11

One major weakness of our analysis presented above is that we only had information as a dichotomous variable to whether registries had met or not met the 12-month standard in the past. From this, we developed the categories “usually or always” met the standard, “sometimes” met the standard, and “rarely or never” met the standard. However, we were unable to distinguish between states that just missed the standard and those that fell well short of meeting the standard. It is possible that these registries differ in meaningful ways. For example, we know from our interviews that at least one state has never seriously pursued meeting the 12-month standard, finding the cost-benefit ratio to be so high that it is not even worth trying. Similarly, there is at least one state that has employed every tool and practice they know of to meet the standard, but without success. The first registry may have typical 12-month completeness of 20%, and the second registry may have typical 12-month completeness of 87%; we have no way to know. Our analysis has shown that these “rarely or never” states have little in common with each other, and this could be one reason why.

In a conference call on August 19, 2019, with CDC representatives in attendance, we requested more information on past completeness results that might allow us to answer this question. CDC representatives indicated they could obtain the information from their contractor in the next few weeks. Unfortunately, this information was not received in time to be incorporated into this report, but we will examine this in the next project period.



## Characteristics of Registries “Usually or Always” Achieving the 12-Month Standard

We examined the characteristics of registries who consistently met the 12-month standard according to NPCR or almost always met the standard. Many (13 of 16) of these states were smaller, predominantly white, with more rural populations. Only four of the 16 states in this category had large populations, one with a good deal of racial and ethnic diversity, with the other three having moderate diversity. Only one of the states received funding from both NPCR and SEER (with two more states receiving SEER funding beginning in 2018).

Eight of these states participated in the interview and assessment portions of our study. Looking across these states for operational procedures related to timeliness revealed the following:

- Seven of the eight states had ePath capabilities. These seven stockpiled the ePath cases until after hospital submissions were completed before processing them. (One registry, which has some built in auto-consolidation capabilities, processed some of the ePath cases as case-finding supplements to the hospitals, but mostly processed the ePaths after hospital submission.) And two registries triage reports from facilities that are not likely to be hospitalized (e.g., dermatology). One state indicated that they tried to process ePath cases early but determined that this was an inefficient and impractical way to process records, given the volume of work and that treatment data were often missing.
- Six of eight registries mentioned using internal management reports to identify facilities that were delinquent in reporting. These registries are in frequent contact with hospitals to encourage timely reporting. They invest in building rapport with these facilities. As one state mentioned, “Smile but be persistent.” One of these states mentioned utilizing an incentive award for hospitals that meet timely reporting goals.
- Three of the eight states warned that processing cases too soon resulted in incomplete information (especially treatment) and that handling cases more than once was inefficient. One state indicated that they do not accept cases from hospitals that are received prior to 4 months post-diagnosis, because they are too incomplete.
- Two of the eight states mentioned having strong regulations to help enforce timely reporting, while another specifically mentioned that their reporting law “had no teeth.”
- Two states mentioned that they relied heavily on electronic reporting.
- One state mentioned that they participated in the CDC/NPCR Early Case Capture (ECC) study and thought that this had a positive influence on timeliness.

## Characteristics of Registries “Rarely or Never” Meeting 12-Month Data Standard

Twenty-six registries (55%) were classified as “rarely or never” meeting the 12-month data standard. These states have a wide geographic distribution and represent a large range of population sizes and diversity. Only one state received SEER funding, with two states having imbedded SEER registries and one recently receiving funding in 2018. Nine of the states participated in our more in-depth analysis. By and large, the states did not identify characteristics that set them off from the “usually or always” groups or the “sometimes” group. (See Section: Factors That Do Not Influence Compliance with the 12-Month Standard below). Some of the comments from the “rarely or never” registries are summarized below:

- Eight of the nine registries indicated that staffing levels were a major factor in their inability to meet the 12-month data standard. They cited diminishing budgets and inability to hire qualified staff and CTRs as major problems.
- Several states would like to see software and technology improvements, including systems that would work with smaller reporting facilities, abbreviated abstracts from physician’s offices, auto-consolidation capability, and improvements to existing data management systems.
- Four registries mentioned delays in software availability and constant changes as a major barrier.
- Four registries mentioned using management reports to identify facilities slow in reporting.
- Three registries mentioned problems with their state laws regarding reporting—either they did not have penalties for nonreporting or were unable to enforce the penalties that they had due to understaffing. Additionally, one state indicated that they had very strong state laws.

## Strategies for Achieving Timely Reporting

Every aspect of this project evaluated ways to improve the completeness and timeliness of reporting to meet the 12-month standard. Several themes have emerged from these various assessments. They included monitoring central registry and facility reporting progress, promoting good relationships with reporting facilities, developing facility-specific displays or record formats for case reporting, establishing a standard timeline for biannual updates to cancer reporting software, developing and implementing procedures to effectively handle ePath volume, developing guidelines to “Grow a CTR,” and strengthening state reporting regulations.

Details of these themes are provided below in discussions of the findings from each assessment.

## Strong Relationships with External Reporters

Developing strong relationships with external reporters is the key strategy most states rely upon to meet 12-month timeliness standards. The stronger the connections between hospitals, non-hospital reporters, and central registries, the better the quality and timeliness of the data. However, relationship building takes time and energy, and the barriers and pressures placed on registries by the barriers to timeliness have made this important task harder and harder to do. Relationships must be established, grown, and maintained through personal contact, communication, and engagement. These steps all take time, energy, and effort to do well. It is especially challenging to deal with an ever-changing healthcare environment where mergers and acquisitions, privatization, the use of outside contractors, regionalization, and an explosion in outpatient ambulatory facilities have shifted the ground where healthcare takes place. Given this dynamic situation, central registries must work even harder at relationship building than ever before.

States reported a variety of action steps that they take to try and strengthen their relationships with external reporters and meet the 12-month completeness (**Figure D**). Strategies including sending quarterly reports out early to hospital registry staff, sending warning letters to senior management when hospitals are seriously behind, using laws and regulations to require ePath reporting and allowing access to electronic medical records, implementing quality measures, monitoring cases using historical data, establishing an annual call out, and relying on electronic reporting of cases.

## Potential Best Practice for Successful 12-Month Reporting



**Figure D**

### Highlights from Summit Group Discussions

One breakout group discussed ways of ensuring high-quality data from non-hospital reporters. These data result in significant amounts of work for a small number of cases,

and the quality is lacking. Some registries abstract the cases themselves, rather than training clerks at the reporting sites. Gathering all the complex data from these sources is impractical.

- A majority of the participants wait for hospital submission before working on non-hospital data.
- Attendees would like to discontinue clinical document architecture files, as part of Meaningful Use, and work on a more manageable process.
- Participants suggested focusing on changing the time frame for releasing data to 18 or 20 months.
- Manuals for different types of reporting (e.g., dermatology) could be developed and shared across states.
- Attendees discussed whether state funding can be used to abstract cases.

A second breakout group discussed ways of ensuring high-quality data from hospital reporters, emphasizing that the main strategy is increased communication. Although some hospitals use contractors, the ultimate responsibility for data quality falls on the hospital, so communication and transparency are essential to ensuring quality. Many registries have a listing of facility profiles, including abstracting vendors and their employees, with whom they can maintain communication and ensure that all parties are familiar with the applicable state-reporting requirements. Other suggestions included automated reports to provide metrics to the reporting facility, robust edits to ensure good data, and re-abstracting and case-finding audits for facilities with concerning data quality. Potentially valuable opportunities for improvement include training contractors on reportability and case-finding lists specific to the state, developing a mechanism to notify the central registry of a potential reportable case, and emphasizing the importance of text documentation to support all coded fields. The group stressed that registry staff should not assume that contractors are aware of which items are deemed reportable and important to each state. Reporting standards should be communicated to vendors, and the reports on timeliness and quality should be provided to vendors and hospitals.

### **Focus Group Findings**

All groups discussed some of their best practices to assure 12-month timeliness standards. It was clear from the discussions that a few common strategies are being used by several states and recommended to be developed as potential best practices for other states.

The following strategies were recommended by various states as valuable in reaching the 12-month data standards. The comments largely focused on strategies to monitor timely reporting via management reports and methods to communicate with facilities to encourage timely reporting. Comments from focus groups include:

- “We have a closeout every year, and we send them a packet that they have to complete, and part of that packet is to update all of their contact information—their administrative information—but also where they think they are and what they anticipate for next year.”
- “Using quarterly audit reports and annual awards or hospital certifications are big motivators.”
- “Maintaining historical variation averages to find gaps and alert hospitals to potential problems.”
- “We have a whole database that we’ve built that houses all of our facilities specific information, so we can you know anybody on the staff can go in and access that entire database at any time.”
- “For the dermatologist account to collect the melanoma cases, we created their own little reporting manual and training that they can view whenever they’d like. We use Web Plus, so it’s completely electronic and the whole process, it makes it a little bit easier for them.”
- “Developing linkages with hospitals and outpatient reporters, using simple applications to collect only essential information.”
- “Using ePath reporting to let facilities know they are missing cases.”
- “Having the ability to hold certificate of need for noncompliant hospitals. It represents a big stick that works very effectively.”
- “Having access to hospital electronic medical records and ePath reports because our legislation allows us access.”

**Major theme:** States are actively engaged in a number of steps to improve the quality and timeliness of reporting. Capturing some best practices that may be used across registry may help some states to improve their timeliness.

### **Quantitative Assessment and Guided Expert Interview Results**

The registries repeated the themes of monitoring timely reporting and communicating with facilities in their responses to the quantitative assessment and guided interviews. Their detailed responses are reflected below.

*Provide management reports to reporting facilities reflecting progress:* Fifteen registries made recommendations such as (1) Send monthly/quarterly letters to hospital registry staff and registry managers informing them of their current completeness and timeliness. Hospitals like receiving letters to see where they are. If the hospital registry is falling behind schedule, some registries escalate their concerns to a higher level in the hospital chain of command. (2) Send to non-hospital sources quarterly, small facilities semi-annually. (3) Provide quarterly completeness and timeliness reports to

reporting facilities that include 10 quality control measures. most hospitals love it and use it. (4) Establish good relationships with registries and give out awards for timeliness to hospitals. (5) Send delinquency reports to hospitals for nonreporting (15 registries).

*Strong state-reporting regulations:* Two states require ePath reporting 15 days after record is complete, and some report daily. However, one registry holds pathology reports to wait and see if they will receive a hospital abstract. The other registry will generate automated follow-back to the physician in the future. Mandate electronic reporting (only). Require monthly reporting. One registry can deny certificate-of-need applications for hospitals if they are noncompliant.

Allow facilities to report in different ways (ePath, HL7 messaging). Rely on electronic data sources (population-based pathology collection (two registries)).

*Internal management reports:* These were mentioned by several registries. Ideas include weekly management reports tracking timeliness and cases in the database waiting to be processed; comparing cases by site, by dx year, and by region to identify which ones are falling behind; and generating a report by case count by Class of Case on quarterly basis. For other internal management reports—

- Establish an annual close-out date for all cases (July 1 of previous year). Send a close out packet of missing cases/information prior to annual close-out date (two states).
- Prioritize processing of cases to those that will contribute to the completeness measures.
- Rely heavily on electronic reporting and process these cases first (three states). Encourage ePath reporting (two states).
- Start case-finding audits of hospitals early.
- Conduct annual case-finding audits using discharge data bases (two registries).
- Process ePath reports last.
- Deemphasize Meaningful Use.
- Path clearance—is a form letter sent to a hospital or physician for more info—including name/diagnosis/treatment, and so on. Ask about race information because that is not in path cases very often. These are all cases where that do not match up to the central database.
- Note that the majority of the cases from CoC facilities helps achieve timeliness.
- Use laboratory-only and physician-only cases to build an incidence case if getting close to call for data and if they have not been reported by a hospital (2 registries).

- Set productivity benchmarks for staff.
- Hire external staff to help with workload.
- Obtain remote access to facility data.
- Do not process second reports that come in on paper.
- Require reports on cases that hospitals have touched in the last 18 months. Do this with 12-month data and call for data in mind. Compare them to what are already on the central registry database and do updates, as well as find new cases.

One state suggested to reject cases that come in too early, because they will not have full treatment information. Require hospitals to wait until they have a full report. However, other states will accept these records and process them multiple times as corrections and modifications are received.

To increase completeness in a non-hospital setting, develop a NAACCR record that has only the minimal amount of data needed to be reported and that will still fit in with the full abstract from an analytic point of view. One Registry has done this with dermatology practices and has increased not only completeness but timeliness, as well. To have it as a NAACCR record type would eliminate the effort necessary to fill in defaults, and it should be geared to someone who can read the medical record and easily fill in the required data items. Of course, edits would have to accommodate this record type.

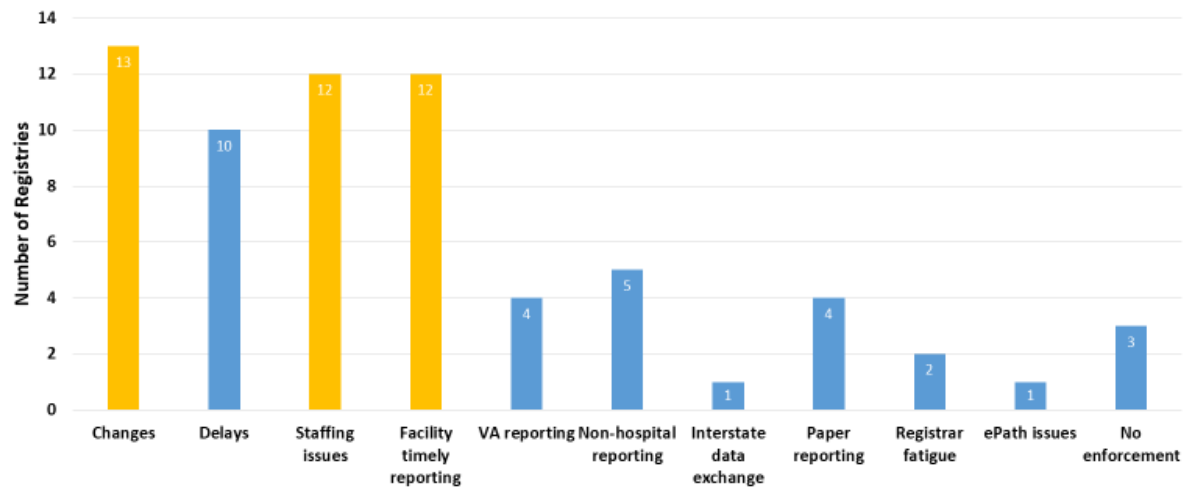
## Characteristics of States with Obstacles

### Barriers to Achieving the 12-Month Standard

#### Summary

Registries identified common themes and system-wide concerns that affect their ability to collect complete, accurate, and timely data. **Figure E** identifies the major factors that hinder this goal. Aside from the frequency of changes in data requirements, staffing issues were most often cited. They included a lack of CTRs, as well as other registry staff. Loss of registry staff due to funding cuts, retirement and staff turnover in reporting facilities is a major hindrance to efficient data collection and processing. States also noted that, as a consequence of the constant staff turnover at reporting facilities, less knowledgeable and experienced personnel resulted in the need for increased education and training for both hospital and central registry staff.

## Major Barriers Identified by States



**Figure E**

The most significant factor influencing timeliness is a lack of qualified CTRs in central registries and hospitals alike, resulting in delays in processing, constant chasing after missing data and increased workload on central registry staff. CTRs are almost impossible to hire and even when they are appointed. They often leave within a couple of years for more flexible and better paying contracting jobs. State department-housed registries have little ability to offer flex time or remote work, so it is hard to compete with private vendors. Training for new staff is time consuming and the learning curve is high. Central registries also are facing reductions in budgets and are having to do more with less. One registry reported that their staff number was down 25%, with little hope of immediate replacements.

Hospitals are facing similar challenges with high turnover, tight budgets, and increased workloads. CoC requires one set of cancer reporting protocols while states require a different set. CoC reporting takes priority with many hospitals considering central registries reporting less urgent. Hospital audits are indicating high levels of missing data from hospital records and complacency in reporting across a number of hospitals, resulting in more follow-up by central registries. Laws exist that require reporting, but fines and penalties are often not enforced.

Non-hospital reporting by large oncology groups, freestanding outpatient centers, ambulatory surgery centers, pathology laboratories, and radiology centers to name a few are increasing and have neither the staff, resources, or disposition to report with accuracy and timeliness. Missing data and late reporting are common and intensify the burden on central registry staff. ePath is inconsistently reported with large amounts of missing data. It takes hours and hours of time to fix these incomplete reports, and it is often better to wait until the hospital reports the case instead of trying to complete an ePath abstract.



As previously reported, the tendency toward centralized IT support using call centers with little knowledge of registry software or operations is also a major barrier. Late software updates and little to no linkages, consolidation capacity, or an inability to process partial records result in time-consuming manual labor to complete the abstracts.

On an even larger scale, continuous and expanding changes in reporting requirements have the potential to take the cancer registries to the edge. The new 2018 changes have created massive delays and recovery from this situation will have long-lasting impact on the ability of states to provide high-quality and timely data. Registrar fatigue is a serious threat to registry sustainability. Seventeen of the 22 states said that not having all the 2018 information, software, and EDITS ready in time have left them feeling frustrated and lost.

### Focus Group Findings

Focus group participants spent considerable time reviewing the key barriers to success, and respondents were mostly aligned with the findings of the quantitative assessment, the guided expert interviews, and Summit breakouts across most of the challenges facing registries. The quotes below are indicative of the strong feelings expressed by the participants on this subject.

- “Workload is unbelievable—it’s a huge burden.”
- “We are tired of all the changes.”
- “We have some good staff, but they feel like they’re doing as much as they can and they can’t take on anything more.”
- “The time it takes to get the non-hospital sources to report is so costly. We spend a lot of man hours, energy, and blood, sweat, and tears to bring in those the last couple of cases to reach the 12-month standard.”
- “We need to prioritize resources better and reduce the amount of data collected to fit the real needs of the registries. We need more help. Asking us to do everything causes us to be mediocre at everything. And I don’t think that’s really where any of us want to see that go”
- “When you release a software product, it should be ready to go.”
- “Most processes by NPCR and NAACCR focus on 24-month standards and do not work for 12-month data timeliness.”

**Major themes:** The burdens carried by registries have reached a breaking point, and short-term and long-term solutions must be applied if registries are to function with efficiency and meet the high-quality standards that have made central cancer registries among the best chronic disease surveillance systems.

## Quantitative Assessments and Guided Expert Interview Results

The following barriers to achieving 12-month with completeness were identified by participants:

- Lack of trained staff (CTRs) at hospitals: A lack of trained staff at hospital registries results in a cascade of problems at the central registry, including delayed/no reporting, and high-error rates on cases submitted. These problems are magnified in rural settings. Staff turnover at the hospital is a major problem. When facilities merge, it affects their cancer reporting. CoC programs have their own protocols, and hospitals prioritize the CoC mandates first, rather than the state mandate. Often central registry staff will need to go to poor reporting facilities to obtain and process cases. Hospitals that use contractors tend to report slowly and have poor quality data (12 registries).
- Late and incomplete reporting from hospitals: Case-finding audits reveal partial reporting in many facilities. Facilities complacent about reporting, reporting regularly then dropping off again (six registries)
- 2018 changes and delays have significantly impacted timeliness of reporting, especially for the 2018 diagnosis year. Not having all the 2018 information, software, Edits, etc., ready in time. Registrar fatigue—not able to master all the changes that affect productivity and constantly having to learn new rules/guidelines. Changes in data items, creating software delays for hospital software and central registry software. Edits metafile changes causes delays as an ongoing process. Delays and inefficiencies in CDC-provided software (17 registries)
- Under staffing at central registries: Registries reported being understaffed due to retirements, cuts in funding in recent years, and staff turnover. Budget constraints have made it difficult to fill jobs, and many CTRS prefer to work remotely and/or for consulting companies compounding the problem. Most registries will not allow telecommuting or at most staff can work one day/week from home due to slow performance of remote access to software and other personnel policies. When seasoned staff retire replacement workers cannot produce at the same level and require extensive training. Cannot focus on 12- and 24- month completeness at the same time, so focus on 24-month (18 registries)
- Insufficient IT support: IT departments are being restructured. It is hard to get IT support when needed. For example, one registry reported waiting over a year to get eMaRC up and running. It is hard to get the right IT person assigned to registry projects, and they are often assigned to someone that does not have the correct skill set.

- Difficulty with ePath: Registries reported pathology labs switching software and failing to report at all. They reported not having the resources to get ePath up and running in their states. Labs that do not report through ePath take a lot of staff time to review. For example, one registry reported one dermatopathology lab that reports about 80,000 cases but only 4% reportable. Even for the electronic cases, they are 9–10 months behind in ePath (three registries).
- Reduced budgets at central and hospital registries: One central registry lost 25% of staff due to funding cuts. Used to be able to cover hospital costs to attend training (travel, hotel, food) but had to stop due to budget cuts. (two registries).
- Training due to changing requirements and staff turnover: Training require substantial effort and resources. Hard to get hospitals to trainings. Used to be able to cover hospital costs to attend training seminars (travel, hotel, food) but had to stop due to budget cuts (four registries)
- Non-hospital reporting sources: Data from non-hospital sources are increasing, and they are incomplete and of poor quality. These incomplete data require extensive processing, including matching, consolidating, and editing. Trying to convince hospital facilities that they are still responsible to report out-patient only cases that their health systems physicians diagnose and treat. Doing outreach to physician offices and cancer centers to get them to report. Registries still abstract cases for ambulatory surgery centers, free standing clinics. Need minimum data standards for these records and automated consolidation rules (nine registries)
- Training new staff and hospital staff is very resource intensive, especially as the data become more complex. Increased training needs due to changing requirements
- As treatment gets more complex and extending longer, it extends the time frame that the data is reported (four registries).
- Lack of enforceable penalties in state regulations/weak regulations: Lack of penalties for outpatient reporting (three registries)
- Sheer volume of work (four registries)
- Lack of electronic reporting and resources and consolidation tools: Inability to process update or modified record—two stage of data reporting—with an incident record and then later getting a treatment record to update with later (10 registries)
- Lack of VA reporting (four registries)
- Meaningful Use activities diverted staff time that should be spent elsewhere
- Out of state reporting (three registries)

- Death certificate-only cases and death clearance

States were asked to share their thoughts and ideas on what might make 12-month reporting easier.

Below are the comments provided by the states:

- More timely software and standards were mentioned by eight states.
- More staff was mentioned by three states.
- Less frequent changes to reporting requirements was mentioned by four states.
- A less complex abstract was mentioned by two states.
- NPCR best practices are focused on the 24-month data set, so certain operations are not focused on the 12-month data set at all. Some of this is due to limitations on both hospital and registry staff, such as annual case finding audits, but death clearance, linkages to state mortality data, site-specific data items (SSDI), and National Death Index (NDI) are all just for the 24-month data set. We could increase our completeness for the 12-month dataset by filling in with paper and eMaRC Plus lab reports, but those reports are of poor quality and are incomplete, so we would be sacrificing data quality for data quantity, so we decided not to do that. We only process those cases once we know we have exhausted all other sources of data for the 24-month data set.
- Ultimately, we are at the mercy of the reporters. The ability to levy fines, even if only once, would change the way delinquent reporters view deadlines. Direct contacts with the reporter's administration explaining the importance of timeliness and allocating resources necessary to meet deadline. This is a touchy issue, because this can have adverse impacts on reporting depending on administrator.
- Reduce or eliminate the 97% edit-free requirement: Because of the number of cases coming from physician office and other non-hospital facilities that do not employ CTRs, these cases create more edits—often they need to be completely abstracted. It would also help to have an automated tool for calculating our completeness (built into DMS), so that we know when we are 90% complete.
- Ability to process M-records; improving interstate data exchange; no repeats of the 2018 debacle
- Ideally, NPCR and NAACCR should not be asking for these data.
- We would have to consolidate a small number of fields and then go back and consolidate everything else. That is not efficient ... we want to consolidate everything once.

- We think that with enhancement in electronic submissions, we can improve the time and efficiency for reporting.
- Getting every facility large and small, but especially small, on board with abstracting own cases and reporting electronically

## Identified Best Practices

### Summary

States openly and willingly shared a variety of methods used to attain 12- and 24-month timely reporting. From seemingly simple things like developing relationships with reporting facilities to more complicated workload processing, states utilize what works well for them and also noted areas of concern. Many of these techniques are shared among registries in each of the categories developed for this project, but not by all.

### Monitor Central Registry and Facility Progress

States discussed the importance of monitoring central registry progress toward data quality standards and submission timelines. Weekly management reports are utilized by many registries that track central registry timeliness, cases in the database waiting to be processed, and relevant quality control benchmarks. States produce reports comparing case submissions by primary site, by diagnosis year, by class of case, and by region to identify facilities that are falling behind. However, states expressed a need for these reports to be built into a “dashboard” within the central registry software systems, so that these types of results are available at the push of a button by management. Lack of management tools within registry software was noted by states that indicated that the development of these tools would help to improve timeliness and free central registry staff for other tasks.

The implementation of a robust communication plan to establish reporting expectations, goals, and timelines for reporting facilities—and the ability to track facility reporting throughout the year to identify and correct reporting problems at their inception—was a method cited by many states ( $n = 15$ ). Sending monthly or quarterly letters to hospital registry staff and their managers informing them of their current completeness, and timeliness is well received. Hospitals like to know their current status which helps them assure hospital administration that their facility is on track and compliant with state reporting. Non-hospital reporting sources and small reporting facilities also appreciate receiving feedback about their status, but states do this on a less frequent basis, either quarterly or semi-annually. Some states utilize an annual “close-out” process where they establish an annual close out date for all cases (July 1 of previous year) and require submission of a close-out form whereby reporting facilities provide their reporting status for the diagnosis year, explain any deficiencies in case submissions, provide the number of expected cases for the coming year, and update facility personnel and contact information. States also noted the importance of establishing

monthly reporting requirements, only accepting cases that pass edits, and the use of electronic reporting to assist in timely case submission.

### **Develop and Promote Good Relationships with Reporting Facilities**

Developing and nurturing relationships between central registries and reporting facilities were cited as beneficial by seven registries during the state interview process. States accomplished this in a variety of ways. Providing positive feedback in the form of timeliness and data quality awards or facility-specific reports that could be shared with facility administration was encouraged and utilized by multiple states. Identified deficiencies in facility reporting are countered by directly contacting facilities to illuminate facility problems, offer technical assistance, and reiterate reporting requirements. One state said, “smile, but be persistent,” illustrating that constant communication is an important tool. Working with state professional associations to establish a presence at educational meetings, confirm state expectations and provide updates, and work in partnership to provide education and training go a long way toward maintaining positive relationships between reporting facilities and the central registry. Having dedicated field staff that can interact and provide support to reporting facilities is also an important investment in developing a positive working relationship. While negative penalties were also discussed, states indicated positive methods to encourage and support reporting were more productive and worked well in most situations.

### **Develop Facility-Specific Displays or Record Formats for Case Reporting**

To increase completeness in a non-hospital setting, the development of a NAACCR record that contains only the minimal amount of data needed from an analytic point of view was suggested. Two registries have done this with dermatology practices, and it has increased not only completeness but timeliness of data from those sources. To develop and promote this as an official NAACCR record type would eliminate the extra effort necessary by central registry staff to develop a customized record layout, fill in defaulted data items, and clear edits. This record type should be geared toward office staff who can read the medical record and easily fill in the required data items. Of course, edits would need to be developed to accommodate this record type, as well as processes to seamlessly incorporate it into central registry software.

### **Establish a Standard for Biannual Updates to Cancer Reporting Software**

Changes to reporting software result in a cascade of work for central registries. When implementing changes results in delayed release of new software versions, it can negatively affect both central and hospital registry timeliness. The establishment of a standard to limit software updates to a biannual timeline would be helpful to central and hospital registries that could then plan for updates and incorporate the resulting workload into standard registry operations. Impacts at the hospital registry level would be minimized, allowing hospitals to plan their state submissions to remain in compliance

with state-reporting requirements. Additionally, delayed software releases from vendors would be minimized or eliminated entirely.

### **Develop and Implement Procedures to Effectively Handle ePath Volume**

ePath is widely used with 19 states (86%) participating in the project having at least some ePath reporting. All 19 states receive ePath reports before receiving hospital abstracts with 16 states (84%) waiting to process the majority of ePath cases after they receive the hospital abstract. Only three states report processing ePath reports as they receive them. States wait to process ePath reports after receiving the hospital abstract for several reasons. ePath reports are not complete abstracts and can produce a significant number of edits that must be resolved by central registry staff. ePath software does have some ability to identify reportable cases, but the reality is many of the received reports must be reviewed for reportability by registry staff to identify cases. In fact, one large state indicated about half of the ePath reports they receive are not reportable cases. And finally, central registry software limitations mean incoming full abstracts from a hospital or facility reporting source is unable to be effectively consolidated against a pathology report already loaded to the central registry database. These limitations hamper the usability of pathology reports for more timely reporting, especially given the large volume of pathology reports received. Development of tools or processes to assist central registries in more effectively identifying and processing reportable pathology cases should be valuable in improving timeliness.

### **Utilize Training Resources to Develop a “Grow a CTR” Program**

With a significant shortage of CTRs nationwide affecting staffing at both hospital reporting facilities and central registries, some states have developed and implemented their own program to train new CTR staff. These programs start by identifying people with the right background for becoming a CTR, such as anatomy and medical terminology training, and the right mindset, which includes independence, a detail-oriented character, and an interest in data. Contact with HIM programs and colleges as sources for recruitment and presentations to public health, biology, or nursing departments can raise interest in the profession. Because standardized programs do not include exposure to registries, connections must be developed in other ways, including offering internships and marketing the field. States suggested the development, delivery, and implementation of a marketing plan at a national level.

Individual training and guidance are important, but the use of readily available training materials such as SEER Educate, NAACCR webinars and the CTR Exam Preparation and Review course, and NCRA case studies workbooks are also valuable training tools. States suggested that NPCR work with NAACCR to develop a basic training webinar for CTR candidates or new CTRs that could be shared by all states, potentially on the FLccSC Learning Management System (LMS). This would save central registry training staff time and allow them to focus on more complex training topics like staging and solid tumor rules when developing new CTR staff and preparing them for the CTR exam.

States also encouraged the development of a clinical practicum program within the central registry to fulfill the NCRA 160-hour requirement for students to be eligible for the CTR exam. A partnership with local hospitals could provide instruction on some of the more hospital-specific clinical practicum components and promote good relationships between hospitals, students, and the central registry.

## Strengthen State Reporting Regulations

During the state interview process, several states indicated their reporting laws had no penalties or “teeth” to compel timely reporting by facilities. This inability to enforce reporting laws can and does hamper state timeliness. Other states mentioned either established practices or updated state laws that help to improve enforcement of facility reporting or solidify reporting time frames. Two states require ePath reporting 15 days after record is complete with some facilities reporting daily. One registry has the ability encoded into state law to deny certificate of need applications for reporting facilities if they are noncompliant in their cancer reporting. Other states mentioned laws mandating monthly reporting or electronic only reporting. The establishment of reporting laws that require ePath reporting, shorten submission timelines, require electronic reporting, and provide enforceable penalties for nonsubmission would all be advantageous to central registries.

## Other Information from Assessments and Interviews

### General Registry Demographics

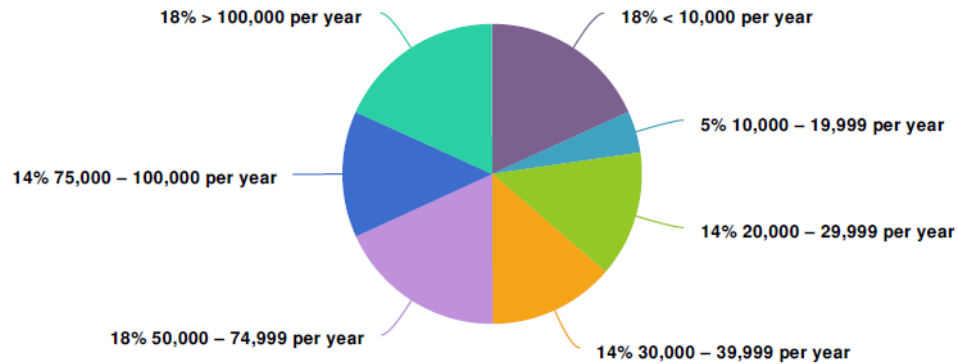
#### Summary

The comprehensive assessments all looked at key demographic and funding sources for the participating registries. While almost all registries meet required funding NPCR matching requirements, sources of funds vary by state. Most of the matching funds are used to support staff positions. There are differences in how funds are budgeted between states that are housed in universities and those in the Departments of Health.

Caseloads vary across all states, ranging from those with fewer than 10,000 cases per year to those with over 100,000 cases per year (see **Figure F**). State laws vary in scope, but 68% of states report that their laws do not require rapid path only reporting or rapid case ascertainment. However, 16 of 22 (73%) states report 100% electronic hospital reporting, and only 2 states report less than 80% hospital electronic reporting. CoC hospitals comprise more than 60% of cases for all states with the majority of states reaching 70–80% or more from CoC hospitals. Cases from out of state catchment areas were all under 10%, with the majority of states in the 5–9% range. However, states that must deal with higher numbers of out-of-state cases struggle with obtaining this data, often resulting in delays in their completeness.



## Average size of incidence file per year










**Figure F**

IT support is located outside of the registry for the majority of states (11), with eight states reporting that the IT services are embedded within their administrative units. However, almost all registries within state government systems are dealing with centralized IT systems where it is common to rely upon call centers and helpdesks where staff have little actual registry background. This is creating significant problems for registry staff when dealing with any software issues.

On the positive side, states report a robust and flourishing use of cancer data both internally and externally (see **Table 11**). Internally, comprehensive cancer plans, breast and cervical screening programs, special cancer reporting, and cluster investigations all rely upon the registry data. Externally, local health departments, county cancer coalitions, hospitals, and nonprofit health agencies use data for their public health activities. Of course, the largest use is by researchers with all registries receiving numerous requests for data for research studies. Universities and colleges also use data for training of students.

**Table 11. How States Use Central Registry Data**

Value		Percent	Responses
Cancer Control Activities		100.0%	22
Research/Clinical Studies		95.5%	21
Program Planning/Evaluation		95.5%	21
Health Care Delivery		68.2%	15
State or Territorial Reporting		90.9%	20
Health Communication		86.4%	19
Other (Specify):		22.7%	5

### Focus Group Summary

As part of the focus group discussions, registries considered the types of characteristics and structure that are most important for their success using the concept of a perfect cancer registry for their reflections. Responses when discussing “what does a perfect cancer registry look like” were summed up in the following quotes:

*“Fully staffed with plenty of resources, strong IT support, complete, timely, 100% electronic reporting, automation that is reliable, physicians who report with timeliness and accuracy, time to do everything that needs doing and the ability to spin on a dime. Given the pressures on resources and changing environment, this does not exist anywhere today.”*

The following structural and resource-focused themes were most commonly discussed across all participating registries and were deemed high priorities for success:

- “Stable staff with comprehensive knowledge”
- “Experienced leadership with historical know how”
- “Completely electronic reporting”
- “Comprehensive reporting law with teeth”
- “Strong hospital and reporter relationships”
- “Location in a medical school/university and not a state department”

However, there are structural and resource concerns that limit the registries’ capacity to be successful, including—

- “Workload is unbelievable – it’s a huge burden.”

- “With less resources and loss of staff, we are just trying to keep our heads above water.”
- “IT is centralized, which means we reach a general call desk when we need help.”
- “We contracted out our IT to the medical school where I am now, so we just have a general homicide agent responsible for our operating systems. So, it’s good and bad sometimes.”
- “We need a more systematic approach to solve problems. Tools for abstracting, training for reporters, IT help...we live in a changing world and we need a more systematic approach to solve problems”

**Data use:** States report strong use of their data both internally within their departments and by a range of external users. Key areas where data are used include updating comprehensive cancer plans, monitoring the breast and cervical cancer program, specialty reports, cluster investigation, environmental tracking, and data visualization reporting. Researchers represent the largest group requesting data, but hospitals, community health departments, county cancer coalitions and universities teaching students are active users.

- “We have between 150 and 200 data research requests per year.”
- “It is a real joy when you provide data for a research study that gets published.”
- “Our one or two-page cancer fact sheets are very popular.”
- “We’re currently working on a state-level data visualization to have it on our website.”

**Major theme:** Registries are able to identify critical resources and the qualities essential for their success, but face a reality where resources are limited, staffing is challenging, and structural problems are significant. However, the data collected is used robustly for public health, surveillance, and research.

### **Quantitative Assessment and Guided Expert Interview Results**

Each of the registries currently are being funded by NPCR and receive supplemental funding from their state government and/or a university; seven also received funding from SEER. States report receiving the required matching funds from their states, but in many cases, state support did not exceed these minimums. A few states receive funding from other sources such as block grants or earned funds from conducting research projects. One state obtains funds from Medicaid Administrative Claiming.

States described their state and other funding as follows:

- 25% of state funding match to federal grant; works out to 20% of overall funding

- State funds that is about 20% of budget
- State funds cover just over half of funding. Some staff positions are paid through a preventive block grant.
- Receives partial state funding. Receives state funds through two streams. One goes right to contracts, and the second is used to hire three regional coordinators, a part-time administrative assistant, and an epidemiologist. A University is the contractor and manages the registry operations. Portion of staff funding also are provided by the University.
- State funding—about 20%
- They have state funds to support registry. Because they are located at the university, they claim registry director for 100% effort, so they really do not have enough staff. Some other staff are also faculty, so they also put in outside office hour time for registry.
- Receive state funds, covering six positions, maintenance of effort. 3:1 match covers the staffing level for hospitals.
- State funds to meet 3:1 match and maintenance of effort. Annually detailed in budget narrative
- They receive funding from the state health department through two appropriations: one for cancer registry and one for epidemiology—and additionally received in-kind funds from the state. Hybrid organization jointly managed through Department of Health and NCI Cancer Center at the University. Funds are funneled through the University
- They have state funding that meets the 3:1 match and also receive about \$150,000 through PHHS block grant. Grant is part of the Affordable Care Act. Funds are being used to IT contract staff.
- Receive funds from the Department of Health
- It is a state mandate that registry is a part of University. They do receive some state funding, but it flows through the University.
- Receive state dollars, \$75,000, with \$13,000 in-kind for some of staff's time. Also receive maintenance of effort in the amount of \$114,000
- Yes, we get two-thirds of our funding from Cancer Prevention Research Institute.
- Yes, we receive a state match of 3:1. Not all funds, half-funds, half in-kind. Also get some earned funds from research projects. Not stable funding source though
- State funds through different initiatives—prop 99. Also funded for biomarker project from NPCR

- State does provide some funding. May get limited additional funding for research work, linkage studies, etc.
- We get state funds annually—started in early 1980s—and continue to receive them. In the past three decades, amount of funding from state has never changed. They have regional registries in different regions; certain cancer centers host regional registries and provide site and computers.
- Funds from Departments of Public Health have staff support from school the Master’s of Public Health program, from faculty in that department, and 30% of effort is for cancer registry and IT staff supported by the school of medicine. Cancer registry resides in pathology departments of the medical school. They are the agent of health departments.
- Receive state support
- State funding provides maintenance of effort and match. State and federal funding has decreased over the years. They also do Medicaid Administrative Claiming – they get some dollars through that, less than \$100,000 per year. It’s funding they do through a claiming process. They have been trying to determine how to get funding from their data requests, but they have not figured that out yet. Have lots of researchers asking for data. As of now, they have not been able to implement that.

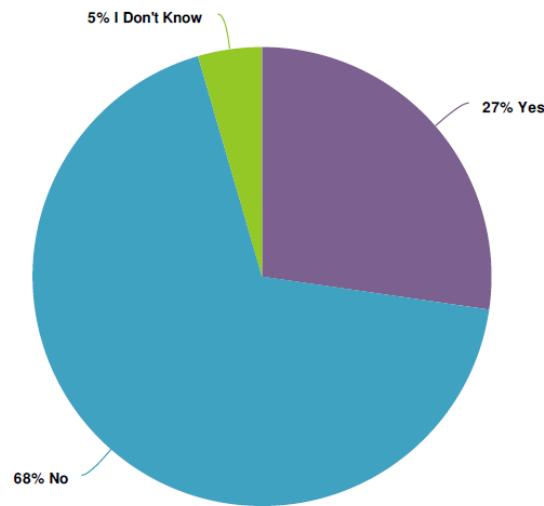
### **Caseload**

The registries covered a balanced range of sizes, from those with fewer than 10,000 incident cases per year to those with more than 100,000 (**Figure F**).

### **State Laws**

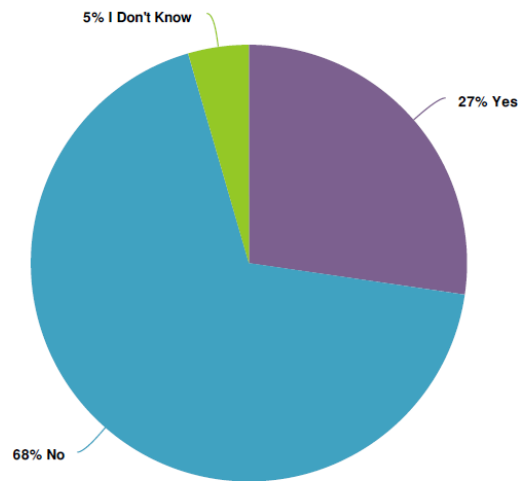
States were asked if rapid pathology laboratory and case reporting were included in their laws. The majority of the states did not have rapid pathology lab reporting specified in their laws (**Figures G and H**).

Does the registry have a State law in place that allows for rapid Path Only reporting?



**Figure G**

Does the registry have a State law in place that allows for rapid case ascertainment other than Path Only requirements?



**Figure H**

### CoC Facilities

States were also asked what percentage of cases were reported by at least one CoC-accredited facility in 2017. All states reported that 60% or higher of their cases were reported by a CoC-accredited facility. Sixteen states reported 70% or higher, and nine states actually reported 80% or higher were reported by CoC facilities.

## Catchment Area

Only three states reported 10% or more of their cases are reported by out-of-state sources in 2017. Eight states reported 5–9% of their cases are reported by out-of-state sources. The rest receive less than 5% of their cases from out-of-state sources.

## Electronic Reporting

States were asked what percentage of cases by facility were reported electronically.

- Hospitals: Sixteen states reported 100% of their hospital cases are reported electronically. An additional four states stated 98–99%, only two states reported 80% or less.
- Pathology labs: Four states reported 100% of their pathology lab cases are reported electronically. An additional seven states stated 90–99%. 4 states reported none of their pathology reports are reported electronically.
- Physician offices: Five states reported 100% of their physician cases are reported electronically. An additional three states reported 90–99%. Six states reported none of their physician office cases are reported electronically.
- Non-hospital treatment centers: Eight states reported 100% of their treatment center cases are reported electronically. Seven states reported none of their treatment center cases are reported electronically.

## IT Support

IT services are located outside the registry in 11 states; it is embedded within their programs in eight states, and three states have IT embedded, as well as having IT support from outside the registry. Many central cancer registries housed within state government are dealing with centralized IT systems that only offer call centers and help desks resulting in significant delays and dealing with IT staff that have no registry experience. Even when funding for IT staff is provided in budgets, this staff become integrated into the centralized state system and essentially are lost to the registries. This is leaving many programs without adequate IT support.

## Data Usage

States reported a robust and flourishing use of central registry data both internally and externally. The consensus is that cancer registry data are valued by state programs, researchers, hospitals, and nonprofits, as well as local and county health departments. Note that only a few states report using 12-month data for any outside purposes and rarely for internal use.

**Table 11** shows how data are being use by the states:

### **Other Data Use Specified**

- Cancer concerns, Market share requests, numbers to support planning for health care facilities
- Cancer studies for communities and individuals that have concerns about high cancer rates in their communities.
- Health investigations, market share estimates for hospitals, needs assessments

### **Staffing**

#### **Summary**

Throughout all assessments, the single most important problem identified remains a critical shortage of personnel trained to work in population-based cancer registries. Extensive on-the-job training is required, and this process takes away from the efficiency of day-to-day operations. Turnover in many registries is high, especially among CTR staff who are often paid more to work in hospitals, take contracting jobs, or prefer jobs that allow working from home options, which are often prohibited by public health agencies. The cancer surveillance work force is aging out of the job market and replacing staff with many years of experience with less skilled and less knowledgeable personnel, which results in additional inefficiencies. There is a recognized need to focus efforts on recruiting and retaining staff at all levels in the field of cancer surveillance. A coordinated effort to train staff in the basics of central registry operations and analysis would be an effective way to provide standardized training and reduce the multiple training efforts that are conducted at the local level.

CTRs are viewed by registries as critical to their success and more than 15 states reported that they have at least one vacancy at this time. Seventeen states reported that more staffing is important to their meeting 12-month completeness standards. As workloads increase, especially in light of the expansion of required data fields, staff are overburdened and are burning out. In addition, retirements of long-time employees mean that inexperienced new staff face steep learning curves, and it takes an estimated three new staff to complete the work of one senior employee. The result is backlogs of 6–7 months, a reliance on overtime at much costlier rates, pulling staff from quality control, training, field visits, and special projects to meet timelines and contracting out to private consultants at higher costs.

An increase in resources for staffing would allow states to better meet the 12-month timeliness standard by fixing missing data, expanding consolidation, and abstracting, as well as allowing for implementation of claims, pathology and discharge data, and other best practices to yield a minimal abstract that would be improved once the cases are



reported. Without new resources and more CTRs, the ability of registries to report high quality data in a timely fashion is at serious risk.

### **Highlights of Summit Discussions**

A breakout group discussed “how to grow a CTR.” Most registry staff identify people with the right background for becoming a CTR, such as anatomy and medical terminology training, and the right mindset, which includes independence, a detail-oriented character, and an interest in data. Training programs vary but include associates degrees, certificate programs, and online training, some of which might involve tuition or test reimbursement. Recruitment can be conducted with presentations at colleges, public health schools, and biology and nursing departments. A member emphasized the importance of making connections and demonstrating the fun aspects of the job. NPCR could be asked to promote the profession in a targeted way to attract people with the right background. A member also emphasized the need for younger people to become CTRs through the development, delivery, and implementation of a marketing plan. The group also suggested developing a basic training webinar for CTRs.

- Efforts from NPCR would help improve nationwide standardization for CTRs.
- Other suggestions included working with the state registry association involving hospital staff in recruitment presentations and accepting potential registrars from other countries.
- Attendees discussed whether training webinars funded by one state should be used by contractors in other states. It was suggested that CTRs are fluid in their employment and may return to that state; she also emphasized the importance of promoting cooperation as a national community, because the CTR shortage is a national problem.
- Participants discussed the types of programs targeted for CTR recruitment. HIM programs are a possibility; although these students might have a lower level of training than those from other programs. Increasing the number of CTRs in the field is necessary. Some schools might offer certificates to students in public health programs if interest is sufficient.

### **Focus Group Findings**

Staffing is the most commonly identified challenge facing registries today. It is viewed as a critical need with an urgency expressed by all groups. Generally, across registries, most staff are regarded as highly competent but rapidly are facing burnout because of the increasing size and complexity of the workload. Constant changes by standard setters are pushing a stressed system to the edge. Retirements and difficulty recruiting their replacements are putting additional pressure on most registries. This is especially problematic if succession planning is not in place, particularly when a long-standing staff

member is replaced by someone with little to no direct experience and a high learning curve ahead of them. A critical shortage of CTRs is leaving both central registries and hospital registries below capacity to function effectively. The following comments verify this issue:

- “Lack of CTRs is at a critical point. We post jobs and get zero applicants.”
- “New recruitment, training, and retention strategies for staff are essential.”
- “Staff is dedicated, but they can simply not do anymore.”
- “Retirements and staff losses are serious concerns for us, and succession planning is essential.”
- “Staffing is always the issue. We train our staff from the very beginning. We go proactively out after potential candidates who have the skills we want. We support them, train them, and work with them continuously. It takes a lot of time.”

**Major theme:** Registry staffing is at a critical point where steps must be taken to increase the number of CTRs available and improve resources to hire more additional staff or both the quality and quantity of registry reporting will suffer.

### **Quantitative Assessment and Guided Interviews**

**Current Staffing:** Ten registries reported 50% or more of their staff are CTRs. Six states reported less than 30% of their staff are CTRs. Fifteen states reported they have one or more vacancies.

**Staffing Needs:** Seventeen states indicated that having additional staff would help in meeting the 12-month standard while four said no or were not sure. Reduced staffing and/or upcoming retirements were mentioned throughout the project as a growing concern for central registries. Staff with 20+ years of experience that are not easily replaced. New staff need extensive training and will not be at a productive level of performance for years. One state estimated that to meet the void of long-time employees, you essentially need three new staff.

**Recommendations:** Staffing is a critical problem. Significant effort and resources from NPCR in conjunction with other stakeholders is needed to address this issue. Focus is needed on recruitment, training, and retention.

States shared their thoughts and concerns about staffing:

- Workloads have increased with the increase in number of data items, numbers of reports and reporting sources, and delays in 2018 changes. Automation is also more limited for Registry Plus users.
- With additional staff, we could increase the number of follow-up activities with delinquent reporters and potentially increase 12-month completeness and

timeliness. We could also explore the implementation of claims, pathology, and discharge data to yield a minimal abstract that would be improved once the cases are reported.

- We are able to meet 12-month standard with current staffing but must use overtime to do so.
- Electronic pathology reports still need to be manually reviewed and abstracted. Additional staff is needed to assist in this process. It will help the 12-month completeness.
- Currently have to use overtime plus some consultants
- Because of the 2018 data changes, it has been reported that it is taking at least double the time to abstract each case. The overall delays of the 2018 specifications compounded by the reports of longer abstracting time are of great concern, and we are currently assessing the long-term effects this will have on our timeliness, completeness, and data quality. Additional staff are needed but also action by standard setters to take this information into account in how future submissions will be handled.
- We have volume needs that warrant additional operations staff but no budget to support this need.
- Case ascertainment coordinator is needed.
- More cancer registrars are needed to process data in a more timely manner. Another supervisor is needed to review and manage timeliness of data.
- We currently submit 12-month data in January. In order to achieve this, we pull staff off of other key projects, including auditing, quality improvement projects, and training, and we cancel educational sessions for internal and external registrars leading up to the submission. We have insufficient staff to meet the submission requirements and maintain other projects.
- Due to retirements and budget restrictions, only one FTE position can be filled at this time. Also, note that the FTE in the other category are for Special Projects and do not contribute substantially to 12-month reporting.
- As our staff on-site have diminished in numbers, we have had to use a local facility to help with abstracting and also performing quality assurance check on submitted cases.
- We need senior/junior CTRs, so that we can keep difficult cases from being mishandled—since then, someone has had to correct and reprocess them.
- We estimate that it will take us 7 months to clear the backlog of pathology reports waiting for review and coding. In the meantime, more reports will be coming in,

so we will never be able to be current, with our current staffing level. Also, our field staff have little time to visit or remotely access non-hospital facilities to abstract the data items missing from the pathology report(s), because they have so many cases that need consolidation. When we submit our file in November, too many cases will have missing information on stage of the disease and treatment. Compared to other states with similar consolidation practices, we estimate that we need 8 to 10 additional operations staff, mostly CTRs. We think that NPCR should back off on its requirement that grantees meet the 12-month standard by the end of Year 5.

- Optimally, we need at least five more CTRs and a programmer. When I started with the registry 15 years ago, operations had 18 staff. We now have nine operations staff and are expected to do even more work than we did 15 years ago. That is untenable.

## Software

### Summary

Registries are faced with many software concerns. Central registries use a variety of software packages, with Registry Plus and SEER\*DMS being the most commonly used. Registries were asked to rate CDC software and tools on a scale of 1–5, with 5 being the very best; almost all CDC software and tools fell into the 3.1–3.8 range. Summit participants indicated a preference for SEER\*DMS, which they felt offers the best options for states and should be increasingly used.

Delays in software updates and spotty technical support create major challenges for cancer registries. Another issue that registries identified as a problem was the inability of many current central registry software systems to incorporate modified records submitted by hospitals without manual intervention from central registry staff. Central registries need automated solutions in order to process these records efficiently. The registries do not have the financial or staffing resources to process records multiple times (i.e., once upon initial receipt and every time there is receipt of modified or updated information).

Equally important is the establishment of standardized rules for consolidating records on the same individual and/or cancer that are obtained from multiple reporting sources. Eighteen of the 22 states report using some type of limited auto-consolidation. Only two states have full auto-consolidation, and one had no auto-consolidation. Choosing known over unknown values when consolidating is fairly straightforward. However, choosing between two plausible values for the same data item is often difficult. With the growing number of records processed by each registry on a single case, these rules need to be developed, standardized, implemented, and evaluated. More report management, pathology screening, claims abstracting, and reporting templates are just a few possible places where auto-consolidation would be beneficial. Only through developing the ability

to auto-consolidate records in a standardized fashion will we be able to make real progress in obtaining accurate and timely data.

## **Recommendations**

Timely data releases and auto-consolidation are critical needs if registries are to advance in completeness and timeliness. NPCR should consider focusing significant effort in supporting the development of standardized consolidation logic and automated processes. When it is within the developer's control, it is important to release software well in advance of the effective year. Limiting software releases to a standardized schedule with no more than two releases per year would also be beneficial.

Participating states reported that software updates that offer better linkages, flexibility, auto-consolidation, and automated fill features are very important to meeting 12-month standards. At this time, there are many gaps in the capacity of software to do the job. A number of suggestions were made for improvements. Participants identified a need to provide support and enhance the features of eMaRC to better screen and process electronic pathology reports and electronic health records from physicians' offices. In addition, efforts should be made to help develop standardized displays for use in Abstract Plus or Web Plus for physicians' offices. MatchPro is now in widespread use and preferred over Link Plus. Other software-specific suggestions across all CDC-based software are listed below.

## **Highlights of Summit Discussions**

A breakout discussion on software improvements focused on a wide range of possible enhancements to improve software concerns, including automatically updating known versus unknown data points, logging all changes, creating consistent methodology for auto-consolidation, developing a way to identify no-added-value records and removing them from the system automatically, and implementing "review by exception" protocols, so that staff can trust the electronic systems to apply the rules automatically; the review would be required only in the cases of critical errors. The group commented that some of these improvements are easy to implement. Other software-related needs include improved identification of reportability in pathology software and improved assignment of primary site and histology. Implementation of NLP functions could improve CTRs' workload significantly.

- Attendees discussed ways to include a rationale in a change log, such as including a comments field.
- Some registries are using systems that other registries can borrow or implement, such as a common dynamic link library or the change-tracking system such as Squish.
- Attendees commented that CDC provides guidelines detailing state-level issues necessary for program compliance. In return, a registry's IT representative could

be asked to sign a letter agreeing to provide support in compliance with CDC standards.

- Participants discussed various software systems, agreeing that SEER\*DMS, with technological support provided by IMS, is the best available option and likely to evolve as more states are added.

Another group focused its discussions on automation around consolidation. Group members were familiar with a variety of systems, but all members stressed the need to develop consolidation rules. They recommended a task force or a working group to develop standardized logic that could be used across registries using guidance from systems already developed by registries. Manual consolidation is a significant cost in terms of staffing time, even for registries with partial auto-consolidation. Group members suggested limiting auto-consolidation to a select few data items and reviewing the core consolidation logic for software systems. A group member stressed that registry staff need to accept that rules will not address every scenario but can be sufficient for the majority of cases. Registries also need to determine how to handle modified records. Group members recommended a third-party assessment of the entire data flow around consolidation to provide ideas on how to improve. It was also suggested developing standardized rules to match patients and tumor data.

- Some systems can consolidate across abstracts, but consolidation across records also is required. Quality control (QC) methods should be built in.
- One participant recommended including maintenance processes for changing fields and standards.
- Another participant recommended that a task force begin with NAACCR's manual on data consolidation.
- Patient data that can be used for linkage, such as social security numbers and names, vary across states and have changed over time, so the task force should include experts on matching.

### **Focus Group Finding**

Participating States reported software updates that offer better linkages, flexibility, auto-consolidation, and automated fill features are very important to meeting 12-month standards. At this time, there are many gaps in the capacity of software to do the job. Technical support is also an issue because IT services are now centralized. Sample-specific comments include:

- "We need better software, and it must be updated in a timelier manner."
- "We can't do anything without good software, so it's a high priority to make it as useful as possible."

- “The software we use is based upon record consolidation of abstracts that might have been okay 20 years ago, but today we really need to go to consolidating consolidated data.”
- “Software processes are a bit cumbersome, but we really need to rethink how our software works.”

### **Auto-consolidation**

The need for standardized auto-consolidation processes, especially around abstracting, is viewed by all registries as an essential next step. The time and energy devoted to manual reporting and quality improvement have become counter-productive. ePath reports are missing large amounts of information and require far too many corrective measures to be useful to the task. Non-hospital reporting is fraught with errors, and its quality is often poor. Improved software and linkages are necessary to correct this situation.

Sample comments include:

- “We need processes for better quality of incoming abstracts and then consolidation.”
- “We need help abstracting at the demographic and tumor level.”
- “Until software exists that reads information and process it that automatically and then only like things that need review when they need review, we will continue to rely upon staff to handle the load.”

**Major themes:** Auto-consolidation is a priority next step to improve both quality and timeliness of reporting. This will take collaboration across many of the key cancer surveillance stakeholders and efforts to mobilize action to address this need is important.





### **Quantitative Assessment and Guided Expert Interviews**

States were asked about software they use and what additional software is needed. The sections below describe specific recommendations for software improvements.

#### **Database Management Systems**

Participating Registries use a range of database management systems: six use Registry Plus alone, five use SEER\*DMS alone, three use Rocky Mountain alone, two use an in-house system alone, and five use multiple systems (**Table 12**). (Note: some registries indicated more than one data management system.)

**Table 12. Database Management Systems Used by Registries**

Value		Percent	Responses
SEER*DMS		31.8%	7
Registry Plus		36.4%	8
Commercial Vendor (specify, e.g., RMCDS, Precis, ERS)		27.3%	6
In-House Software Package (specify)		22.7%	5

### NPCR Software Effectiveness

Registries were asked which of the nine CDC software programs and tools they used and to rate them on a scale from 1 to 5. All products received a mean rating between 3.0 and 3.8, with wide ranges (**Table 13**). Each product had both multiple satisfied and multiple unsatisfied users.

**Table 13. CDC Software Programs and Tools Used by Registries**

Software Tool	# of Users	Mean Rating (Scale 1–5)	Range of Ratings
Abstract Plus	11	3.4	1–5
CDRS+/TLC+	7	3.3	1–4
Link Plus	19	3.5	2–5
Prep Plus	8	3.8	2–5
Web Plus	13	3.6	1–5
eMaRC Plus	17	3.1	1–5
XML Exc. Plus	0	—	—
Online Help	9	3.0	1–5
Utility Programs	7	3.7	2–5

### NPCR Software Requested Enhancements

The registries were asked for suggestions on enhancing CDC software tools. Several states requested more timely releases, more ability to customize, more auto-consolidation, and more robust linking.

The registries offered the following specific suggestions for enhancement of CDC software products. (Registries that did not use the product responded “N/A”):

- **ABSTRACT PLUS:** (Eight states replied “N/A”)



- Two states would like the customization and updates to be more timely.
- Would like to have a module designed for re-abstracting audits
- Have the ability to choose which SSDIs are required within the Site-Specific SSDI section.
- Have an auto-updater for all upgrades; SQL back-end database (SQL Server); ability to update/create/modify reports without the need to contact the CDC; in Open/Find Abstract, add accession number as a search option.
- Does not allow fields to be blank that can be blank
- We are using an old version to abstract and wish we could free-key a facility number.
- It would be nice if once the person enters the date of diagnosis year, the display would automatically show only those data items collected in that year and would allow states to customize or add additional data items.
- None. Not sure why we continue to develop. Hospitals that are CoC-accredited should be purchasing their own software. Non-CoC hospitals can use Web Plus.
- Happy with this software so far
- **CDC/NPCR EDITS TOOLS:** (Three states replied “N/A”)
  - Two states asked for more testing prior to release.
  - Two states stated they would like more timely delivery of metafiles.
  - Webinar and instructions on how to use
  - Increase speed for large files.
  - Good program
  - More modern interface between GenEdits and Edit Writer
  - .csv output option for genedits
  - In EditWriter, the ability to filter out obsolete edits from view
  - Edit Writer Help is much better
  - An enhancement request would be to include the Edit Tag in the import tool.

- Need more flexibility and permit look at specific types versus all or none. We cannot get duplicates sorted out. Codes are not always listed to know what is there.
- **CRS PLUS and TLC PLUS:** (12 states replied “N/A”)
  - Automated consolidation was mentioned by two states
  - Patient linkage improvement
  - Patient matching, consolidation. We need to move to a system where consolidation is against the consolidated record, not abstracts. Ability to handle M records with minimal processing
  - A "work queue" option
  - Be able to do pre-processing within this tool.
  - Kicks users offline often; runs slow (not sure if that is the network or application). Using an older version, we are not familiar with what upgrades may have been made in newer versions.
- **eMaRC PLUS** (four states replied “N/A”)
  - More automation and auto-coding were mentioned by several states.
  - Update in a timely manner
  - Edits in fields while working
  - Better linkages with CRS Plus, so we do not have to process reports we already have
  - Good program
  - Need a Version 18
  - Bundle small files into one.
  - Physician reporting. It would be great if eMaRC displayed whether the file is MU2 or MU3.
  - Enhance auto-coding of pathology data, identification of amended reports, and de-duplication.
  - Modifications to abstract screen are not easy to make. Would like to have a way to store files after they are processed for later lookup when needed
  - Installation is not flexible.
  - There isn't a way to identify duplicates in the physician-reporting module, to quarantine them, or group them. You cannot edit the complete abstract;

no corrections can be made before exporting to Abstract Plus. Lab module need to be able to clear the workbench (unless you check the box to limit cases, you have to wait for all of the cases to load).

- Automated importing from PHINMS queue
- **LINK PLUS:** (Three states replied “N/A”)
  - Five states said they preferred Match\*Pro and no longer used Link Plus.
  - Good program, I use v3.
  - Would like it to be more robust; accept files from different platforms
  - Quality of linkage reports, an API, improvements in number of clericals and increase speed
  - Manual review display could be improved; it is very hard to review the possible matches.
  - Not using; case limits were prohibitive

- **PREP PLUS:** (10 states replied “N/A”)
  - Remove access tables.
  - Have flexible display.
  - Should be incorporated into CRS Plus.
  - Using old version, we think this is the best application.
  - UDF Wizard to write custom UDFs

- **REGISTRY PLUS ONLINE HELP:** (Seven states replied “N/A”)

Many of the registries commented that this product was in major need of updating; see below.

- Keep current and more timely.
- Evaluate usefulness.
- Out of date, so we stopped using it
- Update with 2018 changes.
- Has not been updated for years. Either update it or abandon it.
- Would like to see it updated in a more timely manner
- Update content.
- More detail is needed, as well as more “how-to” instructions.

- **TNM (7TH and 8TH ED) STAGING API:** (Seven states replied “N/A”)
  - Not needed
  - Would like it to be more timely and provide better cross-platform support
  - Would like stability and timely delivery of DLL
  - Incorporated into our software program
  - For the TNM 7th edition Staging API, bugs have been identified but not resolved yet. This affects the way that cases are addressed in terms of QC efforts. Additionally, concerns have been identified in the way that error messages and informational error messages are identified. Confusion among states in how these should be resolved in terms of the requirement to be both edit and API error-free for submissions.
  - Using old version; haven’t had a chance to use the new interactive one
- **WEB PLUS:** (Seven states replied “N/A”)
  - Two registries said it works well.
  - Occasionally, we get reports from users that the program kicks them out of the program and didn’t save their work. Then they have to log back in again and start over.
  - Critical field having the ability to recognize if the right data elements are in the field (e.g., text populating a text-only field).
  - Only use this for file transfers.
  - Improve usability.
  - Not functional. We have put a lot of stake into this application for electronic submission of cases and continue to wait. Please help!!
  - Use in multiple browsers, more reports for statistics on incoming submission files
- **XML EXCHANGE PLUS:**
  - All states replied “N/A.”

### **Auto-consolidation/Automation**

Eighteen of the 22 states use limited auto-consolidation; Two states have full consolidation, and two states have no auto-consolidation. The two states that have full consolidation have home-grown systems. The majority of the states would like a

standardized consolidation logic to be implemented. In addition, several states requested more automation for processing ePath and developing management reports.

The Registries offered the following specific suggestions for manual processes that could be automated.

- Auto-consolidation was requested by 11 states
- Pathology report screening and/or auto-coding was requested by six states.
- More management reports. Thinks SEER\*DMS will include through the dashboard. They currently have to run reports outside of system (e.g., staff production). The use of Web Plus is to eliminate paper records from non-hospitals.
- Management reports
- Quarterly reports are used for hospitals (they have templates, but data are manually entered). The way they receive data—right now data are received via secure email and manually ran through edits.
- Claims/pathology-based abstracting. QC sampling and audits are the only other manual procedures.
- Demographic portions of DCO cases are populated from the death certificate automatically, but there are still a lot of fields that are updated manually (primary site) that could be populated automatically.
- If the CRS Plus software suite could talk to each other a little bit, better reports could be automatically generated. For example, comparing last submissions with the new submissions would be helpful. Export things and then import into another program are difficult. eMaRC doesn't talk to CRS Plus, etc. Elimination of paper files would be helpful.
- Natural language processing and the concept of staging path reports could be implemented. Non-reportable versus reportable needs improvement.
- One registry has automated linkage rules based on SEER multiple primary and histology rules. So, they've automated that work effort and lessened the amount of time needed to determine multiple primaries. However, automation requires frequent revisions to underlying logic especially lately with all of the changes. Researchers and quality control staff are involved. Key factor to note is that when you automate, you can always go follow it back and revise if needed.

The Registries asked for the following tools and support:

- Assistance with process pathology and/or physician office cases (requested by four states)

- Completeness reports that facilities could see from their data submissions, regardless of whether they file upload or directly enter cases

Because reporting is totally dependent on the reporting sources, all we can do is follow up with them. Some additional items that could be useful would be—

- To be able to actually levy fines
- Get hospital discharge data earlier and change our methods of case finding follow back to a year earlier than currently in place. Discharge data are currently used on 24-month data during death clearance. This is also dependent on the when the discharge data are available from the Agency for Healthcare Administration, which is beyond our control. This concept would require much more thought to determine any issues that could affect our 24-month.
- Potential use of claims data, although it might be difficult to ask for in addition to a full abstract
- Potential use of disease indexes from reporters to track missing cases that we can follow back to during follow-back process will help guide case reporting but will not force a facility to meet the 12-month deadlines. Again, our collection is only as good as the reporters submitting the reports.
- CCRs need software that can efficiently process M-records from hospitals and other sources.
- We will need the ability to read, write, and process XML files using the SAS program.
- More automated consolidation

### **Other Software and Tools Used**

In addition to using the database management systems states, use various other software programs. SAS was the most mentioned licensed software. The majority of the responses indicated the use of in-house developed tools to assist with linkages, processing electronic pathology and radiation reports, monitoring reporting (management reports), file preparation, and death matching and clearance.

### **ePath**

#### **Summary**

ePath is widely used by most states, with 19 states (86%) having at least some ePath reporting. All 19 states are receiving ePath reports before receiving hospital abstracts, with 16 states (84%) stockpiling and waiting to process the majority of the ePath cases until after they receive a corresponding hospital abstract. Only three states report

processing ePath reports as they receive them. States wait to process ePath reports after receiving the hospital abstract for several reasons.

First, ePath reports are not complete abstracts, and if loaded as is to the central registry database, these reports will generate a significant number of errors that must then be resolved manually.

Second, states receive large numbers of ePath reports, but not all are reportable cases. While ePath software has nominal ability to identify reportable cases, many of the received reports must be manually reviewed for reportability by registry staff. One large registry indicated about half of the ePath reports they receive are not reportable cases. This creates an enormous duplicative workload for most states.

Third, central registry software lacks the capability to effectively consolidate an ePath report with an incoming full abstract from a hospital or facility reporting source. Instead of incorporating new, more specific data from the facility abstract, the software defaults to retaining the original information based on timing of processing. In order to incorporate the more specific and complete data, the case must be manually consolidated, and all information from the incoming facility abstract must be manually transferred.

Some ePath reports are processed as they are received if the registry suspects another abstract will not come in from a more complete reporting source like a hospital (e.g., melanoma of the skin).

ePath is utilized by a few states as part of their case finding activities with reporting facilities.

**Recommendations:** It would be helpful if eMaRC Plus could improve on the accuracy of identifying reportable cases. Developing auto-coding of available data items would be an important improvement. Registries stated there was a significant need for less manual processing and more interoperability between the various software products in the Registry Plus suite.

## Highlights of Summit Discussions

Each registry uses ePath differently, and many are comfortable with the systems that they have established, but some items could be tweaked, such as by integrating NLP. ePath often is the last step in the data-gathering process.

- One registry noted that some doctors use the hospital laboratory for patient testing without admitting the patient to the hospital.
- Another reported on her team's process of auditing the pathology first and requiring resubmission if more than 5% of pathology cases have been missed.

- Payment for the ePath interface can be a problem. Although IT time is minimal once the interface has been established, those resources often are required elsewhere.
- A registry reported on a rules update for her registry that required electronic submission, although her team has been unable to enforce it at this time, because the circumstances of funding have changed.
- Although electronic submission can be required, ensuring that systems are interoperable is critical to avoiding increased work and errors.

### **Focus Group Findings**

ePath is viewed as a mixed blessing, used mostly for missing case identification, but reports are missing so much data that they are virtually useless for other purposes. ePath reports are not complete abstracts, and if loaded as they are to the central registry database, these reports may produce a significant number of errors that must then be resolved manually. States receive large numbers of ePath reports, but all are not reportable cases. ePath software does have some ability to identify reportable cases, but the reality is many of the received reports must be reviewed for reportability by registry staff. Further, registries do not have the capacity to automatically code these reports by extracting primary site, histology, demographics, and so on. Many registries wait until the hospital reporters do the abstracting and coding of cases before supplementing with ePath information. This saves the registry personnel resources of abstracting and coding. ePath reports are currently used primarily to fill in reporting gaps. All of these problems must be resolved if ePath reports are to become viable tools. Comments include:

- “Using ePath reporting to let facilities know they are missing cases”
- “Having access to hospital electronic medical records and ePath reports because our legislation allows us access
- “The workload, especially around fixing missing data in epath reports, is simply not worth it.”
- “ePath reports have so much missing data that we do not have time to fix them.”
- “Abstracting required for ePath is very time consuming and not worth the effort.”

**Major theme:** ePath creates more of a burden than it helps and, unless major problems can be resolved, this is not a viable tool for completeness or timeliness of reporting.

### **Quantitative Assessment and Guided Expert Interviews**

Registries were asked what data items they received on ePath reports (**Table 14**). The majority of the core data items are received. Race/ethnicity, stage and treatment are rarely available on these reports.



**Table 14. Core Elements of ePath Reporting (19 States Responding)**

Item	Number of States Receiving on ePath Reports
Primary Site	19
Name	19
Gender	19
Race/ethnicity	5
DOB	19
Histology/behavior	19
Date of Diagnosis	14
Age at Diagnosis	13
Stage at Diagnosis	6
First Course of Treatment	2
Other	—

## External Forces Affecting Timely Reporting

### Summary

Registries face challenges from external forces that have a major impact on their timely reporting. Hospitals are understaffed and suffer from similar problems to central registries such as high staff turnover, a lack of trained CTRs, expanding data requirements, more reporting requirements, and a lack of funding. In addition, hospitals are undergoing structural changes through merges and acquisitions. Community hospitals are not part of larger regional or national health systems with central administrative offices in other states, creating roadblocks to reporting. A reliance on third-party contractors has become common and staff in these facilities lack training and sometimes, access to necessary records. Non-hospital sources such as outpatient clinics, physicians, radiation centers, pathology labs, and ambulatory surgery centers are generally slow to report and submit incomplete data of poor quality. Clerks or administrative assistants are often called upon to complete complex registry information with little to no training, this results in missing or poor-quality reporting and extra work for central registry staff.

Overall, registries found laws and rules to positively influence timeliness. Rapid Quality Reporting System (RQRS), interstate data exchange, and fines and penalties also received more positive votes than negative. Laws and regulations are viewed as highly influential on reporting, but states often feel that their own laws lack teeth and are therefore limited in effectiveness. Most state laws require 6-month reporting. States often have penalties and fines attached to their laws, but few are actually enforced.

Several states report strong legislative requirements, including requiring electronic reporting. Some states have laws that are effective, because they require access to pathology reports and electronic records. In addition, some states have laws that include real consequences for not reporting such as withholding hospital certificate of need.

RQRS is viewed positively by slightly more registries than viewed it negatively, but there are serious issues with missing information, and submitted records often only contain initial biopsy findings. Work is duplicated and some contractors do not complete state-required fields, because the CoC required data items and reporting requirements are often considered more of a priority than reporting to the central registry.

Outsourcing is viewed more as a negative impact than a positive because registries are unable to communicate directly with the contractors, thus leading to poor quality work from the contractors and the contractor's unfamiliarity with state requirements.

Seven of 11 negative votes for "other" were documented as delays in software, while two were inadequate staffing at hospitals and/or central registry. While interstate data reporting is in place for most states, those with problems say they are struggling with this issue.

### **Highlights from Summit Group Discussions**

A Summit group's discussion of ensuring high-quality data from hospital reporters, emphasized the main strategy for improvement is increased communication. Although some hospitals use contractors, the ultimate responsibility for data quality falls on the hospital, so communication and transparency are essential to ensuring quality. Many registries have a listing of facility profiles, including abstracting vendors and their employees, with whom they can maintain communication and ensure that all parties are familiar with the applicable state-reporting requirements. Other suggestions included automated reports to provide metrics to the reporting facility, robust edits to ensure good data, and re-abstracting and case-finding audits for facilities with concerning data quality. Potentially valuable opportunities for improvement include training contractors on reportability and case-finding lists specific to the applicable state, developing a mechanism to notify the central registry of a potential reportable case, and emphasizing the importance of text documentation to support all coded fields. The group stressed that registry staff should not assume that contractors are aware of which items are deemed reportable and important to each state. Reporting standards should be communicated to vendors, and the reports on timeliness and quality should be provided to vendors and hospitals.

### **Focus Group Findings**

The problems facing central registries go far beyond their offices. External reporters face many of the difficulties of central registries, including staffing, increased work burdens, and a need for auto-consolidation. CoC hospitals have increased reporting

requirements that create additional work for hospital registries, which in turn results in downstream delays for central registries. Central registries working with the ever-expanding pool of non-hospital reporters face even more challenges. In addition, mergers and acquisitions among hospitals are at an all-time high and registries may be externally located in another state. Hospitals also are contracting out their registry reporting to private vendors that own no allegiance to states but rather work on a rate-based compensation system that focuses on completion rates and not quality data. As the system is becoming more complex and changes to reporting requirements expand, it becomes almost impossible for central registries to train and support their external reporters. The burden is pushing everyone to the edge.

In addition, large-group oncology practices are becoming more common and are often administrated by national offices that are located out of the state from where the actual practice is located. Physician groups often rely upon clerks or administrative staff with no training to complete reporting forms. Radiation, pathology, and surgery centers all function externally to hospital settings and reporting is often inconsistent. In addition, the VA and DOD facilities rarely report any cases and require individual memorandums of agreement for each site and state registry creating an administrative burden that is almost unsurmountable for central registries.

Sample comments around these issues include the following:

- “The real problem is not central registries. Mostly, it is the reporters who have limited resources, no CTRs, and conflicting priorities (and we are low on their list).”
- “Hospitals need more training, especially with all of the new data fields and changes.”
- “Private third-party (abstracting) vendors offer better pay, flexible hours, and allow working from home. We cannot compete.”
- “It’s really difficult to rely on non-hospital data because, you know, those types of facilities don’t have trained registrar’s and there’s turnover, so we cannot really rely on their data.”
- “We have a high percentage of unknowns, and it comes almost always from the non-hospital-reporting facilities.”

**Major themes:** Central registries must work collaboratively with hospital and non-hospital reporters alike. However, the challenges that exist for central registries also exist for external reporters. Any solutions for central registries must also take into consideration the needs of hospital and non-hospital tumor abstractors.

## Quantitative Assessment and Guided Expert Interview Results

States indicated what external forces impact timely submission both positively and negatively (**Table 15**).

**Table 15. External Forces Affecting Timely Submission**

	Positive	Negative	Both Positive and Negative	No Response
RQRS	7	3	0	10
Laws and rules	17	2	1	2
Fines and penalties	7	4	0	11
Outsourcing and contracting	6	7	2	7
Interstate data exchange	9	2	0	11
Other	2	11	1	8

States explained the negative impacts on timeliness:

- Seven states stated delay in 2018 software as a major negative effect.
- Four states indicated their laws are not strong enough to enforce and/or levy fines.

RQRS:

- RQRS cases are generally incomplete and only contain the initial biopsy information. Any further workup for staging and first-course treatment (surgery, chemotherapy, and/or radiation) are not sent until a follow-up file is sent by the facility containing this added information over a series of several months. These additional data involve a manual entry process and are time consuming. Currently, this is complicated by short staffing. Outsourced abstracting is lacking in quality coding, and text information is poor and incomplete. Many times, state-specific data fields are not abstracted.
- RQRS implementation at CoC facilities has an impact on cancer case reporting in a timely manner to the central registry due to duplication of effort by the tumor registrar at the reporting facilities. When facilities outsource abstracting work, we are unable to contact the outsourced company as it located across the state lines. This causes a delay in cancer case reporting. Standard setters must be more timely with their changes.
- RQRS implementation at CoC facilities has an impact on cancer case reporting in a timely manner to the central registry due to duplication of effort by the tumor registrar at the reporting facilities. When facilities outsource abstracting work, we are unable to contact the outsourced company as it located across the state

lines. This causes a delay in cancer case reporting. Standard setters must be more timely with their changes.

- Because of our inability to process M-records efficiently, RQRS is currently a negative factor. Contract companies produce abstracts of inconsistent quality and completeness, which creates additional work for central registry staff to clean it up

Changing standards:

- National standards change too frequently.
- Number and magnitude of changes made by the standard setters where the most dramatic impacts occur when they are delayed and released multiple times to correct mistakes. These requirements have a major negative impact on timeliness for all reporting.

Outsourcing and Contract Employees: (Three states)

- It is more difficult to communicate with outsourced staff, who may or may not be familiar with state reporting requirements. For facilities that outsource their registry, it is usually very difficult to identify someone at the facility who is knowledgeable and responsible for the registry. Also, contractors frequently tell us that they have stopped abstracting because the facility has not paid them or has not sent them cases. The contractor has no incentive to ensure the facility remains compliant with state-reporting requirements.
- Many of our CoC facilities have begun to outsource their abstracting, and we have seen this negatively impact timeliness of reporting due to high turnover and out-of-state registrars. Because these registrars are unfamiliar with state requirements, in addition to being unfamiliar with the facility they are abstracting for, timeliness and quality are impacted.
- Some hospitals/facilities do not closely monitor their contractor and do not provide all access needed to the contractor. Thus, facilities report fewer cases.

Interstate data exchange: (Two states)

- Interstate data exchange is slow and of varying quality, and not all states participate. Being able to enforce interstate data exchange would be helpful, either through incentives or penalties.
- One state has multiple contiguous states with frequent cross-border medical care. Many of the contiguous states have had difficulty meeting NPCR timeliness standards, so interstate data exchange is low priority.

Staffing: (Two states)

- Other factors include hospital staffing (number of staff and varying levels of competency) and reporting from federal agencies.
- Insufficient staffing at hospital registries. Insufficient number of qualified registrars. Insufficient resources in pathology labs to grow electronic reporting (two states)

Other:

- Small hospital abstracting is done by central registry staff. Instead of travel expenses and issues, they now encounter different challenges with getting access to electronic medical records—issues with connectivity, compatibility, security clearance, and reliance on hospital staff for disease indexes correctly generated by ICD-10 codes. We feel this approach gives our registry the most accurate and complete data and is the most efficient approach but takes more time to report.

### **States explained the positive impacts on timeliness**

Legislation and Regulations:

- Our laws allow us to enforce reporting with monetary penalty.
- We have rules that require reporting within six months. However, we do not have staff resources to follow up when facilities are not reporting on time.
- State-reporting law of six months certainly helps, but we don't have any enforcement provisions. Some of our hospitals don't have abstracting staff, so they hire abstracting contractors, which enables them to report. Interstate data exchange results in many sole-source cases.
- (1) Laws or rules—Without them, we would not be a NPCR registry, nor would reporters comply with submitting cases. (2) Outsourcing or contracting out abstracting work by reporting facilities—This adds to the reporter's workforce and allows for more abstracts to be abstracted in a shorter amount of time. (3) Interstate data exchange—This has some impact on timeliness but is dependent on states reporting data timely, currently, and of high quality. Many states data require significant work to clear edits with limited information. This would be more useful if all state registries cleared edits prior to sharing with other states.
- There is a six-month reporting law. Facilities that meet this time frame are able to apply for a "Completeness and Timeliness" award.
- Our laws require that hospitals submit cases to the central registry within six months of diagnosis, so hospitals want to be in compliance with this standard. RQRS implementation has improved the timeliness, because we have set up a

system to provide treatment information received at other facilities, but only for cases that a particular facility has already submitted. Thus, if they want to receive treatment information from us, they need to submit their cases to us.

- Our state does not impose fines or penalties, but these could be a positive factor for those states that have this option. Cancer registry laws and rules theoretically have a positive effect on timeliness if they include language regarding timeliness
- Our state statute was updated in 2016 to clear up reporting requirements and timeliness language. The statute was updated to state hospitals are required to report cases to us within six months from date first contact to the hospital. Free standing diagnostic and/or treatment clinics, pathology labs are now required to report cancer information in a standard electronic format as designated by the Department of Public Health and Environment. The hospital license to operate can be withheld from approval if the hospital fails to meet reporting requirements. Interstate data exchange has provided case reports on patients with a state address giving us a more complete incidence file.
- Laws and rules help the registry in communicating with the reporting facilities regarding timeliness of cancer case reporting. Interstate data exchange helps both registries
- The reporting laws and rules are very powerful in that facilities, and providers do NOT want to break the law and/or incur fines. Delinquent reporters often hire contractors to bring them current for reporting to the state.
- We have no penalty, but reporting requirements are generally respected. Hospitals outsource abstracting when we prod the for being very late.
- We can deny a Certificate of Need if the facilities are not compliant with cancer reporting.
- Laws or rules—As of 1/1/2019, state law requires pathology reports to electronically reported within two weeks of report finalization. This is a step forward towards real time reporting. We anticipate once fully implemented; electronic pathology reporting will allow us to conduct pathology resolution to identify missed cases in a timelier manner. Because of the cancer reporting law, we also have the authority to send regional staff to facilities to report delinquent cases at cost, which has helped to encourage adherence to timely reporting.
- Fines or penalties—Having the ability to inform facilities of the fee for regional staff to report their delinquent cases on their behalf has encouraged more timely reporting.

## RQRS:

- Hospitals work to enter RQRS cases much faster than other cases. Our laws and standards serve to motivate reporting sources to stay in compliance.
- At least 80% of our cases are from COC facilities, so RQRS can help getting the cases completed. Law states cases are required to be reported within 180 days
- We have not formally assessed the impact of RQRS on timeliness of submission, but we have instructed hospitals not to submit cases to us until they are completely abstracted, including treatment, so the impact of RQRS is likely minimal. In some cases, the threat of fines or penalties does help, but that is usually for facilities that are severely delinquent.
- RQRS encourages CoC hospitals to abstract and submit certain cancer site faster. Laws/Rules/Fines and penalties—Allow the registry to use them to enforce and facilitate timely reporting.
- RQRS makes facilities more timely for selected cancer types, which should increase the timeliness of their reporting to us.
- RQRS Implementation at COC—Because of Standard 5.2, our CoC facilities are required to submit new and updated cases quarterly, resulting in more timely cancer reporting to the state.

## Contracting Services:

- Outsourcing or contracting out abstracting work by reporting facilities—The flexibility to utilize these options for expanding the CTR workforce gives facilities the ability to be compliant with reporting requirements.
- Some reporting facilities have hired contractors to abstract, which helps. We have provided Abstract Plus to smaller registries. Noncompliance letters have yielded some improvement in reporting.
- If central registries did not hire contractors, they would be further behind.
- A number of our small facilities rely on contractors to complete their data. We have two in-state contractors that make data submission by small hospitals possible.

## Other:

- Interstate data exchange assures completeness, not timeliness.
- We do send completeness letters, so hospitals use positive letter to demonstrate timeliness to administrators.



- Approximately 10% of our cases come from interstate data exchange. The state does not support firing facilities.

## Technical Assistance Needs

### Summary

First and foremost, registries reported an appreciation of NPCR for its commitment to more open communication and dialogue among its leadership, staff, and state registries. This was recognized as a critical step to solving some of the problems facing central registries and generated a feeling of optimism among registries that real solutions to serious issues will be forthcoming. Expanding such opportunities for discussion among registries and NPCR staff was strongly encouraged by the study participants. It is particularly important for Registry Directors to have more face-to-face time with each other and with NPCR leadership. In addition, it is important for registry leaders to be able to share best practices, work on common problems, and focus on emerging opportunities and challenges as a group on a regular basis.

There was also unqualified enthusiasm for the way this project was developed and implemented. The registries expressed appreciation for the opportunity to work with NAACCR on this project, because NAACCR brings a deep understanding of registries and their problems. This experience allowed the project to move forward quickly in a thoughtful and constructive way, generated by critical analysis and creative problem solving that might not otherwise have been possible. NACDD's support throughout the project helped move it forward efficiently and openly. The registry participants encouraged such collaboration between NAACCR, NACDD, and NPCR in the future.

At the same time, states identified several technical assistance needs related to software improvements, staffing, education and training, and outreach to medical associations and the CoC for assistance with physician and facility reporting and VA reporting. Specifically, five states expressed a need for more timely release of software and the addition of management reports or dashboards to CRS Plus software to better monitor completeness, timeliness, and data quality. Four states recommended more auto-consolidation using natural language, and automation for electronic pathology screening was also suggested.

States requested technical assistance in facilitating VA reporting, as many are currently not receiving cases and are unable even to identify VA staff for assistance. Suggestions were made for the NPCR to work with the CoC to encourage hospital reporting of nonanalytic cases and make physician reporting a requirement for accreditation. Another suggestion requested the NPCR work with medical associations to facilitate and explain the importance of physician reporting to state cancer registries. One registry suggested developing a "mini NAACCR record" for non-hospital reporters that would collect minimal data items with a corresponding edit set. States expressed a concern that some program consultants are not familiar with the technical aspects of registry

operations and this makes it challenging to obtain important information. Vetting consultants more thoroughly or incorporating training and registry-shadowing experiences would help this situation. Finally, it was recognized that NPCR is doing a much better job at actively listening to states and engaging them in valuable dialogue; states expressed a need to be able to exchange ideas, share processes, and learn how other states do more with less.

**Recommendation:** NPCR should continue to expand dialogue with central registries, be a voice or advocate for registries on such things as DOD/VA and Commission on Cancer issues and develop a more systematic and dynamic approach to overarching problems like tools for abstracting, training, staff recruitment, and IT help.

### **Highlights from Summit Group Discussions**

Communications are sporadic and accidental between program directors and central registries; strategies for more intentional communication are needed. Group participants agreed that NAACCR's previous mentoring program was very helpful and discussed ways to replicate its most useful aspects. They suggested adding an option to list areas of expertise in standardized, searchable formats to the NAACCR profile, which could lead to a matching system between program expertise and the users' needs. A participant indicated that NPCR's yearly meeting now includes a program meeting with training for new registry directors, which provides an opportunity to meet face to face, develop personal relationships, and identify contacts with particular expertise. The group suggested the development of webinars dedicated to a single topic, such as one registry's successful method for a particular process. Consensus-building approaches are difficult but could include equal representation—by size, geography, timeliness, and involvement level—as well as providing states with the ability to vote on standards, which would create buy-in. Consensus on a single topic could be developed with a smaller group to smooth any issues before presenting to a larger group. The group also recommended continuing the trend toward more transparency from NPCR, noting that participants anticipated that this would improve soon. The participants would like a forum to propose changes to program standards, which would help in identifying and removing outdated processes, and data items.

### **Focus Group Findings**

A discussion of ways NPCR might better support central registries generated a wide range of ideas. Suggestions included the following:

- “NPCR leadership is listening to us much more now. As a result, we are feeling more optimistic than in the past.”
- “Our strength is in sharing and cooperation. We need more opportunities to learn from each other and share best practices.”

- “Directors meetings in past to share best practices were very useful but cut due to budgets.”
- “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.”
- “Software technical assistance is very good, but the updates are too few and too late.”
- “Too many data items with no real value like the Congressional district reports.”
- “Funding priorities often ignore what is really important for the registry and go in different directions that are not always helpful.”
- “The VA and DOD does not report to us at all anymore. We need help at a national level to address this problem.”

**Major theme:** Communication among NPCR and states is valued and should be expanded with more opportunities for states to interact and share best practices with each other. Delayed software updates create serious backlog and should be a priority. Finally, funding priorities should take into consideration the critical needs of registries rather than be responsive to external forces that are not familiar with cancer surveillance.

### **Quantitative Assessment and Guided Expert Interview Results**

States were asked what technical assistance they needed with respect to cancer registry management and shared the following responses to questions:

- Software Needs
  - More timely software releases. 2018 Software availability. Specifically, Abstract Plus for our small hospitals Delay in support from CDC on Abstract+ and Web+ is an issue. More prompt response is needed (five registries).
  - Automated consolidation, natural language processing (four registries).
  - Automation for screening electronic pathology reports. Getting buried alive by electronic pathology. ePath aren’t coming in fully abstracted so it takes away from staff time. We simply don’t have QA/QC staff to review all of the cases that come in (two registries).
  - Decrease tech support needed from state side for Registry Plus software.
  - To increase completeness in a non-hospital setting by developing a NAACCR record that has only the minimal amount of data needed to be

reported and will still fit in with the full abstract from an analytic point of view.

- One registry was disappointed when public health was made optional for meaningful use. Would like cancer registry to be a priority. For them, meaningful use cases are a gold mine, excellent cases.
- Need more technical assistance implementing eMaRC
- Still need a way to collect clinically diagnosed cases that are found on imaging. Can CDC do something to help us and develop some tool that could help us review imaging/radiation reports for reportability?
- Better methods to monitor completeness.
- Need a way to improve their disease index audit method. Currently, it is mostly manual. Need help with audits (three registries)
- Need more management reports, currently need to run queries to generate this information. SEER\*DMS contains a dashboard that monitors SEER Data Quality measures. Would like to see similar reports based on NPCR standards (two registries).
- NPCR Consultant Support
  - Over that last several years, really noticed there are NPCR program Consultants not familiar with cancer registry field at all or have little central registry experience. Causes difficulties in communication and setting priorities to meet tangible outcomes. Recommend personnel spend time to engage with central registries to understand data flow from the reporters (get an understanding of their barriers) to the central registry. They need to understand consolidation, EDITS (how metafiles are created and maintained), QC, other types of linkages (specifically for researchers), and then how data are prepared send to NPCR. Need to understand volume of work involved. This will help them truly understand the challenges and barriers and be able to assist registries (two registries).
  - It would be nice for program consultants to compile the answers from the progress reports we provide to see what other states are doing.
- VA Reporting
  - Need assistance with VA reporting. A lot are not getting VA cases hinders completeness and identifying disparities. VA reporting is very intermittent. Need personnel in VA to be on board to report. Some VA facilities have eliminated their cancer registries internally and aren't even tracking patients. They are not required to report to state cancer registries, so they just don't (three registries).

- Staffing and Training
  - Need assistance with recruiting and training of new CTRs; needs to come from the top. Presentations and support materials to recruit CTRs. Would love a presentation on careers in the Cancer Registry with technical notes. That they could take to colleges. Need CTR related positions and staffing resources. Have positions and money, just no CTRs available to hire. We need more CTR staff (four registries).
  - Staffing and funding to maintain staffing. How to replace people with a fixed budget? Need more staff as funding goes down, salaries go up, and that means we don't have enough money to maintain the same level of staffing. As a person leaves, you don't have the money to bring them back (four registries).
  - New Education and Training Coordinators (ETC) site is not user friendly.
  - Training in registry operations for new directors. Needs for operations/management—really need to be able to have our standards, edits, rule changes, decisions on required data items, software—need all of that delivered to us in a sufficient time for us to complete our work (two registries).
  - Central registries should be able to get together and discuss their processes and procedures and exchange ideas. How else would we know that if we do not have an opportunity to talk? If these are not going to be coordinated by CDC, maybe some other group could get together to organize these discussions. How do we streamline, how can we be more efficient, what do we cut? Would be nice to talk to other states to see what they are doing and what can we rethink and cut to see what other states are doing.
- Facility Reporting
  - Implementing reporting by physician offices is very challenging. It is not an easy sell. Would like support from national medical associations to do outreach to encourage reporting. “It’s the Law” isn’t enough. Would like ACOS CoC to make reporting by physicians a requirement for accreditation.
  - We really need to get small facilities and physicians to report electronically. Don’t know if that means help in communication with facilities or letters of support illustrating importance of e-reporting.
  - Still have issues with CoC facilities—they don’t screen patient cases thoroughly—it’s requirement to comply with state reporting and they don’t make this a priority. Facilities have resource and staffing issues too, so

they're just trying to do what they can do and focus on analytic cases. They don't focus on submitting nonanalytic cases—need CDC help with this—talk to the college for help?

- Change Management
  - Rapid changes to the healthcare system in parallel with shifts in workforce, advances in genomics, and the development of new technologies are emerging forces that are increasing the burden on an already stressed system. Change requires continuous adaptation. Registries pointed out the complexity of the work now required to meet standards is creating a stress riddled working environment where their ability to meet standards is often outside of their control.
  - There is very little consistency and systematic approaches to registry operations. For example, some states rely exclusively upon electronic reporting. Other states spend hours traveling across large rural geographic areas to collect cases manually. Some states rely upon ePath to find many cases. Others find the missing fields so extensive that the workload is not worth the effort. What is clear is that the historic registry “culture” is no longer capable of adapting to the current operational demands of central cancer registries and new systematic thinking is required.

## Educational Needs

### Summary

The training needs of registries broke down into two major categories: (1) recruitment, retention, and training of registry staff and (2) expanding training opportunities for current central staff and hospital/non-hospital external reporters.

The shortage of CTRs is viewed as critical to the future sustainability of cancer surveillance field (See Staffing Section). States reported the need for a broad national crusade to promote the cancer surveillance field more aggressively (similar to what APHA has done with its “What is Public Health” campaign, which helped expand the number of colleges and universities offering public health baccalaureate degrees.) While current training programs are housed in community colleges and vocational training programs, states see the complexity of cancer surveillance and registry operations as requiring more extensive education. Many states will not hire staff without a bachelor’s degree, and students with strong training in biology, epidemiology, research methods, informatics, and public health are preferred.

At the same time, training is needed for both the central registry staff and at the reporting facilities. This is especially true given the rapidly changing reporting requirements and the complexity of cancer as a disease. The new 2018 reporting

requirements are representative of this problem as all states reported that training is essential to deal with this situation. Some states also requested training on the Registry Plus software, the use of hematopoietic database and manual, and radiation to name a few. Central registry training is needed especially for new staff who face high learning curves. More training materials for new staff are needed and should be developed at a national level to assure quality and consistency of the information. It should be available for central registries and external facilities. In addition, training materials need continuous updating and are often out of date. While FLccSC is gaining acceptance, it is not clear how content will be provided, nor does it address the need for high-quality training materials.

Several registries indicated the current NPCR initiatives have been good and are heading in the right direction. Much more work on the training needs for students and current registry staff is required.

**Recommendations:** Effort should be made in the development of basic training for new cancer reporters at both the central and facility level, and support to academic programs to train new CTRs should be encouraged. CTR recruitment materials or presentations, generation of sample cases for training new CTRs, and webinars on central registry functions and operational best practices would all be beneficial. Continue to focus on providing trainings on the 2018 changes. Additional software training should also be provided.

### **Highlights of Summit Group Discussions**

A Summit group discussed strategies to improve recruitment and retention for central registries, including working with colleges and Health Information Management (HIM) programs. Because standardized programs do not include exposure to registries, connections must be developed in other ways, including offering internships and marketing the field. Retention is often out of the registries' control, but more flexible work practices, reimbursement for memberships or training, and a positive work environment are beneficial. Group members also stressed the importance of including all staff members in decision making to develop buy-in.

- Attendees discussed other options for retention, including providing variety for employees by using their other skills, offering training time—which may encourage staff to value training more, because they “pay” for it with a specific bank of hours—and celebrating successes.
- Participants discussed the benefits of sharing salary information between states. Registrars may telecommute in some states from areas with lower costs of living, but not all states allow telecommuting. Registry staff can promote their registry or geographic location, but CTRs must make the final decision about what is important to them. Some states have unions that ensure that staff receive salaries higher than the cost of living outside major urban areas.

## Focus Group Findings

The need for expanded education and training was highlighted by many states throughout the focus group discussions. Training is often the responsibility of the state registries and given the continuous changes in reporting requirements by standard setters and the complexity of cancer in general, much more support is required in terms of training materials and resources. While NAACCR offers very useful training, the need is great and more help would be invaluable.

- “Hospitals need more training, especially with all of the new data fields and changes.”
- “It’s really difficult to rely on non-hospital data because you know those types of facilities don’t have trained registrar’s and there’s turnover, so we cannot really rely on their data.”
- “We need to support training at a more national level because it is a better use of scarce time.”
- “We need more central registry training for new staff.”
- “We host a lot of students because we’re really dedicated to grow in the field. One of the biggest challenges we see with the hospital is lack of staffing.”
- “We need CTR basics to help non-hospital reporters.”
- “I have a student that I am constantly prepping for the CTR...it takes lots of time...but we have to grow our own CTRs because there is a national shortage.”

## Quantitative Assessments and Guided Expert Interview Results

- The participating registries had the following to share regarding educational needs:
- All things 2018 (16 registries)
- Develop training for new abstractors (hospital and central registry) (two registries)
- Develop a tool with all the required reference manuals with searching capabilities that can reside on a desktop or web based. Based on all the places you need to look just for a histology code this would be useful and would increase the time needed to code and QC an abstract
- eMaRC and Abstract Plus training (two registries)
- Use of hematopoietic database and manual
- Radiation coding (how to read notes and summaries)



- Central Registry training (two registries)
- Would like to see more round table discussions or sharing of processes and ideas for central registries (based on comparative size registries).
- FLccSC being promoted by CDC, but concern who is monitoring the content of the education included
- A review of all trainings out there and identify which are current and have them all in one place or create a list to provide to reporters. Trainings are obsolete shortly after given. Rules are still being updated. They are especially worried about non-CoC abstractors...do they even know that all these changes/updated have happened?
- American Health Information Management Association (AHIMA) course has not been updated they are still teaching pre-2018 rules and current CTR exam is on 2018. AHIMA is most utilized since online. Will be surprised if anyone passes. This is unacceptable especially considering the shortage of CTRs (two registries).
- Best practices for catching up on 2018 backlog
- Produce sample cases for training that could be used by all

### **Special Studies and Additional Special Topics**

A range of important issues were raised in the comprehensive assessments and during the Summit meeting that are important. States felt that these concerns warranted additional attention and have an impact on 12-month timeliness.

### **How M Records Are Processed**

M records are “modified” records that are sent by reporting facilities to update a report that they have previously sent. These records are difficult and take time to process since they often require at least some manual processing. M records are processed using a combination of manual review and auto-consolidation at nine registries. Three states are fully automated, and two states have a fully manual process. Two states currently do not process M records.

### **Timing of NPCR Review Meeting**

Eight states felt it was a good idea to have the NPCR Program Review meeting in conjunction with NAACCR, eight states preferred not to or had concerns, and two states indicated it would be a problem. Concerns were around the length of time away and when NAACCR is in Canada several states are unable to attend. A couple states also mentioned the staff that attend NAACCR are different than the staff that attend the NPCR Program Review Meeting.

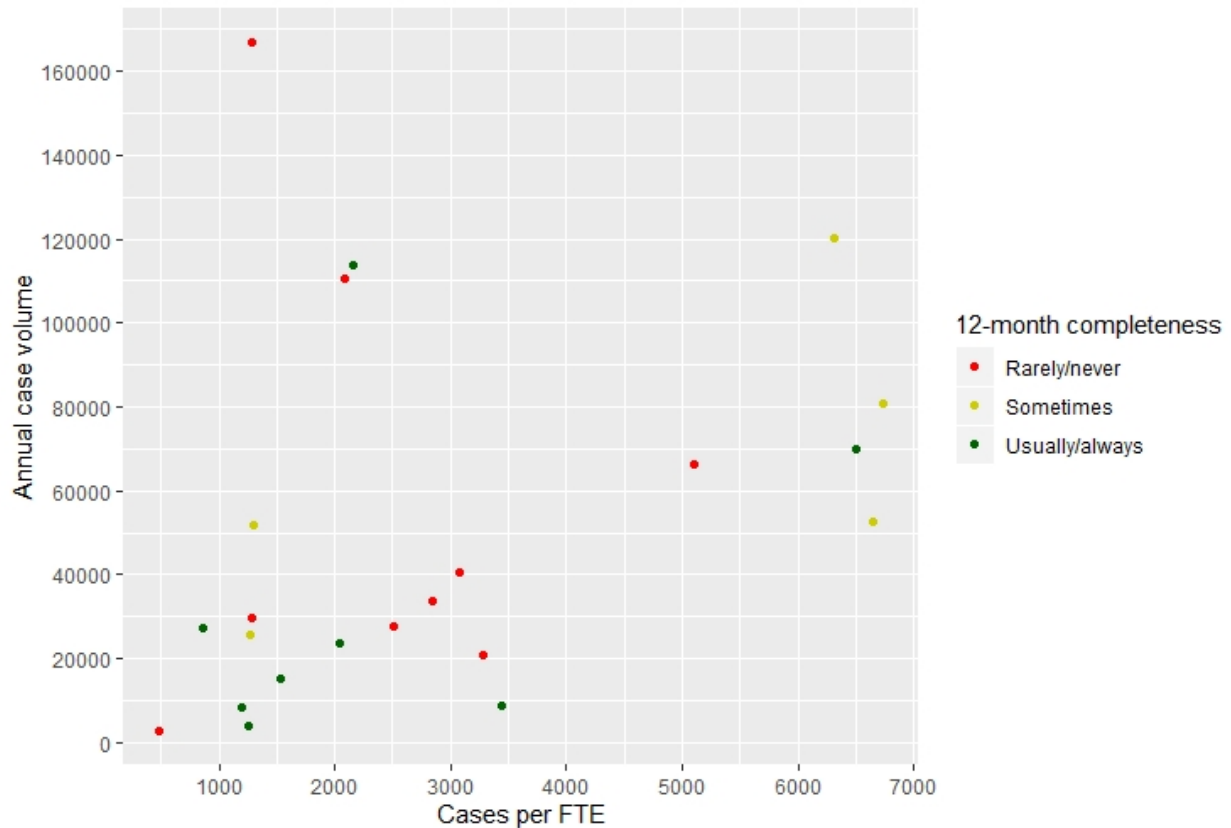
## Rapid Case Ascertainment

Registries were asked if there were any cancer sites they found could be reported and processed more rapidly than others. They were asked specifically about breast, colorectal, lung, prostate, melanoma, and pediatric cancers. To provide a more robust answer, we examined the issue using past NAACCR data submissions. Here, the 12-month data for diagnosis year 2016 from 49 U.S. registries were compared with the same data submitted a year later. The percentage of the cases reported in the second year was computed for each cancer site; the higher this percentage, the slower the reporting.

Overall, 80% of the cases were reported in the first year and 20% in the second year. Colorectal, breast, and pediatric cancers were below this average, indicating more timely reporting; prostate and melanoma were above, indicating less timely reporting. Lung was similar to all sites combined. Uterine and chronic lymphocytic leukemia were also labeled to highlight them as outliers. There was little variation between registries in the relative order of the sites. These results are not consistent with the answers the registries provided to this question—only four thought that breast cancers were reported more rapidly, and nine thought that melanoma cases were reported more rapidly.

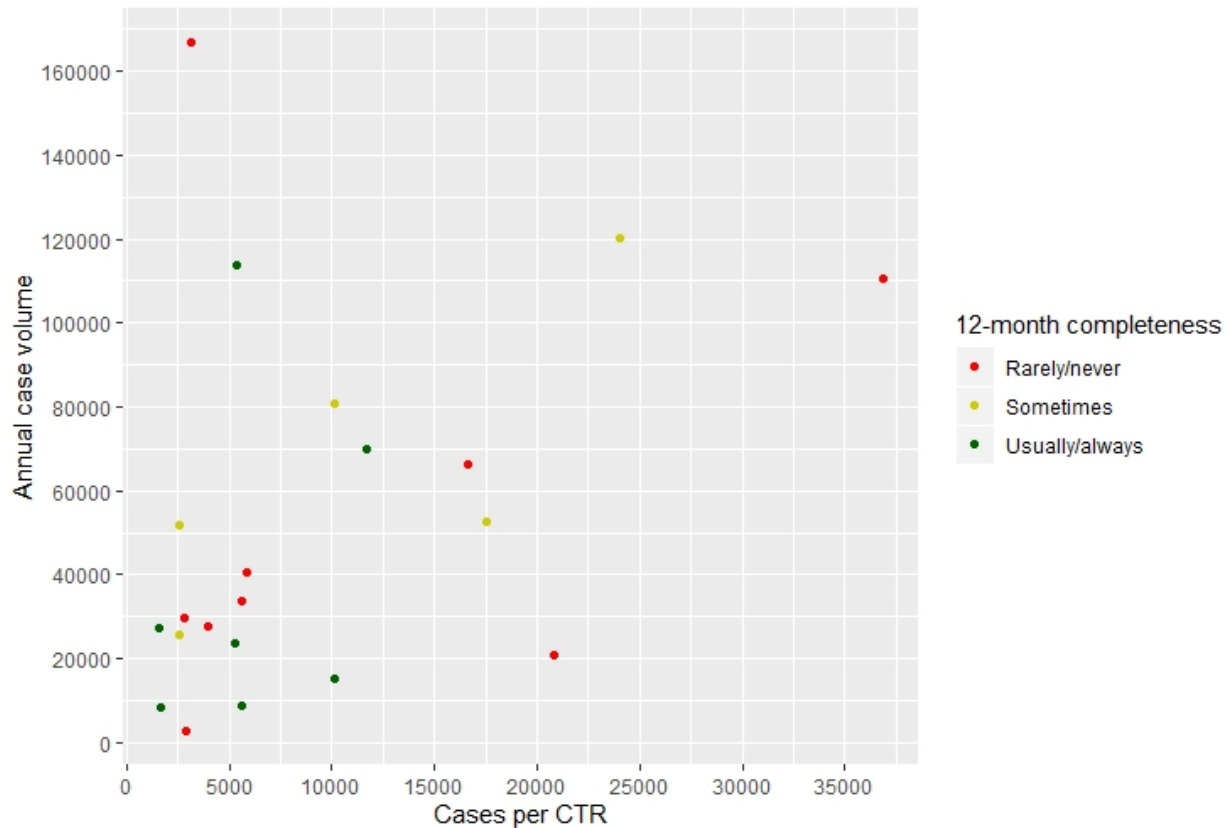
## Cost Per Case Analysis

An analysis of cases per full-time employee (FTE) and cases per certified tumor registrar (CTR) was conducted to see if these were related to the ability to meet the 12-month completeness standard. **Figure I** shows the relationship between case volume and cases per FTE. There is a weak association overall, as states with more cases tend to have more cases per FTE, though with ample exceptions. No pattern appears evident after stratifying by the tendency to meet the 12-month completeness standard. The states with the highest cases per FTE include those that rarely, sometimes, or usually meet the standard. The same is true at the low end of the scale. Taking 2,500 cases per FTE as a seemingly attractive benchmark, below this level, there were six states that usually met the standard, two that sometimes met it, and five that rarely did so. There is no apparent advantage to having a lower case volume per employee.



**Figure I**

**Figure J** shows case volume as a function of cases per CTR, perhaps a more useful measure of registry workload. Here there may be a suggestion of an association, as above the level of 15,000 cases per CTR, no registries are usually meeting the standard—three rarely and two sometimes meet it. At the low end of the scale, there is no apparent pattern; however, below 5,000 cases per CTR, most states fall into the category of rarely meeting the standard. Thus, any temptation to conclude that registries function better when there are less than 15,000 cases per CTR must address the paradoxical conclusion that they also function better when there are more than 5,000 cases per CTR. More likely, these are simply chance findings.



**Figure J**

Cost per case was additionally evaluated, using dollar amounts self-reported by the registries. Unlike with the numbers of FTEs and CTRs, where all 22 registries responded, only 12 registries responded to this question, so the sample was quite limited and not representative. These registries saw a great diversity in responses, ranging from \$15 to \$328 per case.

### Summary of Findings

This project generated a sweeping view of registry operations in 22 states. All of the registries are able to conform to a 24-month completeness data standard, but only 14% of our sample were able to consistently meet the 12-month data standard. Some of the reasons for this may lie in the biases in the completeness measures being used, and work is underway by the Statistical Expert Panel to try and address this issue. Those states that meet the 12-month standard, whether consistently or not, often expressed concerns that meeting the standard required unorthodox methods that could compromise data quality and bias results. Many barriers to achieving completeness were identified, including difficulty completing first course of treatment, lack of qualified staff at both the hospital and central cancer registry level, funding issues, burgeoning workload and lack of technology to assist in auto-consolidation, insufficient IT support, difficulty with ePath applications, weak state laws, and trying to manage reporting from multiple non-hospital sources.

On the other hand, registries had clear ideas about methods they use to overcome some of the barriers, including developing and managing strong relationships with reporting facilities, tools to monitor timely reporting, incentives, and strengthening regulations. Interesting a number of factors thought to be associated with timely reporting were not found to be influential in our sample, although this may be due to classification problems, and we will be reexamining this once more detailed information on state specific completeness scores becomes available.

In addition, many broad themes emerged from the study that could improve overall registry operations and ultimately timely reporting. Registries identified software improvements and a need for auto-consolidation routines to improve the processing of the growing number of records received each year. More timely software releases are needed, and developing a standardized timeline for such releases would be beneficial. More training and education is definitely needed, and creative solutions such as supporting academic programs would be helpful to increase the trained professionals needed to staff the registries now and into the future. Registries also asked for guidance in recruiting and retaining staff, work-from-home policies, and standardized educational opportunities for on the job training. Technical assistance needs focused around software improvements and training, VA reporting, change management, help with improving facility reporting, and staffing and training.

Registries currently prioritize the processing of different types of records differently. We found that all participating states follow different procedures like ePath differently, and there are few common approaches to data collection, analysis, or reporting. Registries are facing multi-layered challenges in a complex ever-changing environment, functioning independently, and following informal procedures and ad hoc workflow processes, as well as using outdated management tools, all the while relying upon ever-shrinking resources and staffing. Process improvement techniques, like LEAN Six Sigma, could be used to identify operational standards that could be recommended across registries.

## Deliverables and Progress

### NACDD-NAACCR Deliverables Table

**Table 16** presents the status of the deliverables for Strategy 1.1: Public Health Infrastructure of the work plan.

**Table 16. Deliverables and Progress for Strategy 1.1: Public Health Infrastructure**

Level	Activity	Resource	Performance Measure	Person(s) Responsible	Status	Time Frame	Activity Completion Date	Output(s)
<p><b>Objective 1.0. By April 30, 2019, NAACCR will conduct a comprehensive evaluation of eight NPCR registries that meet the NPCR 12-month data criteria and eight National Program of Cancer Registries grantees that do not meet the NPCR criteria for 12-month data.</b></p>								
<p>Expected Outcomes: NACDD and NAACCR will work with eight central cancer registries to assess successes, challenges, and lessons learned in achieving the NPCR 12-month data criteria.</p>								
1.1	Establish subcontractor contracts, hire consultants.	NACDD contract request form; agency protocol	At least two new contracts established; new scope of work documents created to include in contract request	McCoy	Completed	Q1	12/31/2018	Fully executed contracts
1.2	Convene webinar to inform CCRs of the assessment and present plan for soliciting participation.	Web-conferencing technology	At least two forms communication to reach target registries	NACDD/NAACCR	Completed via email correspondence and phone calls	Q3	TBD	Emails and notes

Level	Activity	Resource	Performance Measure	Person(s) Responsible	Status	Time Frame	Activity Completion Date	Output(s)
1.3	NAACCR will identify procedures and conditions that support data quality and completeness, identify contributors and barriers, and assess electronic dataflow.	Existing data metrics, assessment tools, and data from physicians and labs, hospitals, and CCRs; NAACCR document/prior work	—	NAACCR	Completed	Q3	TBD	Identified procedures and conditions, including electronic dataflow assessment findings
1.4a	Assess registry operations of 8 registries having difficulty meeting 24-month data standards.	CDC records and data, interviews,	Analysis based on NPCR data	NAACCR	Completed	Q3	TBD	States consistently not meeting criteria identified; 3 states included in statistical analysis
1.4b	Assess registry operations of 8 registries meeting 24-month data standards.	CDC records and data, interviews	Number of assessments completed	NAACCR	Completed	Q3	—	Evaluation criteria, assessment report describing registries meeting standards

Level	Activity	Resource	Performance Measure	Person(s) Responsible	Status	Time Frame	Activity Completion Date	Output(s)
1.5	NAACCR will complete the report/summary of evaluation processes of individually guided interviews with the 16 registries and focus groups.	CDC records and data, interviews	Number of reports created	NAACCR	Completed	Q4	—	Report of comprehensive evaluation, interview schedule, interview reports, focus group reports with identified themes
<p><b>Objective 2.0. By March 31, 2019, use assessment findings to develop at least one list of contributors and barriers and prioritize the metrics that can be modified for the states to meet 12-month completeness.</b></p> <p>Expected Outcomes: NACDD and NAACCR will work with eight central cancer registries to assess successes, challenges and lessons learned in achieving the NPCR 12-month data criteria.</p>								
2.1a	Develop list of contributors and barriers.	CDC records and data, interviews	—	NAACCR	Completed	Q3	—	List of contributors and barriers
2.1b	Define metrics for states that meet 12-month completeness.	12-month data standards	—	NAACCR	Models and options identified and assessment continuing	Q3	—	Models identified for measuring 12-month completeness



Level	Activity	Resource	Performance Measure	Person(s) Responsible	Status	Time Frame	Activity Completion Date	Output(s)
<b>Objective 3.0. By April 30, 2019, convene one Operations Summit to evaluate results of the comprehensive assessment and present recommendations to CDC.</b>								
Expected Outcomes: NACDD and NAACCR will work with eight central cancer registries to assess successes, challenges and lessons learned in achieving the NPCR 12-month data criteria.								
3.1	Convene an Operations Expert Panel to evaluate results of the assessment; present report to CDC.	Assessment findings	—	NAACCR	Completed	Q3	Operations Summit in May 2019	Three-day Operations Summit completed
<b>Objective 4.0. By April 30, 2019, NAACCR, will host a 2-day in-person Statistical Methods Summit with the Statistical Evaluation Expert Panel to discuss results of modeling trials and determine the best objective, unified method of accurately estimating completeness of cancer registry data.</b>								
Expected Outcomes: NACDD and NAACCR will work with eight central cancer registries to assess successes, challenges and lessons learned in achieving the NPCR 12-month data criteria.								
4.1	Establish a Statistical Evaluation expert panel to assess the three essential methods.	Three essential methods used by North America CCRs to estimate cancer registry completeness	—	NAACCR (Frank Boscoe)	Completed	Q2/Q3	To be announced	One statistical evaluation expert panel roster
4.2	Schedule 2-day statistical methods summit and complete event planning.	Personnel, time, funds, statistical evaluation expert panel	—	NAACCR	Completed	Q2/Q3	4/7/2019	Two-day statistical methods summit

Level	Activity	Resource	Performance Measure	Person(s) Responsible	Status	Time Frame	Activity Completion Date	Output(s)
4.3  (move before Summit)	Statistical Evaluation Expert Panel to convene meetings.	Statistical evaluation expert panel, telephone or web meeting software, Microsoft Word	Number of meetings	NAACCR (Frank Boscoe)	Completed	Q2/Q3	—	Meeting schedule, meeting notes
<b>Objective 5.0. By June 30, 2019, NACDD and NAACCR will provide guidance and technical assistance services to state central cancer registries.</b>								
Expected Outcomes:								
Note: Bleed over if NCE provided; funds may not be released before July 2019.								
5.1	Select 8 registries with difficulty meeting the NPCR 12-month data standard to develop and Beta-test recommended procedures.	Operational procedures for 12-month data standard as developed by the operations summit Expert Panel	—	NAACCR	Completed	Q4	—	Grant announcement, grant review panel, grantee eligibility criteria, grant reporting instruction guide

Level	Activity	Resource	Performance Measure	Person(s) Responsible	Status	Time Frame	Activity Completion Date	Output(s)
5.2	Fund up to 8 registries who have had difficulty implementing the 12-month standard to implement one or more identified best practice.	Best practices identified through assessment, interviews, and focus groups	—	NAACCR	Consulting with CDC NPCR about funding models and existing barriers	Q4	—	Eight grant awards made to state central cancer registries, documentation of funding decisions
5.3	Translate and disseminate findings into best practices for all CCRs.	Recommendations gathered from grantees, CCR operations experts	—	—	In progress	—	—	—
5.4	Develop guidance document on CCR operations.	—	—	—	In progress	—	—	—
5.5	Convene project team meeting with CDC to review draft document.	—	—	—	In progress	—	—	Meeting agenda, brief report
5.6	Develop guidance document on recommendations.	—	—	—	In progress	—	—	—

## Recommendations/Conclusions/Next Steps

This project has identified many potential areas for recommendations and next steps. There is a strong relationship between the cancer registries and NPCR with a strong commitment to the accuracy timeliness and completeness of cancer incidence data for public health use and research. Many of the individuals working in this field have dedicated their careers to improving cancer surveillance and providing data to better understand the many facets of cancer. This strong commitment and partnership served as a foundation for many strong and valid recommendations for improving 12-month reporting, as well as improving cancer registry operations, and developing a better completeness estimate.

Many of the ideas put forward in this document could be developed into tools and guidelines for all of the cancer registries in the United States to follow. The concepts and recommendations can and should be collated, developed and tested as Best Practice Guidelines. We will delineate some of the ideas for such tools below. In addition, much work still needs to be done by the Statistical Expert Panel to refine and improve the methods we use to estimate the completeness of reporting at 12 and 24 months. Finally, there are many recommendations that have evolved from the identification of weaknesses and barriers identified herein. These recommendations reflect somewhat broader change. New tools and techniques will need to be developed, because while the registries recognized the deficit of these tools and practices, they have yet to be fully established and/or implemented. These processes and tools will require fresh and innovative thinking and may take longer to fully develop and implement.

In the following section, we will describe some of the strongest recommendations from the work conducted over the past six months. Guidance will be sought from CDC to determine which of these to advance in the near future and which will require long-term strategies. In addition, we will present brief outlines addressing how the recommendations could evolve.

### A Better Measure of Completeness

At this point, it appears that the modeling approach for measuring completeness of 24 - month data preserves many of the features of the existing method while improving the accuracy and precision of the measure by incorporating substantially more information into the measurement. The two measures exhibit moderate correlation, and the majority of registries will see no meaningful difference in the result. Where we expect to see changes will be at the margins; specifically, the new (modeling) approach, by reducing the level of unexplained variation in the measurement, will generate a distribution of completeness scores with a smaller variance. This means that, assuming the cut points for the data standard are retained, we anticipate a net increase in states meeting this criterion. However, we are also exploring whether the cut points should not

be fixed but relative to the overall distribution—states less than 3 standard deviations from the mean, for example.

While our emphasis has been on the 24-month data, having access to multiple years of complete 24-month data submissions to NAACCR, there are no technical reasons why the method cannot also be applied to the 12-month data. To review, tasks anticipated in the next several months will include:

- The generation of historic completeness estimates for diagnosis years 2013 through 2016 using the modeling approach and comparing these with existing completeness estimates for these same years.
- Seeking ways to reduce residuals in the model through the inclusion of other covariate terms. This may include variables that capture interstate migration, international migration, survival, and environmental variables.
- Assessing the implications of the false-negative rate for certification that is implied by the distribution of model residuals and the use of fixed cut points. That is, to make reasonable assumptions about the shape of the distribution of completeness estimates around 100% implies that some states should be in the lower range of completeness estimates for reasons entirely beyond the control of the registries. In other words, even if every registry performs equally well, the stochastic aspects of this measurement mean that some registry has to have the lowest score. This should not automatically be interpreted to mean that cases are missing.
- Ascertainment of which states, if any, tend to be systematically overpredicted or underpredicted.
- Development of communication materials around the modeling approach, so that NAACCR members will have a clear understanding of how it works.

### **Operations Summit Best Practices Recommendation**

The NACDD/NAACCR Operations Summit was convened in Atlanta, Georgia. The 2.5-day summit included representatives from central cancer registries, NAACCR, NACDD, and CDC. During the summit, discussions were on registry operation challenges, opportunities, and best practices. Central registries were forthright during the summit and proposed several suggestions and recommendations. The final recommendations in the outline below were approved by summit participants at the NACDD/NAACCR Operations Summit Follow-up Meeting conducted in Vancouver during the NAACCR conference. The Participants were pleased to have their voices heard, and we respectfully submit these recommendations for the consideration of the NPCR program. Some of these concepts are further developed in our recommendations that follow this section.

1. Create consensus around a common definition of what a source document is to monitor and evaluate operations across registries.

## 2. 12-Month Standard Options

- a. Eliminate 12-month data collection—Use modeled or projected data
  - i. Eliminate the 12-month data requirement and use a 12-month estimated rate based on the actual 24-month submission (statistical approach solution, using imputed rates with delayed adjustment for major sites).
    1. Staff resources can be focused elsewhere if not working on 12-month data.
  - ii. Compare projected counts to actual counts to refine statistical model; if projection is within 90% of actual, the projection is just as good as actual. (Consider that the Census Bureau uses interpolated population counts between census survey years and this is the denominator in all calculated rates—Use a projected cancer count for the numerator.)
  - iii. Focus on 24-month data quality and then start working back (e.g., 22-month submission, 20-month submission, etc.).
- b. Keep the 12-month standard—Modify required data collection parameters
  - i. Develop auto-consolidation rules all registries can use.
  - ii. Only focus on certain primaries for 12-month data. For example, sites for Comp Cancer and Breast and Cervical programs.
  - iii. Only collect treatment that is given within six months of the date of diagnosis.
  - iv. Reduce the number of required data items.
    1. Focus on incidence data, drop all treatment, and only collect SEER Summary Stage
    2. Reduce overall number of data items collected by all registries and then fund states for special projects on specific cancers requiring additional data collection
  - v. Implement a reduced edit set for 12-month data.

## 2. Staffing

- a. Spotlight cancer surveillance and CTR profession
  - i. Develop targeted materials to promote the field of cancer registration/surveillance at the national level.

- ii. Develop standard presentations or materials that can be used to recruit at HIM, nursing, biology, or public health programs.
- iii. Recognize that retiring CTRs with 25–30 years of experience aren't equaled in productivity or knowledge by one or even three new CTRs. Training and development of new staffs takes time and can affect a registry's ability to weather changes.

b. CTR professional development

- i. Develop career path for CTR 1, 2, 3, etc.
- ii. Complete salary comparison for central registry staff.
- iii. Develop support/documentation to assist with obtaining higher salaries.
- iv. Have NPCR contract with NAACCR to develop a basic training webinar that all states could utilize to train cancer data reporters.

c. Student recruitment, training, and development

- i. Consider central registries establish a clinical practicum program, either alone or in conjunction with a local hospital, to facilitate CTR students sitting for the exam.
- ii. Develop a clear training plan for potential CTRs utilizing existing training resources like SEER Educate, NAACCR webinars, NAACCR CTR Prep Course, NCRA workbooks. Consider developing a set of practice cases for students.

3. Auto-consolidation

a. Develop auto-consolidation rules that all states agree to use

- i. Obtain an assessment from outside third-party consultants to provide a data flow assessment, including consolidation and tumor linkage.
- ii. Request consolidation rules from central registries that already have auto-consolidation in their software.
- iii. Collaborate with the SEER Auto-consolidation Work Group.
- iv. Review and develop consolidation rules (including Modified Records, Correction Records, etc.).
  - 1. Review core consolidation logic and rules.
  - 2. Focus on specific required data items (not every field).

3. Update unknown values with known values automatically.
  4. Incorporate the Solid Tumor Rules into auto-consolidation logic.
  5. Develop a way to identify a “no added value” record (like non-analytic cases, hospitals that are behind, VA/DOD cases, cases from a different accession year, pathology cases). SEER\*DMS has this now.
  6. Review by exception like coded solid tumor versus a hematopoietic case, large tumor size versus an early stage.
  7. Use a common, routine .dll that everyone contributes to for solid tumor rules and auto-consolidation.
- b. Develop consolidation edits that enhance source record edits
4. Software improvements
    - a. Improve identification of reportability for ePath software
    - b. Software should keep a record or log of all changes made—What was changed, why, and who changed it?
    - c. Improved technical support for software
    - d. NLP for text to code and flag cases for review
    - e. NLP for pathology cases or mandated CAP checklist
    - f. Institute a change/control board for state input on changes (similar to DMS Squish)
  5. Develop best practices
    - a. Model for data processing of source records
      - i. Prioritize source records
      - ii. Define partial records (minimum required data items)
    - b. Staffing
      - i. Monitor productivity of remote staff

## Recommendations for Best Practice Documents

### Summary

Recommendations for best-practice documents and tools were selected from the variety of suggestions and techniques currently in use by central registries while other



recommendations address needs identified during state interviews, focus groups, and the Operational Summit. All are considered feasible and will have a positive impact on timeliness. As noted below several of these tools could be developed by December 13, 2019, but others are more resource intensive and we anticipate that they may take longer.

### **Recommendation 1: Best Practice Tools to Monitor Central Registry and Facility Timely Reporting Progress**

Registries utilize a variety of benchmarks to monitor both central registry progress and timely facility case submission. The development of a more complete and standardized array of central registry management reports or a “dashboard” to monitor registry progress toward 12 and 24-month reporting parameters was suggested to facilitate timeliness assessment. Detailed ideas expressed by the registries around this concept are discussed thoroughly in this report. We would cull, organize and develop these ideas into a library of tools for the registries. This could include:

- Percentage of abstracts received from reporting facilities vs. previous year
- Percentage of consolidated cases vs. previous year
- Percentage of cases with unknown values like race, gender, and primary site
- Number of death certificate only cases as a percentage of total expected cases
- Develop software capability to examine cases and compare by primary site, by diagnosis year, by class of case, and by region

Also suggested was the development of a communication plan to provide feedback to reporting facilities including:

- Establish a timeline for case submission and reporting with specific deadlines that is communicated to facilities.
- Track facility submissions on a biweekly or monthly basis and compare to previous year submissions.
- Provide timeliness and data quality feedback to reporting facilities.
- Provide monthly or quarterly submission reminders for facilities that aren't reporting on a regular basis.
- Develop and implement an annual “close-out” process where reporting facilities detail case submission status, explain dips in case numbers, and update facility personnel and contact information.
- Establish timeliness, completeness, and data quality standards and provide feedback to facilities that meet those standards.

This best-practices document will consist of both a central registry and a reporting facility section and will focus on recommendations gleaned from state interviews, focus groups, and the operations summit. States that have already implemented specific standards or documents will be asked to provide examples that will inform the development process. While certain components involve the addition of capabilities to central registry software, all recommended tracking and measurements will be described in detail within the best-practices document itself and be used by software vendors to facilitate the development of management reports. It is anticipated this best-practice document could be completed by June 2020.

### **Recommendation 2: Best Practices Tool to Develop and Promote Good Relationships with Reporting Facilities**

The development of good relationships between central registries and reporting facilities is an important tool in central registry timeliness. Again, many ideas were put forth by registries and these will be compiled. Components of this best practice include:

- Provide reporting software (Abstract Plus or Web Plus) and technical assistance and support for installation and use.
- Provide access to NAACCR training webinars and utilize the FLccSC system for additional training materials.
- Develop relationships with state professional organizations by taking part in annual educational meetings to reiterate state reporting requirements and provide support for educational activities.
- Provide positive feedback by developing timeliness and data quality awards that can be shared with facility administration.
- Provide access to death certificate information from state vital records for the purposes of follow-up.
- Consider using motivational awards for complete facility reporting.
- Positive letters to registries and their administration when goals are met.

This best-practices document will detail strategies for developing good working relationships between central registries and reporting facilities. Strategies will be gleaned from current state practices that have proven useful in the states that employed them. Production of this document could be completed by the project deadline of June 2020.

### **Recommendation 3: Best Practice to Develop Facility-specific Displays or Record Formats for Case Reporting**

One suggestion from the Operations Summit was the development of a limited record or minimal record type containing the minimal amount of data required for incidence

reporting. This is designed to lessen the burden on non-hospital reporting sources while still maintaining compliance with state reporting requirements and capturing a significant amount of case detail. Components of this include:

- Develop and implement a limited record for dermatology reporting.
- Define a minimal record type for 12-month reporting.
- Develop a process to handle partial records.

This recommendation is for the development of potentially two new NAACCR record types. The first would be a limited record for dermatology reporting. Several states are already using a modified Web Plus reporting layout for dermatology reporting, which could be used as a model for development. The second would be a new minimal record type for 12-month reporting that would focus on data items necessary to calculate early incidence rates. If either is developed, a corresponding edit set would also be necessary along with the development of a process to handle partial records within the central registry. This recommendation would necessitate buy-in from standard setting organizations along with development resources which could be, in part, provided by NAACCR work groups and task forces. In addition, software development and testing would be required by several central registries utilizing a variety of central registry database software. An estimated timeline for production of these two NAACCR record types would be well outside the established project deadline of June 2020.

#### **Recommendation 4: Best Practice Tool to Establish a Standard Timeline for Biannual Updates to Cancer Reporting Software**

The establishment of a standard to limit software updates to a biannual timeline would be helpful to central and hospital registries who could then plan for updates and incorporate the resulting workload into standard registry operations. Again, this recommendation would require buy-in from each of the standard setting organizations and software vendors and would necessitate adherence to the agreed upon and established timeline. Project staff would meet with software vendors to determine how quickly software updates could be prepared and what kind of time frame would be necessary. A new timeline would be developed and proposed to the High-Level Tactical Group for approval and implementation. The timeline for establishment of this standard could be completed by June 30, 2020.

#### **Recommendation 5: Develop and Implement Procedures to Effectively Handle ePath Volume**

ePath is widely used among central registries, but most states stockpile cases and do not process them until they receive the associated hospital abstract for reasons discussed elsewhere in this report. The number of pathology reports coming into a central registry are increasing annually and many are not actually reportable cases. To

streamline this process and make ePath work more effectively and result in more timely cases, the following would be necessary:

- Provide processing tips to manage volume of ePath reports.
- Define a workflow processes to postpone low-quality sources until later in the process when a more complete case may already be on the database.
- Improve eMaRC assessment of reportability.

Development of workflow processes and tips to manage ePath reporting volume would best be served by a new summit meeting with central registries and possibly software vendors as this is a complicated topic that will take time and concerted effort to implement. It would also require additional input from NPCR to improve eMaRC's assessment of reportability.

### **Recommendation 6: Best Practices Guideline to “Grow a CTR” Program**

Shortages of personnel trained to work in population-based registries, especially lack of experienced CTRs, was the major problem identified by almost all central registries participating in the project. While more long-term solutions like expansion of college programs to train new CTRs and a targeted national recruitment plan for cancer surveillance are discussed, central registries must do what they can now to address significant staffing shortages. A program to “Grow a CTR” at the central registry level should include the following:

- Focused recruitment of persons with appropriate scientific and medical backgrounds including biology, nursing, and public health
- Development of a written training plan using established training sources
  - FLccSC
  - SEER Educate
  - NAACCR webinars and CTR prep course
  - NCRA case studies workbooks
- Exploring partnerships with local hospital registries to cover hospital components of the clinical practicum required for CTR candidates to be eligible to sit for the exam

This recommendation is to develop a best practices document detailing available resources and providing an outline of recommended recruitment and retention tactics central registries can reliably apply. States with programs already in place will be asked to share documents, tools, and resources for review by project staff and possible inclusion. NAACCR's Professional Development Steering Committee has valuable expertise in this area and may be able to provide additional resources for this

document. It is anticipated this best practice document could be developed by the June 2020 project deadline.

### **Recommendation 7: Best Practices Guideline—Strengthen State Reporting Regulations**

Several states mentioned the inability to enforce reporting requirements to assure timely data submission by facilities. Strengthening and clarifying state reporting regulations could have a positive impact on registry timeliness. These regulations should include:

- Toughening reporting requirements
- Requiring ePath reporting
- Requiring electronic case submission
- Shortening case submission timelines
- Providing significant penalties for nonreporting

This recommendation is for a best-practices document that will detail each of the provisions above and provide examples of existing state laws. Project staff will request and review examples from both participating states and states not currently part of the project that may have pertinent examples to contribute. This best-practices document is expected to be completed by the June 2020 project deadline.

The seven best practices suggested above are for consideration and prioritization by CDC. While we anticipate that any of the projects could be completed by June 2020 it is not feasible to complete all seven by that date.

### **Recommendations for Broad Change and Infrastructure Improvement**

#### **Auto-consolidation**

**Recommendation:** Develop auto-consolidation rules and software to be used by all registries

In recent years, registries have been inundated with partial records from a variety of reporting sources (labs, radiation facilities, physicians, etc.). The volume of these records has increased significantly as we have developed more efficient ways of providing electronic reporting systems for these sources. This problem of increased volume is compounded by the reduction in staffing at most registries due to level or reduced funding and a significant paucity of CTRs across the country. This leaves the registries ill-equipped to process the large number of records received on an annual basis. Instead of processing these partial records upon receipt, most registries stockpile them until the majority of hospital abstracts have been received, and then try to identify missing cases and cobble together a case report from inadequate data. This process,

which attempts to manage the workload, contributes significantly to reporting delays and the overall timeliness of registry data.

To address these problems, investment in software that could process and consolidate multiple partial records is highly desirable. A few cancer registry systems are indeed using “auto-consolidation” software, and other groups are studying the problem. A thorough review and comparison of the logic employed in these systems could prove to be a foundation for algorithmic software modules to be used by all registries. A system that could process and consolidate partial reports according to agreed-upon rules would greatly reduce the number of cases that would need to be reviewed manually by staff. In addition, such records could be processed in “real time” rather than being stockpiled until the close of the year.

A starting point would be critically review existing software that consolidates multiple tumor records following the multiple primary rules in use by registries. A few versions of such software exist or is in development. Comparing and contrasting these systems and seeking consensus on automating these rules could prepare the foundation for software that could be distributed to all registries.

Another focus should be on the consolidation of other variables collected on each case such as treatment and stage information. Rules to consolidate such data that move beyond keeping a known data value over an unknown data value should be explored. Incorporating information such as “class of case,” reporting source, and specificity of assigned codes could provide a framework for making such decisions.

Investment in the development of auto-consolidation and auto-coding software is a major commitment of time and resources. It will require financial and intellectual investments by many. Consideration should be given to partnering with other cancer agencies to make this a priority and shared responsibility. A shared investment of this type also contributes to consistency of data by ensuring that all registries will be following standardized practices.

## **Education**

The most significant call for action among the states participating in this research was to deal with the staffing shortages and expand and improve training opportunities for potential and existing CTRs and other registry staff. These problems are not easily solved and will require new ways of approaching these issues. States reported the need for a broad national crusade to promote the cancer surveillance field more aggressively (similar to what APHA did with its “What is Public Health” campaign, which helped expand the number of colleges and universities offering public health baccalaureate degrees). While current training programs are housed in community colleges and vocational training programs, the states see the complexity of cancer surveillance and registry operations as requiring more extensive education. Many registries prefer to hire staff with a bachelor’s degree and students with strong training in biology, epidemiology,

research methods, informatics, and public health. With this in mind, the following short-term and long-term steps are recommended.

### **Action Step 1: Develop Partnerships with Colleges and Universities**

Conduct pilot projects with one to two 4-year colleges and universities to develop concentrations or certifications in cancer registry operations that would provide core courses for CTR training for public health, biology, informatics, HIMS, and other related majors. Internships in central cancer registries and local hospitals could be included and students graduating would have completed the core CTR training with statistics, anatomy and physiology, epidemiology, health systems, information systems/informatics, research methods, and medical terminology. Students graduating would be well prepared to enter the cancer surveillance workforce and take the CTR exam, as well as perform many other critical tasks at a central registry.

**Justification:** At this time, the majority of CTRs are trained at community colleges and proprietary vocational schools (HIMS) with a narrow range of skills that do not prepare them for the complexity that cancer registry operations required, including knowledge and understanding of biology, genomics, informatics, information systems, and research. Critical thinking, problem solving and analysis, informed decision making, and communication are also essential competencies required for the modern CTR. This level of training is more advanced, and a baccalaureate level of training offers a better platform to grow the next generation of CTRs.

**Timelines:** Six months from start of project

**Deliverables:** A proposed curriculum for certification or concentrations and a marketing analysis would be developed and pretested in collaboration with 1–2 colleges or universities.

### **Action Step 2: Develop a Marketing Campaign to Promote Careers in Cancer Surveillance**

Explore viable strategies and themes to market and promote careers in cancer surveillance that are aimed at high school and college students with a special focus on careers as a CTR. This would be similar to the successful marketing initiatives that American Public Health Association and CDC conducted for careers in public health that has resulted in an explosion of new public health programs at the undergraduate level. NAACCR would develop preliminary themes and content working with both the registry community and undergraduate students from a variety of colleges and universities to capture best marketing concepts. These ideas could then be used by NPCR to design a large national campaign to market careers in cancer surveillance to targeted colleges and universities.

**Justification:** This was identified as a high-priority action by participating states. Campaigns such as APHA's "What is Public Health" have been effective in promoting

careers in public health. A similar but more targeted campaign aimed at specific undergraduate majors such as public health, health informatics, biology, and health information systems could be pilot tested.

**Timeline:** This recommendation is beyond the scope of this project, but some preliminary groundwork could be explored in the coming year.

**Deliverables:** Themes and content for campaign developed and pretested

### **Action Step 3: Central Registry Training**

CTR Training: A basic CTR training program should be developed to provide the core skills needed to grow new staff and reduce the high learning curve that presently takes time and energy for employees who have other job responsibilities. Staff training in central registries is long and laborious, requiring over one year of on the job training. Registries have developed training outlines that could be shared with other registries, and modules that could be used by all could be developed. Although there are several modules available through SEER, NCRA, NAACCR, and NPCR, they are not compiled into one comprehensive training course. Special attention needs to be placed on central registry operations and procedures.

### **Action Step 4: Training Materials and Modules for Hospital and Non-hospital Reporters**

Training materials and modules are needed to train hospital and non-hospital reporters to handle the complexities of their work. These could be used across registries who could supplement with registry specific information as required. The community is in constant need of training materials directed at abstracting and coding, as they frequently become out of date. In addition, specific training for non-hospital reporting sources (dermatologists, urologists, radiation centers) would greatly reduce the burden on central registry staff who often have to develop tailored programs for each specialty. Again, although there are numerous webinars available there needs to be a “one-stop shop” based on reporting facility type as well as a method to monitor the accuracy of the modules, especially as rules change or clarifications are provided.

## **Workflow Process**

### **Priority Area: Workflow guidelines**

This assessment demonstrated quite clearly that there are few standards for processing and managing central registry operations. All 22 participating states manage their registry operations differently. For example, registries currently prioritize the processing of records differently. Some registries process electronic pathology reports first, while others process them last (neither method was associated with 12-month reporting compliance). An analysis based on established process improvement techniques like LEAN Six Sigma of the timing and order of processing the different types of source



records may elicit efficiencies that could be adopted by all registries. In addition, we have already recognized that healthcare delivery is becoming more complex and integrated. As this trend continues, it will be more and more important to have more consistent and efficient processes in use across all central registries.

### **Action Step 1: Employ LEAN Six Sigma Process Improvement Analysis to Identify Efficiencies and Best Practices in Central Cancer Registries**

Lean Six Sigma is a proven process improvement tool that can be used to identify efficiencies and best practices in central cancer registries that could then be adapted across all registries at a system-wide level. Lean Six Sigma methods have been around for many years and have a proven track record of helping different industries improve their processes. In recent years, Lean Six Sigma has made a big impact on improving healthcare delivery across small clinics and large health systems alike. The idea of applying this process to the public health sector is relatively new and quite innovative, but a preliminary discussion with a LEAN Six Sigma certified black belt instructor generated significant interest in trying to pilot this approach in central registries, which were viewed as ideal settings for such process improvement. With this in mind, NAACCR would like to explore and pilot this practice in several voluntary central registries over the remaining project period. Green Belt students will be used to conduct the LEAN processes as part of their course requirements.

**Justification:** The need for consistent and efficient processing of registry records was clearly identified as a high priority for action during all of the deliberations of this study. LEAN Six Sigma is a proven and useful tool to develop these improvements that can be applied in a test setting to see if this is a viable option for a much larger initiative in the future.

**Timelines:** Planning would take 2–3 months from onset and full implementation, would take 2–6 months depending upon availability of registry staff to participate and complexity of the process identified for improvement.

**Deliverables:** A pilot test of LEAN SIX SIGMA would be completed in two to three volunteer registries, and results would determine if this is a viable strategy for larger-scale implementation.

### **Evaluate the Importance of Collecting Certain Data Items**

**Recommendation:** To evaluate the importance of collecting certain data items

Many registries spoke of the overwhelming workload associated with collecting information on incident cancer cases. In truth, the number and complexity of the data set has grown exponentially over the past few years. Although many of these new data requirements are in response to changes in oncology and patient management, some of the data are considered of limited value due to incomplete data availability, limited resources, and timing issues.

One of the major barriers to the collection of timely data is the requirement of collecting treatment. Registries are required to collect the first course of treatment on all newly diagnosed cases of cancer, and in recent years, the first course of treatment for many cancers has become more and more prolonged, extending for many months. Most state regulations require cases to be reported within six months of diagnosis and hospitals delay reporting cases until that six-month window in order to include as much treatment as possible. However, with today's therapy regimens, cases reported at six months or earlier, often do not contain full information on initial therapy. Thus, the requirement to collect first course of therapy not only leads to delays in reporting from facilities and therefore delays in timeliness, it also results in incomplete treatment data, even for the first course of therapy.

In addition, treatment data are highly unreliable on a population level, and data from population-based cancer registries is rarely used in research studies without being supplemented with other data sources or major re-abstracting studies. These factors make treatment data very costly to obtain and of limited value.

Many registries at the Operations Summit advocated strongly for the elimination of collecting treatment data by NPCR registries. Some registries harkened to the establishment of the NPCR program when treatment was only collected "as it appeared in the record" and no special effort was required to obtain these data. While this may seem to be an audacious suggestion on the part of the registries, careful consideration of the concept is warranted. In the times increasing demands for timely data and diminishing resources, this proposal could go a long way to increasing compliance with the 12-month standard.

An argument for collecting simplified stage data was also made by participants at the Registry Operations Summit. Stage data is vital to monitoring many public health objectives such as success of screening efforts, and progress toward cancer control objectives. However, once again, due to a constantly changing definition of cancer stage and complex data collection requirements, stage data lack continuity over time, and is "unknown" more often than is desirable in registry data sets. Collecting simplified stage data such as SEER Summary Stage or even the newly developed Essential TNM staging system could greatly reduce the efforts of registries across the country. In addition, collecting Essential TNM could make NPCR data compatible with data from other parts of the world, creating a new demand for U.S. data, while collecting SEER Summary Stage would increase comparability within the United States.

Of course, evaluating the need for other variables currently collected by the NPCR registries would also achieve some efficiencies, and a thorough assessment could be beneficial. It should also be noted that eliminating treatment or stage requirements could also be done on a site by site basis and still result in positive effects. That is, perhaps collection of treatment data for breast, prostate, colorectal, cervical, and lung cancer could be retained, but eliminated for other sites with less public health interest.

However, this solution might introduce unanticipated complexities in data collection that would need to be evaluated.

### **Statistical Solutions to Producing 12-Month Incidence Rates**

There are two ways that national incidence rates delayed by one year may be produced. By “delayed by one year.” we mean, for example, that following the 2019 data submission, which includes cases diagnosed through December 2018, national incidence rates for 2018 would be available. Under current practice, incidence rates only through 2017 will be available.

The first method has already been discussed in detail in Section III.D. This approach, discussed and developed at length by members of the Expert Panel, involves using delay adjustment to inflate the 12-month counts to their eventual expected values. Registries potentially included in this process would be limited to those achieving at least 80% 12-month completeness for at least three of the four most recent years and achieving gold or silver certification all four years to ensure data quality. Initially, the process would be limited to all sites combined and the four major sites (breast, prostate, colorectal, and lung). Because of high variability in the recent past owing to changing recommendations about PSA testing and higher-than-average reporting delay resulting from non-hospital reports, prostate may have to be withheld from this list, at least initially.

The second way that these rates may be produced is to estimate them based entirely on the 24-month data, or more precisely, the time series of recent 24-month data submissions, projecting them one year into the future. The same modeling approach that is used by the American Cancer Society in their *Cancer Facts and Figures* publication to estimate counts three years into the future could be applied here. Whereas the American Cancer Society most recently used the data from cases diagnosed in 2016 to estimate data for 2019, here the same data and same process would be used to estimate data for 2017. This idea emerged from the Registry Operations Summit and has not been discussed by the statistical Expert Panel.

### **Pilot Testing Best Practices and Recommendations**

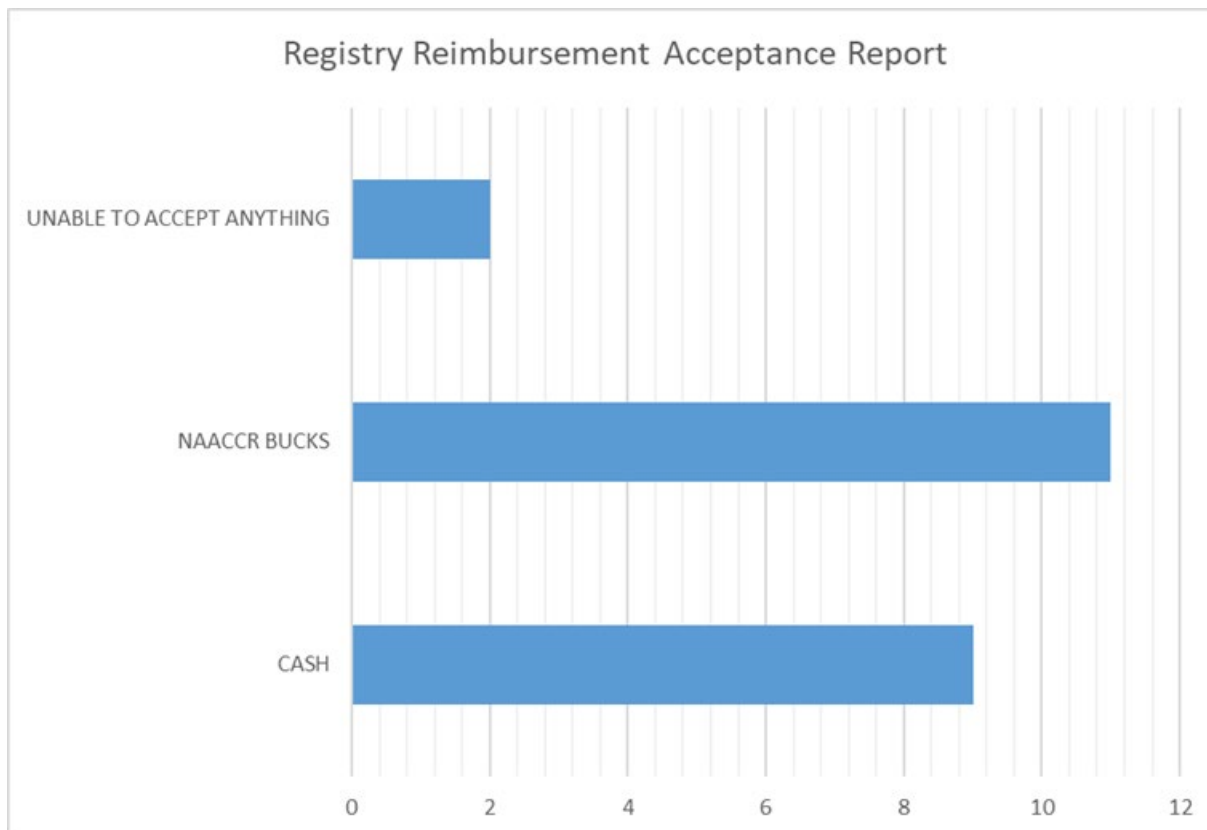
The next step in implementing the best practices outlined above is to award funding to registries to test and implement these processes through a pilot program. However, registries have historically had difficulties accepting funding because of various state laws and policies.

### **Funding to Registries for Pilot Testing Best Practices**

During the interview process, the registries were asked about their reimbursement options for participating in the registry operations project. Seven registries responded they could accept payment directly, and four states said they could accept indirect reimbursement in the form of NAACCR Bucks, a credit system to provide NAACCR

services in lieu of monetary compensation. Nine registries did not know if they could receive funds and needed to check with other personnel, and two could not accept direct payment or NAACCR Bucks.

NAACCR followed up with registries after the completion of the assessment, interviews, focus groups, and summit and 9 registries were able to accept cash, 11 registries were able to accept NAACCR Bucks and 2 registries were unable to accept cash or NAACCR Bucks (**Figure K**).



**Figure K**

An alternative solution and recommendation to increase the potential of registries accepting financial support to implement and test best practices is a Best Practices Grant Process. This concept would be handled by NAACCR in conjunction with any stakeholders that CDC deems necessary. This concept would essentially “piggy back” off of the Application and Review Process outlined below. The process would then be tied to an eventual monetary award to forward registries needed dollars for participation in the program. In short, the mechanism to forward registries money would be through a NAACCR managed Grant. The application and review process would be handled through NAACCR’s web site with a simple, reliable, and trusted grant application. A simple plug-in will help ensure the proper process will be completed from application to award while keeping recurring development and maintenance costs minimal. A start-up

development cost would be required but recurring costs would be low. Once a registry has been awarded a Best-Practices Grant, then NAACCR will make the cash award via check to the registry. This solution will be investigated in full in the next few months.

### **Pilot 1: Promoting Best Practices in States That Almost Never or Sometimes Meet NPCR 12-Month Standards**

**Purpose:** Provide funds/resources to support small pilot projects that adapt any and/or all of the methods described in the Guidelines for Best Practices to Meet NPCR 12 Month Timeliness Standards to central registries.

**Eligibility:** States that almost never or sometimes meet NPCR 12-month timeliness standards may apply for funding through the NAACCR Best Practices Grant Process.

**Application Process:** Applicants are encouraged to apply any and/or all of the Guidelines for Best Practices to Meet the NPCR 12 Month Timeliness Standards to their central registry operations. Proposals will be due not later than (DATE) and should include the following categories: Project Purpose, Description, Methods, Outcomes, and Evaluation. Justification for choices and anticipated deliverables should be described. An evaluation method that includes benchmarks and metrics demonstrating success should also be included.

**Review Process:** A fair and equitable Request for Proposal (RFP) will be released to all NPCR-funded states that are interested in applying. A peer review panel will review and rate all proposals based on quality, feasibility and likelihood of success following standard scientific review practices.

**Timelines:** A call for proposals will be released shortly after the Guidelines documents are finalized to all NPCR-funded states. Deadlines for proposals will be 3–4 weeks after release and start dates within 3–4 weeks after notification of award.

**NOTE:** Anticipated end date is June 30, 2020.

### **Pilot 2: Development of Innovative Strategies, Methods, or Tools to Help Central Cancer Registries Meet 12-Month Timeliness Standards**

**Purpose:** Provide funds/resources to support small pilot projects that seek to develop new and innovative strategies, methods or tools that will support states to improve workflow processes in central registry operations or enable more accurate and timely reporting by hospital or non-hospital reporters. It is anticipated that projects will all contribute to helping states better meet NPCR 12-month timeliness standards.

**Eligibility:** All states that are funded by NPCR may apply for funding through the NAACCR Best Practices Grant Process.

**Application Process:** Applicants are encouraged to develop new and innovative strategies, methods, or tools that will support states to improve workflow processes in central registry operations or enable more accurate or timely reporting by hospital or

non-hospital reporters. Proposals will be due not later than (DATE) and should include the following categories: Project Purpose, Description, Methods, Outcomes, and Evaluation. All proposals must offer justification on how the project will enhance the capacity of states to meet the NPCR 12-Month Timeliness Standards. An evaluation method that includes benchmarks and methods of success should also be included. All strategies, methods, and tools must be shared with all other states through written reports, videos, or other materials.

**Review Process:** A fair and equitable RFA will be released to all NPCR-funded states that are interested in applying. A peer review panel will review and rate all proposals based on quality, feasibility, and likelihood of success following standard scientific review processes.

**Timelines:** A call for proposals will be released shortly after the findings in this report are made available to all NPCR-funded states. Deadlines for proposals will be 3–4 weeks after RFP release, and start dates will be 3–4 weeks following award notification.

**NOTE:** Anticipated end date is June 30, 2020.

### **Action Steps to Move Forward HIGH-PRIORITY Recommendations**

We would like to move forward with the following action steps proposed under the recommendation sections and request that NPCR prioritize which steps are most important. Because these are large in scope, long term, and high priorities for action, NAACCR in partnership with appropriate experts will take the lead on these projects and work collaboratively with NPCR and NACDD in meeting deliverables. As described in the original work plan, NAACCR has extensive skills in project management and an understanding of the complexities of cancer surveillance to be successful.

- Develop standardized auto-consolidation logic working with representatives from several registries and vendors, using existing logic sets as a basis for comparison and improvement.
- Develop partnerships with Colleges and Universities to develop undergraduate education programs that offer concentrations or certifications in cancer registry operations.
- Explore 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 career campaigns.
- Pilot test the use of LEAN Six Sigma process improvement practices in volunteer registries to identify ways to improve both the quality and timeliness of cancer reporting.
- Consider steps to study the impact of changing burdensome and costly data elements, including eliminating the collection of treatment data from NPCR

requirements and simplifying staging data. Work with states, researchers, public health officials, and CDC leadership to evaluate this possibility.

**NOTE:** All of these action steps are preliminary but expected to lay groundwork of NPCR to move forward on a larger scale with any of them. These could be completed by June 30, 2020.

## Conclusion

*“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.”*

This comprehensive and multidimensional project offers a wide ranging analysis of how to improve the compliance of cancer registries with the National Program of Cancer Registries (NPCR) 12-month data standard and assess many aspects of registry operations that are of interest to NPCR. We conducted a written assessment, in-depth interviews, and focus groups and held in-person summits to review findings. We studied the basic statistical aspects of the completeness measures and examined processes within registry operations thought to influence timely reporting of cancer data, including software, staffing, reliance on ePath reporting and a variety of other measures. We held a Statistical Summit and an Operations Summit where in depth analysis of the problem took place. We then held follow-up meetings with our expert statistical panel and the participating states to review and approve the recommendations within this report. We expanded the focus of the project to a broader range of challenges and threats to registry operations. Finally, we presented recommendations for next steps to further develop best practices for 12-month reporting.

The NPCR in partnership with NAACCR and NACDD is well positioned to reshape the cancer registry terrain by giving careful consideration to the many findings from this project and by carefully considering the recommendations made by the participating registries. Many of these concepts are worthy of further exploration and development, continuing beyond the scope of this initial reporting period. We expect to meet all of the deliverables laid out in the original project by June 2020. In addition, several immediate next steps have been recommended within the report, and we are looking for guidance from NPCR on how to prioritize these so we can lay the groundwork to move forward on those.

NPCR is the only government agency which funds 46 states, the District of Columbia, Puerto Rico, the U.S. Pacific Island Jurisdictions, and the U.S. Virgin Islands. Similarly, NAACCR draws its strength from its membership which consists of: a) population-based cancer registries in every state, province, and territory in North America; and b) all of the major cancer organizations involved in standard-setting and cancer surveillance

activities across the continent. In addition, NACDD has a history of constructing collaborative networks and community partnerships aimed at building coalitions and alliances. Working together to address the challenges and embrace the opportunities for solutions presented in this report represents in itself a worthwhile endeavor to streamline systems and adopt modern approaches to central cancer registries.

Finally, we want to express our heartfelt gratitude to all the participants in this project for your dedication, diligence, and thoughtfulness throughout the project. These participants demonstrated sensitivity, creativity, and honesty throughout all of our deliberations. Their significant contributions to this work were critical to its success.



## Appendix A: Glossary

**AHIMA** – American Health Information Management Association. Founded in 1928, AHIMA is the premier association of health information management (HIM) professionals worldwide. Serving 52 affiliated component state associations and more than 103,000 health information professionals, AHIMA is the leading authority for "HIM knowledge" and widely respected for its esteemed credentials and rigorous professional education and training.

**API** – Application Program Interface- A set of functions and procedures allowing the creation of applications that access the features or data of an operating system, application, or other service.

**Auto consolidation** – Automated rules-based selection of the best value when discrepant values are present in accordance with coding rules and published standards.

**Capture/recapture method** – Method for measuring completeness that uses counts of reports from multiple sources to infer the number reported by no sources. In its simplest form, there are two sources- reports to registries and to vital records. Requires that reporting sources are independent and that cases are equally likely to be reported by a given source, neither of which is true in practice.

**Cancer in North America (CINA)** – Publication which provides cancer incidence and mortality statistics for the United States and Canada.

**Case finding** – A system for identifying patients with a reportable diagnosis.

**CiNA Deluxe** – Data set containing deidentified data on demographics, cancer type, and treatment information for U.S. and Canadian residents diagnosed since 1995.

**Certificate of Need** – A Certificate of Need (CON) is an endorsement that numerous states require before approving the construction of a new health-care facility. The central idea of CON legislation is the assertion that overbuilding and redundancy in health-care facilities leads to higher health-care costs.

**CoC** – Commission on Cancer- A program of the American College of Surgeons (ACoS) that recognizes cancer care programs for their commitment to providing comprehensive, high-quality, and multidisciplinary patient centered care.

**DCO** – Death Certificate Only- deaths with a reportable condition mentioned as a cause of death that are not found in the registry database.

**Delay-adjustment** – Method for anticipating the number of cases still to be reported based on historic reporting patterns. Nearly all cases are reported within 3 years, but case counts tend to rise for 8 years beyond that.

**Delay factor** – A number that is multiplied with a current case count to yield an eventual expected case count. For example, a delay factor of 1.05 means that the final case count is expected to be 5% higher.

**DLL** – Dynamic Link Library. A DLL (.dll) file contains a library of functions and other information that can be accessed by a Windows program.

**DOD** – Department of Defense

**ePath** – Electronic pathology reports

**FLccSC** – Fundamental Learning Collaborative for the Cancer Surveillance Community (pronounced 'Flossy') is learning management system (LMS) developed to provide cancer surveillance professionals a web-based educational platform. Courses are designed for students of all experience/skill levels. There are courses and modules for those that are new to the cancer surveillance field and continuing education courses for the seasoned professional.

**Flow method** – Method for measuring completeness which considers the probabilities that patients were registered while alive, that cancer was properly noted on the death certificate, and expected patient survival. Not all necessary inputs are collected by U.S. registries.

**HIM** – Health Information Management

**Incidence-to-mortality rate ratio method (IMRR)** – The method currently in use by NAACCR and NPCR to measure completeness. The expected number of cases for each registry is calculated based on its mortality rate. Completeness is defined as the ratio of observed to expected cases. It assumes that mortality data are complete and that the incidence-to-mortality ratio for each cancer site is constant everywhere in the United States.

**Internal method** – Method for measuring case completeness where a registry's own past case counts are used to predict future counts.

**Lean Six Sigma** – A process improvement methodology designed to eliminate problems, remove waste and inefficiency, and improve working conditions by combining tools, methods and principles of Lean and Six Sigma into one methodology to improve an organization's operations.

**Modeling approach for measuring completeness** – Regression modeling is used to calculate the expected number of cases for a registry based on its population demographics, behavioral risk factors, screening rates and other available information. Completeness is defined as the ratio of observed to expected cases.

**M Records** – Modification Record – Record Modified since previous submission to central registry (identical in format to the "A" record type (full abstract); used to submit changes to data already submitted.

**Naïve method** – Informal term for the simplest form of the capture/recapture method for measuring case completeness used during the statistical summit.

**NLP** – Natural Language Processing (NLP) is the ability of a computer program to understand human language as it is spoken.

**RQRS** – Rapid Quality Reporting System (RQRS) is a reporting and quality improvement tool which provides real clinical time assessment of hospital level adherence to quality of cancer care measures. RQRS was developed to assist CoC-accredited cancer programs in promoting evidenced-based cancer care at the local level. It is a Web-based, systematic data collection and reporting system that advances evidenced-base treatment through a prospective alert system for anticipated care which supports care coordination required for breast and colorectal cancer patients at participating cancer programs.

**SEER** – The National Cancer Institute’s Surveillance, Epidemiology and End Results program, which currently funds 19 state, regional, and tribal cancer registries covering about 35% of the U.S. population.

**SEER 11** – Refers to the 11 members of the SEER program as of 1992- Atlanta, Connecticut, Detroit, Hawaii, Iowa, Los Angeles, New Mexico, San Francisco-Oakland, San Jose-Monterey, Seattle, Utah.

**Squish** – a SEER web-based tracking system used to track bugs, questions, manage quality assurance issues, and organize registry requests.

**VA** – Veteran’s Administration

## Appendix B: Expert Panels and Participating Registries

### Registry Operations Summit Expert Panel

Wendy Aldinger	Pennsylvania Cancer Registry
Lynn Giljahn	Ohio Cancer Incidence Surveillance System
Lori Havener	NAACCR
Mona Highsmith	Minnesota Cancer Surveillance System
Ann Marie Hill	Consultant
Stephanie Hill	New Jersey State Cancer Registry
Leslie Hoglund	Virginia Cancer Registry
Mei-Chin Hsieh	Louisiana Tumor Registry
Deborah Hurley	South Carolina Central Cancer Registry
Mary Jane King	Ontario Cancer Registry
Lori Koch	Illinois State Cancer Registry
Betsy Kohler	NAACCR
Sue Lai	Kansas Cancer Registry
Gary Levin	Florida Cancer Data System
David O'Brien	Alaska Cancer Registry
Winnie Roshala	Consultant/Cancer Registry of Greater California
Frances Ross	Kentucky Cancer Registry
Colleen Sherman	New York State Cancer Registry
Valerie Somma	Colorado Central Cancer Registry
Melanie Williams	Texas Cancer Registry

## Statistical Summit Expert Panel

Bob Anderson	NCHS
Francis Boscoe	Pumphandle
Huann-Sheng Chen	SEER
Barnali Das	NCHS
Rocky Feuer	SEER
Rick Firth	IMS
Don Green	IMS
Ann Marie Hill	Consultant
Betsy Kohler	NAACCR
Andy Lake	IMS
Lihua Liu	Los Angeles Cancer Surveillance Program - USC
Paul Sutton	CDC
Trevor Thompson	CDC
Paulette Valliere	NACDD
Kevin Ward	Metropolitan Atlanta SEER Registry
Hannah Weir	CDC
Chuck Wiggins	New Mexico Tumor Registry
Manxia Wu	CDC
Li Zhu	SEER
Joe Zou	IMS

## List of Participating Registries

Alaska Cancer Registry  
California Cancer Registry  
Cancer Data Registry of Idaho  
Colorado Central Cancer Registry  
Florida Cancer Data System  
Georgia Comprehensive Cancer Registry  
Illinois State Cancer Registry  
Kansas Cancer Registry  
Kentucky Cancer Registry  
Louisiana Tumor Registry  
Maine Cancer Registry  
Massachusetts Cancer Registry  
Minnesota Cancer Surveillance System  
New Jersey State Cancer Registry  
New York State Cancer Registry  
North Dakota Statewide Cancer Registry  
Ohio Cancer Incidence Surveillance System  
Oregon State Cancer Registry  
Pennsylvania Cancer Registry  
South Carolina Central Cancer Registry  
Texas Cancer Registry  
Virginia Cancer Registry

## Appendix C: Statistical Summary

### Introduction

Following a series of conference calls, an in-person statistical summit was convened in Gaithersburg, Maryland, on April 8 and 9, 2019. There were 21 attendees in all, including representatives from CDC, NACDD, NAACCR, SEER, individual registries, and outside consultants. Most of the meeting was spent carefully evaluating the pros and cons of various methods for measuring registry completeness, then selecting the most promising of these for more rigorous analysis, focused on cases diagnosed between 2013 and 2016. IMS made the NAACCR data submissions from these years available to selected group members following the summit. Then, following additional conference calls in April and May, a second in-person meeting was held at the NAACCR annual conference in Vancouver, on June 12 to report on progress.

The workgroup considered a number of methodological approaches to solving both the problem of measuring completeness and the additional problem of using the 12-month data submission to develop national incidence rates. We describe the latter topic first, since it informs the discussion of the completeness measures.

### Using delay-adjustment to develop national rates from 12-month data

The workgroup finds that it is feasible to use data from existing 12-month data submissions to project national cancer rates. This can be accomplished by taking the cases reported in the 12-month submissions and projecting them to the anticipated final counts using the delay-adjustment methodology already in widespread use in U.S. cancer surveillance (Lewis et al. 2018). Delay-adjustment uses the ratios of current to past case counts to anticipate cases still to be reported. The method developed by SEER statisticians considers 11 years of data, though in practice virtually all the cases

have been received within 3 years. Figure 1. shows a typical matrix of case counts, where the 24-month data are inflated by 3.2% and previous years by smaller amounts.

Figure 1. Typical matrix of case counts

Diagnosis Year	Submission Year										Delay Factors	Expected Count After 11 Years
	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017		
2006	17083	17422	17603	17638	17725	17754	17763	17765	17780	17787	1.000	17787
2007		17262	17621	17701	17885	17901	17940	17996	18015	18027	1.000	18027
2008			18076	18255	18482	18522	18561	18568	18583	18596	1.000	18596
2009				18137	18782	18856	18908	18940	18971	18990	1.000	18990
2010					19440	19802	19886	19923	20383	20409	1.001	20429
2011						19882	20113	20161	20600	20643	1.002	20684
2012							20673	20828	21216	21278	1.003	21342
2013								20294	20939	21059	1.005	21164
2014									21149	21356	1.014	21655
2015										21251	1.032	21931

With 24-month data, delay factors are typically under 5%, though this varies by cancer site and registry. If we were to apply this methodology to 12-month data, delay factors are likely to be closer to 20%. Nationwide, in the most recent NAACCR data submission, about 80% of the cases reported in the 24-month data submission were also present in the 12-month submission (Figure 2). We chose to stratify the counts by type of reporting source to illustrate that the distribution of source types between the two years does not change dramatically – the hypothesis that the second year submissions are fundamentally different from the first year submissions and thus a source of bias is not supported by the evidence. While there are more death certificate only cases after the second year, and proportionally fewer cases from freestanding surgery and other hospital outpatient centers, these are small shares of the total. It may be true that individual registries may exhibit bias, but the goal here is to estimate rates for the nation, not individual registries, so the influence of any individual registry is diluted. Furthermore, registries with highly incomplete data will be excluded from this calculation, as will be explained shortly.



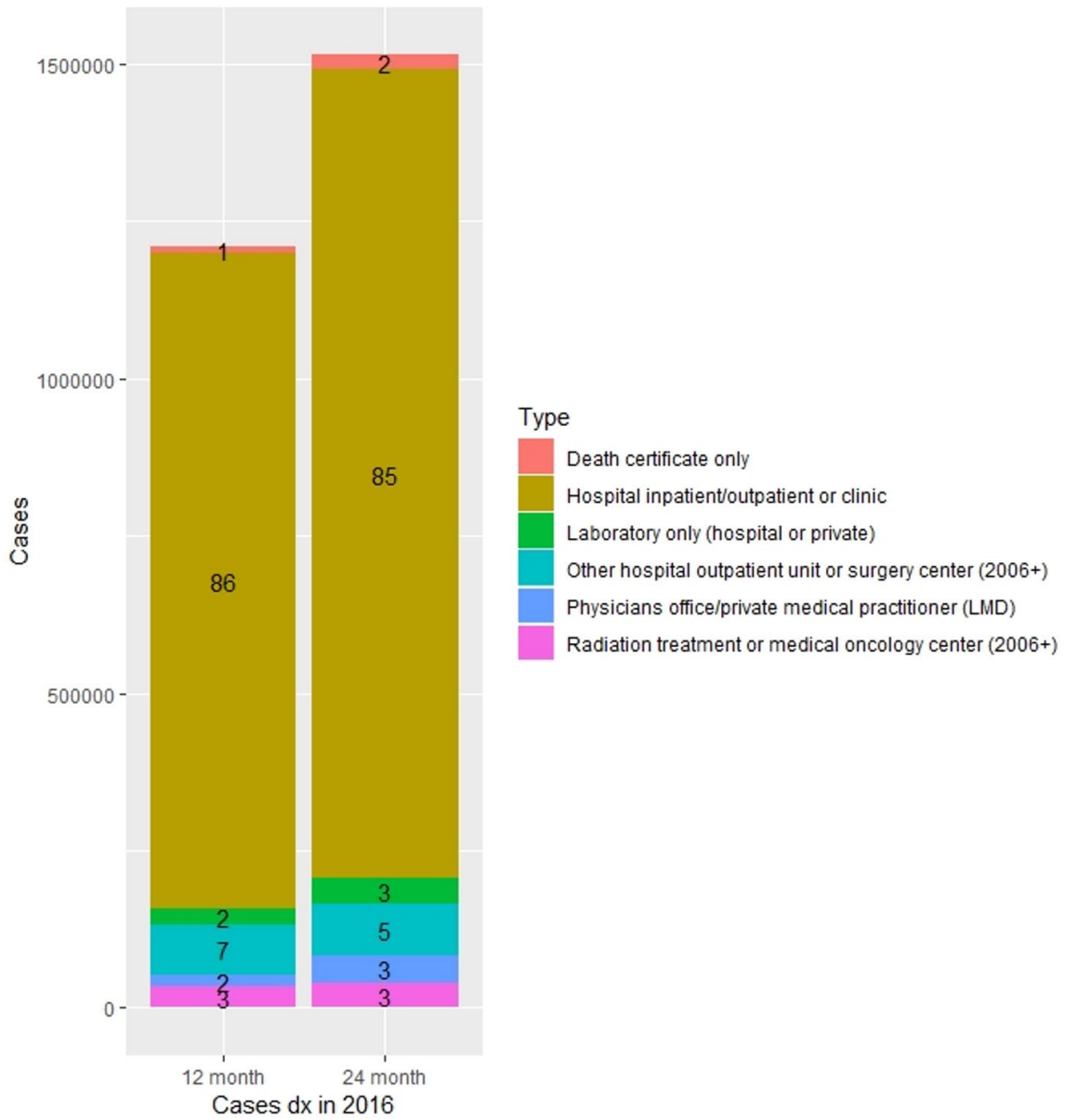


Figure 2. Cases reported in the 24-month and 12-month data submission

The ratio of 12-month cases counts to 24-month case counts varies by cancer site (Figure 3). Ignoring a few rare sites, the range is seen to extend from about 67% for chronic lymphocytic leukemia to 88% for uterine cancer (these figures were obtained by subtracting the value on the y-axis from 1). For certain sites such as CLL and possibly melanoma and prostate, the

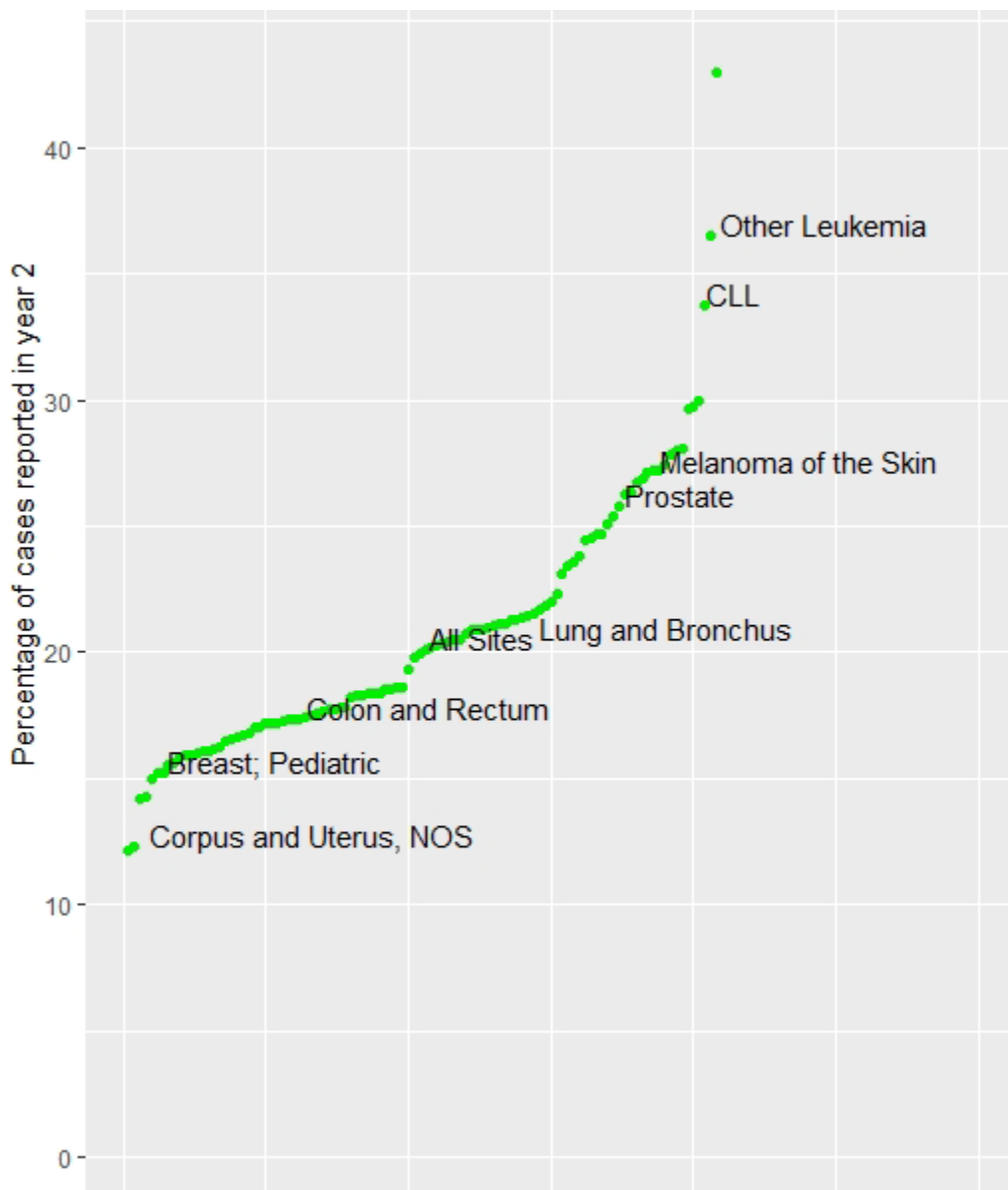


Figure 3. Ratio of 12-month cases counts to 24-month case counts

projection of national rates may be less feasible given higher uncertainty. Knowing which cancer sites may be projected and under which circumstances will require further analysis. The above figures made use of all data available to the work group – specifically, data for cases diagnosed in 2016 submitted to NAACCR between

November, 2017 and January, 2018 (what we will henceforth refer to as 12-month or one-year data, even though technically it ranged between 11 and 13 months), and data for cases diagnosed in 2016 submitted to NAACCR in November, 2018 (what we will call 24-month or 2-year data, even though technically it was 23-month data). However, the picture is better than this if registries with an unusually poor 12-month reporting performance are excluded. Drawing upon prior analysis among SEER registries, the work group is proposing to limit the basis for national projections to only those registries that had a 12-month case count to 24-month case count ratio of at least 0.8 in at least 3 of the 4 most recent diagnosis years, and to those that were certified gold or silver in all four of these years.

Applying these criteria to the NAACCR data submissions for cases diagnosed between 2013 and 2016, 36 registries would meet these criteria (Figure 4). We anticipate that the picture would improve still further if NPCR rather than NAACCR and SEER submissions were used for the analysis. For many registries these are the same, but some registries separately submit 12-

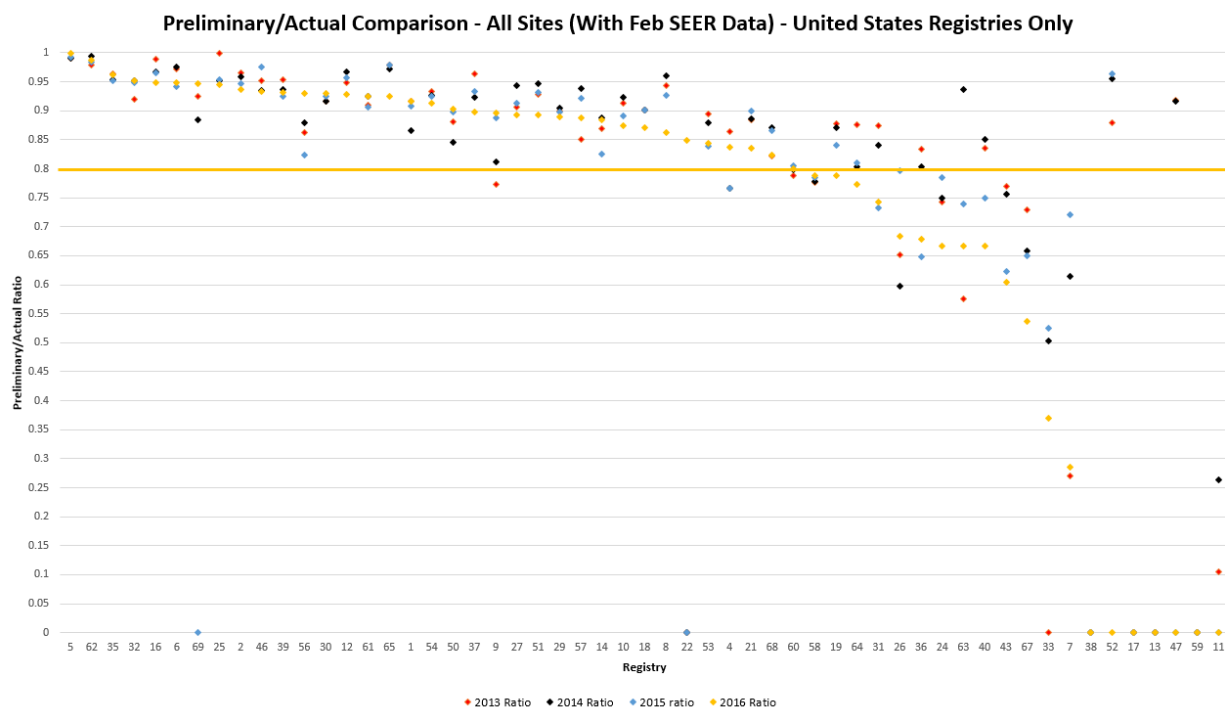


Figure 4. 2013-2016 Preliminary/Actual Comparison All Sites

month data to NAACCR in November and then again to NPCR in January. In one state the difference between these submissions is substantial – typically below 80% complete in the first submission, and above 90% complete in the second. In addition, there are several states that only submit their 12-month data to NPCR and not to NAACCR. The total number of states included could potentially be raised to at least 40.

Based on the 22-registry used in our in-depth assessment, 11 registries responded that they typically report 12-month data to NAACCR in January, 10 report in November, and one does either. Whether the registries who report in November make a separate submission in January to NPCR was not assessed. Regardless, if 12-month data are to be used going forward, there are obvious advantages to placing all registries on the same calendar. While it is possible to continue to analyze a mixture of 11-, 13-, and 14-month data, it complicates the analysis and delays the eventual release of the data by three months.

## Measuring Completeness

The workgroup considered four different approaches for measuring completeness. The workgroup recommends that two of these be considered for continued development and assessment, one not to be further considered, and one to be considered to the extent that it informs the delay-adjustment methodology just described.

### Incidence-to-mortality ratio method

This is the method currently used by NAACCR and NPCR to measure registry completeness. There are minor differences between the methods used by the respective organizations; a recent comparison found that the estimate differed by more than 1% for only five registries, and by more than 2% for just one registry. This summary considers only the NAACCR version of the method.

The method defines completeness as the ratio of observed to expected incidence rates for a registry. As is characteristic of such ratios, the average value across all registries is 1 or 100%; values are distributed around this average so that roughly half have values above 1 and roughly half have values below 1. The observed incidence rate is calculated by summing age-adjusted rates stratified by sex, race, and cancer site. Many race and site classifications have been assessed. Currently, the method considers 18 sites for men and 15 for women, including nearly all of the most common sites but excluding the two most common, breast and prostate. Currently, race comprises whites and blacks, but Hispanics and “other” categories also have been proposed for inclusion. For minority race groups, a rule of thumb has been that such groups must comprise at least 10% of the population in a registry to be included in a calculation.

The expected number of cases is obtained by multiplying the registry’s mortality rate by the national incidence-to-mortality rate ratio (IMRR), again stratified by sex, race, and cancer site. Thus if the national IMRR is 1.5 for, say, white male bladder cancer, then the incidence rate of white male bladder cancer in that state would be expected to be 1.5 times the mortality rate. In order to achieve a more stable measure, the IMRR makes use of 5 years of data, and the registry’s mortality rate uses 2 years of data (3 years for small registries with less than 500,000 people). National IMRRs use national mortality but incidence from 11 SEER registries.

The core assumption of this method is that incidence tracks mortality in a constant and universal manner by sex, race, and cancer site. This is not the case, of course, and indeed much of cancer surveillance is concerned with showing how this relationship is not constant, insofar as it is driven by factors such as screening, health care access, and quality of care. One way of addressing this issue has been to introduce an adjustment term to the method which effectively smooths the calculated IMRRs toward 100%, raising them for registries with low measured completeness and lowering them for registries with high measured completeness. However, the existence or magnitude of this adjustment term is only an estimate and lacks any empirical basis.

The primary advantages of this method are its long tenure and familiarity within the registry community and its transparency - it is a simple matter to independently verify the calculation using routine surveillance data. In addition, a spreadsheet is available that allows any registry or researcher to assess the implications of varying parameters such as sex, race, and site stratification and the adjustment term.

The primary disadvantages include the indefensibility of the constant IMRR assumption; instability of the measure for small registries, particularly the most sparsely-populated Canadian provinces and territories; exclusion of the most common cancer sites; and a seeming systematic underestimation of completeness in areas with heavily Hispanic populations. In recent years, nearly all NAACCR registries have been certified gold. For cases diagnosed in 2015, for example, 49 U.S. registries were certified gold, 6 silver, and 2 were uncertified. The registries certified silver or uncertified most often in recent years have included Nevada, Arizona, New Mexico, Los Angeles, and Minnesota. (Minnesota's status was not due to completeness.) Four of these five are in the Southwest and each of these four has a large Hispanic population, representing the registries with the first, second, sixth and seventh largest percentages of Hispanics in the country. However, adding a Hispanic stratum into the method does not improve the completeness of these registries substantially, and this issue has not seemed to affect Texas, with the third highest Hispanic population.

A final limitation is that a registry's classification as gold, silver, or uncertified can be sensitive to whether and how sex, race, and site are stratified, and which adjustment term is chosen. At the second in-person meeting in Vancouver, there was a demonstration of how one registry (Arizona) could have fallen into any of these three categories depending on what assumptions were made. Other registries straddled two categories. Prior work by one workgroup member showed that this characteristic is not only a property of parameter selections but of sampling variability (Das et al, 2008). The Vancouver presentation was limited to four registries, all of which have had difficulty meeting the NAACCR completeness standard consistently (New Mexico, Arizona, Nevada, Los Angeles). Work group members agreed it would be useful to expand this analysis to all registries to see if the conclusions are broadly applicable or confined to these negative outliers.

## Modeling method

The modeling method is adapted from the method used to predict current cancer counts for the nation that was jointly developed by the National Cancer Institute and the American Cancer Society (Pickle et al, 2007; Das et al., 2008; Zhu et al, 2012). That method uses a hierarchical Poisson regression model which includes spatial and temporal random effects across counties and years of diagnosis. Using county-level cancer incidence counts from the CiNA Deluxe file stratified by age, sex, race, and diagnosis year as an input, it models incidence as a function of cancer mortality, sociodemographic variables for each county (urban/rural status, household characteristics, income, education, medical resources) and behavioral risk factors (smoking, obesity, health care coverage, cancer screening). To adapt this model to measure completeness, the work group agreed to remove the spatial and temporal random effects to minimize the problem of overfitting the data for large registries.

Completeness is then taken to be the ratio of the observed counts submitted by registries to the expected counts from the model. Like the IMRR method, this method is a relative method that implicitly assumes that completeness is 100% for the reference population, which in this case is the entire nation. Half of the population will belong to registries with completeness below 100%, and half will belong to registries with completeness above 100%.

Preliminary results for cases diagnosed in 2015 using 2015 as the reference year were presented at the in-person meeting in Vancouver and revealed a moderate correlation with the IMRR method and a narrower range of estimates (Figure 5). Since the method uses data from CiNA Deluxe, five registries that did not meet the standards for inclusion in this volume or that opted not to have their data included are not reflected in the figure. Additionally, states with multiple registries (California, Washington, Michigan) were grouped.

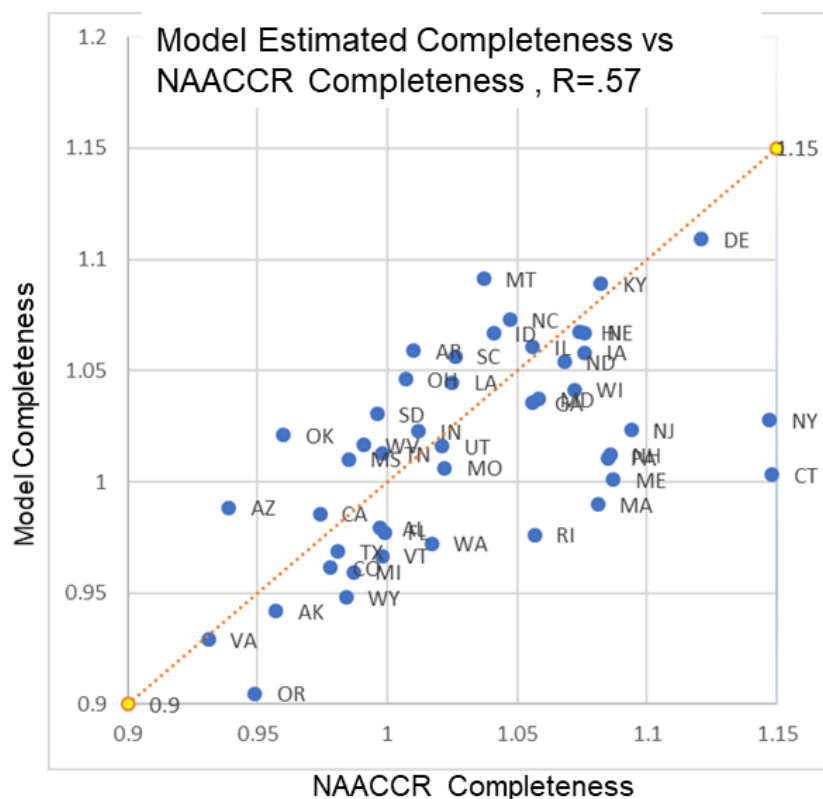


Figure 5. NAACCR Estimated vs. Actual Completeness

	NAACCR	Model
<88.9%	2	2
89.0-93.9%	2	1
94.0-99.9%	23	25
100.0-104.9%	10	17
105.0-109.9%	9	1
110.0%+	5	2
Total	51	48

Table 1.

Advantages of this method include the fact that all cases are counted equally, regardless of site or race. This would presumably remove the temptation for registries to delay the processing of some cases intentionally because they do not count toward completeness. It also does not depend on a problematic assumption (i.e. that incidence and mortality are perfectly correlated), but instead incorporates factors known to

influence cancer rates for which data are available, including demographic, behavioral and institutional data.

The major disadvantage is that the model is something of a black box and its expected case counts are not independently reproducible. A spreadsheet similar to that developed for the IMRR method could be developed to potentially ameliorate this problem. Another issue is that deriving both observed and expected counts from the same year of data means that changes in absolute case counts cannot be captured. This will likely be an issue when estimating completeness of 2018 data, where reporting reductions of 5% or even 10% are anticipated. The modeling method will assign an average completeness of 100% to the nation, with individual registries mainly distributed between 95% and 105%, as if nothing had changed. Reintroducing temporal random effects to the model could solve this problem.

### Flow and capture-recapture methods

The flow method is a method for measuring completeness that was developed in Great Britain about 20 years ago and was subsequently adopted by several European registries (Bullard et al. 2000). The term “flow” comes from the way that the computation draws upon the flow of cases through a registry as part of its routine operation. It categorizes all cancer cases into one of seven different categories. Five of these are easily counted:

- Patients alive at the time of interest and registered
- Patients deceased at the time of interest and registered, with cancer recorded on the death certificate
- Patients deceased at the time of interest and registered, with cancer not recorded on the death certificate
- Patients deceased at the time of interest but not registered, with cancer recorded on the death certificate, and with cancer information obtained through follow-back (“death certificate initiated” cases)
- Patients deceased at the time of interest but not registered, with cancer recorded on the death certificate, without cancer information obtained through follow-back (“death certificate only” cases)

The remaining two cannot be counted and must be estimated:

- Patients alive at the time of interest and not registered (“missing” cases)
- Patients deceased at the time of diagnosis, with cancer not recorded on the death certificate, and not registered (“lost” cases)

Estimating the missing and lost patients is accomplished by estimating the probability that a patient is registered while alive, the probability that cancer is accurately mentioned on a death certificate, and expected patient survival.

This method has a number of obvious drawbacks. It assumes that the survival of missing and lost cases matches those of recorded cases, when they would be expected to be quite different (Tervonen et al. 2017). It also requires that death certificates are timely and of high quality. Since, in general, death records require more than a year for



acquisition, linkage, and processing, it would be impossible to use the flow method to estimate completeness for periods of one year or less, a crucial consideration for this project. The method also requires registries to identify “death certificate initiated” cases, which is not a property U.S. registries record. Workgroup members felt that while some registries could likely deduce this information, others would find it difficult or impossible. On the positive side, completeness obtained from the flow method matches people’s intuitive sense of the concept – what you have is an estimate of the ratio of recorded cases to total cases, with an upper limit of 100%.

Silcocks and Robinson (2007) attempted to validate the flow method by creating the most realistic simulated data set they could, then removing up to 3% of the data for three different cancer sites and seeing if the method would correctly identify completeness values of 97% and above.

The group also discussed the capture-recapture method, whereby completeness is ascertained by comparing reporting to different entities (Brenner et al. 1995). In its simplest form, it involves comparing cases reported to a central registry and cases reported on a death certificate. Assuming the two are independent, then the number of cases not reported to either location (D) can be derived algebraically as:

$$D = (ABC + B^2C + BC^2) / (A^2 + AB + AC)$$

Where variables A through D correspond to the following:

		Reported on death certificate	
		yes	no
Reported to cancer registry	yes	A	B
	no	C	D

Completeness is then simply 1 minus D.

A test of this approach on a past NAACCR data submission revealed immediate problem, however. One state reported zero death-certificate-only cases (cell C), implying a completeness of 100%. Another registry reported very few cancer deaths (cell B), implying poor completeness. In both instances the limiting factor was not the cancer registry data but the timeliness and accuracy of the mortality data. Whether that was because the mortality data was incomplete or in error in its original form or because the registry did not process it correctly is not known. In any case, “completeness” as measured this way ends up being a hybrid measure of both incidence and mortality completeness that is not interpretable.

Any method that relies heavily on death-certificate-only rate is also subject to the problem that as the rate diminishes toward zero, as has been the general trend in North American cancer registries in recent years, the proportion of cases that are not true DCOs increases. Cause of death coding, while extremely good, is not perfect, and an unpublished study conducted by one registry found that a significant share of the DCOs actually died of other causes; sometimes through what appeared to be simple typographical errors.

Given these issues and problems, the flow method and the two-source capture-recapture method were not given further consideration by the work group. We note that the term “capture-recapture” was not actually used during the summit – no one present made the connection to the earlier work of Hermann Brenner and others – and the notes refer to this as the “naïve method” because the assumptions that central cancer registries and vital records were independent and that the vital records data was error-free seemed naïve.

### Internal method

In this approach, registries’ past case counts are taken as the sole input to predicting future case counts and assess the completeness of current counts. The logic is the same used to calculate delay-adjusted rates (see section 1), wherein rates are inflated by small amounts, depending on cancer site and other variables, based on historic patterns of delayed case reporting beyond the 24-month data submission. The advantage of this method is that it is straightforward to calculate and does not depend on external demographic or mortality data. SEER uses it to estimate completeness in its internal February (14-month) data submission. Many other registries do this implicitly when they provide mid-year progress reports back to facilities. For example, if a facility is told they had 93 cases reported at this time last year, but 76 cases this year, there is an implication that this number may be too low, that they may be behind in their submissions, because this year’s number is expected to be equal or greater.

The disadvantage is that it can be thought of as more of a measure of consistency than quality. To take a naïve example, imagine a national registry in a developing country where there are 10 hospitals, only 2 of which report to the registry. As long as this year’s case counts are similar to or greater than last year’s case counts – which will be true as long as the same two hospitals continue to report – completeness will appear high. The method thus assumes that a registry was virtually complete at least one time in the past. This is probably a reasonable assumption for United States registries, but it is difficult to know just which ones. A registry that was consistently 90% complete has the same issue as the registry in the developing country. For this reason, this approach was not considered for further development as a completeness measure.

## Recommendations and next steps

No method of measuring completeness is perfect, but the modeling approach holds the most promise at present. Unlike any of the other approaches, it accounts for variability in health care systems and behavioral risk factors that explain much of the state-level variation in incidence, mortality, and their ratio. However, there is still much to do before it is considered ready. It must be run using data from all NAACCR member registries, including those excluded from the CiNA file. The manner in which prior years of data can inform the completeness measurement of the present data year must be worked out. Ways of making the method more transparent, through some combination of a spreadsheet tool, journal article or white paper, and education through webinars or conference workshops, must be determined.

For the existing IMRR method, we need to extend the analysis presented in Vancouver to all registries, in order to see how sensitive the method is to different choices of reference files, stratifications, categorizations, and adjustment terms.

With respect to estimating 12-month cancer incidence rates, we need to continue our work pinning down the inclusion criteria and applying the delay adjustment factors.

We believe that each of these activities can reasonably be completed during 2019. Pending feedback from the recipients of this report, the work group will reconvene conference calls as needed, if funding permits.

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*We would like to express our deep gratitude to the members of the Statistical Work Group who gave so generously of their time and expertise to this project. The group worked with purpose and thoughtfulness on finding the best way to measure registry completeness. It also assisted in the development of a potential time delay projection model for 12-month reporting. Your generous support is very much appreciated.*

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Hannah Weir, CDC

Chuck Wiggins, New Mexico Tumor Registry

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Joe Zou, IMS

## Appendix D: Statistical Summit Notes

Marriott Washingtonian Center

Gaithersburg, MD

April 8–9, 2019

The North American Association of Central Cancer Registries (NAACCR) and the National Association of Chronic Disease Directors (NACDD) convened a Statistical Summit on April 8–9, 2019, to discuss the merits of various methods for estimating case completeness at NAACCR cancer registries and approaches to developing an improved method. Dr. Frank Boscoe, Founder of Pumphandle LLC, and previous NAACCR President-Elect, presided over the meeting. Ann Marie Hill of Rutgers University facilitated the meeting. NAACCR, NACDD, the Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries (NPCR), National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results Program (SEER), Information Management Services, Inc. (IMS), and cancer registry representatives participating in the Summit included:

Robert Anderson, National Center for Health Statistics (NCHS), CDC

Frank Boscoe, Pumphandle LLC

Kathy Brown-Huamani, the Scientific Consulting Group, Inc.

Huann-Sheng Chen, NCI

Barnali Das, NCHS, CDC

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Manxia Wu, CDC

Joe Zhou, IMS

Li Zhu, NCI

## **Day 1: April 8, 2019**

### **Action Items**

- Dr. Ward agreed to update the NAACCR workbook by loading new data.
- Dr. Zhu agreed to re-run the data for the American Cancer Society (ACS) model with 1996–2015 data with the five missing uncertified registries included. She might run the model without random effects but will discuss the analysis approach with Drs. Das and Feuer before proceeding.

- Dr. Feuer agreed to redo the validation analyses of the 1-year NAACCR data for diagnosis years 2015–2018 with some modifications (e.g., only for major cancer sites).
- Dr. Thompson agreed to check on the best source of tumor record number.
- Dr. Boscoe agreed to test his Naïve Method using data for all NAACCR registries.
- Dr. Boscoe agreed to send Outlook notifications for planned calls on May 2, 2019, (1:30-3:00 pm) and May 31 (1:00-2:30 p.m.).

## Background

*Betsy Kohler*

Ms. Kohler discussed the history behind the development of a method for measuring the completeness of cancer registry data. NAACCR first developed a data completeness measure approximately 25 years ago to aggregate data from registries across the United States and Canada in preparation for publishing *Cancer in North America, 1996–2000 (CiNA)*. Completeness standards helped to clarify when registries had data of sufficient quality to publish incidence rates and eventually served as criteria for registry certification. NCI’s SEER program and the CDC also have developed completeness measures. NAACCR, SEER, and CDC measures all have weaknesses but provide an indicator of whether a registry is capturing all cases in its jurisdiction.

Measures of completeness periodically have been reviewed, and attempts have been made to improve them. Dr. Ward recently worked on improving the NAACCR measure by including more racial/ethnic groups. Currently, NAACCR is evaluating the completeness of data submitted approximately 12-months after the end of the diagnosis year (early submission) and determining whether the measure now used to evaluate the completeness of data submitted approximately 24 months after the end of the diagnosis year (regular submission) also can be used to measure completeness at 12 months. Ms. Kohler would like the completeness measure to allow registries to determine how many cases in their coverage area have been captured at a specific point in time and whether completeness is adequate to use the aggregated data for public health and surveillance research efforts and publication.

## Defining Completeness

*Frank Boscoe and Hannah Weir*

Efforts to certify cancer registries began in the late 1990s with the implementation of NAACCR Data Evaluation and Certification Committees. The Evaluation Committee first evaluated registry data using the NAACCR Data Evaluation and Publication Committee method of case completeness. The incidence/mortality rate ratio (IMRR) used in this method is problematic because case completeness often exceeds 100 percent, a result that is difficult to interpret. Efforts to improve the method have involved adding race/ethnicity and decreasing mortality. In modifying the completeness measure, an



important goal is to create a tool that registries can use to determine where to focus their case completeness improvement efforts.

## Presentation

*Frank Boscoe*

Dr. Boscoe presented a working definition of completeness for the purposes of discussion at this Summit. He highlighted the difference between an idealized definition of completeness, with the goal of capturing every incident cancer case in the registry's jurisdiction, versus the practical definition of completeness with the goal of capturing incident cases that realistically can be captured because the cases have been captured by the medical system. The idealized definition likely would always lead to lower-than-expected completeness because of the "dark number" of unreported cases. The dark number concept comes from the field of criminology; analysts in this field attempt to estimate the dark number of cases from unofficial sources, such as self-report surveys, and then retroactively calculate estimated crime rates. Lyme disease surveillance offers an example of a practical definition of completeness. They are not trying to count all cases, just those that have been diagnosed. Reviews of clinical laboratory and private insurance claim data have been used for this purpose; estimates are only really to the nearest 100,000 cases.

The Flow Method (discussed on a prior call) and Dr. Boscoe's Naïve Method are potential measures of ideal completeness. Measures of practical completeness would have registerable cases as the denominator.

Measures of completeness also can be divided into external and internal approaches. An external measure can use either registries considered "high quality" or an average across all registries as the reference. External approaches, therefore, measure relative rather than absolute completeness. Measures of relative completeness include the current NAACCR IMRR and the SEER modeling methods. Internal approaches would measure completeness based on a comparison with a registry's own past performance. This approach assumes the registry achieved very high case completeness at some point, otherwise a registry that was consistently poor could appear to be doing ok. The current SEER completeness method is an example of an internal approach.

The current external NAACCR method measures completeness based on a comparison with other registries considered to have high quality data. The completeness of the external reference data is assumed to be 100 percent, which causes completeness rates for individual registries to be distributed around 100 percent. Some registries, therefore, would be expected to have above 100 percent completeness. NAACCR might need to better communicate the reason for 100 percent being the standard.

Delay adjustment is not a completeness measure, but can be a component of a completeness measure that considers data timeliness. Delay adjustment is not based on assumptions regarding case counts or trends, it simply estimates the increase in cases counts between points in time based on historical data.

## Discussion

Participants agreed to focus on the practical definition of completeness, although consideration of an idealized definition completeness was not ruled out. Special studies might be used to retroactively improve estimates for case completeness, although ideal completeness likely is unattainable. Special studies of certain cancers that might be underreported in the medical system, such as thyroid cancer or chronic lymphocytic leukemia (CLL), might be informative. Some studies have compared self-reported cancer history to registry data. For example, Dr. Lynn Penberthy examined self-reported CLL and found that a large proportion of CLL cases were missing from cancer registries. Participants agreed that examining unreported cancers would be useful but should not be the focus of this meeting.

Initially, completeness measures were validated based on manual case finding. An independent party was responsible for looking for new cases that might have been missed by the central registry. No current statistical method has been validated based on manual case finding. This approach likely would not have found all cases but might have been more accurate, especially in an era when most cases were seen at hospitals. Another advantage of manual case finding was the ability to quantify the number of cases identified through case finding compared to regular facility reporting. NAACCR continues to rely primarily on hospitals to report cases, but the cases most often missed are those diagnosed outside of hospitals. Registries have information on the proportion of their cases received from hospitals and the proportion received from other sources. Participants suggested using these proportions to estimate the proportion of cases that might be missed.

Participants noted the need to distinguish between registries that might not meet standards because of reporting delays and registries with low case counts that never capture those missing cases. Both situations occur.

The IMRR is not constant across all populations. Attempts have been made to adjust for race/ethnicity, but the assumption that the IMRR is constant continues to be false.

Participants discussed whether the goal should be to develop a method for estimating overall completeness or completeness across different cancer sites. Participants agreed that completeness should be measured for different cancer sites, but they also might want to measure overall completeness. The barrier to estimating overall completeness in the past was that the NAACCR method excluded major cancer sites. When breast and prostate cases were added back into the measure, completeness estimates moved closer to 100 percent, which reduced completeness estimates for some registries. Participants agreed it is important to include counts for the major cancer sites when estimating completeness.

Participants emphasized the need to consider variance when examining completeness methods. Larger registries have smaller variances, which might put smaller registries at a disadvantage. One option would be to adjust standards based on registry size. Other

factors that generate variability in completeness between registries is health care access for different populations within the coverage area and care seeking patterns of those populations. The NAACCR algorithm was designed to be the measure that works best for most of the registries. Participants discussed whether registries that cover large populations with challenges to obtaining cancer care might improve their completeness counts over a longer period as death certificates (DCs) for missing cases are received. Registries handle DCs differently.

The current NAACCR method is a model that includes gender, race, and cancer site. Participants discussed other ecologic covariates that might be included in the model at the county or state level to adjust for variation between registries. Source of registry data might be one important covariate. Many registries are using a wider range of reporting sources than in the past, but reporting sources vary widely across registries. Registries with a wider range of reporting sources can be expected to have better completeness. Different registries also might have different proportions of cases for different cancers from different reporting sources. If this is the case, it might be worthwhile to examine whether these differences result from different local healthcare systems or different practices in case-finding and use of reporting sources. Participants suggested examining reporting source by cancer site. Most registries identify death certificate only (DCO) as a reporting source, but other reporting sources might not be documented. More detailed information on reporting sources would allow NAACCR to provide guidance to registries about stronger and weaker data sources overall and for certain cancer sites.

Reporting practices are changing with changes in hospital structure and a greater number of auxiliary care facilities taking over care for cancer patients. This trend merits consideration because it likely affects case completeness. NAACCR would need to examine local changes in health care systems to determine what system variables might affect case completeness for specific registries.

NAACCR will need to consider actions to take when a rapid change occurs at the national or registry level that has the potential to affect completeness.

## **Recapitulation of Conference Call Presentations—Strengths and Weaknesses of Each Method**

### **Current NAACCR Completeness Method**

*Kevin Ward and Chuck Wiggins*

Dr. Ward reviewed the findings of a task force organized to compare SEER, NPCR, and NAACCR completeness methods and examine modeling approaches for estimating completeness. A key strength of the NAACCR method is its transparency, which allows registries to evaluate their own data. The method also is robust and has worked well with minor modifications over time. Weaknesses of the method include the tendency to inflate estimates, leading to estimates over 100 percent; underestimation of

completeness in most states where Hispanics are a large proportion of the population; and problems measuring completeness for small populations, such as those in Canadian territories.

In the United States, 90 percent of NAACCR registries were gold certified in 2014 and 2015. Only two registries did not achieve certification in 2015 and only one in 2014. In both years, the four registries where Hispanics made up the largest proportion of the population received silver or no certification.

The current NAACCR Method initially calculates separate completeness estimates within each race strata (weighted proportion to race distribution). The race strata are White and Black... Completeness across cancer sites (with breast and prostate excluded) is calculated as the ratio of observed cancer incidence to expected cancer incidence within each race/gender strata. The ratio is weighted by gender within each race strata and age-adjusted to the 2000 U.S. population. The expected incidence rate is the 5-year SEER11 incidence rate divided by the 5-year U.S. mortality rate (i.e., IMRR) multiplied by the 2-year registry mortality rate. An adjustment for Hispanic ethnicity has been explored using alternate race strata of non-Hispanic Black, non-Hispanic White, non-Hispanic Other, and Hispanic, but only strata representing at least 10 percent of the population in the registry area are included in the calculation

The Method assumes a constant IMRR within each subgroup. The NAACCR Method attempts to adjust for case fatality, but registries with higher-than-expected mortality relative to incidence still have lower completeness estimates. Survival disparities, therefore, create a problem for registries serving large populations affected by those disparities. Incorporating survival or stage into the model might resolve this problem.

Dr. Wiggins demonstrated how increases in mortality could substantially reduce completeness using the NAACCR algorithm with a simulated data set. He argued that the NAACCR Method IMRR is strongly affected by cancer disparities when the populations affected by those disparities represent a relatively large proportion of the total population covered by a registry. For example, in New Mexico, non-Hispanic Whites are the minority, and Hispanics and Native Americans combined comprise nearly 60 percent of the population. Research has shown that these populations tend to access care differently than most of the U.S. population. Hispanic populations also tend to have a lower median age when compared to non-Hispanic White populations. Participants noted that some attempt is made to control for disparities by calculating a separate IMRR for each racial/ethnic group examined, but this approach might not be sufficient to eliminate the effect of disparities on completeness estimates. The four racial/ethnic groups used in the NAACCR Method might not be sufficient to capture other disparities, particularly disparities within the Hispanic group. For example, cancer outcomes in Cuban Americans in Florida might differ markedly from outcomes in Mexican Americans in New Mexico. In addition, Dr. Wiggins and colleagues performed analyses demonstrating profound differences in cancer incidence between different Native American populations across the U. S. Dr. Wiggins concluded that the

assumption of a constant IMRR was invalid because that ratio can vary by race/ethnicity, urban versus rural residence, and other factors. A measure that does not rely on this assumption might be more accurate.

The fact that SEER11 incidence is used to calculate expected incidence creates an independence problem because some NAACCR registries that are certified are part of SEER11. Normally, the group examined should not comprise a large portion of the reference group. Some NAACCR registries that were among the SEER11 registries contribute a large proportion of the reference population, which violates statistical assumptions. Participants discussed whether a registry that comprises a large proportion of the SEER11 sample receives an advantage when completeness is calculated using the NAACCR algorithm. NAACCR could conduct analyses to examine this question or address concerns by replacing the SEER11 incidence rate in the model with another incidence rate, such as that of all U.S. NAACCR registries combined. Participants appeared to favor the suggestion to replace SEER11 incidence with incidence for all U.S. registries to improve fairness, particularly in view of the fact that most NAACCR registries now have a level of completeness that is acceptable for research purposes.

Another major limitation of the current NAACCR Method is the exclusion of the most common cancers—breast and prostate—from calculations. Participants generally agreed that breast and prostate cancers should be included in future completeness estimates.

## **Modeling Methods**

### *Li Zhu*

Dr. Zhu discussed a modified version of Dr. Das's spatial-temporal model developed in collaboration with the ACS to produce Cancer Facts and Figures 2019. This model was run using data from 1996 to 2015 for all but five registries, county by county, for the ACS report. The explicit statistical model includes mortality, demographic, lifestyle, and other variables that have been shown to affect incidence and these variables have been updated periodically. Participants noted that identifying the best covariates would be important. Dr. Zhu and colleagues used the expected case counts from this model and compared them with observed case counts for NAACCR-certified U.S. state registries. The completeness rates generated by this model are correlated with completeness rates generated by the current NAACCR Method, but the spatial-temporal model generates fewer completeness estimates above 100 percent. The advantages of the model are that it borrows strength across years and space; is based on county-level data; and includes all racial/ethnic groups, both genders, and all cancer sites. The model mimics observed counts very well, which might create problems when used to evaluate data quality. In smaller areas, observed and expected incidence are almost exactly aligned across several diagnosis years. Dr. Feuer explained that this method generates the proportion of covariates contributing to completeness for each year in addition to the completeness estimate. The problem with the model is that large

registries with small variance would have high completeness estimates regardless of performance. The goal would be to use only the portion of the model that is a function of the covariates. This alternative model would be run each year; retain covariates on mortality, demographic factors, and lifestyle factors (e.g., smoking prevalence, screening behaviors); and exclude spatial and temporal effects. Dr. Zhu clarified that the covariates currently in the model are based on county-level data and are divided by race or gender. Dr. Feuer recommended adding stage distribution to the model (at either the state or county level). County-level covariates might work better than state-level covariates for capturing variation. If state-level data are used for the covariates, dividing covariates into race/gender categories might improve accuracy.

The model has been used to predict counts and was validated. The model now is being updated, and cross-validation will be performed. The fact that the model considers random effects improves accuracy but might make the model overly complex (and therefore less transparent) for the purpose of measuring registry case completeness.

## Delay Adjustment Methods

### *Rocky Feuer*

Dr. Feuer discussed the use of the reporting delay adjustment method to measure completeness for 1-year data. Questions to consider regarding the use of this method include: (1) Should NAACCR certify 1-year data? and, (2) Can delay adjustment produce 1-year data of adequate quality? Delay adjustment has allowed SEER to produce trends using 1-year data from registries. The method uses delay factors based on historical data to predict how much case counts will increase over time. More recent data are more heavily weighted. The method assumes that data are complete 11 years after the diagnosis year; therefore, the case count 11 years post diagnosis represents the expected count. Delay factors by themselves are not a viable measure of completeness but can serve as an indicator of registry quality.  $1/\text{delay}$  is a metric measured on a scale similar to that for completeness that represents the underreporting of current cases compared to what might be found eventually.  $1/\text{delay}$  is the observed number of cases after a set number of years of delay (usually 2 years) divided by the expected number of cases after an 11-year delay. The delay method measures additional cases that are expected to be received in the future (usually 3 to 11 years later), whereas the NAACCR Method measures expected cases after 2 years. Reporting delay can be used as component of completeness. One component would be the expected number of cases for a certain number of years after submission. Expected cases would be based on an average of all registries or SEER registries for the submission, adjusted for gender, race, mortality, fatality, and other relevant characteristics. A second component could be the additional expected number of cases after 11 years, if NAACCR wanted to examine this number. This component would use a composite delay factor for the group of registries used to compute the expected number in the first component. If a component of the delay adjustment method was

included in the NAACCR algorithm, completeness standards might need to be lowered because the adjustment is based on what would be expected after 11 years rather than 2 years. Alternatively, the standard could remain the same, but fewer registries would be certified. The delay adjustment method also could be used to estimate the number of cases that never would be found, but Dr. Feuer did not recommend this approach. IMRRs are based on 5-year estimates, and 2-year mortality is used in the NAACCR Method, so delay adjustment might not be necessary.

All registries experience delayed reporting of some cases, and should estimate the proportion of cases still missing at the time of a submission. Participants asked what is known about these cases that are received late. Others responded that most late reporting of cases is linked to patient care patterns, which may vary by cancer site but is likely to be consistent across registries. Other factors associated with reporting delays, such as a new reporting facility, affect individual registries and are difficult to predict.

Dr. Feuer discussed the use of delay adjustment for SEER registries, which have an early data submission date in February of each year, approximately 1-year after the end of a diagnosis year. Delay adjustment is used to predict the shortfall in the February submission compared to the November submission, which is approximately 2 years after the diagnosis year. Four February submissions were used to predict the delay for the SEER registries. The delay factors for the February submission are more than twice as large as those for the November submission, but produce highly accurate adjustments. This level of accuracy allows delay-adjusted data from the February submission to be used to calculate trends. These trends are posted on a web site and are presented as preliminary. It is not clear how delay adjustment would work for subsets of data from the SEER submissions.

NAACCR has been receiving early data submissions for enough years to perform delay adjustment of the next January submission. Dr. Feuer analyzed NAACCR January submissions and noted that their completeness was improving over time. NAACCR registries are allowed to submit the 1-year data before January, which might explain improvements in completeness. A quality program might help improve the ratio of the January to December case counts. Data quality criteria could be examined after one more 1-year data submission is received by NAACCR, but significant, sudden improvements in data quality would make it difficult to produce accurate delay factors.

## **Flow and Naïve Methods**

*Frank Boscoe*

Dr. Boscoe discussed the Flow Method developed at European registries to estimate missing living cases and lost deceased cases for whom the cancer is not noted on the DC. Missing and lost cases are derived from the time distribution of three probabilities: (1) survival, (2) registration during the patient's life, and (3) the cancer being mentioned on the DC. An attempt was made to validate the Flow Method with a simulated data set and the results of this analysis were published. With this method, over time the estimate

approaches the true completeness value. The advantage of the Flow Method is its simplicity and ability to be easily explained. A major weakness of the Flow Method is the time needed to achieve a high level of confidence regarding the estimate, which would be a minimum of 5 years after the diagnosis year. Another weakness is that the method appears to depend on assumptions that cannot always be supported.

Dr. Boscoe also presented a Naïve Method for measuring completeness. This simple method would calculate missing cancer cases not on the DC or reported to the registry based on the assumption that these represent independent events. The DCOs used in this calculation would be for the most recent diagnosis year, and historical submissions could be examined to predict case counts and DCOs. Participants discussed the fact that DCs can include as many as 20 cause of death (CoD) fields and cancer might be mentioned on any of them. It is unclear whether state registries examine all fields to identify a reportable cancer that might have been missed.

## **Data Collected by NAACCR**

*Kevin Ward*

Dr. Ward presented a list of data elements included in the NAACCR submission. These elements include patient care variables; stage at diagnosis; county variables; state and other census tract information; race/ethnicity including NAACCR Hispanic Identification Algorithm, Asian/Pacific Islander, and Indian Health Service variables; sex; age at diagnosis; cancer-specific clinical codes; diagnostic confirmation (indicating whether cancer was pathologically confirmed); type of reporting source (sources are prioritized by best expected source, so hospital takes precedence over other reporting sources); histology and behavior; primary payer at diagnosis; socioeconomic status (SES) measures if available (including one census tract-level poverty measure); tumor, node, and metastasis (TNM) staging variables and summary stage; treatment variables (dates of initial treatment course, surgery variables, radiation and adjuvant therapy variables); date of last contact; vital status and source of this information; collaborative stage variables; and some site-specific factors.

Participants expressed particular interest in the reporting source variable. Relatively low diversity of reporting sources could be an indicator of poor data quality and might be incorporated into the completeness estimation method for some cancer sites.

Participants also expressed interest in survival data. The NAACCR data set includes one census tract-level survival field. Most states have performed linkages to obtain survival data. Stage distribution data would be expected to be related to survival, but a large proportion of stage fields are coded as “unknown.” “Unknown” stage could indicate missing stage information or information that is not sufficient for distinguishing between regional and distant metastases. NAACCR collects data on cause-specific death, which would permit cause-specific survival analysis.



## Group Discussion

Participants joined one of the following four separate discussion groups as indicated below:

Topic	Leaders	Members
Existing NAACCR Method	Kevin Ward Chuck Wiggins	Lihua Liu, Andy Lake, Hannah Weir, Manxia Wu
Modeling Method	Li Zhu	Barnali Das, Trevor Thompson, Joe Zhou
Other Methods (SEER Internal using historical data, Flow, Naïve)	Frank Boscoe Rocky Feuer	Robert Anderson, Huann-Sheng Chen, Betsy Kohler

Participants agreed to discuss delay adjustment in all groups. Delay adjustment could be incorporated into any method.

Participants were encouraged to interact across groups to cross-pollinate ideas. Ideally, the final method selected by the group would be informed by multiple methods. Groups also were asked to consider approaches for testing the methods they discussed, as well as modifications to those methods. The goal is to generate four to 10 measures of completeness that IMS can test and compare using NAACCR data. Each group was asked to recommend at least one method. Groups were asked to consider the following questions: (1) Should we continue to consider each method for measuring NAACCR registry case completeness? (2) Are there improved versions of each method that should be tested? (3) Is each method and modified method testable at this point? (4) If certain methods are not viable for measuring completeness, could a component of those methods be integrated usefully into another acceptable method? (5) How should NAACCR move forward with testing each selected method?

Specifically, the NAACCR Method group was asked to develop a recommendation regarding whether to continue using the current algorithm or make recommendations for a modified version of the algorithm. The Modeling Method group was asked to determine which method is most viable for measuring case completeness and make recommendations for testing models. The Other Methods group was asked to consider how the other methods could be integrated into the NAACCR or Modeling Methods and how these could be tested. Groups met separately for approximately 1 hour.

## NAACCR Method Report Back

*Kevin Ward*

The NAACCR Method group proposed some enhancements to the existing method alone and in combination with other methods. For example, delay adjustment might be used to help validate models. Dr. Wiggins raised the question of possible variation in the

quality of data provided by the Bureau of Vital Statistics in different states. This type of variation could affect the completeness of mortality data and, in turn, affect the IMRR and registry case completeness. Other participants explained that mortality reporting does not vary much between states, overall, but can vary at different points in time because of delays in death reporting. Timeliness of death reporting, however, varies substantially by CoD. For example, reporting of deaths caused by drug overdose, suicide, and homicide are delayed about 6–9 months relative to other CoDs. States also vary in lag time for reporting deaths, but cases are reported within about 1 year, so the lag should not affect cancer registry completeness. State Bureaus of Vital Statistics now auto code CoD in approximately 75 percent of cases and expect to auto code CoD for 95 percent of cases soon. Dr. Wiggins suggested matching the cancer registry data to death data to determine what percentage of registry cases die of cancer.

Participants noted that certain states are likely to have higher mortality rates. For example, states where substantial numbers of people retire and subsequently die might experience higher mortality rates. Dr. Feuer's analyses of incidence-based mortality for lung cancer found discrepancies between registry cases and DC-reported cases of lung cancer. When researchers examined all cancer cases, however, they found that many DC-reported lung cancers were originally other cancers that had metastasized to the lungs. This finding suggested that DC-based lung cancer mortality was not as accurate as incidence-based mortality for this cancer. Incidence-based mortality, which represents only cases diagnosed in the state, might be used to examine migration of cancer cases between registries.

The NAACCR Method group also discussed additional adjustments related to case fatality. One concern was variation in case fatality within racial/ethnic these groups. The group discussed cause-specific survival data in the SEER registries. The two registries with the largest Hispanic populations had the lowest cause-specific survival among Hispanics. One of these registries also had the lowest cause-specific survival among Asians. Review of the SEER data also revealed that cause-specific survival varies substantially within racial/ethnic groups. These findings raise the question of how to adjust for these variations in survival in the NAACCR algorithm. Dr. Ward also examined case fatality at the four registries with the largest Hispanic populations that were not gold certified in the past 2 years. He found that raising the adjustment factors for these registries increased completeness estimates by four or five percentage points for two of the registries but did not change case completeness rates for the other two registries. Completeness estimates might not have changed for the latter two registries because the states are poorly resourced and, as a result, could have lower actual completeness rates.

The group considered whether the model would be improved with the use of age-specific rather than age-adjusted rates. NAACCR formerly used age-specific rates. Dr. Zhu's approach that adjusts to the registry rather than the U.S. standard for a specific race/gender group might achieve the same effect. Participants suggested adjusting a (i)

rates for all registries with the  $i$  value determined by the state-specific survival. Dr. Ward suggested raising the value to improve completeness for registries with high mortality rates relative to the United States as a whole. He also suggested testing methods that adjust for case fatality by comparing to NAACCR Method estimates for highly fatal cancers.

A combination of methods might be used for registry certification purposes. Components of certain methods could improve other methods. Dr. Ward supported the IMRR because it does not rely on historical incidence data (it uses mortality data to estimate expected incidence). He suggested combining this external method with an internal method that relies on historical data, such as the SEER method, and use weighting to ensure appropriate contributions from each method.

The group could not identify a way to use reporting source in the NAACCR Method. Other participants suggested examining reporting source to determine ways to improve actual completeness. Registries will be able to better assess completeness with real-time pathology reporting and the ability to distinguish incident and prevalent pathology. Optimal pathology reporting should identify approximately 94 percent of cancers in the United States. Assessment of completeness also could improve with knowledge about the proportion of clinically diagnosed cases and variability in this proportion across registries.

The group considered the possibility of using stage data but confirmed that too many cases had stage coded as “unknown.” Stage is the strongest predictor of survival, but some other survival adjustment factor might be needed until the quality of stage data improves. Survival data are fairly complete, but completeness varies across registries.

Participants proposed using a national reference rather than using SEER11 as the reference. If this change causes completeness to decline for some registries, however, it could be problematic. First, NAACCR might want to investigate what factors drive differences in completeness.

Participants agreed to upload new data and possibly modify the NAACCR workbook. One variable that could be added is “region” to allow for regional comparisons.

Dr. Ward suggested running all proposed completeness models using NAACCR data for different populations to see differences in completeness results and trends. It might be informative to rank registries using the NAACCR and modeling methods. Differences in ranking would highlight potential discrepancies in methods. Participants generally agreed that ranks would be useful.

Participants also suggested running different permutations of the NAACCR Method using a single registry’s data. The New York registry might be ideal because of the diversity of populations and the ability to compare New York City with the demographically different portions of the state outside New York City. Dr. Ward noted

that every registry's completeness increases when race is removed from the I/M model, so investigating the effects of race on completeness would be worthwhile.

Participants noted that cases from hospitals run by the Veteran's Health Administration of the U.S. Department of Veterans Affairs (VA) are missing for many registries because these hospitals do not report in many locations. VA hospital cases are excluded from submissions in California because the proportion of cases contributed by VA hospitals varies substantially across registries. Participants discussed approaches for handling missing VA hospital cases at other NAACCR registries. VA hospital cases cannot be removed retrospectively. If most registries are missing VA hospital cases, no registries would be penalized because their completeness estimates would be compared to the U.S. average. CDC collects data on the number of VA hospital cases by state, so it might be possible to estimate the proportion of missing cases that are accounted for by VA facilities. Some participants believed that VA hospital cases do not substantially affect differences in completeness across registries.

### **Adjusting for Case Fatality in the NAACCR Method**

*Barnali Das*

Case fatality is not constant across registries, so failure to adjust for case fatality can produce inaccurate completeness estimates. If a registry has low case fatality compared to the average, it will have a lower- than-expected incidence rate and higher completeness. Conversely, higher-than-average case fatality leads to a higher-than-expected incidence rate and lower completeness. Some ad hoc survival adjustments already are included in the NAACCR algorithm to address differences in case fatality. For example, breast and prostate cancer are excluded because these cancers have different case fatality at different locations because of differences in screening rates. The IMRR also is constant for a fixed geographic unit. The use of SEER incidence divided by U.S. incidence rather than SEER incidence divided by SEER mortality is another adjustment for case fatality differences, although this adjustment might not work for all registries.

Drs. Das and Tom Tucker performed an in-depth examination of different approaches for calculating case fatality using data from SEER registries. This analysis was done before survival data was available for many other NAACCR registries. Dr. Tucker decided to use differences in site- and sex-specific 12-month survival rates to adjust for differences in case fatality in place of the ad hoc adjustments employed by the NAACCR Method. Dr. Tucker decided not to use race-specific survival, but this could be added to the model. Drs. Das and Tucker calculated mortality adjustment factor alpha with SEER as the target. If the alpha for a registry differed from the SEER standard, the mortality rate was adjusted. Dr. Das ran this new adjusted model excluding breast and prostate cancers, using SEER incidence divided by SEER mortality rather than SEER incidence divided by U.S. mortality for the IMRR. This analysis generated completeness rates closer to 100 percent for the registries. Notably, the analysis generated higher completeness for the New Mexico and Utah registries when compared to the NAACCR

Method. Dr. Das then ran the same model, still excluding breast and prostate cancers, using SEER incidence divided by U.S. mortality for the IMRR. This approach over adjusted resulting in completeness estimates over 100 percent for all registries. Dr. Das tried this model including breast cancer but excluding prostate cancer and including both. These analyses revealed that including breast and prostate cancers was not problematic when the model was adjusted for case fatality. Dr. Das concluded that it is important to adjust for case fatality, which brings completeness estimates closer to 100 percent. She also recommended not using SEER incidence divided by U.S. mortality rates for the IMRR in this adjusted model because of over adjustment. In addition, the same geographic units should be used in calculating the IMRR.

## Day 2: April 9, 2019

### Modeling Report Back

*Li Zhu*

Advantages of modeling include the ability to add covariates, including county-level small area variables related to behavior and sociodemographic, and the flexibility to remove random effects and add data sources and delay factors. The current ACS model takes the delay adjusted observed counts divided by delay adjusted expected counts. Participants discussed whether standards should be changed if this model is used, because the model lowers completeness rates, with rates for many registries falling below 95 percent, and rates for some currently certified registries falling below the certification standard. The model still needs fine tuning, so the completeness rates might change. If NAACCR has confidence in the delay factors for this model and those factors are consistent over time, the model might help to measure delays in reporting for registries. Model results should be compared to the completeness rates generated by the NAACCR Method when delay adjustment is performed. Participants proposed examining how much control registries have over delays in reporting, reasons for those delays, how much delay should be expected 2 years after the diagnosis year, and, on average, how many more cases can be expected to be added between 2 and 11 years after diagnosis. Ms. Kohler expressed interest in this proposal. Participants discussed whether to use registry-specific delay or average delay across all registries. Participants suggested examining average case count after 11 years, after delay factors and registry-specific delay adjusted counts have been put in the model, and after adjusting for covariates. Participants also suggested using delay factors to rank registries for cancers that historically have more delayed reporting. If registries demonstrate no delay, they either are not finding new cases after a submission or are capturing cases in a timely manner. The model might be measuring expected case counts rather than completeness and, therefore, might need to be modified before it can be used as a measure of completeness.

Dr. Das recently developed a model to measure the variability of completeness rates at each registry and demonstrated how the difference between predicted and observed

case counts is greater in states with small populations. The model included mortality as a fixed covariate; other covariates were selected through a stepwise process. The model presented by Dr. Zhu also can incorporate a measure of registry variability. Registry variability of completeness estimates would be presented as a confidence interval that might cross different certification thresholds. Ms. Kohler suggested that registries might be certified at the highest level reached by their confidence interval. Dr. Das' paper discusses approaches for calculating the probability of a registry's completeness rate falling into each certification category, so an alternative approach would be to certify the registry in the category with the highest probability of being correct. Participants discussed covariates that might be useful to include in this type of model, such as reporting source, county-level sociodemographic, stage distribution, or survival. Coefficients in the model would provide some information about the variables that are most likely to influence completeness, and the degree to which different covariates influenced the final completeness rate could be reported. A disadvantage of this model is its complexity, but Dr. Das believes that the model is transparent in terms of what goes into it and how it arrives at the completeness estimate. The model also is flexible and allows for appropriate weighting and easy adjustment of the weights once the model is built. There also are strong rationales for the model's components. In addition, the model generates expected case counts by cancer site. If the model is used, a decision would need to be made regarding whether to use state or county level data. A participant noted that models built on national data would give less weight to smaller registries. This is a problem for rarer cancers.

The greatest challenge for modeling is determining how to validate a model. The modeling group proposed validating models using data from a test registry. Past projected counts for that registry, perhaps obtained from Cancer Facts and Figures, would be compared to observed counts for a given year. Another method would be needed to validate how well a model measures completeness, perhaps through reabstraction of cases at the test registry. Participants indicated that reabstraction probably was not feasible. An important consideration when selecting models would be whether they could be run with 1-year data.

Dr. Feuer proposed comparing the different models with different covariates with different years of data. Dr. Das expressed concerns about overfitting but agreed this approach was feasible. This testing also would generate a measure of average observed completeness across registries, which would inform NAACCR standard setting. The average would be based on the assumption that 2015 was a normal diagnosis year. The American Community Survey, ongoing annual Census, and other new data sources provide useful covariates for testing. Covariates likely will not change much from year to year. Modeling methods would be useful for determining causes of poor completeness or timeliness.

Canadian registries present a challenge for modeling. Race data are not collected in Canada and the population and health system are different compared to the United

States. Participants discussed whether to use a separate model to calculate completeness for the Canadian registries.

### **Delayed Reporting Issues**

Participants emphasized the need to recognize that not all registries operate under the same conditions, so reporting criteria might need to differ depending on those conditions. Differences between registries have meaning beyond completeness and timeliness that is worth investigating. Reporting delay might be more within the control of the registry than other factors that affect completeness. Delay also might be a better indicator of quality than completeness. Delay factors could be used to validate models. Participants suggested identifying differences between registries with larger and smaller delay factors and comparing how well models perform for these two groups of registries. Delay factors for SEER and NPCR registries differ. Participants expressed interest in examining the types of cancer cases that are reported late and possibly those that might never be reported to registries.

Dr. Boscoe mentioned another NAACCR project that involves interviews with registry staff to determine reasons for problems in timeliness of reporting. Some information collected suggests that cases diagnosed outside hospitals eventually go to a hospital, often several years after diagnosis. NAACCR could have a sample of registries examine cases that they receive after submission for reporting source, pathologic confirmation, and other variables that might explain the delay. SEER\*DMS can show when a case came in and how many times it was modified before it became a Cancer/Tumor/Case. This information might point to registry processes that explain delayed reporting.

Dr. Zhu is able to examine which cases are delayed, and IMS already has examined this issue and has data on reporting source. It would be useful to construct a data set to identify very delayed cases and their reporting sources for each state. Currently, no information is available on whether a case came from another state. The number of cases that are never reported also is unknown.

### **Other Methods Report Back**

*Frank Boscoe and Rocky Feuer*

The NAACCR registry reporting source categories include hospital, radiation facility or medical oncology center, physician's office, nursing home, DC, autopsy only, and other hospital outpatient unit. Dr. Boscoe confirmed the high variability in reporting sources across registries but did not see a strong correlation between reporting sources and registry completeness measures. High levels of cases reported by hospitals suggest some cases might have been missed, although this could simply reflect the state's healthcare system. Because of Dr. Boscoe's findings, participants questioned the utility of reporting source as a covariate. Reporting source might have more effect on the model if categories were collapsed. Participants recommended including reporting source in models, but it might be dropped in stepwise analysis because of low variation. Reporting source might be useful in predicting the distribution of delayed cases reported

at different points in time after the submission. The New York registry might serve as useful case study of the relationship between reporting source and completeness.

Dr. Boscoe described the distribution of completeness rates if the U.S. average rather than SEER11 was the incidence reference. He explained that outliers with completeness rates well above the average would make registries with below-average rates less likely to be certified because they would move farther from the average.

## **SEER Internal Method**

*Huann-Sheng Chen*

Dr. Chen discussed the SEER Internal Method, which can predict case counts up to 11 years. The model assumes that delay is constant, but the expectation is that delayed reporting will decrease. SEER examines changes in delay by comparing delay for earlier and later years. If delay improves, separate analyses are run for years with less delay. Improvements in delay for smaller registries might not be identified because of insufficient power to measure the change. The new SEER method uses Joinpoint to analyze trends unlike the older linear SEER method. The year that SEER switched to the new method, analysts compared registry rates using both methods. SEER has modified the method based on feedback from the registries. A weakness of the SEER Method is that registries with consistently poor completeness would not be identified because each year's completeness rates are compared to the registry's own history of completeness. Over time poor completeness would become clear based on information from DCs, but this would take too long. For most registries, delay is improving or remaining stable. On average, about three to four percent of cases are delayed at SEER registries.

Participants discussed whether to test the SEER method for all NAACCR registries. This method likely would inflate completeness for some registries. It would be informative to see the outliers on a scatter plot of SEER Method results for all registries. The SEER Method might be useful for examining delay patterns. For example, it is expected that small numbers of delayed cases are going to be received over time. A problem arises when a registry submits a large amount of delayed cases at one time. In these cases, Ms. Kohler would like registries to examine the delayed cases for reporting source and other factors that might explain the delay. Participants suggested presenting a measure of delay/timeliness separate from the completeness measure.

## **Naïve and Flow Methods**

*Frank Boscoe*

Dr. Boscoe discussed the Naïve Method, which uses only a few variables. This simple method might not work for every cancer site and every registry because of small cell sizes. Dr. Boscoe recommended including the Naïve Method in method comparison analyses, because correlation with other completeness measures might be informative.



A problem with the Naïve Method is that some cases in a specific diagnosis year will not fall neatly into any of the following four categories: (1) cancer captured by the registry and reported on the DC, (2) cancer not captured by the registry but reported on the DC, (3) cancer captured by the registry but not reported on the DC or no DC is available, and (4) cancer not captured by the registry and not reported on a DC. For example, some cancer deaths might have been diagnosed in another state and should not be in the registry. Participants discussed the possible effect of cancer patients who are diagnosed in one state and die in another state. Some “snowbird” states have agreements with registries in northern states. Participants also noted that the four categories might not be independent. The number in the fourth category likely is unverifiable.

The Other Methods group did not see the Flow Method as a feasible measure of completeness. This method, as published, depends on data items that are not collected or not collected well by NAACCR registries. Dr. Boscoe did not recommend including this method in the comparison analyses.

### Testing the Methods

Participants recommended testing different models using 2015 data with different sets of covariates, with and without random effects, at the state and county level. Recommended covariates included survival and stage distribution. They recommended testing and comparing different variations of the NAACCR Method, the new SEER Method, and modeling methods. Participants recommended using data from all NAACCR registries, not just the certified registries. An alternative for testing purposes would be to use SEER data only. IMS will perform the testing of most methods.

Participants discussed the timetable for the analyses. They recommended a monthly check in to provide updates and share and resolve problems together. The deadline for completing testing of the methods is the end of July 2019, but there is an opportunity for a no-cost extension. The Canadian model is low priority and likely will take more than six months to develop and test. Ms. Kohler would like some analyses to be run before the NAACCR conference so that the results can be discussed at that meeting. The NAACCR conference is scheduled for June 9–13, 2019.

One task is comparing completeness estimates produced by the different methods, another is examining the ability of different methods to accurately estimate 1-year trends. Dr. Ward recommended a simple approach to estimating these trends: using 2-year estimates when they are received, and NAACCR has confidence in them. The question that needs to be answered is: “How well can they estimate rates and then trends based on 1-year NAACCR data?” Once NAACCR has an improved measure of completeness, the Association can examine the possibility of certifying 1-year data. In addition, if NAACCR plans to release 1-year incidence rates at some point, those rates will need to be produced earlier than 15 months after the diagnosis year. Participants asked about potential users of 1-year data. These data would be useful for identifying

sudden changes in cancer trends early, conducting certain kinds of research (especially on childhood cancer), and informing policy. A more realistic goal might be to have NAACCR 1-year data available on January 1 of the second year after diagnosis instead of April 15. SEER already has been able to estimate rates and produce accurate trends using 1-year data from the February submission. SEER still does not release a data file of the 1-year data because of the larger delay factor for these data. Instead, SEER releases preliminary delay-adjusted rates and trends based on the early submission on a website with many caveats. SEER is working to release these preliminary statistics earlier.

Dr. Feuer presented the 1-year delay modeling approach used for SEER18. He noted that delay factors need to be aggregated across registries for stability. Delay factors are generated for all cancer sites in the February submission, which are validated against the November submission. NAACCR has three years of validated 1-year data to date (diagnosis years 2013-2015). Dr. Feuer now is comparing NAACCR 1-year data to data from the December submissions for the respective years by cancer site. To be included in this analysis, registries had to be NAACCR certified for at least three of the four years. Dr. Feuer also set a completeness threshold for inclusion in the analysis. Participants recommended redoing these analyses using the four major cancer sites only. Once Dr. Feuer validates the 1-year data against the December submission, he might try the analysis using Joinpoint. Participants asked whether the 1-year data identified the change in prostate cancer incidence. If not, a more useful approach might be to use actual counts from the previous two years with Joinpoint to project incidence.

## Priority Actions

*Ann Marie Hill*

Ms. Hill led a discussion with the goal of prioritizing actions toward developing a new NAACCR completeness measure. She asked participants to categorize actions as either important or less important and as either short-term or long-term. Participants agreed that identifying an item as long-term means that the action can be completed after the NAACCR meeting. They also agreed that all analyses should be run on data from all NAACCR registries (certified and uncertified) for diagnosis years 2013 and 2015.

### *Important/Short Term*

#### NAACCR Method

- Update the workbook with the new NAACCR incidence data and mortality data.
  - Include non-certified registry data.
  - Include historical delay adjustment factors.
  - Possibly include cases received since the last submission date.
  - Add SEER mortality data.
- Run the NAACCR Method using the revised workbook and assess results.
- Determine permutations of the NAACCR model.

- Consider Dr. Das' approach that adjusts for case fatality. SEER mortality should be examined as a denominator.
- Include race/ethnicity and gender in the model.
- Calculate registry-specific case fatality ratios.
- Test using 5-year U.S. incidence rates, SEER11 incidence rates, and SEER18 incidence rates with the associated mortality rates.
- Determine geographic areas to test.
- Compare age-adjusted to age-specific survival modeling.
  - Consult with Dr. Zhu on this effort.

#### Modeling Methods

- Obtain the ACS model and data for test years.
  - Test the model with specific cancers sites using the NAACCR workbook structure.

#### Other Methods

- Run the old linear SEER Data Completeness Estimation method in SEER\*Edits using 10 years of data in the NAACCR workbook.
- Create scatter plots to compare Naïve, SEER, and current ACS methods.

### *Important/Long Term*

#### NAACCR Method

- Run 1-year delay adjustment rates and trends. Test the effect of delay on the IMRR using the last year of data.
  - Decide what diagnosis years to include in the IMRR.
- Estimate completeness for the southwest region only, using regional incidence and mortality as the reference.

#### Modeling Methods

- Run the ACS model for each cancer site in the NAACCR workbook.
  - Decide whether to run state- or county-level data for each registry.
  - Use the Black/White/Other race categories initially. Then add other races/ethnicities (Hispanics are high priority).
  - Run with and without random effects.
  - Add covariates such as data source, percent foreign born, stage distribution, case fatality ratio, and survival. The last three variables may be run by race/ethnicity.
  - Determine how to add a delay factor.
  - Validate model.

#### Other Methods

- Redo comparisons of NAACCR 1-year data for diagnosis years 2015-2018 to data from the December submissions for the respective years by the four major cancer sites.
- Run the current and new SEER Data Completeness Estimation methods in SEER\*Edits using the NAACCR workbook data (10 years of data). Create scatter plots.
  - Assemble data for each method.
  - Determine the criteria.
  - Obtain delay factors.

- Apply the new SEER Internal Joinpoint Method to every NAACCR registry. Use the 11-year observed count to calculate completeness.
- Examine the cause of delayed cases qualitatively (Where do they come from? What cancer sites? How could they be obtained sooner?).
  - Identify the data set with the tumor record numbers (NPCR or NAACCR?).

### *Less important/short term*

#### Other Methods

- Run the Naive Method. Use all NAACCR registry data.
  - Test the relationship between reporting source and completeness.
  - Use underlying CoD.

### *Less important/long term*

- Develop a Canadian model in collaboration with Canadian registrars.
- Create a toolbox for the new model.

## Next Steps

Participants agreed to monitor progress toward completing each of the prioritized tasks. They agreed to conduct two calls before the NAACCR meeting to provide updates on progress and troubleshoot. The first call was scheduled for May 2, 2019 (1:30–3:00 p.m. EDT) and the second for May 31 (1:00–2:30 p.m. EDT). NAACCR also will notify stakeholders regarding model changes in advance of implementing the final model, particularly if some registries might experience a decline in completeness as a result.

## Registry Certification Standards

The primary goal of this meeting was to examine methods for measuring completeness, but standards and the interpretation of completeness estimates were frequent discussion topics. Dr. Kohler emphasized the need to differentiate between the estimate of completeness and the interpretation of that estimate. For example, if 100 percent completeness is expected 11 years after the diagnosis year, 95 percent might be an appropriate standard at two years. In addition to completeness, registry data quality can be evaluated based on reporting delays or the proportion of DCOs. SEER notes these criteria in its data quality profile. Participants agreed that another important task, after developing the completeness measure, is to identify methods for diagnosing the reasons for delay. They agreed that guidelines and best practices for improving completeness would be useful.

The purpose of standard setting and measuring data quality and completeness is to help registries improve. Almost all registries now have annual data submissions that are sufficiently complete to be used in research, so certification standards might no longer be necessary. Completeness rates could serve simply as information to help registries improve. Data quality metrics also are important for motivating registries to improve and to assure data users that the data meet their needs. If standards are eliminated, it would

be important to monitor trends in completeness and other data quality measures at each registry. Metrics also can help identify important changes in the registry area (demographic, environmental, etc.).

Many states with low completeness rates have large Hispanic populations, and the number of reported cancer cases for Hispanics have been lower than expected in these states. Hispanic populations, however, historically have had low cancer rates. Cancer mortality in this population, however, tends to be higher than among non-Hispanic Whites. These trends might be explained by the younger average age of most Hispanic populations, low screening rates, and lower access and utilization of the healthcare system. Both Native American and Hispanic populations have lower screening rates. Lower screening and healthcare utilization rates are particularly low among low-SES and foreign-born populations. Another possible problem is racial misclassification on DCs, particularly among Native Americans.

In California, large proportions of cases now are covered by ePath, and a new law will increase reporting from smaller laboratories, so completeness might improve in California registries. The law took effect in January 2019, but the implementation of the new law will take time. Small laboratories already are contacting the Los Angeles registry. Many of these laboratories only send PDFs currently, and registries do not have the resources to manually abstract from the PDFs. Participants added that cases missed as a result of non-reporting likely are captured through DCs.

Data runs will help reveal possible causes of lower data completeness rates at some registries. Participants discussed other approaches for evaluating the reasons for low data completeness at registries that have taken all possible steps to ensure completeness. Participants suggested hiring an outside evaluator to examine registry practices and other factors, such as different cancer patterns at locations struggling with low completeness rates.

Participants recommended examining cases initiated by DCs as an indicator of what registries might be missing. For example, many registries initiate follow back if cancer is mentioned as any CoD on the DC. This practice identifies several thousand missing cases. Participants also suggested examining in- and out-migration in states and its effect on mortality rates and completeness.

The number of duplicate cases across state registries might be significant. States with large numbers of cases that were diagnosed in other states but who died in their state could negatively affect completeness, particularly in states with smaller populations. Registries currently send cases to the National Death Index for linkage, and this linkage allows them to identify cases who died in another state. Registries generally do not contact the other state registry, however, to inform them that they have a DCO in their file that links back to a case in a different state registry. The Virtual Pooled Registry (VPR) will allow the identification of duplicate cancer cases across registries. DCO cases should decline once registries start using the VPR. Prior to submitting their data,

registries could use the VPR to determine what proportion of their cancer deaths were incident cases in other states. The VPR might be ready before the December 2019 submission.

## Appendix E: Assessment Report

### Purpose

A structured assessment tool was designed and distributed to 22 participating registries to evaluate both general registry operations and 12-month timeliness, specifically. The following areas were included: electronic reporting, staffing, rapid reporting practices, external forces impacting timeliness, software tools and other miscellaneous topics.

### Methods

Twenty-two state registries were asked to complete a 27-question assessment of their registry operations. The registries were chosen to represent a geographical cross-section of the country and a range of 12-month completeness estimates for cases diagnosed between 2010 and 2016 as submitted to NPCR. Eight of the registries met the 90% completeness standard at least five of the seven years and were classified as “usually or always” meeting the standard, nine met the standard two or fewer times and were classified as “rarely or never” meeting the standard, and five met the standard four or five times and were classified as “sometimes” meeting the standard.<sup>1</sup> None of the registries had difficulty meeting the 24-month NAACCR standard: 20 were certified gold and two silver for cases diagnosed in 2016.

The questions in the assessment, developed in consultation with NPCR and NACDD, covered case volume, source types, software, electronic reporting, staffing, data use, and relevant state laws. A primary aim of the assessment was to see whether any of the responses to the questions correlated with 12-month completeness.

Each of the registries is currently being funded by NPCR; five also received funding from SEER for the data years of interest, and three registries have more recently begun receiving funding from SEER. There was no relationship between SEER funding and completeness; SEER-funded registries were represented in each of the completeness categories.

The registries covered a balanced range of sizes, from those with fewer than 20 thousand incident cases per year to those with more than 100 thousand (Figure 1), and they used a range of database management systems: six used Registry Plus alone, five SEER\*DMS alone, three Rocky Mountain alone, two an in-house system alone, and five used multiple data management systems (DMS). Note that registries answered this question based on the DMS in use at the time of the assessment (spring 2019), which may have differed from the one used when processing cases diagnosed in 2010 to 2016.

### Summary

The most remarkable finding from the assessment is that not a single question was correlated with 12-month completeness. Every practice or behavior that might be

thought to result in better completeness was seen in each of the groups in roughly equal proportions. For example, it might be expected that registries having a higher proportion of cases reported from Commission on Cancer-approved facilities would correlate with higher 12-month completeness. However, among the 10 registries with at least 75% of their cases reported this way, three were in the “rarely or never” group, three in the “sometimes” group, and four in the “usually or always” group. For another example, it might be expected that the ability to process modified or updated records to existing cases is an asset for complete reporting. But of the five registries that responded they lacked this capability, two were in the “rarely or never” group, one in the “sometimes” group, and two in the “usually or always” group. It seems that each registry has evolved its own workflow practices that are informed by a unique mix of experience, working relationships with reporting facilities, and selective use of technological assistance that allow them to reach a similar 24-month endpoint, if not necessarily the same 12-month endpoint. It does not appear that registry metrics can predict the quality of a 12-month data submission. The following paragraphs describe the responses to each of the other questions.

### **Electronic Reporting**

Registries were asked the percentage of reports from hospitals, pathology labs, physician offices, and non-hospital facilities that were submitted electronically. Hospital reports were nearly all electronic across the board, with only two registries reporting values below 98%. Pathology reports, in contrast, varied widely, with half the registries receiving at least 90% of their pathology reports electronically and five others receiving almost no electronic path reports. This was uncorrelated with completeness; the 11 registries with at least 90% electronic pathology reporting were evenly drawn from the three completeness categories, and two registries managed high 12-month completeness despite negligible electronic pathology reporting (Figure 2). A similar pattern was found with physician reporting and non-hospital reporting: in roughly half the registries, at least 90% of the reporting was electronic, in the other half, electronic reporting was below 5%, with just a handful of registries falling in between, and no correlation with completeness. A follow-up question revealed that most registries see occasional paper reports (Figure 3), but again with no correlation with completeness.

### **Staffing**

Registries were asked to provide the number and type of employees and how many of them were certified tumor registrars (CTRs). Registries were categorized as high, medium and low-CTR registries based on the percentage of management and operations staff who were CTRs. This again was uncorrelated with completeness (Figure 4): at least one registry was to be found in every cell of the table. Registries were asked if they felt that additional staffing would be needed to meet the 12-month standard in the future. 17 of 22 answered yes, including five that had already been usually or always meeting the standard. This was not necessarily a contradiction as the comments associated with these answers revealed that 2019 staffing levels, reflecting



the time the question was asked, were lower than those from the past years on which the completeness measurements were based.

There was a positive correlation between staffing levels and case volume (Figure 5), as would be expected, though the form of the linear relationship is unclear (a logarithm is shown, but the fit is not especially good). Here again, there was no relationship with 12-month completeness. For example, there was a registry with 10 FTEs and nearly 70,000 cases per year that usually or always had met the 12-month standard, and a registry with 10 FTEs and fewer than 30,000 cases per year that rarely or never had met the standard. There are other such examples of red and green points that align on one or both of the axes.

### **Cancer Sites with More Rapid Processing**

Registries were asked if there were any cancer sites they found could be reported and processed more rapidly than others. They were asked specifically about breast, colorectal, lung, prostate, melanoma, and pediatric cancers. In contrast to most of the questions, this was one that could be answered empirically using past NAACCR data submissions. Here, the 12-month data for diagnosis year 2016 from 49 U.S. registries were compared with the same data submitted a year later. The percentage of the cases reported in the second year was computed for each cancer site; the higher this percentage, the slower the reporting. The results are presented in Figure 6.

Overall, 80% of the cases were reported in the first year and 20% in the second year. Colorectal, breast, and pediatric cancers were below this average, indicating more timely reporting; prostate and melanoma were above, indicating less timely reporting. Lung was similar to all sites combined. Uterine and chronic lymphocytic leukemia were also labeled to highlight them as outliers. There was little variation between registries in the relative order of the sites. These results are not consistent with the answers the registries provided to this question – only four thought that breast cancers were reported more rapidly and nine thought that melanoma cases were reported more rapidly.

### **External Forces That Influence Timeliness**

Registries were asked if there were any external forces that influenced timeliness of reporting, either positively or negatively. Specifically, they were asked about the Rapid Quality Reporting System (RQRS), laws and rules, fines and penalties, outsourcing and contracting, and interstate data exchange. The results are summarized in Figure 7. Overall, registries found laws and rules to positively influence timeliness, with a weaker positive sentiment for most of the other categories. The results for outsourcing and contracting are interesting because not only was opinion divided, it was mainly divided along completeness lines. Registries rarely or never meeting the 12-month completeness standard found that outsourcing and contracting exerted a positive influence, while those usually or always meeting the standard found it to exert a

negative influence. It appears that for the incomplete registries the sentiment was that they would have fared even worse were it not for the outsourcing, while for the complete registries the sentiment seemed to be that outsourcing tended to slow down their operations.

## Software Tools

Registries were asked which of 9 CDC software programs and tools they used, and to rate them on a scale of 1 to 5. All products received a mean rating between 3.0 and 3.8, with wide ranges -each had both multiple satisfied and multiple unsatisfied users (Figure 8). Registries were also asked for suggestions on improving the software, with these ideas mentioned by more than one registry:

- Abstract Plus: two registries would like to be able to customize the software.
- CDC/NPCR edits: two registries would like to see more thorough testing of edits; two others would like more timely metafiles.
- CRS+/TLC+: two votes each for enhanced functionality related to automated consolidation and to patient matching.
- eMaRC+: two votes each for the ability to identify duplicates, greater editing capabilities, and for more timely updates.
- Link Plus: many registries noted that have switched or will soon be switching to Match\*Pro.
- Online Help: six registries noted the content was outdated and not useable as a result.
- TNM Staging API: Multiple registries noted problems with timeliness.

## Miscellaneous

This section summarizes findings from questions that did not fit elsewhere or that generated similar responses from all registries.

- Nearly all registries responded that reporting was required within 6 months, aside from one that responded 3 to 10 months, depending on the source, and one that responded within 15 days.
- All registries responded that at least 95% of their cases were reported from within-state.
- All or nearly all registries responded that their data are used for cancer control (22 of 22), research and clinical studies (21), program planning evaluation (21), state reporting (20), health communication (19) and health care delivery (15).
- Six states reported that they have a law mandating rapid reporting of pathology reports, but these laws were typically passed recently, and so after the data years under evaluation.

- Equal numbers of registries responded that they report their 12-month data in either November or January. While it might seem the January reporters would benefit from the additional two months of processing time, there was no correlation between this and 12-month completeness.

<sup>1</sup> One registry that met the standard five of seven years was classified in the “usually or always” group because it met the standard in the four most recent years. Three registries that met the standard five of seven years were classified as “sometimes” meeting the standard because one or more of the missed years were in the four most recent years. Placing all four of these registries into the “sometimes” category would not have meaningfully impacted the findings.

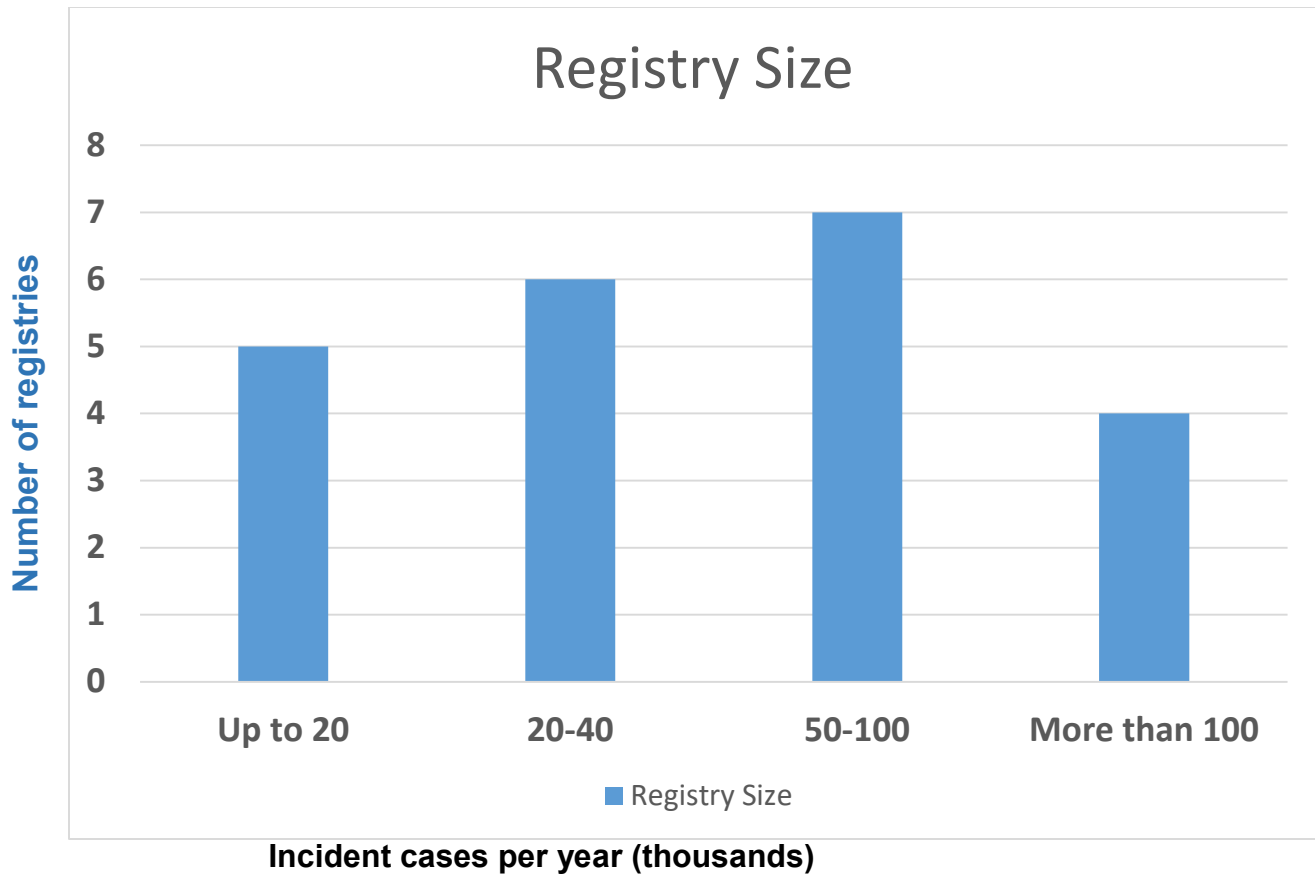


Figure 1. Range of registry sizes

## Percentage of pathology reports received electronically

12-month completeness standard	0%-2%	20%-50%	70%-82%	90% and above
Never or rarely	3	1	1	4
Sometimes	0	0	1	4
Usually or always	2	2	1	3
<b>TOTAL</b>	<b>5</b>	<b>3</b>	<b>3</b>	<b>11</b>

*Figure 2. Number of registries at various levels of electronic pathology reporting, 2017.*

### Percentage of Source Records Received on Paper

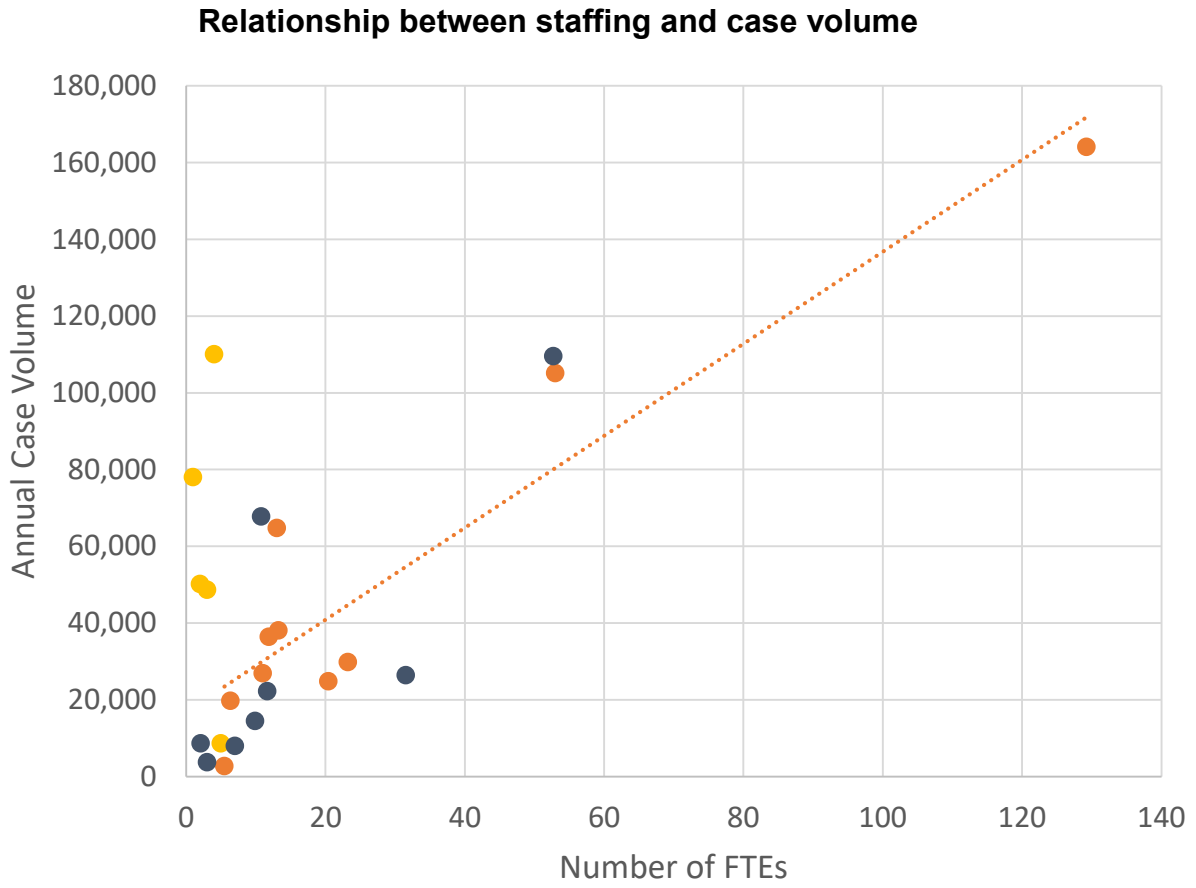
12-month completeness standard	0%	1%-6%	10%-18%
Never or rarely	3	5	1
Sometimes	1	3	1
Usually or always	3	2	3
<b>TOTAL</b>	<b>7</b>	<b>10</b>	<b>5</b>

*Figure 3. Number of registries at various levels of paper reporting, 2017.*

## Percentage of Management and Operations Staff Who are CTRs

12-month completeness standard	7%-49%	61%-73%	78%-100%
Never or rarely	4	3	2
Sometimes	1	2	2
Usually or always	3	2	2
<b>TOTAL</b>	<b>8</b>	<b>7</b>	<b>6</b>

Figure 4. Number of registries at various staffing levels, 2019.





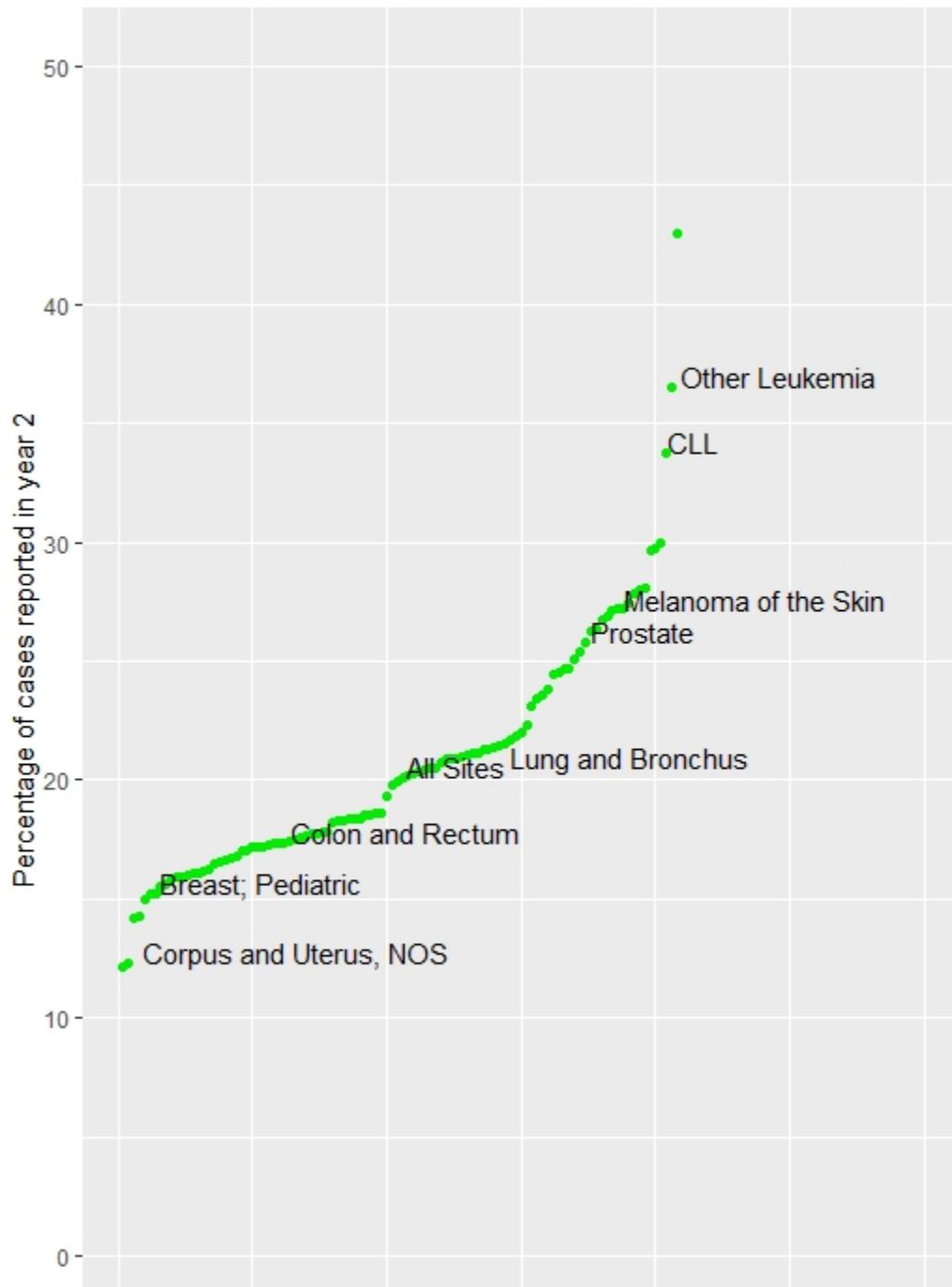


Figure 6. For cases reported within 2 years of diagnosis, the percentage of cases reported in year 2. Diagnosis year 2016, 49 U.S. registries.

	Positive	Negative	Both positive and negative	No response
RQRS	7	3	0	10
Laws and rules	17	2	1	2
Fines and penalties	7	4	0	11
Outsourcing and contracting	6	7	2	7
Interstate data exchange	9	2	0	11

*Figure 7. Forces exerting positive and negative influences on timeliness*

Software tool	Number of users	Mean Rating (scale 1-5)	Range of Ratings
Abstract Plus	11	3.4	1-5
CDRS+/TLC+	7	3.3	1-4
Link Plus	19	3.5	2-5
Prep Plus	8	3.8	2-5
Web Plus	13	3.6	1-5
eMaRC Plus	17	3.1	1-5
XML Exchange Plus	0	-	-
Online Help	9	3.0	1-5
Utility Programs	7	3.7	2-5

*Figure 8. Evaluation of CDC software programs and tools*

## Appendix F: Interview Report

### Introduction

The second phase of the project involved a series of expert interviews that were conducted by project consultants with expert background in central registry operations over a two-week period.

### Methods

Twenty-two states were asked to participate in individual interviews conducted by project consultants over a three-week time period (See appendix 1). All states were provided with the same 13 interview questions in advance and each interview lasted anywhere from 30-60 minutes (See appendix 2). States were categorized by how consistently they met the 12-month National Program of Cancer Registries (NPCR) standard of 90 percent case completeness with eight states usually or always meeting, nine states rarely or never meeting, and five states sometimes meeting the standard.

State responses were both transcribed by project consultants and recorded. Results were tabulated and aggregated.

### Findings and Results

#### Funding Sources

When asked about funding sources, 21 of 22 states shared they received state or university funding in addition to NPCR federal funds. Block grants or earned funds from conducting research projects were also cited as sources of additional funding. Eleven states indicated they from a single person at 50% effort to multiple team members at 100% effort. In addition to dedicated staff, six of these states also had additional IT support at the university or state agency level. Most of the university or agency level IT support consisted of central database and server housing and support. Eleven other states indicated they had no IT staff embedded within their registry and one state had contracted out all IT services. Almost all States without embedded IT indicated their IT services were either centralized at the agency/university or state level. Four states said IT issues were difficult to resolve due to: 1) no embedded IT staff with knowledge of cancer registry software or needs, 2) the necessity of getting several groups together from different areas/agencies to work on issues, or 3) because the cancer registry was not a priority for IT services.

#### Registry Technical Assistance Needs

States identified several technical assistance needs related to software improvements, staffing, education and training, outreach to medical associations and the Commission on Cancer (CoC) for its assistance with physician and facility reporting, and Veterans Affairs (VA) reporting. Specifically, states expressed a need for more timely release of

software and for the addition of management reports or dashboards to CRS Plus software to better monitor completeness, timeliness and data quality. Also mentioned were improvements in response time from Registry Plus support staff, less need for state IT assistance, and training on software use. States requested development of new software tools to assist in re-abstraction audits including calculation of errors and a way to capture clinically diagnosed cases from imaging. States indicated a need for improvements in the eMaRC Plus software to manage volume and eliminate the need for manual review.

States stressed a need for assistance in recruitment, retention, and training of new registry staff, specifically Certified Tumor Registrars (CTR). States also indicated a need for development of basic training for new cancer reporters at both the central and facility level, CTR recruitment materials or presentations, generation of sample cases for training new CTRs, and webinars on central registry functions and operational best practices.

States requested technical assistance in facilitating VA reporting as many are currently not receiving cases and are unable even to identify VA staff for assistance. Suggestions were made for the NPCR to work with the CoC to encourage hospital reporting of non-analytic cases and make physician reporting a requirement for accreditation. Another suggestion requested the NPCR work with medical associations to facilitate and explain the importance of physician reporting to state cancer registries. One state suggested developing a “mini NAACCR record” for non-hospital reporters that would collect minimal data items with a corresponding edit set. Another state suggested obtaining Accurant for all states or supplying roving linkers as needed. Finally, states expressed a need to be able to exchange ideas, share processes, and learn how other states do more with less.

## **Barriers and Challenges to Completeness**

Since States currently have limited resources both in funding and staff, emphasizing timeliness means limited completeness.

- *One state said, “You can’t have both – timeliness and completeness. If you want both, then you have to move to some manner of a two-tiered system”*
- *Another state said, “You can have timeliness or completeness, but you can’t have both.”*
- *A third state said, “it’s hard to meet benchmarks on 12-month data when you’re focusing on benchmarks for 24-month data.”*
- *Other states said, “Central registries touching cases multiple times is not efficient” and “double touching an abstract isn’t feasible or worth it.”*

States identified a ‘disconnect’ between the 6-month timely reporting standard and the actual time needed for patients to complete first course treatment. Reporting facilities will send cases without fully capturing first course treatment in order to submit cases to the central registry in a timely manner. Most current central registry software systems

are not able to incorporate modified submission records without manual intervention from central registry staff. Central registries do not have the monetary or staffing resources to move to a two-tiered system in which cases are manually processed twice – once upon initial receipt and secondly upon receipt of modified or updated information.

State registries identified a variety of barriers and challenges to completeness. Responses for this question (n=10) cited a lack of CTRs and other registry staff, retirements or funding cuts resulting in loss of registry staff, and staff turnover in reporting facilities being most common. States also noted that the constant staff turnover at reporting facilities resulted in less knowledgeable and experienced personnel requiring increased education and training by central registry staff.

Constant data changes, non-adherence to implementation timelines, and delayed software were also considered major challenges by nine registries.

- ***One state said, “Constant changes and reductions in funding for training at both hospitals and central registries have caused registrars to feel they are unable to master any of the changes, resulting in registrar fatigue.”***

Other barriers mentioned by states included non-compliant facility reporting (n=5), issues with VA and military reporting (n=3), interstate data exchange delays (n=1), and outpatient reporting, small facility/physician reporting or reporting clinically diagnosed cases (n=7).

Three states said they had facilities still reporting on paper which was less efficient and more labor intensive for their staffs. Three states mentioned their reporting laws had no teeth for enforcement of reporting requirements or they contained a provision whereby, if the facility did not report, the state could abstract the cases and charge the facility for that work resulting in a shift of workload to the state. Issues with ePath were barriers to completeness for some states and included laboratories changing software, not reporting cases, and the need for more labs to begin to utilize ePath. States indicated varying negative and positive influences of the CoC Rapid Quality Reporting System on 12-month timeliness.

When states were asked what their single biggest roadblock is to timely reporting, fifteen states (68%) identified staffing issues both in reporting facilities and at the central registry. Lack of qualified CTR staff in reporting facilities, constant staff turnover, and the use of consultants for reporting can result in lack of timeliness and poorer quality data as central registries have to spend more time performing QA/QC activities, clearing edits, and processing data. Competing tasks for non-CTR staff at smaller facilities and a complex collected data set mean more errors for central registry staff to correct and an increased need for additional education and training. Central registries have fewer staff due to retirements and budget cuts and have a difficult time recruiting and retaining CTRs who are in high demand among hospital registries and consulting companies. This, coupled with the current CTR shortage and desire for remote work positions,

means central registries have difficulty hiring. Additionally, new staff need time for training and development and do not have the skill set to reliably take over tasks that someone with 25 years of experience can handle with ease.

Frequent data changes, delayed 2018 changes, and the complexity of collected data were also cited as a major roadblock, but by fewer states (n=5). Delayed interstate data exchange, the inability to process modified records, and limited or no auto-consolidation were mentioned by a few states as their primary roadblock.

### **Strategies to Improve Timeliness**

States cited several methods to improve timely reporting from their facilities. Consistently tracking facility timeliness and data quality and providing feedback on a monthly, quarterly or semi-annual basis were cited by fifteen states as a primary strategy. Some states utilize an end-of-the-reporting-year-close-out process which requires facilities to report their current status by an established deadline. Three states present timeliness awards to reporting facilities that meet central registry established benchmarks. Seven states also mentioned developing good relationships with reporting facilities and view that established relationship as enormously influential on data timeliness. The establishment of a data submission policy or protocol with a defined timeline and published calendar was one state's primary method. Other methods mentioned included making a variety of reporting methods available, penalties and fines, and requiring a special additional annual submission from hospitals for any case touched in the last 18 months.

States were also asked about strategies they utilize to assist facilities with reporting. States mentioned providing training and education to reporting facilities and making available technical assistance both in case abstraction and software support. Some states provide customized software with limited data items or defaulted values. This, however, is limited mostly to physician reporting. Many states use electronic reporting and are actively reducing paper submissions. Several states mentioned working with their state professional organizations to facilitate training and develop positive relationships with cancer data reporters

### **ePath**

ePath is widely used by most states, with nineteen states (86%) having at least some ePath reporting. All nineteen states are receiving ePath reports before receiving hospital abstracts with sixteen states (84%) waiting to process the majority of the ePath cases until after they receive the hospital abstract. Three states acknowledge processing ePath reports as they receive them. States wait to process ePath reports after receiving the hospital abstract for several reasons:

- ePath reports are not complete abstracts and, if loaded as-is to the central registry database, may generate a significant number of edits that must then be manually resolved;

- While States receive large numbers of ePath reports, not all are reportable cases. ePath software does have some ability to identify reportable cases, but the reality is many of the received reports must be reviewed for reportability by registry staff. One large state indicated about half of the ePath reports they receive are not reportable cases;
- Central registry software lacks the capability to consolidate effectively a pathology report with an incoming full abstract from a hospital or facility reporting source. Instead of incorporating new, more specific data from the facility abstract, the software keeps the pathology information in place because it was the first to be reported. But in order to preserve the more specific and complete data, the case must be manually consolidated and all information from the incoming facility abstract must be manually transferred. Some ePath reports are processed as they are received if the state suspects another abstract will not come in from a more complete reporting source like a hospital (e.g., cases of melanoma of the skin).

ePath is utilized by a few states as part of their case finding activities with reporting facilities. When asked about what core data items are consistently received from ePath reports, respondents cited data items like name, gender, date of birth, primary site, and histology/behavior, while race, ethnicity, staging, and treatment were often not available. States indicated that eMaRC Plus needed to be far more accurate in identifying reportability and auto-coding available data items, adding, there was a significant need for less manual processing and more interoperability between the various software in the Registry Plus suite.

### **Automation**

States were asked what processes that currently were not automated that could be. Suggestions included data consolidation at the data item level, patient level, and tumor level. Also included were improved reportability screening with automatic coding of ePath cases in eMaRC Plus, and automatic coding of DCO cases from the death certificate. Two states identified as important production and automation of management reports that could track facility submissions, data timeliness and quality, and staff productivity. The development of a more streamlined process, allowing the Registry Plus software products to talk more readily to each other without manually importing and exporting files between them, was also requested. Most participants indicated that manual consolidation is extremely labor intensive and can no longer be sustained.

Most states utilize some limited auto-consolidation of cases combined with manual review, but only two states reported being almost fully automated, with less than 10 percent of cases requiring manual review. Two states do not use any auto-consolidation at all. One state shared their definition of auto-consolidation saying, “something that



requires no human touch with complex logic” and noted that when automation is used, it can always be evaluated, followed back, and revised as needed.

Limited auto-consolidation used by most states consisted of person-level and tumor-level matching of incoming records to those already housed on the central registry database. Additionally, there is some data level auto-consolidation, but it is mostly limited to taking known values over unknown values for particular data items like race, Social Security number, place of birth, date of last contact, and vital status. Several states using different central registry software were concerned about overriding information in the consolidated record with newly received information in newly submitted abstracts and felt this should be addressed when designing and implementing auto-consolidation rules; however, all states expressed an interest in implementing more auto-consolidation within their software systems. Surveillance, Epidemiology, and End Results (SEER) states indicated that the SEER registries have convened a workgroup to develop standardized auto-consolidation rules to be implemented within the SEER\*DMS software.

Lack of standardized auto-consolidation rules and software able to handle modified records leads to more manual review and processing by central registry staff, resulting in diminished timeliness and data quality. It also means central registry staff has less time for other activities beneficial to both central registry operations and cancer surveillance research. Almost all states indicated a desire for more automation in their registries.

## Summary

States expressed concern about a number of issues affecting central registries which directly impact data timeliness, completeness, and quality. Regardless of whether or not they met the 90 percent timeliness standard, almost all states cited staffing deficiencies, within both the central registry and at reporting facilities, as major barriers to timeliness. Constant changes to data collection requirements, coding instructions, edits, and delayed software availability were also cited by many registries as significant barriers to producing more timely data. Software limitations and the inability to apply auto-consolidation rules to decrease manual workload have additional negative consequences. While ePath is employed by almost all central registries, most process these partial reports at a later time in the hopes of first receiving a complete abstract from a hospital reporting source. This intentional delay is due, in part, to the limitations of current registry software which cannot process partial reports or auto-consolidate data without manual review by registry staff.

States have developed significant strategies for improving and maintaining timeliness. Developing and nurturing relationships between central registries and reporting facilities were often cited as beneficial. States spoke about establishing reporting expectations, goals, and timelines for reporting facilities or providing positive feedback by way of awards for facility-specific reports. While negative penalties were also discussed, states

indicated a preference for positive methods to encourage and support cancer reporting as more effective in strengthening reporting facility relationships in most situations.

Finally, states were eager to participate in the interview component, offering candid information about, and insights into, challenges to registry operations and data acquisition. Participants welcomed and appreciated the opportunity to share their perspectives and experiences. Their willingness to share not only their successes but their failures made the interview component informative and valuable specifically to this project and more generally to the cancer surveillance community as a whole.

## Appendix 1: List of Participating States for Expert Interviews

Alaska Cancer Registry  
California Cancer Registry  
Cancer Data Registry of Idaho  
Colorado Central Cancer Registry  
Florida Cancer Data System  
Georgia Comprehensive Cancer Registry  
Illinois State Cancer Registry  
Kansas Cancer Registry  
Kentucky Cancer Registry  
Louisiana Tumor Registry  
Maine Cancer Registry  
Massachusetts Cancer Registry  
Minnesota Cancer Surveillance System  
New Jersey State Cancer Registry  
New York State Cancer Registry  
North Dakota Statewide Cancer Registry  
Ohio Cancer Incidence Surveillance System  
Oregon State Cancer Registry  
Pennsylvania Cancer Registry  
South Carolina Central Cancer Registry  
Texas Cancer Registry  
Virginia Cancer Registry

## Appendix 2: NACDD/NAACCR Project Interview Questions

- 1) Besides support from CDC and not including NCI, does the program have state support or support from their organization (e.g., Funds, staffing, etc.), or other sources (specify source)?
- 2) What are the current education and training needs of NPCR registries? As it pertains to 2018 changes, 12-month timeliness, etc.?
- 3) What are your registries technical assistance needs with respect to cancer registry management, operations?
- 4) What are the barriers or challenges programs face with respect to CCR data completeness?
- 5) What strategies do you use to improve the timeliness of your data?
- 6) What is the biggest roadblock to more timely reporting?
- 7) What is your strategy to enable hospitals, doctors, and others to report faster with more complete information?
- 8) Do you use ePath? If so, have you found it useful for timeliness?
- 9) Does it come in before hospital abstracts or afterwards?
- 10) Do you process ePath reports before or after hospital abstracts?
- 11) Which of the core early data items does your ePath provide? (Synoptic versus narrative reports)

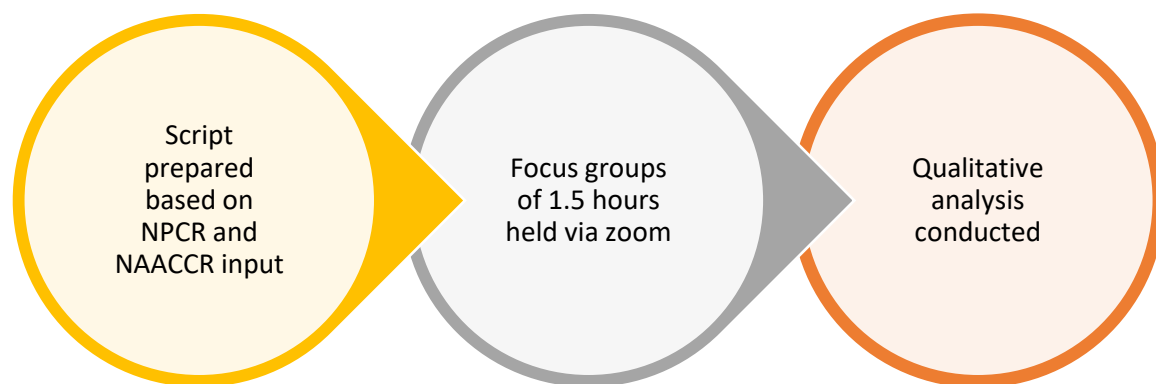
<input type="checkbox"/> primary site	<input type="checkbox"/> date of diagnosis
<input type="checkbox"/> name	<input type="checkbox"/> age at diagnosis
<input type="checkbox"/> gender	<input type="checkbox"/> stage at diagnosis
<input type="checkbox"/> race/ethnicity	<input type="checkbox"/> first course of treatment
<input type="checkbox"/> DOB	<input type="checkbox"/> Other
<input type="checkbox"/> histology/behavior	Please Specify _____
- 12) Does your registry use automated consolidation of case reports? If so, what system is used?
- 13) Are there central cancer registry manual processes that could be automated?
- 14) Is IT embedded within your registry or is it located elsewhere?
- 15) Registry reimbursement comments: \_\_\_\_\_

## Appendix G: Focus Group Report

### Introduction

Three focus groups were held over a one-week period for central cancer registries that fell into the following categories: usually or always meets NPCR 12-month timeliness requirement, rarely or never meets 12-month timeliness requirement, and sometimes meets 12-month timeliness requirement. A facilitator's script was developed based on questions from NPCR staff, Registry Directors and NAACCR staff. Zoom meetings were used for all focus groups and a content analysis of key concepts around each question was undertaken and results organized into themes with recommendations.

*Figure 1. Focus Group Process*



This report highlights the findings of these focus groups conducted in April 2019, following standard qualitative analysis methodology. The findings of this report, in conjunction with the quantitative assessment and expert interviews, served as the background for an expert Summit where participants gathered for 2.5 days in Atlanta Georgia in early May 2019.

### Methods

The focus groups were conducted, using the cohort registries who usually or always met the NPCR 12-month data criteria, sometimes met the 12-month data criteria and rarely or never met the 12-month data criteria. Three states, Idaho, Maine and North Dakota were not available to participate in the focus groups (See appendix 1). A facilitator's guide was developed based on input from NPCR staff, central registry

directors, operational staff and NAACCR staff (See appendix 2). After feedback on the initial guide, the scope of the script was expanded to include overarching questions related to central cancer registry operations generally and 12-month data criteria specifically. General overarching topics included: staffing and training, resources, IT and software needs, automation and electronic reporting, technical assistance particularly around NPCR services, data usage along with factors that contributed to the overall success of central registry operations, and finally barriers and threats that interfered with central registry effectiveness. A second layer of questions focused specifically on factors preventing timeliness of 12-month data and potential best practices that might be adapted across all central registries, leading to improvement and more success in reaching 12-month criteria. A script was prepared for use across all focus groups and members were invited to participate using a 1.5 hour Zoom meeting format that allowed for recording and transcription of results (see attached script). Qualitative/content analysis processes were then applied across all focus groups. The n for participants was as follows:

- Participants from States that meet 12-month standards regularly (n=4 participants)
- Participants from States that sometime meet 12-month standards (n=7 participants)
- Participants that rarely meet 12-month standards (n=10 including 2 states represented by multiple participants)

## Findings and Results

There appeared to be little difference among the groups regarding any of the discussion points except for how registries rate themselves in comparison to the perfect central registry ideal. Groups who usually or always, or sometimes met the 12-month reporting standards rated themselves consistently higher than groups that rarely or never met the 12-month standards. There was also a slight difference in the number of barriers and in the critical need for more resources, identified by the latter group. Otherwise, there was consistency across all groups. As a result, major themes discussed below are representative across all groups.

### Qualities of a Successful Central Cancer Registry

A major theme among all registry groups was the qualities and characteristics that lend themselves to a high performing registry. These were broken down into two levels: Structure/ Resources and Cultural Qualities/Characteristics. A summary of the discussion surrounding “What is the perfect cancer registry” concluded with the following description:

***“Fully staffed with plenty of resources, strong IT support, complete, timely, 100% electronic reporting, automation that is reliable, physicians who report with timeliness and accuracy, time to do everything that needs doing and the ability to spin on a dime. Given the pressures on resources and changing environment, this does not exist anywhere today.”***

## Key Structure and Resources Important to a Successful Registry

The following structural and resource-focused themes were most commonly discussed across all participating registries and were deemed high priorities for success:

- *“Stable staff with comprehensive knowledge”*
- *“Experienced leadership with historical know how”*
- *“Completely electronic reporting”*
- *“Comprehensive reporting law with teeth”*
- *“Strong hospital and reporter relationships”*
- *“Location in a medical school/university and not a state department”*

## Organizational Culture and Characteristics

Discussions also addressed some of the characteristics, attitudes and the organizational culture that impacts a successful registry. These included the following:

- *“Be collaborative and build relationships”*
- *“Be flexible and embrace change”*
- *“Be willing to do what it takes to succeed”*
- *“Be prepared to think out of the box”*
- *“Be forward thinkers”*
- *“Be team players”*
- *“Be problem solvers”*
- *“Be priority setters”*

**Recommendation:** While the ideal central registry does not exist, increasing budgetary support, setting priorities based upon important operational needs, supporting registry best practices and promoting shared values across all central registries would contribute significantly to moving registries closer to this goal.

## Challenges Facing Central Cancer Registries

Staffing is the most commonly identified challenge facing registries today. It is viewed as a critical need with an urgency expressed by all groups. Generally, across registries, most staff are regarded as highly competent but rapidly are facing burnout because of the increasing size and complexity of the workload. Constant changes by standard setters are pushing a stressed system to the edge. Retirements and difficulty recruiting their replacements are putting additional pressure on most registries. This is especially problematic if succession planning is not in place, particularly when a long-standing staff member is replaced by someone with little to no direct experience and a high learning curve ahead of them. A critical shortage of CTRs is leaving both central registries and hospital registries below capacity to function effectively. The following comments verify this issue:

- *“Lack of CTRs is at a critical point. We post jobs and get 0 applicants.”*

- *“New recruitment, training and retention strategies for staff are essential.”*
- *“Staff is dedicated but they can simply not do anymore.”*
- *“Retirements and staff losses are serious concerns for us, and succession planning is essential.”*
- *“With less resources and loss of staff, we are just trying to keep our heads above water.”*
- *“Workload is unbelievable – it’s a huge burden.”*
- *“We are tired of all the changes.”*

**Recommendation:** Staffing is the most critical problem identified through focus groups, requiring significant effort and an infusion of resources to deal with the existing challenges. NPCR, NAACCR and other stakeholders should consider working collaboratively to address the CTR shortage and expand training for central registry staff.

### Auto-consolidation and IT Support

The need for standardized auto-consolidation processes, especially around abstracting, is viewed by all registries as an essential next step. The time and energy devoted to manual reporting and quality improvement have become counter-productive. E-Path reports are missing large amounts of information and require far too many corrective measures to be useful to the task. Non-hospital reporting is fraught with errors and its quality is often poor. Improved software and linkages are necessary to correct this situation.

At the same time, there is an administrative shift by states towards centralized IT services. Many central cancer registries housed within state government are dealing with centralized IT systems that only offer call centers and help desks that result in significant delays and require dealing with IT staff who have no registry experience. Even when funding for IT staff is provided in budgets, this staff becomes integrated into the central state system and essentially lost to the registries. This is leaving many programs with no IT support. In addition, delayed software- updates are retarding systems significantly. This, at a time, when more automation and electronic reporting are necessary. As such, auto-consolidation and software improvements with IT support included, are deemed as an urgent priority for registries.

- *“The workload, especially around fixing missing data in ePath reports, is simply not worth it.”*
- *“ePath reports have so much missing data that we do not have time to fix them.”*
- *“Unknown staging makes completeness and timeliness difficult.”*
- *“We need better software and it must be updated in a timelier manner.”*
- *“IT is centralized which means we reach a general call desk when we need help.”*



**Recommendation:** Auto-consolidation, improved software and IT support are critical needs if registries are to advance in completeness and timeliness. Registries urge NPCR to consider putting substantial effort and resources to resolving these issues.

## Hospitals and Other Reporting Sources

Central cancer registries are working tirelessly to meet their responsibilities and goals, however, many of the intervening problems appear to be outside of the registries' control. These are system wide issues that will require a concerted effort on the part of all cancer registry stakeholders to resolve. For example, the Commission on Cancer (CoC)-accredited hospitals are facing added reporting requirements that are forcing registrars to choose what reports to complete and what to put on back burners. According to central registry participants across different groups, some CoC accredited hospitals were making state reporting of cancer cases a lower priority.

Furthermore, as mergers and hospital systems grow, additional challenges are appearing. It becomes harder and harder to identify who is the reporting agent for a system. Relationships are less stable and reliance on personal contacts is declining. Hospital networks often cross state lines so jurisdiction becomes challenging. Non-hospital reporters are growing in number and difficult to identify and locate. The quality of their reporting is suspect. Often, clerks or office staff with no training are completing case reports. Missing data and follow-up are required by central cancer registries, taking more time and resources from a burdened staff. Large group oncology practices are becoming common, and are often national in scope, also making reporting a challenge.

In addition, third party vendors are now being used to outsource cancer case reporting by hospitals and large physician groups. These vendors appear to have poorer quality reporting as training and poor access to required health information result in incomplete reports. Communication with these proprietary organizations is difficult since they are responsible to the hospitals and groups that hire them, not the central registry. Third party vendors are cherry picking CTRs from other sources, offering flexible hours and working conditions. Nonetheless, central registries must remind reporting facilities of their responsibility to ensure timely, accurate data from whoever performs their cancer reporting.

Problems with interstate reporting are difficult for many states. Some states are not allowed to report cases outside of their jurisdiction. Others face delays in obtaining the case information in a timely fashion. Finally, the VA and DOD data reporting has deteriorated to a point where many states are unable to obtain any case data from this critical source.

- *“The real problem is not central registries. Mostly, it is the reporters who have limited resources, no CTRs and conflicting priorities (and we are low on their list).”*
- *“Hospitals need more training, especially with all of the new data fields and changes.”*

- *Private third-party (abstracting) vendors offer better pay, flexible hours and allow working from home. We cannot compete.”*
- *“The VA and DOD does (sic) not report to us at all anymore. We need help at a national level to address this problem.”*

**Recommendation:** Where possible, NPCR, NAACCR and other key stakeholders should work to advocate with CoC, VA/DOD and other national vendors to work systematically with registries across the country.

## Technical Assistance

A discussion of ways NPCR might better support central registries generated a wide range of ideas. Suggestions included the following:

- *“NPCR leadership is listening to us much more now. As a result, we are feeling more optimistic than in the past.”*
- *“Our strength is in sharing and cooperation. We need opportunities to learn from each other and share best practices.”*
- *“Directors meetings in past to share best practices were very useful but cut due to budgets.”*
- *“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.”*
- *“Software technical assistance is very good, but the updates are too few and too late.”*
- *“We need a more systematic approach to solve problems. Tools for abstracting, training for reporters, IT help...we live in a changing world and we need a more systematic approach to solve problems.”*
- *“Too many data items with no real value like the Congressional district reports.”*
- *“Funding priorities often ignore what is really important for the registry and go in different directions that are not always helpful.”*

**Recommendations:** Focus group members felt that NPCR should continue its dialogue with central registries, be a voice or advocate for registries on such things as DOD/VA and CoC issues and develop a more systematic and dynamic approach to overarching problems, like tools for abstracting, training and IT help.

## Data Usages by Central Registries

All groups reported a robust and flourishing use of central registry data both internally and externally. The table below highlights major data uses across states. The consensus is cancer registry data are valued by state programs, researchers, hospitals and non-profits as well as local and county health departments. We note that few states report using 12-month data for any outside purposes and rarely for internal use.

# Data Usage

## INTERNAL USES

Reports & Website

Tracking & Monitoring incidence & mortality

Comprehensive Cancer Control plans

Breast & Cervical Programs

BRFSS

Survivorship & Special Topics

Cluster and environmental assessment

## EXTERNAL USES

Research – robust use across all states

Local and county health departments

Community health assessments

Hospitals for market share and strategic planning

Community health agencies for health priority setting

Student training

Health Education programs

Figure 2. Data Usages by Central Registries

## Part 2: Finding Ways to Improve 12-Month Timeliness Standards for More States

### Best Practices for Meeting 12-Month Timeliness

All groups discussed some of their best practices to assure 12-month timeliness standards. It was clear from the discussions that a few common strategies are being used by several states and recommended to be developed as potential best practices for other states.

The following strategies were recommended by various states as valuable in reaching the 12-month data standards.

- ***“Using quarterly audit reports and annual awards or hospital certifications are big motivators.”***
- ***“Maintaining historical variation averages to find gaps and alert hospitals to potential problems.”***
- ***“Developing linkages with hospitals and outpatient reporters, using simple applications to collect only essential information.”***
- ***“Using ePath reporting to let facilities know they are missing cases.”***
- ***“Having the ability to hold certificate-of-need for non-compliant hospitals. It represents a big stick that works very effectively.”***
- ***“Having access to hospital electronic medical records and ePath reports because our legislation allows us access.”***

- *“Developing simple electronic reporting for physicians (dermatology almost instantly reports now).”*

Despite some very good models for potential use across registries to improve 12-month reporting timeliness, challenges to 12-month reporting remain significant for many registries. This is especially true for registries that never meet the standards.

- *“We have to steal from Peter to pay Paul. If we focus on timeliness, we have less time for completeness.”*
- *“Abstracting required for ePath is very time consuming and not worth the effort.”*
- *“Most processes by NPCR and NAACCR focus on 24-month standards, and do not work for 12-month data timeliness.”*
- *“If we really want 12-month data, it should be for incidence only.”*
- *“Natural disasters have a significant impact on us, e.g., 3 Hurricanes in 1 year and these are never accounted for in the process.”*

Other challenges noted across groups include:

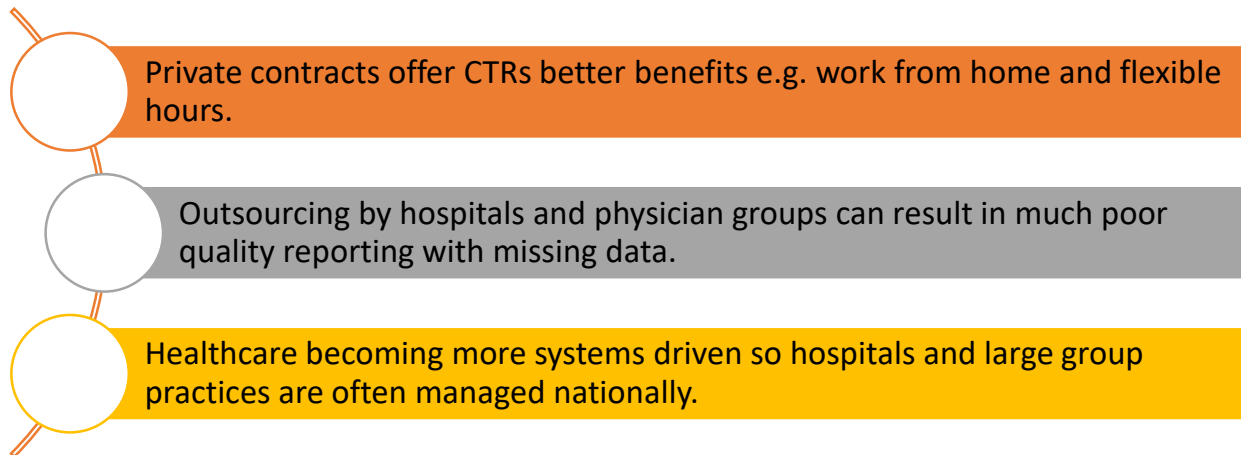


Figure 3. Challenges to 12 Month Reporting

### Adapting to a Rapidly Changing and Complex Environment

Rapid changes to the healthcare system in parallel with shifts in workforce, advances in genomics and the development of new technologies are emerging forces that are increasing the burden on an already stressed system. Change requires continuous adaptation. Registries pointed out that the complexity of the work now required to meet standards is creating a stress-riddled working environment where their ability to meet standards is often beyond their control. Resources are cut but costs continue to rise. States with large geographic and rural areas often have smaller budgets and less staff. Non-hospital reporters are ill equipped to handle reporting burdens resulting in the poorer quality of reporting.

Interestingly, one of the interesting observations from the focus groups is the noticeable absence of consistency and systematic approaches to registry operations. This may be related to an earlier observation that the historical development of operations across registries appears somewhat *ad hoc* and related to registry culture. NAACCR has played a key role in developing stringent standards and served as a force to move the field forward as a whole. However, the everyday work functions vary significantly across the states. For example, some states rely exclusively upon electronic reporting. Other states spend hours traveling across large rural geographic areas to collect cases manually. Some states rely upon ePath to find many cases. Others find the missing fields so extensive that the workload is not worth the effort. What is clear is that the historic registry “culture” is no longer capable of adapting to the current operational demands of central cancer registries and new systematic thinking is required.

**Recommendation:** This project began with a focus on identifying best practices for central registries around 12-month timeliness. The focus groups revealed that developing best practices across a wide scope of registry operations may be an even more valuable exercise for the future. Coordinated steps to streamline systems and adopt modern approaches to central cancer registries are urgently needed.

## Appendix 1: Participating States

Alaska Cancer Registry  
California Cancer Registry  
Cancer Data Registry of Idaho  
Colorado Central Cancer Registry  
Florida Cancer Data System  
Georgia Comprehensive Cancer Registry  
Illinois State Cancer Registry  
Kansas Cancer Registry  
Kentucky Cancer Registry  
Louisiana Tumor Registry  
Massachusetts Cancer Registry  
Minnesota Cancer Surveillance System  
New Jersey State Cancer Registry  
New York State Cancer Registry  
Ohio Cancer Incidence Surveillance System  
Oregon State Cancer Registry  
Pennsylvania Cancer Registry  
South Carolina Central Cancer Registry  
Texas Cancer Registry  
Virginia Cancer Registry

## Appendix 2: Focus Group Script

Good afternoon and thank you for agreeing to participate in this focus group. As you may know, NAACCR is partnering with NACDD to identify and provide strategies for implementation of best practices to improve compliance with NPCR standards for reporting of 12-month data. In preparation for an operations summit to be held in early May, a series of assessments and expert interviews were conducted that provided valuable data for analysis and strategic development at the Summit. Today, we are undertaking the last of these data gathering steps by holding a focus group that will explore in more detail, successful strategies that might contribute to best practices in reaching these standards and assessing any challenges that registries face surrounding the 12-month timeliness. In addition, we may explore some broader issues including ways to improve the NPCR's responsiveness to central registries concerns and strategies to share best practices across the larger central registry community.

We are very aware that most of you are very concerned about the 2018 data delays and understand that the challenges this situation raises for registries is foremost in your minds. We do ask that we try to restrain from making this the main subject of today's discussion. It is real. It is serious and we get that. However, we ask that you focus on the task at hand and discuss the 2018 problems only as they might relate to timeliness or the other areas that will be raised today.

Let me introduce myself. I am Ann Marie Hill and I will be the moderator in today's discussion. A focus group is a conversation that focuses on specific questions in a safe and confidential environment. I will guide the conversation by asking questions that each of you can respond to. There are no right or wrong answers to these questions. Just be honest. If you wish, you can also respond to each other's comments, like you would in an ordinary conversation. It is my job to make sure that everyone here gets to participate and that we stay on track., I want to let you know two things. First, the information we learn today will be compiled into a final report. That report will include a summary of your comments and some recommendations. It will be shared with participants at the Summit. This focus group today is anonymous and confidential. We will not be using your names and you will not be identified as an individual in our report of this project. "Confidential" means that what we say in this room should not be repeated outside of this zoom meeting. Obviously, I cannot control what you do when you leave, but I ask each of you to respect each other's privacy and not tell anyone what was said by others here today. Although we hope everyone here honors this confidentiality, please remember that what you say here today could be repeated by another focus group member.

Let us begin by thinking a little out of the box...please tell everyone your name, what registry you represent and if your registry were a car, what model, year and color would it be? Please think about the culture, structure and overall nature of your registry when responding.

- 1) When I say "the perfect central cancer registry" what comes immediately to your mind?

- 2) On a scale of 1 – 10 with 1 being completely imperfect and 10 being perfect, where do you think your registry would fall in this concept of perfection? What factors influenced your rating?
- 3) Which of these factors do you think are the most important to your registry's success?
- 4) What are some of the barriers/obstacles that hinder your ability to be closer to perfect?

We would now like to think about the types of resources that are most important to your success as a central cancer registry. On a scale of 1-5 with 1 being least critical and 5 being most critical, please think about how critical each of the following is to the success of your registry in the short term and long term:

- 1) More operations staffing including more FTEs, recruitment and training.
- 2) More analytic resources including statistical and epidemiologic analysis.
- 3) Improved IT systems and better software.
- 4) More automation and electronic reporting.
- 5) More technical assistance from NPCE e.g. Technical assistance and guidance provided by PCs or accessibility to SMEs, resources.
- 6) Other.

Now that we have a general feel for what success looks like, let's turn our attention to timeliness and think about what factors are critical to your reaching the 12-month data timeliness standard successfully. Let us begin by discovering how these data are used.

- 1) Who uses your 12-month data?
- 2) How often do you receive requests for this data?
- 3) How is it generally used?

For those of you who do reach 12-month timeliness standards, can you please share any best practices or success stories that you employ that might be useful to other registries? For example, do any of you use different strategies to handle staff shortages, software delays/IT interface, the need for more analytic resources, improved hospital or non-hospital linkages, automation and electronic reporting issues or additional technical support.

Are there other things you do that improve efficiency in your 12-month data collection processes that you might like to share with us?

As we all recognize, the value of our data is rooted in the ways that data are being used to reduce the burden of cancer. With this in mind, we would like to understand how cancer data are used in your state or territory specifically around things such as research, program development/implementation; targeted health services; and cancer communication to name a few?

- 1) How does your state use cancer surveillance data?



- 2) Who else currently uses NPCR Data, and in what ways?
- 3) How useful is the cancer data to these stakeholders?
- 4) What could be done to expand or improve the use of cancer data by more stakeholders?

The NPCR is interested in knowing more about the value of its services to you. Are there things that NPCR supports that you find valuable to your registry's operation? Are there ways NPCR could improve or serve you better?

- 1) Communication?
- 2) Technical assistance?
- 3) Help with supportive services?
- 4) Streamline things better?

Thank you so much for your participation today. Your contribution to this assessment is invaluable and we truly appreciate your giving your time and energy to us.

## Appendix H: Operations Summit Notes

Atlanta, GA

May 6 – 8, 2019

Representatives from NAACCR, NACDD, the Centers for Disease Control and Prevention (CDC), and central cancer registries across North America convened in Atlanta, Georgia, for a 2.5-day summit to discuss challenges, opportunities, and best practices regarding the collection and submission of cancer incidence data.

### *Participants:*

Wendy Aldinger (Pennsylvania)  
Lynn Giljahn (Ohio)  
Lori Havener (Project Manager, NAACCR)  
Mona Highsmith (Minnesota)  
Ann Marie Hill, (Facilitator, Rutgers University)  
Stephanie Hill (New Jersey)  
Leslie Hogle (Virginia)  
Mei-Chin Hsieh (Louisiana)  
Deborah Hurley (South Carolina)  
Mary Jane King (Canada)  
Lori Koch (Illinois)  
Betsy Kohler (Executive Director, NAACCR)  
Sue Lai, (Kansas)  
Gary Levin (Florida)  
Natasha McCoy (Project Manager, NACDD)  
Sally Paustian (Scribe, SCG)  
David O'Brien (Alaska)  
Winnie Roshala (Greater California)  
Frances Ross (Kentucky)  
Colleen Sherman (New York)  
Valerie Somma (Colorado)  
Melanie Williams (Texas)

## Day 1: May 6, 2019

### Meeting Purpose and Goals

Betsy Kohler explained this project is designed to assess ways to improve central registries' compliance with the NPCR 12-month data standards. This group was convened to evaluate completeness measures, particularly regarding 12-month data, and discuss registry operations to determine ways to improve 12-month data collection. Another group discussed the statistical aspects of this process. To begin this process, central registry staff were asked to complete on-line assessments, participate in interviews, and attend a focus group. Betsy commended participants for their enthusiastic and creative participation. A best-practices report is planned for completion before July 31. This group will meet again at the NAACCR/International Association of Cancer Registries (IACR) Combined Annual Conference to consolidate and review findings from this summit. Findings from the NAACCR Assessment of Central Cancer Registry Timeliness and Reporting Standards Task Force (2017).

### Background and Significance

Winnie Roshala summarized the activities conducted by NAACCR's Assessment of Central Cancer Registry Timeliness and Reporting Standards Task Force which was conducted prior to the beginning of this project. She indicated the need to determine the difference between real-time and timely reporting and to assess whether the criteria for timeliness standards need to change. The task force also aimed to identify the barriers and challenges to improving timeliness, with the ultimate goal of submitting a report with recommendations to the steering committee. The project engaged hospital registrars, central registry staff, and the NAACCR task force to discuss ways to improve both data quality and speed, with the caveat that speed is not worthwhile if quality is low. One point of discussion was the possibility of using a subset of the data that could be deemed complete faster.

Ms. Roshala reported on the results of a survey of U.S. and Canadian central registries. The majority of respondents indicated their registries were considering or implementing initiatives to improve timeliness, but the degree to which they are planning such initiatives can vary. Almost half of the registries reported that the data they receive met state timeliness requirements, and 45 percent of registries use the data before submitting to national programs. Approximately one-third of registries favor assessing whether reporting timeliness standards for research purposes can be changed. Focus groups then were conducted to collect more detailed information and discuss strategies used by the respective registries. The study identified considerations when discussing two-tiered reporting or the submission of an earlier version of a case followed by a later, more complete version. Registry representatives have indicated they use early data, particularly for generating preliminary incidence statistics.

The key barrier noted in the steering committee's task force study was restrictive informational systems, including the inability to process NAACCR-modified records; inadequate and manual consolidation routines; incompleteness; lack of resources to implement a two-tiered system; incomplete early records; and frequent changes to data-reporting requirements, coding guidelines, and staging variables. Suggested improvements include leveraging existing strategies, providing routine feedback to reporting facilities, improving electronic reporting, and training more certified tumor registrars (CTRs).

The task force assessing found the data at 12-months are generally about 80 percent complete. A study of resubmissions showed that they resulted in improved data with feasible updates. In an assessment of the data, a portion of cases were deemed to be quickly reportable, such as surgically treated melanoma cases, as well as cases of colorectal and breast cancers. *In situ* and blood cancer cases, as well as patients who died shortly after diagnosis may also be easily processed, however, these represented a small percentage of a typical registry's caseload.

This initial study found that although software issues remain the most significant barrier to improving timeliness, automation is critical to helping registry staff "work smarter, not harder." Generating more current incidence rates has long been an argument for timeliness, but producing such statistics has implications for the hospitals that provide data and may affect state reporting laws and resources. However, a significant proportion of data could be made more available in a shorter timeline. Respondents to these measures also emphasized that rapidly changing clinical standards make it difficult to report cases faster while collecting the first course of treatment. Software tools should be improved to allow registries to accept incomplete early cases and decrease the manual work involved in consolidation at a later time by developing robust consolidation routines. Guidelines should be developed for central registries, including identification of which data elements are critical for early incidence cases. Recommendations included allowing central registries to determine the optimal timeliness standards, identifying resource constraints, evaluating the resources required to ensure that reporting requirements are met, developing an ongoing NAACCR process to monitor the quality and completeness of data, and improving the metrics by which data can be measured.

- Ms. Roshala explained that these interviews and surveys served as a foundation for the assessments, and interview questions circulated prior to this summit. Next steps should include detailed steps for the next phase of improvement, exploration of the uses of 12-month and 24-month data, and determination of which paths are most realistic for moving forward. A participant indicated that the estimated or projected incidence data, such as those provided by the American Cancer Society, are respected by the lay community. The benefits to using calculated data, which are less useful to researchers but could be appropriate for politicians and advocates, are being explored by the participants in the Statistical Summit.

## Identifying and Implementing Best Practices for Registry Operations: A Summary of the Comprehensive Assessments

### Summary Assessment Analysis

Ann Marie Hill outlined the results of the written assessments conducted with the registries. Registries use a variety of software systems, but users are only moderately satisfied with any system. Most registries have good rates of electronic reporting, and many of them use electronic pathology reporting (ePath). Respondents noted that physician reporting remains problematic but that electronic submission of all ePath reports is unlikely to improve timeliness. Registries receive electronic reports from non-hospital sources; some continue to receive paper submissions, but many do not have the resources to process these incomplete submissions. Even representatives of registries that meet the 12-month standards indicated more staff are necessary and hiring enough CTRs is extremely difficult.

- A participant indicated that the term “12-month reporting” should more accurately encompass the 12 to 14 months allowed by the reporting deadlines.
- Another participant pointed out that any data meeting the 12-month standard do not include all race divisions or those data that would require quality control (QC) actions. To meet timeliness standards, completeness must be sacrificed by dropping those cases that require more work.

### Summary of the Interviews

Wendy Aldinger explained that most of the interviewed representatives reported receiving additional funding from states and universities, as well as block grants and compensation from data provided for research studies.

- The majority of interviewees reported sufficient IT support, but many still struggle to get enough support.
- Two states reported fully automated consolidation (auto consolidation), two reported no auto consolidation, and the remaining registry representatives reported some limited auto consolidation.
- The majority of interviewees use some ePath, but many registries process these after the hospital abstracts are processed.

#### ***The overall needs identified during the interviews include:***

- Educational needs created by the significant changes that were instituted in 2018.
- Staff training unified across states, and additional training on central registry functions.

#### ***Technical assistance needs include:***

- Assistance related to the 2018 changes,
- More timely software releases,
- Standardized management reports,
- EPath processing,
- Natural language processing (NLP) integration,

- Help with disease index audits, and
- More avenues for idea sharing.

Some of these functions can be automated, but the needs associated with personnel—such as the significant shortage of CTRs also are critical to address.

Lori Koch explained that timeliness and completeness are a balance, with staffing resources as the foundation; with enough staff, both timeliness and completeness can be improved, but because registries generally are very short-staffed, improving either timeliness or completeness occurs at the expense of the other.

Interview respondents were divided on whether the Commission on Cancer's Rapid Quality Reporting System (RQRS) was helpful, and they also noted a disconnect between the 6-month reporting requirement for treatment data and the 2-year time frame that treatment data are known to encompass.

***Challenges to completeness include:***

- Constant changes in many areas,
- Delayed software updates and software related problems, and
- Staff turnover and lack of staff at both the hospital and central registry level.

Noncompliant facility reporting and competing priorities for facilities also challenge completeness.

***Timeliness challenges include:***

- Interstate data exchange,
- Outpatient and small-facility reporting,
- Clinically diagnosed cases, and
- Registrar fatigue.

Other issues affecting timely and complete reporting include ePath issues, changes to laboratory software, and lack of reporting from laboratories.

The most significant barriers identified by states were constant changes, delays, staffing issues, and the lack of timely reporting from facilities. Lack of CTR staff, including staff turnover and use of consultants, was identified as a major challenge. Strategies used by respondents include establishing data submission policies, tracking facility timeliness, offering a variety of reporting methods, providing status reports or a year-end closeout process, and implementing timeliness awards.

Participants emphasized the development of good relationships with reporting facilities is undervalued. Strategies to assist facilities include training and education, reducing paper submissions, and developing customized software with limited data items for specific types of reporting facilities.

- Attendees agreed that the suggestion to provide customized software with limited data items was promising. Many registries already are doing so, but customizing software on their own requires time. It was suggested that creating a treatment data set that could

meet the requirement to collect treatment data but auto populate or limit treatment fields for visits to specific types of providers.

- Another comment was that overwriting some aspects of the data should be prevented. Because various reports are submitted throughout the year, certain aspects can be prioritized.
- Many registries postpone abstracting ePath or nonhospital cases, because a better case might be submitted by a hospital.
- Many registries prioritize data for certain cancer sites or types. The data from cancer types that do not result in hospitalization can affect the processing timeline.
- Attendees agreed that staff reductions force registries into a “survival mode” in terms of developing ways to prioritize their work.

## Report on Focus Group Findings

Three focus groups were held via Zoom over a 1-week period, with representatives from registries with varying levels of compliance with the 12-month standard. Participants outlined their requirements for a perfect cancer registry, and most of them rated their own registries highly in fulfilling these goals. Central registry employees are experts in their field, but the challenges that come from outside forces are out of their control. The positive qualities of central registry staff include collaboration, flexibility, actions taken to succeed, and problem-solving skills. Staffing is the biggest challenge faced by the registries. Registry representatives emphasized that their strengths are in sharing and collaboration, but they do not have enough opportunities to learn from each other. Once the data are submitted, they are used widely and other disease registries are using cancer registries as a model.

## CHARGE FOR THE SUMMIT

Ann Marie Hill displayed the charge for the summit, emphasizing the importance of making sure that the issues discussed are important to the attendees.

- Attendees discussed the importance and difficulty of building relationships with consultants and hospital registrars. When hospitals are outsourcing, relationships cannot be built; however, these relationships are priceless when they can be developed.
- It was suggested that we define ideal staffing for a central registry. It has been suggested that one full-time equivalent (FTE) covers 300 hospital cases, but this has not been vetted.
- Participants commented on the difficulty of replacing retiring staff; even when new CTRs can be found, multiple newer employees cannot replace the knowledge and experience of long-time CTRs.
- Attendees discussed whether NPCR could support a push for such CTR programs as nationally standardized degrees or online certification courses. Ann Marie suggested promoting the field to students and others entering the workforce, many of whom are interested in data and outcomes but possibly are unaware of cancer registries.

- It was indicated that younger workers are more likely to be drawn to careers that allow them to work from home and have flexible work schedules and younger workers are less likely to remain in one position for a long time.
- A participant asked about ways to monitor for errors when auto-consolidation is implemented. Attendees discussed the types of statistical errors caused by various submission processes and which data items should be released and used.

## **Breakout Session 1: Discussion on Key Barriers**

Ann Marie encouraged attendees to propose strategies for improving the challenges registries face, in general, and specifically for 12-month data submission timeliness. The summit attendees were asked to identify best practices and recommend actionable steps to better support central registries, rather than focusing only on improving timeliness or 12-month submission, Ann Marie suggested that broader issues are likely and could be included in the summit's output. Attendees were divided into breakout groups for discussion and then reported back to the group.

Group A discussed software improvements, reporting that possible enhancements include automatically updating known versus unknown data points, logging all changes, creating consistent methodology for auto consolidation, developing a way to identify no-added-value records and remove them from the system automatically, and implementing "review by exception" protocols so staff can trust the electronic systems to apply the rules automatically; the review would be required only in the cases of critical errors. Lori commented that some of these improvements are easy to implement. Other software-related needs include improved identification of reportability for pathology software and improved assignment of primary site and histology. Implementation of natural language processing (NLP) functions could improve CTRs' workload significantly.

- Attendees discussed ways to include a rationale in a change log, such as including a comments field.
- Some registries are using systems that other registries can borrow or implement, such as a common dynamic link library or the change-tracking system, such as the one used by Information Management System, Inc. (IMS) for SEER registries called Squish.
- Attendees commented that CDC provides guidelines detailing state-level issues necessary for program compliance. In return, a registry's IT representative could be asked to sign a letter agreeing to provide support in compliance with CDC standards.

Participants discussed various software systems, favoring Surveillance, Epidemiology, and End Results (SEER) Data Management System (DMS), with technological support provided by IMS,

Group B's discussion focused on ensuring high-quality data from nonhospital reporters. These data result in significant amounts of work for a small number of cases, and the quality is lacking. Some registries abstract the cases themselves, rather than training



clerks at the reporting sites. Gathering all the complex data from these sources is impractical.

- Attendees discussed whether state funding can be used to abstract cases.
- A majority of the participants wait for hospital submission before working on nonhospital data.
- Attendees would like to discontinue clinical document architecture files, as part of Meaningful Use, and work on a more manageable process.
- Participants suggested focusing on changing the time frame for releasing data to 18 or 20 months.
- Manuals for different types of reporting (e.g., dermatology) could be developed and shared across states and remain applicable.

Group C's discussion of ensuring high-quality data from hospital reporters, emphasized that the main strategy is increased communication. Although some hospitals use contractors, the ultimate responsibility for data quality falls on the hospital, so communication and transparency are essential to ensuring quality. Many registries have a listing of facility profiles, including abstracting vendors and their employees, with whom they can maintain communication and ensure that all parties are familiar with the applicable state reporting requirements. Other suggestions included automated reports to provide metrics to the reporting facility, robust edits to ensure good data, and reabstracting and case-finding audits for facilities with concerning data quality. Potentially valuable opportunities for improvement include training contractors on reportability and case-finding lists specific to the applicable state, developing a mechanism to notify the central registry of a potential reportable case, and emphasizing the importance of text documentation to support all coded fields. The group stressed that registry staff should not assume that contractors are aware of which items are deemed reportable and important to each state. Reporting standards should be communicated to vendors, and the reports on timeliness and quality should be provided to vendors and hospitals.

### **Breakout Session 2 Continuation of Discussion on Key Barriers**

Group A's discussion focused on communication breakdowns. Communications are sporadic and accidental between program directors and central registries; strategies for more intentional communication are needed. Group participants agreed that NAACCR's previous mentoring program was very helpful and discussed ways to replicate its most useful aspects. They suggested adding to the NAACCR profile an option to list areas of expertise in standardized, searchable formats, which could lead to a matching system between program expertise and the users' needs. A participant indicated that NPCR's yearly meeting now includes a program meeting with training for new registry directors, which provides an opportunity to meet face to face, develop personal relationships, and identify contacts with particular expertise. The group suggested the development of webinars dedicated to a single topic, such as one registry's successful method for a particular process. Consensus-building approaches are difficult but could include equal representation—by size, geography, timeliness, and involvement level—as well as

providing states with the ability to vote on standards, which would create buy-in. Consensus on a single topic could be developed with a smaller group to smooth any issues before presenting to a larger group. The group also recommended more transparency from NPCR, noting that participants anticipated that this would improve soon, as well as the ability to propose changes to program standards, which would help in identifying and removing outdated sections.

Group B: “ePath: Why?”. Each registry uses ePath differently, and many are comfortable with the systems that they have established, but some items could be tweaked, such as by integrating NLP. EPath often is the last step in the data-gathering process.

- It was noted that some doctors use the hospital laboratory for patient testing without admitting the patient to the hospital.
- A participant reported on her team’s process of auditing the pathology first and requiring resubmission if more than 5 percent of pathology cases have been missed.
- Payment for the ePath interface can be a problem. Although IT time is minimal once the interface has been established, those resources often are required elsewhere.
- New Jersey reported on a rules update for her registry that required electronic submission, although they have been unable to enforce it at this time, because the circumstances of funding have changed.
- Although electronic submission can be required, ensuring that systems are interoperable is critical to avoiding increased work and errors.

Group C’s discussion of maintaining quality with improved timeliness. Currently, too many data items are collected, and efforts are needed to assess the existing data and identify any items that can be removed to maintain relevance. The group suggested that not all items need to be collected by all parties and that some items might be less appropriate for collection by population-based registries. The group suggested that treatment data or data on certain cancer sites could be reduced and that modified - records should be accepted only for some data items. Registries also must determine how precision medicine fits into the processes of population-based registries.

- Concerns were raised about data quality, noting that simple errors proliferate. Current automation rules are based on the premise that the incoming data are correct, even though the registry staff know that this is not always true. Attendees discussed whether tests or basic skills requirements for registrars would decrease errors. Some errors are likely related to resource limitations, and it was suggested that sharing information about systemic errors might be helpful, because other registries might also experience them.
- It was suggested that any changes implemented should be maintained for a longer period; registries should be more cautious about implementing changes from the TNM Classification of Malignant Tumors.
- Attendees discussed the importance of gathering input from registries before any changes are made.

## Day 2

### Discussion on Successful Strategies and Initiatives

Ann Marie Hill reviewed discussions from the previous day and asked attendees to comment on other practices that have been successful.

- A participant clarified that many delays are caused not by a lack of reporting, but by a backlog of editing. Her team prioritizes editing and consolidation tasks for data that would be most meaningful in completeness estimates, and they use multiple primary rules to find data that are most likely to indicate a new primary cancer site. Other attendees commented on similar processes in their systems and the other methods of prioritizing data known to be important in completeness calculations. It was emphasized that these practices bias the data, because some cancers will have a greater level of completeness. She questioned the value of data that are manipulated artificially.
- It was also noted that all of the registries are using shortcuts, because otherwise they cannot reach the submission goals and deadlines. Registry staff can decide which cases to prioritize based on the factors used in various completeness estimates, with the understanding that some of these are weighted disproportionately in the completeness calculations. This allows staff to focus their work on cancer sites and populations that have a greater impact on completeness estimates.
- It was noted that as physician reporting becomes more common, the collection of race and ethnicity data becomes more difficult.
- A participant requested technical help with NAACCR's completeness calculations, which her staff have been unable to determine how to use.
- Attendees questioned the need to put so much time and effort into meeting 12-month requirements when the data are not used. Participants suggested conducting a cost-benefit analysis that would show the loss of staff resources in this process.
- It was suggested that registries could prioritize sites in high demand for early release; if the data are not needed at 12 months, registries could provide a form indicating their current progress. It was also suggested that registry staff could focus on compiling and completing 24-month data and, over time, reduce that timeline incrementally, particularly if the resources currently used to meet 12-month requirements are released.

### Breakout Session 3: Examination of Best Practices in Operations

Group A's discussions of "how to grow a CTR." Most registries identify people with the right background for becoming a CTR, such as anatomy and physiology and medical terminology training, and the right mindset, which includes independence, a detail-oriented character, and an interest in data. Training programs vary but include associates degrees, certificate programs, and online training, some of which might involve tuition or test reimbursement. Recruitment could be conducted with presentations at colleges, public health schools, and biology and nursing departments. The importance of making connections and demonstrating the fun aspects of the job

were emphasized. NPCR could be asked to promote the profession in a targeted way to people with the right background. Participants emphasized the need for younger people to become CTRs, suggesting the development, delivery, and implementation of a marketing plan. The group also suggested developing a basic training webinar for new cancer reporters and CTRs.

- Efforts from NPCR would help improve nationwide standardization for CTRs.
- Other suggestions included working with the state registry association, involving hospital staff in recruitment presentations, and accepting potential registrars from other countries.
- Attendees discussed whether training webinars funded by one state should be used by contractors in other states.
- Participants discussed the types of programs targeted for CTR recruitment. Health information management (HIM) programs are a possibility; although these students might have a lower level of training than those from other programs, increasing the number of CTRs in the field is necessary. Some schools also offer certificates to students in public health programs if interest is sufficient.

Group B's discussion of recruitment and retention for central registries, noting that their discussions were similar to those of Group A, including working with colleges and HIM programs. Because standardized programs do not include exposure to registries, connections must be developed in other ways, including offering internships and marketing the field. Retention is often out of the registries' control, but more flexible work practices, reimbursement for memberships or training, and a positive work environment are beneficial. Group members also stressed the importance of including all staff members in decision making to develop buy-in.

- Attendees discussed other options for retention, including providing variety for employees by using their other skills, offering training time—which may encourage staff to value training more, because they “pay” for it with a specific bank of hours—and celebrating successes. Gary cautioned against creating high expectations for bonuses, given the restrictions in funding.
- Participants discussed the benefits of sharing salary information between states. Registrars may telecommute in some states from areas with lower costs of living, but not all states allow telecommuting to other states. Registry staff can promote their registry or geographic location, but CTRs must make the final decision about what is important to them. Some states have unions that ensure that staff receive salaries higher than the cost of living outside major urban areas.

Group C's discussions of automation around consolidation. Group members were familiar with a variety of systems, but all members stressed the need to develop consolidation rules. They recommended a task force or a working group, as well as any guidance already developed by registries. Consolidation is a significant cost in terms of staffing time, even for registries with partial auto consolidation. Group members suggested limiting consolidation to a select few data items and reviewing the core consolidation logic for software systems. Registry staff will need to accept that rules will not address every scenario but can be sufficient for the majority of cases. Developing standardized rules to match patients and tumor data are needed.

- Registries also need to determine how to handle modified records. Group members recommended a third-party assessment of the entire data flow around consolidation to provide ideas on how to improve. Some systems can consolidate across abstracts, but consolidation across records also is required. QC methods should be built in.
- A participant recommended including maintenance processes for changing fields and standards.
- There was a recommendation that the task force begin with NAACCR's manual on Data Item Consolidation.
- Patient data that can be used for linkage, such as social security numbers and names, vary across states and have changed over time, so the task force should include experts on matching.

### What Have We Missed?

Ann Marie Hill led a discussion to determine if there were important topics that had not been discussed. Some of the issues include:

- Difficulty of getting approval for sending staff to conferences and meetings, which are considered to be nonessential. Attendees recommended that CDC's funding letter include specific requirements for conferences and trainings.
- Attendees reiterated the most important problems and suggestions:
  - Increase funding.
  - Improve software.
  - Discontinue TNM staging.
  - Discontinue collection of treatment data.
  - Discontinue collection of 12-month data.
  - Evaluate a new timeline.
  - Discontinue Meaningful Use.
  - Include funding for special projects (e.g., a consolidation working group).
  - Support recruitment and career development for CTRs.
  - Ensure that the American Joint Committee on Cancer (AJCC) does not dictate registries' practices.
- Attendees recommended defining which registries are succeeding and what elements are critical to success; those elements and any associated models (e.g., progress reports that have improved auditing) then should be shared across registries.
- NPCR should contract more frequently with NAACCR across the board.
- Registries should move to a single central registry software, such as SEER\*DMS.
- Additional areas that need to be addressed include clarifying reporting standards for physician practices that operate in multiple states and determining which entity is responsible for managing the DMS database.

### Comments from CDC Representative

Netta Apedoe explained that a review of the strategic plan resulted in CDC's renewed focus on strengthening cancer surveillance data collection. The leadership team has indicated that 24-month data are too old and has requested quicker data, which could be published if additional registries meet the 12-month deadline at 90 percent

completeness. CDC is evaluating its own practices—including hosting this summit—to determine how to support states in reaching that goal.

- Attendees reiterated that all registries reaching the 12-month goal do not recommend publishing those data. They emphasized the significant resources expended on reaching the 12-month requirement and the deleterious effects on quality, completeness and timeliness. If registries were not required to collect treatment data, reports could be completed in a timelier manner, because delays are inherent in the cancer treatment timeline.
- Netta explained that some of the 12-month data requirements are dictated by Congress and other stakeholders who are not aware of the difficulty in gathering the data.
- Participants requested information on how CDC will use the data, which will allow registries to provide constructive feedback on which shortcuts are being taken to reach this goal and how the data will be biased. It was pointed out to Netta that some registries reach the 12-month goal by ignoring cases that are not black or white, as well as prostate and breast cancer cases, because these cases are not counted in the completeness estimate.
- A participant noted that central registries are at the mercy of their reporters and recommended helping the hospitals as well as the registries.
- Netta recommended developing a narrative rationale to explain why the current data are not sufficient and advocate for additional resources.

Ann Marie stressed the need to prioritize among the many issues discussed at the summit. Betsy recommended that each breakout group decide what initiatives might help all states achieve the 12-month goal.

#### **Breakout Session 4: Improving Registry Operations to Meet 12 Month Completeness and Timeliness Standards**

Group A's suggestion to develop projections or models for 12-month data. These models could be compared with actual past data and refined; if the model data meet the 90-percent completeness standard, they could be submitted. U.S. Census, which does not collect population data every year. Using projections for 12-month data would release registry resources to produce high-quality comprehensive data at 24 months. Other ideas include reporting 12-month data without the treatment field, collecting fewer items for 24-month reports or limiting the collected treatment time frame to 6 months, or providing 12-month data only for particular subsets of registries when requested for a specific study—although this last strategy would require hiring and preparation that might increase the timeline beyond 12 months.

Group B's suggestion to hone in on certain sites and assess them in conjunction with the priority site funding opportunity announcement (FOA) the for comprehensive cancer programs. Perhaps restricting 12month data collection to the CDC comprehensive cancer program sites (breast, cervical colorectal, etc.) would be fruitful. Data items could be limited to basic incidence variables. Data also could be provided without editing guarantees. Auto-consolidation and NLP could help with ePath. Group B emphasized that registries need a focus, rather than trying to accomplish a large range

of tasks beyond their capabilities, and CDC could provide more specific direction about the goals instead of a broad requirement to meet a deadline.

Group C's suggestion to take a statistical approach, such as estimating 12-month data, limiting edits, using discharge data, removing the meaningful use requirement, limiting data changes for 12 months, and dedicating more CDC resources to onboard national pathology laboratories.

Ann Marie recommended that attendees determine what evidence they can provide to support their ideas. It was noted that the American Cancer Society and some completeness estimates already use projections, which proves that such an approach is reasonable. Attendees emphasized that any activities currently conducted with 12-month data could be conducted with estimates. A participant indicated that registry staff can convince their states to use estimates wisely, but at the national level, CDC must be relied upon to convey the message that more resources are required to support better data.

Representatives from registries that meet the 12-month requirement discussed their practices, including a long-standing culture that promotes rapid reporting, close monitoring of hospitals with frequent communication, prioritization, and abstracting pathology laboratory information for nonlinked cases by the registries.

Attendees requested information from CDC on the number of FTEs and cost required per case. Assessments of staff effort also must consider the lack of equivalence between retiring and new CTRs, the amount of time required to use ePath, the resources required for tracking each facility that a patient visits, and the effects of geographic size. CDC also could enforce rules on how states are allowed to appropriate CDC funds.

## Day 3

### What Support and Services Might NPCR Offer?

Ann Marie reviewed previous suggestions for NPCR support and asked attendees for additional ideas.

- CDC formalize a process for meeting with new registry managers in their states; this process could include a requirement for basic manager training. NPCR's new program consultants also could visit registries to learn the process.
- Participants recommended revisions to the NPCR website aimed at CTRs, such as adding more resources—including the program manual—and more links to information on any related websites.
- National promotion of the field in a way that includes both registries and hospitals.
- NAACCR and NPCR should ensure that the Commission on Cancer accredit only facilities in compliance with state reporting laws.
- Attendees discussed how they are able to stay informed about news within the community, including subscribing to multiple newsletters, relying on staff knowledge, and

making connections at conferences. A monthly newsletter with bullet points for important news that central registries should know was suggested.

- Participants emphasized that NPCR should protect CTRs, which are registries' most important resource, adhere to agreed-upon change implementation procedures, and simplify systems to allow registries to produce more timely, complete, and accurate data.
- Increased automation overall, including linkage and interface improvements.
- Engaging with AJCC on cooperative efforts in data collection; such an effort also would positively affect hospital processes.
- Limiting 12-month data to cancers within the scope of CDC's prevention mission. These rates do not fluctuate year to year, as infectious disease rates do.
- Attendees discussed the difficulty of gathering timely data from out-of-state reporters. Funding is based only on in-state caseload, so additional resources are required to support out-of-state reporting. This system becomes more complicated in areas where patients may be treated in multiple states, particularly because patient data do not always include addresses.
- An evaluation to identify duplicated efforts.
- A standard for nonhospital reporting sources, with a diminished data set and allowable percentage, which would allow registry staff to adjust expectations and improve efficiency. This could include limiting treatment data to 6 months or requesting a 1-page abstract or other limited data set.

## **Key Messages from the Summit**

At the close of the meeting, participants selected their highest priorities:

- Development of 12-month estimates using a statistical model based on 24-month data
- Auto consolidation
- The labor shortage (i.e., CTR development, recruitment, and retention)

## **Action Steps and Conclusions**

Betsy thanked the attendees, CDC, and NACDD. The information discussed will be combined with summaries of the assessment, interviews, and focus groups to produce an initial report; this group will meet at the NAACCR/IACR conference to review the report, identify areas for further investigation, and develop the recommendations due to CDC on July 31.

Attendees planned to send information about the number of staff at each registry to Lori Havener and to send any further ideas to Ann Marie. Ann Marie commended participants for their honesty, participation, commitment, and passion.



## NACDD/NAACCR Operations Summit Follow Up Meeting

### Review and Approval of Summit Recommendations

Vancouver, Canada  
June 13, 2019

Final Action Steps were reviewed and approved by the Operations Summit participants at a follow up meeting held at the NAACCR/IARR Conference on June 13, 2019.

#### **Attendees:**

Wendy Aldinger (Pennsylvania)  
Vicki Benard (CDC NPCR)  
Lynn Giljahn (Ohio)  
Lori Havener (Project Manager, NAACCR)  
Mona Highsmith (Minnesota)  
Ann Marie Hill, (Facilitator, Rutgers University)  
Mei-Chin Hsieh (Louisiana)  
Deborah Hurley (South Carolina)  
Lori Koch (Illinois)  
Betsy Kohler (Executive Director, NAACCR)  
Sue Lai, (Kansas)  
Gary Levin (Florida)  
Winnie Roshala (Greater California)  
Frances Ross (Kentucky)  
Randi Rycroft (Idaho)  
Colleen Sherman (New York)  
Valerie Somma (Colorado)  
Nan Stroup (New Jersey)  
Melanie Williams (Texas)  
Dr. X Wu, (Louisiana)

## Action Steps and Final Recommendations

1. Create consensus around a common definition of what a source document is to monitor and evaluate operations across registries.
2. 12-Month Standard Options
  - b. Eliminate 12-month data collection – use modeled or projected data
    - i. Eliminate the 12-month data requirement and use a 12-month estimated rate based on the actual 24-month submission (statistical approach solution, using imputed rates with delayed adjustment for major sites)
      1. Staff resources can be focused elsewhere if not working on 12-month data.
    - ii. Compare projected counts to actual counts to refine statistical model; if projection is within 90% of actual, the projection is just as good as actual. (Consider that the Census Bureau uses interpolated population counts between census survey years and this is the denominator in all calculated rates – use a projected cancer count for the numerator).
    - iii. Focus on 24-month data quality and then start working back e.g., 22-month submission, 20-month submission, etc.
  - c. Keep the 12-month standard – modify required data collection parameters
    - i. Develop auto-consolidation rules all registries can use
    - ii. Only focus on certain primaries for 12-month data. For example, sites for Comp Cancer and Breast and Cervical programs.
    - iii. Only collect treatment that is given within 6 months of the date of diagnosis.
    - iv. Reduce the number of required data items
      1. Focus on incidence data, drop all treatment and only collect SEER Summary Stage
      2. Reduce overall number of data items collected by all registries, then fund states for special projects on specific cancers requiring additional data collection
    - v. Implement a reduced edit set for 12-month data
3. Staffing
  - a. Spotlight cancer surveillance and CTR profession
    - i. Develop targeted materials to promote the field of cancer registration/surveillance at the national level.
    - ii. Develop standard presentations or materials that can be used to recruit at HIM, nursing, biology, or public health programs.
    - iii. Recognize retiring CTRs with 25-30 years of experience aren't equaled in productivity or knowledge by 1 or even 3 new CTRs. Training and development of new staffs takes time and can impact a registry's ability to weather changes.
  - b. CTR professional development
    - i. Develop career path for CTR 1, 2, 3 etc.
    - ii. Complete salary comparison for central registry staff.
    - iii. Develop support/documentation to assist with obtaining higher salaries.
    - iv. Have NPCR contract with NAACCR to develop a basic training webinar that all states could utilize to train cancer data reporters.
  - c. Student recruitment, training, and development

- i. Consider central registries establish a clinical practicum program, either alone or in conjunction with a local hospital, to facilitate CTR students sitting for the exam.
  - ii. Develop a clear training plan for potential CTRs utilizing existing training resources like SEER Educate, NAACCR webinars, NAACCR CTR Prep Course, NCRA workbooks. Consider developing a set of practice cases for students.
- 3. Auto-consolidation
  - a. Develop auto-consolidation rules that all states agree to use
    - i. Obtain an assessment from outside third-party consultants to provide a data flow assessment, including consolidation and tumor linkage
    - ii. Request consolidation rules from central registries that already have auto-consolidation in their software
    - iii. Collaborate with the SEER Auto-consolidation Work Group.
    - iv. Review and develop consolidation rules (including Modified Records, Correction Records, etc.)
      - 1. Review core consolidation logic and rules
      - 2. Focus on specific required data items (not every field)
      - 3. Update unknown values with known values automatically
      - 4. Incorporate the Solid Tumor Rules into auto-consolidation logic
      - 5. Develop a way to identify a “no added value” record (like non-analytic cases, hospitals that are behind, VA/DOD cases, cases from a different accession year, path cases). SEER\*DMS has this now.
      - 6. Review by exception - like coded solid tumor versus a hematopoietic case, large tumor size versus an early stage
      - 7. Use a common, routine .dll that everyone contributes to for solid tumor rules and auto-consolidation
  - b. Develop consolidation edits that enhance source record edits
- 4. Software improvements
  - a. Improve identification of reportability for e-path software
  - b. Software should keep a record or log of all changes made – what was changed, why, and who changed it
  - c. Improved technical support for software
  - d. NLP for text to code and flag cases for review
  - e. NLP for path cases or mandated CAP checklist
  - f. Institute a change/control board for state input on changes (similar to DMS Squish)
- 5. Develop best practices
  - a. Model for data processing of source records
    - i. Prioritize source records
    - ii. Define partial records (minimum required data items)
  - b. Staffing
    - i. Monitor productivity of remote staff
  - c. Auto-consolidation Rules
- 6. Next steps
  - a. Written report by July 31

## Appendix I: References

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# Partners

Centers for Disease Control and Prevention

National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP)

Division of Cancer Prevention and Control

Cancer Surveillance Branch

North American Association of Central Cancer Registries

The North American Association of Central Cancer Registries, Inc. (NAACCR, 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.

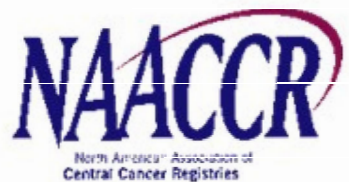
The National Association of Chronic Disease Directors

Promoting Health. Preventing Disease.

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 U.S. 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](http://chronicdisease.org).



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