Identify and Implement Best Practices for Cancer Registry Operations

Executive Summary

January 2020

Acknowledgment

This publication was supported by the Cooperative Agreement Number 6-NU38OT000286-01 funded by the Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the author and do not necessarily represent the official views of the CDC or the Department of Health and Human Services.

Table of Contents

Identify and Implement Best Practices for Cancer Registry Operations

Executive Summary

Project Overview and Findings

Background and Significance

The American cancer surveillance system is one of the most developed and standardized disease surveillance systems in the world. The National Program of Cancer Registries (NPCR) of the Centers for Disease Control and Prevention (CDC) has collected population-based cancer incidence data in the United States since 1995. NPCR currently supports central cancer registries in 46 states, the District of Columbia, Puerto Rico, the U.S. Pacific Island Jurisdictions, and the U.S. Virgin Islands; representing 97 percent of the U.S. population. NPCR's data provide the foundation for the research and medical communities, policymakers, and members of the public to understand and address the nation's cancer burden. Data are most useful when available in a timely manner; currently, national cancer surveillance organizations require complete reporting of cancer data within 23 months of diagnosis, leading to a 2-year lag between diagnosis and reporting. CDC now requires reporting within 12 months of diagnosis, but many registries are unable to fully meet this standard, which prevents the accurate reporting of cancer incidence rates at an earlier time. Factors known to delay reporting include the need to consolidate reports from multiple institutions for each cancer case, the possibility of the first course of cancer treatment extending for months after initiation; state laws regarding cancer reporting; and a shortage of trained staff.

NPCR's benchmark is that 90 percent of cancer cases diagnosed within the past 12 months are reported to the central cancer registry. However, because the final number of cases for a given year is unknown at the 12-month mark, determining whether 90 percent of these cases have been reported is challenging. NPCR currently calculates the completeness of reporting using the ratio of newly diagnosed cases to deaths in the same area, but this measure was developed for data reported 24 months after diagnosis, and the applicability of this measure to 12-month data has not been demonstrated.

CDC contracted with the National Association of Chronic Disease Directors (NACDD) to address these concerns who subcontracted with the North American Association of Central Cancer Registries, Inc. (NAACCR), an organization uniting cancer registries, government agencies, professional associations, and private groups interested in enhancing the quality and use of cancer registry data, to analyze methods to improve registries' compliance with the 12-month data reporting standard. A Statistical Expert Panel examined the statistical validity of completeness and timeliness measures currently in use, and an Operations Expert Panel evaluated the best practices for collecting and processing cancer incidence data within 12 months of diagnosis. Representatives from registries with various levels of compliance with the 12-month standard participated in written assessments, interviews, and focus groups, as well as one in-person summit each for the statistical and operational parts of the project.

Two-Pronged Approach

One arm of this investigation endeavored to analyze the statistical methods used to measure cancer registry completeness and determine which measure(s) are most effective at the 12- and 24-month deadlines. The Statistical Expert Panel assessed the main methods used in North America and made recommendations for an objective, unified, and accurate metric. Panel

members carefully evaluated the benefits and drawbacks of various methods for measuring completeness and selected the most promising methods for more rigorous analysis. The panel met biweekly on a virtual basis and convened in person in Gaithersburg, Maryland, in April 2019 to conduct an intensive review of all models. Two models were identified for additional study: (1) the incidence-to-mortality rate ratio (IMRR) method and (2) a modeling approach that estimates the expected case counts for each registry based on population demographics, smoking and other behaviors, screening rates, and other characteristics of health care systems. The Panel then met at the NAACCR Annual Conference in Vancouver, Canada, to review the preliminary analysis of the models and define a more robust assessment. All methods considered had disadvantages, and significant biases were uncovered in relation to the nature of the measures themselves. The complexity found in the initial review requires additional analysis, which is expected to be completed in June 2020.

For the operations arm of the study, a total of 22 registries were evaluated in three groups: (1) eight NPCR registries that always or usually met the 12-month 90-percent completeness measure in recent years, (2) five registries that sometimes met the measure, and (3) nine registries that rarely or never met the measure. The analysis included a quantitative assessment of critical registry practices, guided expert interviews, focus groups, and special studies of workflow procedures. These data were presented at an in-person Operations Summit in Atlanta, Georgia, in May 2019. The attendees reviewed the findings, discussed guidelines for best practices for meeting the 12-month standard, and set priorities for moving forward. Additional topics that were discussed included staffing and education, software and information technology (IT), auto-consolidation, operational workflow, external reporting bottlenecks, and technical assistance improvements. The group reconvened at the NAACCR Annual Conference in Vancouver, Canada, in June 2019, to reach a final consensus on the recommendations.

Methodology

This comprehensive and multidimensional project offers a wide-ranging analysis of how to improve the compliance of cancer registries with NPCR's 12-month data standard and assesses many additional aspects of registry operations that are of interest to NPCR. NAACCR conducted a written assessment, in-depth interviews, and focus groups and held in-person summits to review the findings of these investigations. In addition, the Statistical Expert Panel studied the basic statistical aspects of the completeness measures and examined the processes within registry operations thought to influence timely reporting of cancer data. The Statistical and Operations Summits allowed in-depth analyses and discussion, and follow-up meetings with the Statistical Expert Panel and participating states included review and approval of the recommendations.

Registries were selected for inclusion in the Operations Assessment based on their ability to meet the NPCR 12-month data completeness standard in recent years. Those registries that met the standard in at least six of seven recent 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. The 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. No registries met the standard exactly three times.

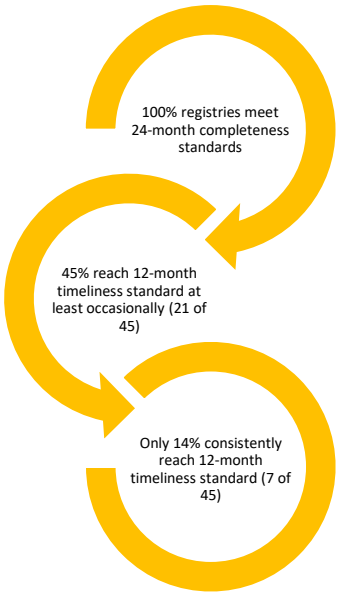
Of the 16 registries classified in the "usually or always" category, eight geographically and demographically diverse registries were selected to participate in the assessment, interviews, focus groups, and other project activities. Nine diverse registries of the 26 in the "rarely or never" category were selected to participate, and all five registries in the "sometimes" category were invited to participate.

Summary Findings

Completeness

This project generated a sweeping view of registry operations in 22 states. All registries sampled were able to meet the 24-month completeness data standard, but only 14 percent of the sample group were consistently able to meet the 12-month data standard. Meeting the 12-month standard often required unorthodox methods that could compromise data quality and form biased results. Although biases in completeness measures may contribute to this statistic, participants identified many barriers to achieving completeness, including difficulty collecting the first course of treatment, a lack of qualified staff at both the hospital and central cancer registry level, funding issues, burgeoning workload, lack of technology to assist in auto-consolidation of multiple records per case, insufficient IT support, difficulty with electronic pathology applications, weak state laws, and the complexity of managing the reporting from multiple nonhospital sources. However, participants had clear ideas about the methods they use to overcome such barriers, including developing and managing strong relationships with reporting facilities, implementing tools to monitor timely reporting, providing incentives, and strengthening regulations.

Achieving 12-month data standards



Best Practices: 12-Month Timeliness Standards

Registries currently prioritize the processing of records differently. All participating states follow different procedures, and few approaches to data collection, analysis, or reporting are common among registries. Registries are facing multilayered challenges in a complex and ever-changing environment. They function independently and follow informal procedures and *ad hoc* workflow processes, as well as use outdated management tools, while relying upon ever-shrinking resources and staffing. Every aspect of this project evaluated ways to improve the completeness and timeliness of reporting to meet the 12-month standard. The themes that emerged from these assessments include monitoring the progress and timeliness of central registry and facility reporting, 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 electronic pathology volume, developing guidelines to "grow a certified tumor registrar (CTR)," and strengthening state-reporting regulations.

General Best Practices Across Registry Operations

Many broad themes emerged from the study that could improve overall registry operations and, ultimately, timely reporting. Registry representatives have identified potential software improvements, such as auto-consolidation routines to improve the processing of the growing number of records received each year. More timely software releases and a standardized timeline for such releases would be beneficial.

More training and education are needed, and creative solutions would increase the number of trained professionals needed to staff the registries now and into the future. Project participants also asked for guidance in recruiting and retaining staff, implementing work-from-home policies, and standardizing educational opportunities for on-the-job training. In addition to the need for general software improvements and training, technical assistance should focus on Veterans Administration (VA) reporting, change management, improved facility reporting, and staffing.

The NPCR, in partnership with NAACCR and NACDD, is well positioned to reshape the cancer registry landscape by carefully considering the findings and recommendations of this project. NAACCR and NACDD expect to meet all deliverables noted in the original project by July 2020. Several immediate steps are outlined below.

Statistical Approach to Evaluating Completeness

Methodology

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. However, estimating how many cases are undetected is difficult. Cancer is distinguished by its relatively clear diagnostic criteria, yet cases often remain unidentified by the health care system. Several completeness assessments have been developed to estimate the accuracy with which cancer registries are able to identify all cases within their catchment areas. The Statistical Expert Panel considered all of the most commonly used completeness measurement approaches.

The Statistical Expert Panel carefully evaluated several models for estimating completeness of cancer reporting by central cancer registries. All the methods considered had disadvantages,

and aspects of the measures could systematically disadvantage some registries in achieving completeness. In short, no single method has emerged as a satisfactory measure. However, the group wishes to continue working on this problem and to conduct further analysis and modeling, with the intent of improving the methods currently in use. In addition, the Panel believes that reliable cancer incidence rates for the nation and states can be produced by applying statistical modeling to data collected by registries 12–13 months after diagnosis.

Model Evaluations

NAACCR and NPCR currently use the IMRR method, which defines completeness as the ratio of observed to expected incidence rates for each registry. The average value across all registries is 1, or 100 percent; values are distributed around this average so that roughly half of registries have values greater than 1, and roughly half have values less than 1. The observed incidence rate is calculated by totaling age-adjusted rates stratified by sex, race, and cancer site. 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—breast and prostate. Current race categories are limited to whites and blacks, but Hispanics and "other" categories also have been proposed for inclusion. Generally, minority race groups were included in the calculation only if the group comprised at least 10 percent of a registry's population. The expected number of cases is obtained by multiplying the registry's mortality rate by the national IMRR, again stratified by sex, race, and cancer site. The national IMRR uses five years of data to achieve a more stable measure, and the mortality rate calculation uses two years of data for most registries and three years for registries with fewer than 500,000 people.

This method relies on the assumption that incidence tracks mortality in a constant and universal manner by sex, race, and cancer site; however, this assumption is flawed, and much of cancer surveillance is concerned with demonstrating how this relationship is affected by such factors as screening, health care access, and care quality. One way of correcting for these complications 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 percent, 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 would be using only itself as a reference; thus, all registries would be 100 percent complete. The appropriateness of such an adjustment term is unknown and lacks any empirical basis.

The advantages of the IMRR method, as discussed by the Statistical Expert Panel, include its long tenure and familiarity within the registry community, as well as its transparency. The primary disadvantages include the constant IMRR assumption, instability of the measure for small registries, exclusion of the most common cancer sites, and a seemingly 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, but many registries in areas with large Hispanic populations frequently have not attained the level of completeness required to receive "gold" certification because of the limits of the race classification in the measure, even after the introduction of a Hispanic ethnicity factor. Another limitation is that a registry's completeness estimate can be sensitive to whether and how sex, race, and cancer site are stratified and which adjustment term is chosen.

With the existing IMRR 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. The IMRR method for measuring completeness also favors

larger states. Some registries are able to achieve completeness much more easily for reasons beyond the registry's control, such as the age structure of the population, its migration patterns, its ethnic composition, and its health care delivery patterns, whereas other registries may never obtain them.

Another method, called the modeling method, uses a hierarchical Poisson regression model, which includes spatial and temporal random effects across counties, as well as 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, this method models incidence as a function of cancer mortality, sociodemographic variables, and behavioral risk factors. Completeness is then taken to be the ratio of the observed counts submitted by registries to the expected counts from the model. This relative method assumes that completeness is 100 percent for the reference population, which is the entire nation. Half of the population will belong to registries with less than 100 percent completeness, and half will belong to registries with more than 100 percent completeness.

Preliminary results of the modeling method, using a single reference year, correlate moderately with the IMRR method and a moderately narrower range of estimates. The advantages of this method include counting all cases equally, regardless of site or race/ethnicity and incorporation of factors known to influence cancer rates for which data are available. The major disadvantage is that the model is complex and not transparent; its expected case counts are not independently reproducible by the registries. Another concern 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 likely will be an issue when estimating completeness of data from 2018—when significant changes in data collection were mandated—because reporting reductions due to procedural delays of more than 5 percent are anticipated. Similar to the IMRR method, the modeling approach has included estimates greater than 100 percent completeness, which must be ascribed to un-modeled variation.

The Statistical Expert Panel also considered three less common methods: the flow method, the capture-recapture method, and the internal method. The flow method for measuring completeness categorizes cancer cases into one of seven categories, five of which are easily counted. The remaining two categories, "missing" and "lost" cases, are assessed by estimating the probability that a patient is registered while alive, the probability that cancer is mentioned accurately on a death certificate, and the expected patient survival. The disadvantages of the flow method include expected differences in the survival of missing and lost cases compared with the records, the tendency of U.S. death records to require more than 1 year for processing, and the necessity of identifying properties that U.S. registries do not currently record. The advantage of this method is that completeness is intuitive and the estimate's upper limit is 100 percent.

The capture-recapture method compares cases reported to a central registry with those reported on a death certificate and algebraically derives the number of cases not reported to either location. However, this method is subject to timeliness and accuracy of mortality data, and the completeness measurement becomes a hybrid of incidence and mortality completeness that is not interpretable. Heavy reliance on death certificate–only rates and a lack of independence among sources also decrease accuracy.

The internal method uses the registries' past case counts as the sole input to predict future counts and assess the completeness of current counts. This method is straightforward to

calculate and does not rely on external data. However, the method measures consistency within a registry, rather than broad accuracy.

The Statistical Expert Panel also considered options to use existing data to produce national cancer incidence rates at 12 months after diagnosis, using statistical solutions to account for incomplete data. Feasible projections of national cancer rates are possible using the cases reported in the 12-month submissions and projecting the data to the anticipated final counts using the delay-adjustment methodology already widely used in U.S. cancer surveillance. Delay-adjustment uses the ratios of current to past case counts to anticipate cases still to be reported. Although delay factors for 24-month data typically are less than 5 percent, using this methodology for 12-month data likely would produce delay factors around 20 percent.

Recommendations

The Statistical Expert Panel recommends further analysis of the modeling approach to measuring the completeness of cancer reporting, which is likely to provide the most accurate estimate of completeness, because it accounts for many local factors that influence cancer rates. 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. Although the modeling approach is the best current option, it still needs further refinement.

Regarding the existing IMRR 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 meeting, as indicated in Table 1. In some cases, 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 could demonstrate how completeness scores might have changed in the past or will change in the future.

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
Total	**46**	**46**

The flow and capture-recapture methods studied are not recommended for further analysis at this time because of significant problems discovered with these methods. The internal method should be used only to evaluate 2018 data if reduced completeness nationwide occurs. The

internal method would be more useful than the modeling method in such a case because of its 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. The group believes that using data from NPCR states that are at least 80 percent complete and representing approximately 70 percent of the population could yield reasonably accurate incidence rates for the nation and states for public health purposes. Using appropriate statistical techniques, the data from the sample group would be adjusted to account for the cases not yet reported. These techniques would be based on results of the delay-adjustment modeling conducted by the National Cancer Institute (NCI), CDC, and NAACCR over the past several years.

Next Steps

Short-term plans for improving completeness estimates include generating historic completeness estimates for previous years using the modeling approach and comparing them to existing estimates; seeking ways to reduce residuals in the model; considering the implications of the false-negative rate for certification; ascertaining which states are systematically over- or under-predicted; developing communication materials regarding the modeling approach; and expanding the demonstration of IMRR sensitivity to include all registries. In the long term, the delay-adjustment–based method should be developed and refined further.

Examination of Registry Operations and Best Practices Regarding 12-Month Timeliness Standards

Methodology

A comprehensive evaluation of operations in central cancer registries participating in the NPCR program was conducted with eight registries that meet the 12-month data criteria, five that sometimes meet the criteria, and nine that do not meet the criteria. The criteria also were evaluated to identify best practices for collecting and processing cancer incidence data within 12 months of diagnosis. 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 be limited to, suggested enhancements to the CDC Registry Plus software suite, technical assistance needs, educational and training needs, staffing, external funding, and ePath reporting. Evaluation processes included quantitative assessments of all 22 participating registries, individual guided interviews with participating registries conducted by consultants with operations expertise, focus groups, and an in-person Operations Summit meeting with representatives from the 22 registries and other experts.

During the Operations Summit, results from the quantitative assessment, guided expert interviews, and focus groups were presented to lay the groundwork for the rest of the summit. A combination of brainstorming sessions, group discussions, and consensus-building activities were conducted to examine the advantages and disadvantages of various practices for meeting 12-month reporting standards, as well as review 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. After identifying viable solutions, setting priorities, and developing recommendations, participants were asked to carefully review and discuss the findings of the Summit with their staff and

stakeholders within their state. The participants reconvened at the NAACCR Annual Conference in Vancouver to further deliberate and reach final consensus on the recommendations.

Factors Influencing Whether States Meet 12-Month Reporting 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 seven years. Some factors that influence a registry's ability to meet the standard are inherent in the completeness measure, placing some states consistently at an advantage and others consistently at a disadvantage. External forces that influence timeliness are summarized in Table 2. In addition, some states have adopted practices that maximize their potential for meeting this criterion, but these practices may result in biased data.

Table 2. 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

Representatives from the 22 participating NPCR registries indicated that meeting the 12-month data standard comes at a significant cost to other operations and may require the introduction of unorthodox methodologies. Many participants reported setting specific work priorities to process cases that were included in the completeness calculations, while setting aside other cases not considered in the calculations, as a strategy to meet the 12-month benchmark. Participants also tended to believe that 12-month data were not actively used 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. Although these practices may not be incorporated by all registries, at least some of these practices are used by many—if not most—registries. Several registry representatives reported that using these tactics was the only way that they could achieve the current standard.

Factors found to show no correlation with 12-month completeness include percent of Commission on Cancer (CoC) cases, ability to produce modified or updated records, electronic reporting, physician and nonhospital reporting, paper reporting, use of electronic pathology reporting, submission time (December or January), and the 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 these factors beneficial, whereas those generally meeting the standard found them detrimental. Each registry seemingly has developed its own workflow practices—informed by a unique mix of experience, working relationships with reporting facilities, and selective use of available technological assistance—that allow them to reach a 24-month data standard, if not necessarily the 12-month endpoint. Registry metrics do not appear able to predict the quality or completeness of a 12-month data submission.

Identified Best Practices

State registry representatives openly and willingly shared a variety of methods used to attain 12- and 24-month timely reporting. From seemingly simple activities—such as developing relationships with reporting facilities—to more complicated workload processing, states rely upon various strategies, often based on their own unique situations. Many of the following best-practice techniques are shared among registries in each of the categories developed for this project.

Monitor Central Registry and Facility Progress: States discussed the importance of monitoring central registry progress toward data quality standards and submission timelines. Many registries use weekly management reports to track central registry timeliness, cases in the database waiting to be processed, and relevant quality control benchmarks. The presence of a "dashboard" within the central registry software systems allows users to generate reports quickly. Many states cited the implementation of a robust communications plan to establish expectations for reporting facilities and the ability to track facility reporting throughout the year to identify and correct problems at their inception. Some registries send letters to reporting facilities to inform them of their current completeness or use an annual "close-out" process, including submission of a form explaining any deficiencies and updating any information. Registry staff also noted the importance of establishing monthly reporting requirements, accepting only cases that pass edits, and using electronic reporting to assist in timely case submission.

Develop and Promote Good Relationships with Reporting Facilities: Several states' representatives cited developing and nurturing relationships between central registries and reporting facilities as beneficial. The methods used included providing positive feedback in the form of awards or reports, directly contacting facilities to discuss any problems, offering technical assistance, working with state professional associations, and partnering to provide education and training. Dedicated field staff also offer the opportunity to enhance a positive working relationship.

Develop Facility-Specific Displays or Record Formats for Case Reporting: Some registries have successfully increased completeness in nonhospital settings by developing NAACCR records containing only the minimal amount of data needed. Developing such records as an official NAACCR record type would eliminate the extra effort necessary by central registry staff. This record type should be geared toward office staff who can read the medical record and easily complete the required data items.

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 affect both central and hospital registry timeliness negatively. The establishment of a standard to limit software updates to a biannual timeline would be helpful to central and hospital registries, which could then anticipate and 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 electronic pathology Volume: Electronic pathology reporting is used widely—19 states (86%) participating in the project use at least some electronic pathology reporting. All 19 states receive electronic pathology reports before receiving hospital abstracts, and 16 states (84%) wait to process the majority of these cases until after they receive the hospital abstract. Only three states report processing electronic pathology reports as the reports are received. Many states wait to process electronic pathology reports until after receiving the hospital abstract for several reasons. Electronic pathology reports are not complete abstracts and can cause a significant number of edits that must be resolved by central registry staff. Electronic pathology software has some ability to identify reportable cases, but most of the received reports must be reviewed for reportability by registry staff to identify cases. Central registry software limitations prevent effective consolidation of incoming full abstracts from a hospital or facility-reporting source 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 would be valuable in improving timeliness.

Use Training Resources to Develop a "Grow a CTR" Program: In this assessment, state representatives identified a significant shortage of CTRs nationwide affecting staffing at both hospital reporting facilities and central registries. In response, 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 having training in anatomy and medical terminology—and the right mindset, which includes independence, a detail-oriented character, and an interest in data. Contact with health information management programs and colleges as sources for recruitment and presentations to public health, biology, or nursing departments can increase interest in the profession. Because standardized programs do not include exposure to central registries, connections must be developed in other ways, including offering internships and marketing the field. Participants suggested the development, delivery, and implementation of a marketing plan at a national level. Individual training and guidance are important, but readily available training materials would be beneficial. State registry representatives suggested that NPCR work with NAACCR to develop a central registry oriented basic training webinar series for CTR candidates or new CTRs that could be shared by all states. Participants also encouraged the development of a clinical practicum program within the central registry to fulfill NCRA's 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 among hospitals, students, and the central registry.

Strengthen State-Reporting Regulations: During the state interview process, several state representatives indicated their reporting laws had no penalties or way to compel timely reporting by facilities. This inability to enforce reporting laws can and does hamper state timeliness. Other states had improved enforcement of facility reporting or solidified reporting time frames with the help of either established practices or updated state laws. Two states require electronic pathology reporting 15 days after the record is complete, with some facilities reporting daily. Other states mentioned laws mandating monthly reporting or electronic-only reporting. The establishment of reporting laws that require electronic pathology reporting, shorten submission

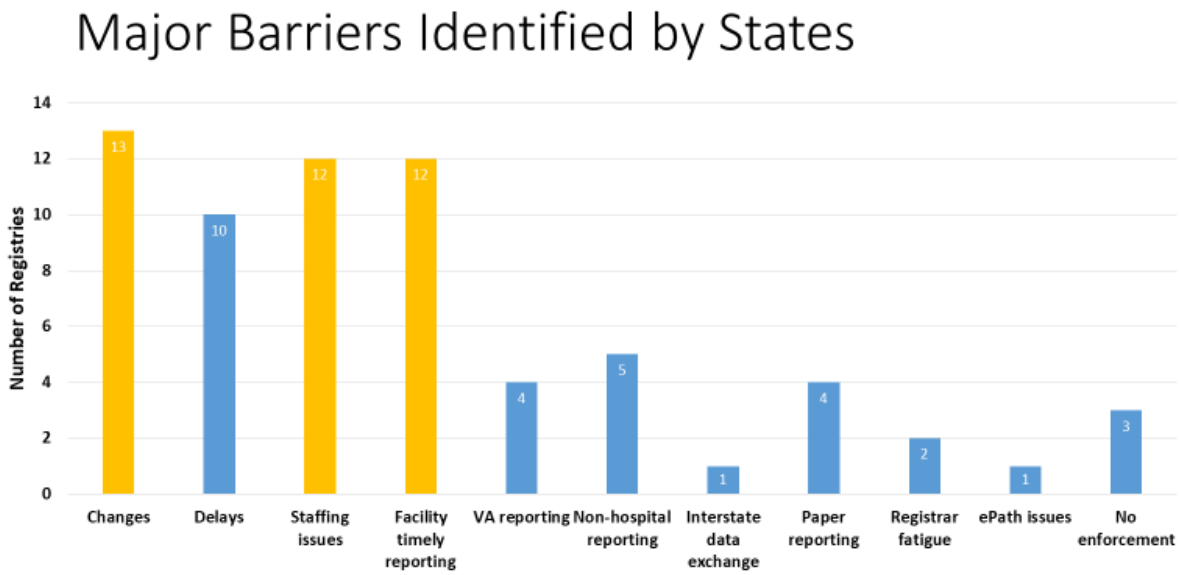
timelines, require electronic reporting, and provide enforceable penalties for non-submission all would be advantageous to central registries.

Assessment of NPCR Registry Operations and Recommendations for Broad Best Practices

Methodology

Recurring themes that are overarching issues for registry operations emerged from the discussions at the Operations Summit, the focus group discussions, and the qualitative assessments. Registries are able to identify critical resources and the qualities essential for their success, but face a reality in which resources are limited, staffing is challenging, and structural problems are significant. However, the data that registries collect are used robustly for public health, surveillance, and research. Figure 1 identifies factors that hinders the ability of registries to collect complete, accurate and timely data.

Figure 1.



Factors Affecting Registry Operations

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 but reduces the efficiency of day-to-day operations. Turnover in many registries is high, and many CTR staff accept better-paying or more flexible jobs. Many experienced CTR staff are retiring, and their replacements tend to be younger and less efficient; inexperienced new staff face steep learning curves, and it takes an estimated three new staff to complete the work of one senior employee. Registries recognize the need to focus on recruiting and retaining staff at all levels, as well as the critical importance of CTRs. As workloads increase, especially in light of the expansion of required data fields, staff are overburdened and burn out.

Registries also are faced with many software concerns. Central registries use a variety of software packages, but they rate only a few systems highly. Delays in software updates and spotty technical support create major challenges, and many current systems are unable to incorporate modified records submitted by hospitals without manual intervention from central registry staff—central registries need automated solutions to process these records efficiently. Equally important, standardized rules are needed for consolidating records on the same individual and/or cancer that are obtained from multiple reporting sources. Eighteen of the 22 participating states report using some type of limited auto-consolidation; only two states have full auto-consolidation, and one has no auto-consolidation. Only through developing the ability to auto-consolidate records in a standardized fashion will registries be able to make progress in obtaining accurate and timely data.

External forces also significantly affect registries' ability to report in a timely fashion. Hospitals are understaffed and suffer from problems similar to central registries, such as significant staff turnover, a lack of trained CTRs, expanding data requirements, increasing reporting requirements, and a lack of funding. In addition, hospitals are undergoing structural changes through mergers and acquisitions. Community hospitals are now 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 by hospitals and non-hospital reporters has become common, and staff in these facilities lack training and sometimes access to the necessary records. Nonhospital sources—such as outpatient clinics, physicians, radiation centers, pathology laboratories, and ambulatory surgery centers—generally are slow to report and submit incomplete data of poor quality.

Overall, registries have found that laws and rules positively influence timeliness, as do the Rapid Quality Reporting System (RQRS), interstate data exchange, and fines and penalties. However, many participants thought that their states' laws lack "teeth," limiting effectiveness. RQRS is viewed positively by a slight majority of participating registry representatives, but it also presents serious issues. Outsourcing and contracting also have negative effects on registry operations. Central registries must work collaboratively with hospital and nonhospital reporters alike. However, the challenges that exist for central registries also exist for external reporters. Any solutions for central registries must consider the needs of hospital and nonhospital tumor abstractors.

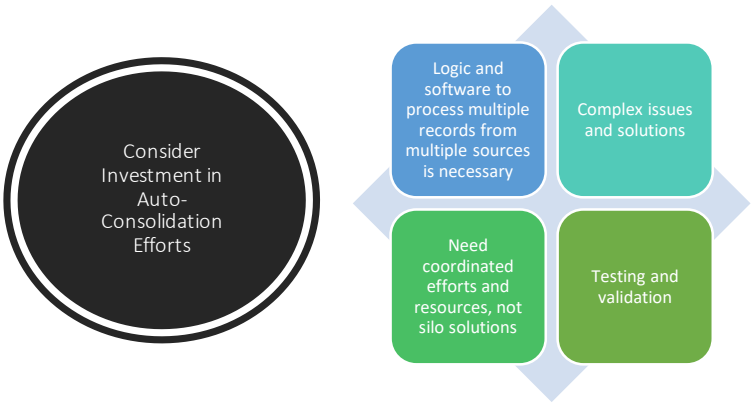
Participants also identified several technical assistance needs related to software improvements, staffing, education and training, and outreach to medical associations and the CoC for assistance with physician and facility reporting and VA reporting. The new 2018 reporting requirements have challenged registries' ability to effectively train current staff to meet these changes.

Identified Priorities

From the discussion above several priorities were identified. **Staffing** is a critical problem. Significant effort and resources from NPCR, in conjunction with other stakeholders, must be used to address this issue. Focus is needed on recruitment, training, and retention. 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 time to focus on **more efficient operations** such as processing of additional data sources (claims, pathology and discharge data), and the development and implementation minimal abstract for non-hospital sources that would be improved once supplemental reports are received. Without new resources and more staffing, the ability of registries to report high-quality data in a timely fashion

is at serious risk. Additionally, **training opportunities** for current central staff and external reporters are needed, particularly given the rapidly changing reporting requirements and complexity of cancer as a disease.

Timely software 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.



Participants emphasized that the main strategy for improving collection of high-quality data from hospital reporters is **increased communication**—although some hospitals use contractors, the hospital retains the ultimate responsibility for data quality.

Efforts should be made to develop basic **training for new cancer reporters** at both the central and facility levels, and support for 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. Continued training on the 2018 changes is needed, and additional software training should also be provided.

Additional issues briefly raised in the comprehensive assessments and during the Operations Summit that can affect meeting the 12-month standard include the methods for processing modified "M" records, the timeline of the NPCR Program Review Meeting, rapid case ascertainment, and the cost per case.

Recommendations

First and foremost, registries reported an appreciation for NPCR's commitment to more open communication and dialogue among its leadership, staff, and state registries. Participants recognized this project as a critical step to solving some of the problems facing central registries, and the project generated optimism among registries that real solutions to serious issues will be forthcoming. **Expanding such opportunities for discussion among registries and NPCR staff was encouraged strongly by the study participants.** More face-to-face time among Registry Directors and between Directors and NPCR leadership is particularly important. The ability of registry leaders to **share best practices, work on common problems, and focus on emerging opportunities and challenges as a group on a regular basis** also is

important. Registry representatives also recommended additional future collaborations between NAACCR, NACDD, and NPCR, with the same level of efficiency, creativity, and openness as this project.

This project has identified many potential areas for recommendations and next steps that can and should be collated, developed, and tested as Best-Practice Guidelines. In addition, much work still needs to be done by the Statistical Expert Panel to refine and improve the methods for estimating the completeness of reporting at 12 and 24 months. Finally, many recommendations reflecting broader change evolved from the identification of weakness and barriers and will require development of new tools and practices.

A Better Measure of Completeness: 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 majority of registries will see no meaningful difference in using this method instead of the IMRR; at the margins, 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, increasing the number of states that meet this criterion. Although this assessment emphasized 24-month data, the method should also be applicable to 12-month data.

Recommendations for Best-Practice Documents

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

Registries use 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 would facilitate timeliness assessments. Ideas expressed by the registries around this concept should be organized and developed into a library of tools. The idea of developing a communication plan to provide feedback to reporting facilities also was suggested.

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. This best-practices document should detail strategies for developing good working relationships between central registries and reporting facilities, based on the experiences of states currently using such strategies successfully.

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

Development of a limited record containing the minimal amount of data required for incidence reporting would reduce the burden on nonhospital reporting sources while still maintaining compliance with state-reporting requirements and capturing a significant amount of case detail. This new, limited record is recommended for dermatology and other medical specialty reporting and would be based on existing models and a new minimal record type for 12-month reporting that would focus on data items necessary to calculate early incidence rates. This recommendation would require buy-in from standard-setting organizations, as well as resources to support development of the record itself and the necessary software.

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

Establishing a standard to limit software updates to a biannual timeline would allow central and hospital registries to plan for updates and incorporate the resulting workload into standard registry operations. Again, this recommendation would need buy-in from each of the standard-setting organizations and software vendors and would require adherence to the 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.

Recommendation 5: Best Practice Procedures to Effectively Handle Electronic Pathology Volume

Electronic pathology reporting is widely used among central registries, but most states stockpile cases and do not process them until they receive the associated hospital abstract. The number of electronic pathology reports submitted to central registries is increasing, despite the fact that many are not reportable cases. Many elements are necessary to improve electronic pathology reporting efficiency, and these improvements would best be served by a new summit meeting with central registries and possibly software vendors. A LEAN analysis of electronic pathology reporting is also recommended.

Recommendation 6: Best Practices Guidelines for a "Grow a CTR" Program

The shortage of personnel trained to work in population-based registries, especially the lack of experienced CTRs, was the major problem identified by almost all central registries participating in the project. This recommendation is to develop a best-practices document detailing available resources and providing an outline of recommended recruitment and retention tactics, and training materials 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 such a document.

Recommendation 7: Best Practices to Strengthen State-Reporting Regulations

Strengthening and clarifying state-reporting regulations could have a positive impact on registry timeliness. This recommendation is for a best-practices document that would detail each of the provisions above and provide examples of existing state laws this would entail a review of examples from participating states and from states that are not currently part of the project but may have pertinent examples to contribute.

Recommendations for Broad Change and Infrastructure Improvement

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, compounded by an additional increase in volume as more efficient ways of electronic reporting become available to these sources and registries' staffing and funding are reduced. Instead of processing these partial records upon receipt, most registries stockpile them until the majority of hospital abstracts have been received. They then try to identify missing cases and piece together a case report from inadequate data. Although this process is an attempt to manage the overwhelming workload, it contributes significantly to reporting delays and reduces the overall timeliness of registry data.

Software to process and consolidate multiple partial records on the fly could help manage these problems, and a few cancer registry systems already have begun using such "auto-consolidation" software. A thorough review and comparison of the logic employed in these systems could provide a foundation for algorithmic software modules that could be used by all registries. In addition to reducing the workload for staff, auto-consolidation software could allow records to be processed systematically in real time, thus improving reporting timeliness.

Investment in the development of auto-consolidation and auto-coding software is a major commitment of time and resources. Partnerships with other cancer agencies should be considered to make this project a priority and a shared responsibility; collaborative development also would create a consistent system and standardized practices.

Education

The most significant call for action among the states participating in this research was to address the staffing shortages and expand and improve training opportunities for potential and existing CTRs and other registry staff. These problems are not solved easily 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. Although current CTR training programs are housed in community colleges and vocational training programs, participants 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.

Workflow process

This assessment demonstrated clearly that few standards are in place for processing and managing central registry operations. All 22 participating states vary in how they manage their registry operations. For example, registries currently prioritize the processing of records differently. Some registries process electronic pathology reports first, whereas others process them last; neither method was associated with the 12-month reporting compliance. An analysis of the timing and order of processing the different types of source records, based on established process improvement techniques like LEAN Six Sigma, may elicit efficiencies that could be adopted by all registries. As health care delivery becomes increasingly complex and integrated, consistent and efficient processes across all central registries will be critical.

Evaluation of certain data items

Many participants spoke of the overwhelming workload associated with collecting information on incident cancer cases, because the data items have increased in number and complexity exponentially over the past few years. Although many of these new data requirements correspond to changes in oncology and patient management, some of the data are of limited value because of paucity of data, limited resources, and timing issues. One major barrier to the collection of timely data is the requirement for collecting treatment information. Most state regulations require hospitals to report on the initial course of treatment within 6 months of diagnosis, but current therapy regimens prolong initial therapy past this window, resulting in incomplete information provided to registries and delays in reporting. In addition, treatment data are highly unreliable on a population level, and data from population-based cancer registries are rarely used in research studies without significant supplementation or alteration. These factors make treatment data very costly to obtain and of limited value. Many registry representatives at the Operations Summit advocated strongly for eliminating collection of treatment data. Although this may seem to be an audacious suggestion, careful consideration of the concept is warranted. With an increasing demand for timely data despite diminishing resources, this proposal could significantly increase compliance with the 12-month standard.

Operations Summit participants also strongly argued for collecting simplified stage data, which is vital to monitoring many public health objectives and progress toward cancer control objectives. The constantly changing definition of cancer stage and complex data collection requirements have resulted in a data set that currently lacks continuity over time and contains many “unknown” values. Simplifying stage data collection could ease the efforts of North American registries, increase comparability within the United States, and make NPCR data compatible with data from other parts of the world. In addition, eliminating treatment or stage requirements on a site-by-site basis could produce positive effects with less effort but may introduce unanticipated complexities in the data collection. A thorough assessment of other variables currently collected by NPCR registries could result in additional efficiencies and should be considered.

Next Steps

- This project elucidated many opportunities for improving the timeliness, completeness and accuracy of cancer reporting in the United States. The NPCR Program will be focusing on the following priorities identified during the course of the project in the coming months: Continue to assess completeness measures and recommend a method that will be suitable for public health purposes. Focus will be on testing methods in smaller states and states with racial/ethnically diverse populations. Methods will be vetted with states and stakeholders.

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

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

- Bring Registries together at workshops in Atlanta to discuss best practices and share knowledge. The focus will be on comparing and contrasting different registry operations methods to learn which methods are the most effective in different settings.

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

Closing Remarks

This report reflects an overview of the major activities conducted on this project this summary report includes the findings from each arm of the project through September 2019. A final report will be prepared at the completion of this project as work continues through July 2020.

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) 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 than7,000 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.