NPCR's State of Program Evaluation

DP17-1701 Progress Report 2022

Division of Cancer Prevention and Control

Cancer Surveillance Branch

Operations, Research, and Technical Assistance Team (ORTAT)

The CSB Evaluation Sub-Group

Paran Pordell (CSB Lead Evaluator)

Corinne Fukayama (CSB Evaluator)

Sofia Huster (CSB Evaluation Fellow)

Emily Nethercott (CSB Evaluator)

Table of Contents

DP17-1701 NPCR Program Evaluation

Introduction/ Background

In 2018, the National Program of Cancer Registries (NPCR) Evaluation Working Group (NPCR EWG) created an evaluation plan[1] based on *CDC's Framework for Program Evaluation*[2] to monitor and evaluate NPCR priorities, strategies, and activities under the DP17-1701 cooperative agreement. NPCR evaluation goals were to increase completeness, timeliness, and quality of 12- and 24-month data submitted by recipients and learn more about NPCR best practices, facilitators, and barriers to effective registry program implementation. The main drivers for producing the plan and conducting the evaluation were to: (1) demonstrate NPCR impact and value; (2) improve state and territorial registry program operations, management, and reporting; (3) strengthen CDC's accountability to the public and U.S. Congress, and recipient accountability to CDC; (4) enhance understanding of national and local cancer burden through surveillance focused on demographic and geographic distribution; and (5) inform future cancer surveillance program planning and public health policies.

Using the evaluation goals, drivers, NPCR Program Standards, and logic model as the foundation for evaluation activities, the NPCR EWG compiled a list of 30 (later revised to 25) process and outcome evaluation questions (see appendices) focused on staffing and recipient infrastructure, education and training, building and strengthening partnerships, program monitoring and evaluation, funding, customer service, technical assistance, and guidance to recipients. The intent of this report is to share our evaluation progress and accomplishments to date with internal and external partners and provide tangible recommendations that will help identify **DP22-2202 NPCR evaluation priorities.** These recommendations will be used to draft

the **DP22-2202 Evaluation Plan,** which will serve as our **roadmap for conducting NPCR evaluation activities.**

Methods

CDC, RTI, and NACDD/NAACCR evaluators fully or partially answered prioritized evaluation questions by conducting primary or secondary data analyses. For this report, four evaluators conducted extensive document reviews of DP17-1701 evaluation briefs and reports. A question was defined as *fully answered*, if all question sub-components were answered or the question was adequately addressed based on document reviews conducted by at least three CDC evaluators. Questions were defined as *partially answered*, if at least one component of the question was adequately addressed based on document reviews conducted by at least three CDC evaluators.

Internal and external evaluators analyzed NPCR Program Evaluation Instrument (PEI), DP17-1701 cooperative agreement information, recipient financial documents (e.g., FFRs, internal CSB budget spreadsheets, GMM forms, budget justifications, annual Notice of Award (NOA) documents), Registry Plus help desk tickets and emails, USCS website use, Data Evaluation Reports (DERs), NPCR-CSS Data Quality Compliance Reports, and other available data sources to answer evaluation questions (Appendix, Table 14). Additionally, RTI, CDC, and NACDD/NAACCR study teams performed primary data collection using quantitative surveys, focus group discussions, and in-depth interviews with NPCR recipients and CSB staff. RTI staff participated in recipient site visits (in-person and virtual due to COVID-19) to learn more about cancer registry operations, staffing, costs, and efficiencies.

Results

Staffing and Grantee Infrastructure

Average Number of Registry Staff, Roles, and Where Registry Housed

We reviewed 17-1701 FOA application submissions (2017), approved budgets (2017 and 2018), and annual progress reports (2018), and analyzed 2017 Program Evaluation Instrument (PEI) survey results from 50 NPCR-funded states and territories to identify which organizations housed cancer registries. The majority (84%) of recipients were organized within the state health department (*n* = 42) while 14% were housed within an academic institution (*n* = 7), and 2% (*n* = 1) at a hospital association (p.1).[3] Recipients had an average of **9 NPCR-funded personnel** in each registry and staff were categorized as coordinators, scientists, program managers, informatics and IT support personnel, upper management, administrative support personnel, policy and communications personnel, and students (p.7).[3] NPCR-funded personnel contributed an average of **72% of staff time** to NPCR registry activities for all recipients.

Based on PEI 2017 results, 17-1701 FOA application, and budget justification document reviews, it appeared that most cancer registry staff were arranged by operational duties and/or registry roles and responsibilities with some staff serving in multiple registry roles (e.g., program director and epidemiologist). Year 2 DP17-1701 budget justifications from annual progress reports (APRs) indicated a total of 283 personnel identified as completing registry operations duties. The 2017 PEI results identified a total of 368 Certified Tumor Registrars (CTRs) employed in registries as full-time employees, contractors, or consultants (p. 9).[3] CTR results do not include other personnel in the registry that are CTRs such as program directors, program managers, or epidemiologists.

Twelve registries employed staff that served dual roles. For example, there were seven program directors, one co-program director, five program managers, two IT support staff, and one epidemiologist who were also CTRs.[3] Based on PEI 2017 results and budget justification reviews, most registries lack robust IT support. While employee cross-training may be conducted in some NPCR-funded registries as part of standard operating procedures, cross-training was not mentioned as a widespread practice among cancer registries.

Expertise, Skills, and Other Staffing Characteristics

Coordinators and CTRs comprised the highest proportion of staff at both NPCR-funded and dually funded 17-1701 registries, followed by scientists, program managers, and administrative support; the smallest proportions of staff were informatics personnel, policy and communications personnel, students, and advisors (p. 9).[3] Additionally, results from our analyses confirmed staffing shortages across all registry positions. Challenges contributing to personnel shortages were burnout, retirements, and lack of succession planning. Some registries experienced high rates of turnover without qualified applicants to backfill vacant positions.

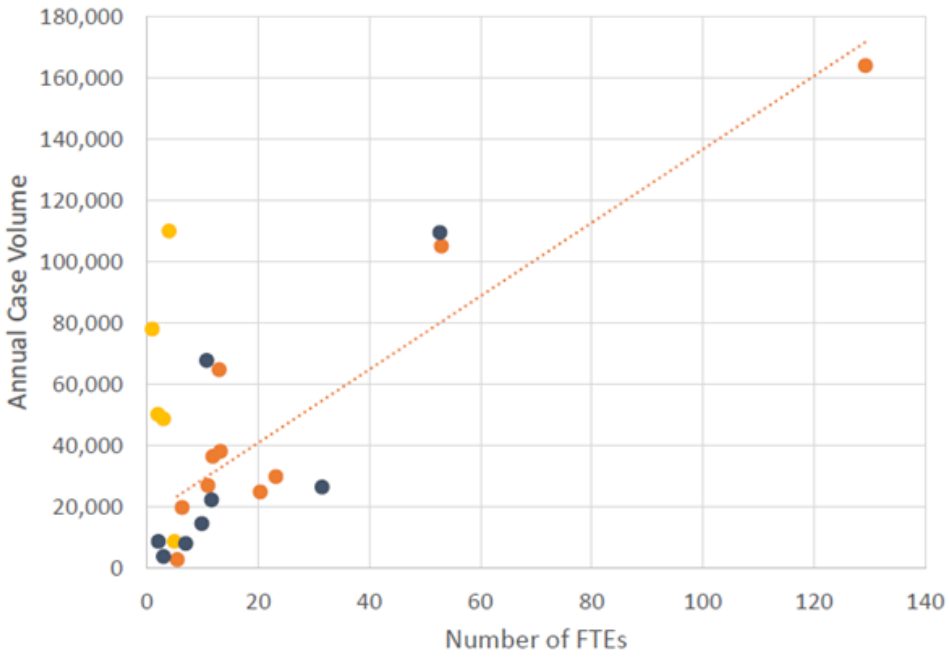
CTR staff had the highest rates of turnover in comparison to other position vacancies, due in part to increasingly competitive compensation offered at hospitals and contracting agencies (p. 62).[4] Salaries for key positions (e.g., PD, CTR, ETC, epidemiologist) varied across registries. In a review of 88 NPCR-funded CTR salaries in 17-1701 applications, the average salary was $57,600 (p. 9).[3] In contrast, the average salary of CTR-credentialed cancer registrars, according to the National Cancer Registrar's Association (NCRA), was $72,720.[15]

NPCR registry directors exhibited a wide range of skills, expertise, and qualifications. Based on information gleaned from 17-1701 budget justifications and applications, program

directors had between <5 to 20+ years' experience. It was not uncommon for registry directors to be new to cancer registry operations. We found an array of educational attainment among registry directors; some acquired associate's, bachelor's, or master's degrees while others held doctoral (MD, PhD, DrPH) degrees.

Data were not readily available on average years' experience or average qualifications of other registry staff. CDC/NAACCR/NACDD examined the relationship between total staff size and caseload. There was a positive correlation between staffing and case volume, with most registries employing 10 or fewer staff and handling fewer than 30,000 cases (Figure 1) (p. 182).[4]

Figure 1. *Relationship between Staffing and Case Volume*



Caseload productivity varied. For example, one registry with 10 FTEs had approximately 70,000 cases per year and usually met the NPCR Advanced National Data Quality standard, while another registry with 10 FTEs had fewer than 30,000 cases per year and rarely or never met this standard. 2,500 cases per FTE appeared to be the average benchmark across all central cancer registries (p. 96). [4]

Management and Operation of Registries Through Partnerships

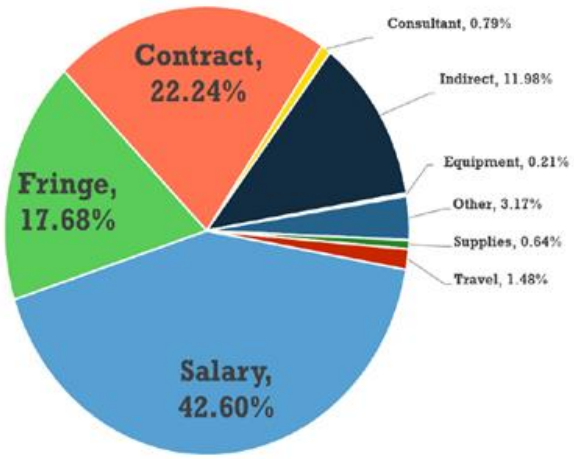
Central cancer registries were managed and operated in health departments (n=42), academic institutions (n=7), and health associations (n=1) (p. 10).[3] In some instances, a state health department received NPCR funding, but another entity implemented registry management and operations on behalf of the state. For example, Delaware's health department used a large portion of funding to contract with a consultant for registry operations. Rhode Island Department of Health allocated a substantial percentage of funding to a health association to conduct cancer registry management and operations.

One academic institution applied for funding as the bonafide agent, and the university implemented several subcontracts with academic institutions and health departments to support registry operations for each of the jurisdictions (p.10).[3]

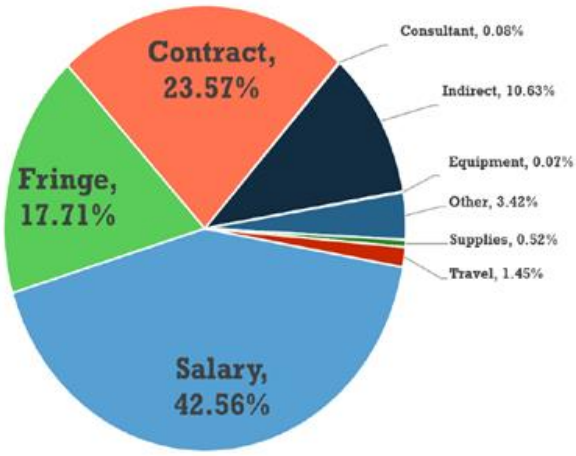
Breakdown of 17-1701 Recipient Funding Allocation

Recipients allocated the greatest proportion of their DP17-1701 NPCR funding for personnel costs in 2017 (42.60% for personnel/salaries and 17.68% for fringe benefits) and 2018 (42.56% for personnel/salaries and 17.71% for fringe benefits). Very few recipients requested funds for equipment and consultants. However, some recipients used funds for contracts to pay for consultants. The pie charts below illustrate the proportion of total recipient funds used in DP17-1701 year 1 (2017) and year 2 (2018) for each budget category (p. 2).[3]

Graphs 1 & 2. Allocation of NPCR Funds for 2017 and 2018



Graph 1. Allocation of Funds for 2017



Graph 2. Allocation of Funds for 2018

Sources of Supplemental Funding from Non-CDC Sources

During the DP17-1701 funding cycle, state funds were a common source of non-CDC or supplemental funding for NPCR-funded registries. Other sources of additional funding included the Surveillance, Epidemiology and End Results (SEER) program, block grants, earned funds from conducting research projects, and in-kind resources.[4] Non-CDC financial and in-kind resources will be covered in greater depth in the **Funding-Related** subsection.

Education and Training

The CDC/NAACCR/NACDD Best Practices project[4] asked registries about their education and training needs through quantitative assessments, guided expert interviews, and focus groups. Two key themes emerged: (1) recruitment, retention, and training of registry staff; and (2) expanding training opportunities for current staff and hospital/facility reporters. Newly hired staff faced a steep learning curve to cover the work of departed staff. Registries estimated that when an experienced staff member left for another opportunity or retired, it took three new staff to complete the same quantity and quality of work.

Training new staff is critical, yet it also takes time away from the efficiency of day-to-day registry operations. To save resources, registries desired assistance with general training materials for new CTRs and staff, leaving registries more time to focus on specialized or complex training topics. Other needs included a clinical practicum program within the CCR to fulfill the NCRA requirement and additional training in registry operations for new program directors. Moreover, registries described additional topics that could benefit registry staff and hospital/facility reporters during CDC/NAACCR/NACDD interviews and focus groups.

Topics included 2018 reporting requirements, Registry Plus software, the use of hematopoietic database and manual, and radiation coding. A major challenge identified by registries entailed keeping training materials up to date to satisfy evolving reporting requirements and training needs.

Program Monitoring and Evaluation

Cancer Registry Management, Implementation, and Evaluation Barriers and Facilitators

One of the objectives of CDC and RTI's feasibility assessment of electronic reporting[5] by registries and CDC/NAACCR/NACDD's Best Practices Final Report[6] was to identify barriers and facilitators that recipients encounter when managing, implementing and/or evaluating their cancer registry programs. Evaluators summarized results by subsection below.

Managing Cancer Registry Programs

NPCR recipients identified a variety of program management barriers and facilitators. Staffing, legislative and regulatory operations, and the COVID-19 pandemic represented key topic areas explored during focus group discussions and interviews that had implications for ongoing cancer registry management and operations. Throughout all assessments, the single

most important barrier identified to managing a successful cancer surveillance program was a critical shortage of trained, experienced, and available personnel to work in state and territorial population-based cancer registries. While onboarding new staff requires extensive on-the-job training, it entails a tremendous time commitment and reduces the efficiency of registry day-to-day operations.[4]

It is worth noting that a significant shortage of CTRs nationwide impacted staffing at hospitals, facilities, and central registries (p.7).[6] Legislative and regulatory successes and challenges encountered when managing cancer registry programs were explored during interviews with ten registries. Many registries review, attempt to revise, and enforce their laws and public health rules to advance strategies to improve case reporting and timeliness and keep registry operations current in a changing environment. In most cases, registry staff avoid amending laws and rely on updates to administrative codes and regulatory rules to move their agenda forward.

Registry staff identified several overarching themes for registry success:[6]

- Embrace the value of laws and regulations
- Broad laws with authorization to the executive branch allow for flexibility
- Non-cancer registry laws around hospital licensing and certificates of need may be helpful
- The ability to use your administrative codes and regulatory rules proactively keeps you nimble
- Implementing partner relationships are still critical for success

Interview participants specified a variety of challenges associated with legislative and regulatory changes for registries. Challenges included:[6]

- High political risks when amending laws
- Time consuming, cumbersome processes
- Lack of political will to enforce penalties
- Confidentiality and privacy issues
- Funding and budgetary concerns

Achievements and challenges encountered by registries with implementing legal and regulatory strategies related to cancer surveillance are discussed in greater depth on pages 86-91 of Best Practices, 2021.[6] Another major challenge to effective program management faced by cancer registries was the COVID-19 pandemic. For many registries, the COVID-19 pandemic resulted in a significant disruption to registry operations. Registries were forced to be agile and adjust very quickly without any prior experience dealing with a similar public health emergency.

Some key barriers for registries included: transitioning to remote work, finding a balance between work and home life, maintaining productivity, training and onboarding new staff, reallocating budgets and resources, and ensuring confidentiality of cancer data and information. However, most registries performed extremely well and were able to implement policies that facilitated cancer registry management. These included implementing remote work policies, balancing human needs with business needs, and finding ways to enhance teambuilding and communication (p. 137-147).[6]

Implementing Cancer Registry Programs

Registries cited several barriers and facilitators to implementing cancer registry programs during a registry feasibility assessment of electronic reporting and automation of registry processes led by RTI and CDC in 2018.[5] RTI contractors conducted focus group discussions and in-depth interviews with staff to identify factors that impact four cancer registry domains: electronic reporting, cost, case ascertainment and data quality, and timeliness outcomes. Based on a summary of participant responses, the study team used the following working definition of **electronic reporting**: *"receiving data from reporting sources via secure and encrypted mechanisms and in a standardized format (such as NAACCR format or HL7 CDA for*

Hospitals/Physicians, HL7 Version 2 format for laboratories), where the CCR can create a completed abstract that meets quality thresholds with minimal need for manual data entry."[5]

Study participants identified staffing, technical expertise, legislation and regulation, capacity of and sub-optimal quality of reporting sources, increasing case volume, data requirement changes from standard setters, software, and lack of support for software implementation as barriers to implementing cancer registry programs. Registries discussed partnerships, funding availability, interstate data exchange, legislation and regulation, having a registry champion, good IT systems/infrastructure, and management support as facilitators to implementing cancer registry programs (tables 1a and 1b).[5] Staffing, technical expertise, IT systems/infrastructure, staff training, interstate data exchange, capacity and quality of reporting sources, software and support for implementation, and partnerships impacted registry outcomes across all domains. CDC/NAACCR/NACDD's Best Practices report and CDC/RTI Feasibility Assessment of e-Reporting projects yielded similar results for cancer registry legislation, staffing, IT systems, infrastructure and support, case volume, funding, software, support for software implementation, and need for software automation.

Table 1a. *Facilitators and Barriers That Affect Registry Outcomes*

	Electronic Reporting	Cost	Case Ascertainment and Data Quality	Timeliness	Comments
Internal Factors					
Staffing	X	X	X	X	▪ Need for staff positions in IT, programming, quality assurance, and data processing; turnover and salary concerns ▪ Limited staffing cited as a reason many registries in smaller states are not looking to expand electronic reporting, and as a barrier to implementing or onboarding providers for Meaningful Use
Technical expertise	X	X	X	X	▪ Lack of technical skillset adds time to data processing ▪ Many registries lack dedicated IT role
Having a registry champion	X		X	X	▪ Leaders with longstanding knowledge of registry processes often drive the direction of new legislation and process improvements
IT systems/ infrastructure	X	X	X	X	▪ Some registries have remote access to a virtual desktop for electronic abstraction directly from sources
Staff training	X	X	X	X	▪ Use of online training videos for reporters who abstract cases helps reduce training load
Management support	X		X	X	▪ Guidance and long-term commitment from registry management supports the implementation and sustainability of registry processes

Table 1b. *Facilitators and Barriers That Affect Registry Outcomes*

	Electronic Reporting	Cost	Case Ascertainment and Data Quality	Timeliness	Comments
External Factors					
Legislation and regulation	X			X	▪ Most registries have legislation requiring electronic reporting, though legislation is not always enforced and does not always specify what qualifies as electronic; many registries actively work to update laws to better encourage electronic reporting
Interstate data exchange	X	X	X	X	▪ Interstate data exchanges supports completeness as registries obtain data on residents who seek care outside the registry geographic coverage area
Capacity and quality of reporting sources	X	X	X	X	▪ Smaller physician offices or laboratories often do not have the capacity, motivation, or resources to start reporting electronically
Funding availability	X				▪ Some registries have multiple funding sources to help them achieve economies of scale or electronic reporting
Volume of cases received		X	X	X	▪ Increased volume often increases time spent on data processing and consolidation, and registries emphasized need for automation in processing to reduce burden of visual review; Meaningful Use has often led to this increased volume
Software and support for implementation	X	X	X	X	▪ Although data often come in electronically, registries do not have the software to support a fully automated electronic reporting system
Partnerships	X	X	X	X	▪ Partnerships, collaboration, and knowledge sharing across registries and organization supports registries with key functions and improvements to processes

The CDC/RTI Feasibility Assessment of e-Reporting [5] generated the following recommendations from participants (note that each recommendation includes a CDC status update in parentheses):

- Establish a platform for sharing best practices between registries (created via short-term and ongoing workgroups, forums, webinars, and list-servs)
- Create workgroups to discuss issues with electronic data exchange (created via NPCR advisory committee and CDC/NAACCR/NACDD workshops)
- Improve CDC manuals and training materials for software (in process)
- Enhance IT support for smaller-volume registries (case-by-case TA provided to the extent that IDSAT resources are available for Registry Plus software suite only)
- Provide seed funds to registries to conduct innovative pilot studies or software modifications (partially accomplished via availability of NPCR DMI year 5 funds)
- Streamline cancer reporting requirements to avoid iterative changes (dependent on standard setters coming to consensus)

Rutgers LSS students conducted in-depth interviews with cancer registries in four states to identify barriers and facilitators to the electronic pathology (e-path) reporting process. Table 2 displays e-pathology benefits and drawbacks (p. 69).[6]

Table 2. *Electronic Pathology Benefits and Challenges Reported by Registries*

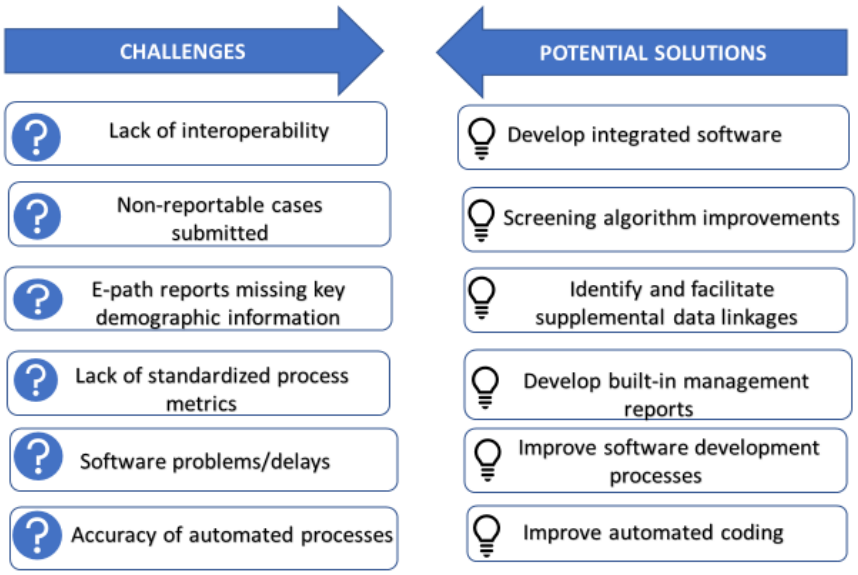
Benefits				
	REGISTRY A	REGISTRY B	REGISTRY C	REGISTRY D
Identification of missed cases	Y	Y	Y	Y
Quality control	Y	Y	N	N
Collection of information missing from reports received from other sources.	Y	Y	N	Y
Education and training	Y	Y	N	N
Hospital case finding audits	Y	N	N	N
Challenges				
	REGISTRY A	REGISTRY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

For benefits, all four registries reported the identification of missing or otherwise unreported cases as the primary benefit. Moreover, most registries benefited from using e-path reports to supplement missing or non-specific information pertaining to cases from other sources. Registries that processed all e-path reports indicated an additional benefit of validating and correcting case information from other sources (e.g. date of diagnosis, histology, site-specific data items, treatment dates).

In terms of challenges, lack of interoperability or ‘communication’ between software systems was a challenge identified by all four registries. Examples included (1) inability of CRS

plus to import or process HL7-formatted records; (2) inability to filter e-path reports in eMaRC Plus based on cases already in CRS Plus: (3) and lack of edits built into eMaRC Plus. Additionally, all four states require some degree of manual effort for processing e-path reports and following back to the data sources to acquire additional information. Figure 2 displays potential solutions to the challenges identified.[6]

Figure 2. *Electronic Pathology Reporting Challenges and Potential Solutions*



In January 2020, CDC, NAACCR, and NACDD implemented a project to evaluate best practices in automated data consolidation within the CCR setting. Data item consolidation created a substantial burden as part of the cancer case review and data cleaning process. Due to the resource burden (time, staff, software) required, registries explored enhanced automation options (p. 95)[6]. The value of the automated data consolidation rules seems to lie in the ability to improve the registry workflow, take advantage of efficiencies within the process, and give trained staff the ability to better focus their energy on the core work of confirming final data value decisions, especially among the most critical and/or newer data items.

This study demonstrated that before adopting any specific automated consolidation rules, it will be important that CCRs test the rules using actual registry data to determine which rule works best for specific data items. As standard setters and CCRs continue to evaluate their preferences for how much automation to include in the data consolidation process, a key consideration will be the trade-off between the often resource-intensive manual review and the ability of more automated methods to produce the preferred answer for a data item. If at any point automated data item consolidation fails, the incoming abstract is sent to a pending system for manual review. The thought process behind sending records to pending is that the records will be reviewed prior to adding to the database and fully disposing of the records.

However, once the data are added to the database, registries may not have the time or resources to go back and review cases. The trade-off values will differ for data items, and CCRs will likely have different levels of tolerance for what they are willing to accept based on their resources and workload. Many registries exhibit resource limitations and will not be able to invest ample staff time to conduct visual reviews, which can directly impact cancer data quality. Additionally, for multiple reasons, CCRs may have different preferences and levels of acceptance related to implementing and routinely using automated data consolidation.

For example, higher volume CCRs may be more willing to adopt full automation rules while lower-to mid-volume CCRs may prefer more moderate levels of automated data consolidation that send more cases in pending status for final manual review (p. 95-109).[6] The choice between early or late adoption for registries regardless of case volume depends on expertise, technology, management support, and other related sources being readily available within the registry environment, as adopting automated processes depends on major systems-level changes.

Evaluating Cancer Registry Programs

Barriers and facilitators to evaluating cancer registry programs was not explored in depth as part of priority evaluation activities during the 17-1701 funding cycle due to resource limitations. For registries, barriers may consist of lack of staff expertise and time, limited funding, too broad of an evaluation plan with too many questions, and lack of accountability. For CSB, barriers to evaluating cancer registry programs included staffing, funding, and competing priorities. Facilitators for registries may include staff expertise, a focused and feasible evaluation plan, and supplemental funds or in-kind resources devoted to conducting evaluation activities (e.g., evaluation expertise from CCC coalition, other cancer programs, or from university).

For CSB, facilitators included collaboration with EARB and RTI, funding, staff, and feasible evaluation priorities for the funding cycle. This area may be worth further exploration as part of DP22-2202 evaluation priority activities.

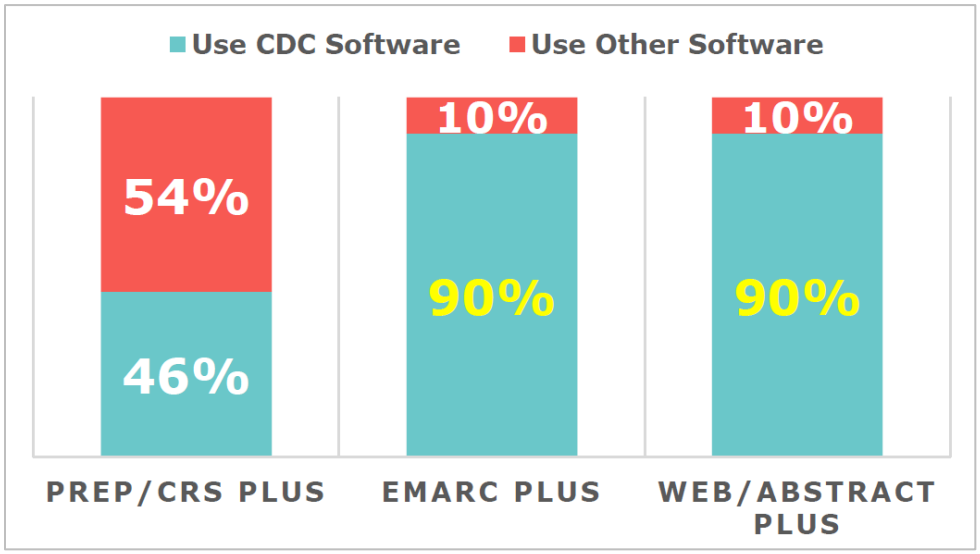
Information Technology and Software Utilization, Support, and Needs of Recipients

NPCR recipients used a variety of software to support cancer surveillance data management, quality assurance/control, consolidation, and submission. As of 2019, the most frequently used software to manage cancer surveillance data included CDC's Registry Plus (n=50), the Rocky Mountain Cancer Data Systems (n=14), and the National Cancer Institute's (NCI's) SEER*DMS (n=9) software systems (required, if funded by NCI SEER). Other registries utilized "homegrown" (internally developed) software systems (n=2), Elekta (n=1), and Eureka (n=1) software.[7]

All recipients used some component of the Registry Plus Software Suite (n=50). About 90% of recipients used eMaRC Plus for receiving and processing Health Level Seven (HL7) files

from anatomic pathology labs and physician offices in HL7 Clinical Document Architecture (CDA) format (n=45). Almost half (n=23) of recipients were converting to or using Prep Plus or CRS Plus software, and 8 recipients considered converting to this software (Figure 3). About 38 recipients used Web Plus for secure, web-based cancer data collection electronic reporting (online abstracting, file upload/download, and follow-back), and half used Abstract Plus software to collect and summarize medical records into electronic reports of cancer diagnosis and treatment.[7]

Figure 3. *Use of CDC Cancer Registry* Software



*Web Plus and Abstract Plus was combined into one group as some recipients use Web Plus for abstracting features.

Registries noted several concerns about cancer registry software. Specifically, when CDC/NAACCR/NACDD asked recipients about TA needs related to Registry Plus software, some program staff mentioned that delays in software updates and inconsistent technical support created major challenges for registry management and operations. Many registries also struggled to incorporate modified records from hospitals without manual intervention from central cancer registry staff. Furthermore, most registries did not have staffing or financial resources to process

records multiple times (i.e., once upon initial receipt and every time there is receipt of modified or updated information) (p. 66).[4]

Additional recipient technical assistance needs were revealed during CDC and RTI qualitative interviews and focus groups (Figure 4).

Figure 4. *Software Technical Assistance and Support Received*

▪ **Help Desk at CDC**

− Registries broadly consider the help desk at CDC to be helpful as registries worked to troubleshoot Registry Plus software issues they encountered.
− The CDC help desk was also helpful for troubleshooting issues at the source, such as working with hospital IT staff.

▪ **CDC eMaRC Plus team**
− CDC helped a registry onboard large laboratories in their state.

▪ **State IT department/internal IT staff**
− Some registries received technical assistance from the state IT department, whereas other registries had their own IT staff to troubleshoot.
− Registry IT or technical personnel were often funded by sources other than NPCR.
− Registries that relied on their state's IT department sometimes indicated that the state IT personnel were not familiar with cancer registry software. Therefore, staff at these registries had to reach out to CDC more frequently than registries that had their own IT staff

▪ **Other vendors**
− Registries noted in interviews that technical support for Microsoft's software packages or for packages from other vendors are costly, and some registries noted the expense of alternate software as a motivation for converting to CDC's software.

In response to technical assistance needs, registries shared several suggestions for software-related improvements. When it is within the developer's control, registries stated that it was important to release software as soon as possible, so deployment could be planned. Additionally, registries noted that limiting software releases to a standardized schedule with no more than two releases per year would be beneficial. Registry staff also suggested that CSB host a webinar and include instructions on how to use NPCR edits tools; test tools prior to release; ensure more timely delivery of metafiles; create a more modern interface between GenEdits and

Edit Writer; be able to filter out obsolete edits from view in EditWriter; and include Edit Tag in import tool.

Overall, participating states reported that software updates that offer better linkages, flexibility, auto-consolidation, and automated fill features are very important to meeting NPCR data quality standards.[4] Participants identified a need to provide support and enhance the features of eMaRC Plus to better screen and process electronic pathology reports and electronic health records from physicians' offices. Furthermore, efforts should be made by CSB to help develop standardized displays for use in Abstract Plus or Web Plus for physicians' offices. MatchPro software is now in widespread use and preferred over Link Plus.

Table 3 below outlines some of the proposed software enhancements recommended by registry staff.

Table 3. *Proposed Software Enhancements*

Proposed NPCR Software enhancements*		
Overall	**CRS and TLC Plus**	**eMaRC Plus**
- **More timely updates and customization** - **Design module for re-abstracting audits** - **Ability to choose which SSDIs are required within site-specific SSDI section** - **Auto-updater for all upgrades** - **Ability of Abstract Plus to allow fields to be blank that can stay blank**	- Automated consolidation - Patient linkage improvement - Patient matching, consolidation and ability to handle M records with minimal processing - Work queue option - Ability to perform pre-processing in tool	- Greater automation and auto-coding - More timely software updates - Better linkage with CRS plus - Ways to store files after processing for later lookup - Automated importing from PHINMS queue

*Additional suggested software enhancements on pp. 70-76.[3]

In addition to enhancements listed above, CDC and RTI identified additional software support requested by NPCR-funded registries based on qualitative study findings, listed in Figure 5.[5]

Figure 5. *Technical Assistance and Support Requested*

▪ **Software documentation**
− Many registries want better documentation of Registry Plus software from a technical point of view so they can better solve errors on their own before reaching out to CDC.

▪ **Software implementation support**
− Registries that have not yet adopted electronic reporting indicated the need for NPCR support in installation and implementation of new Registry Plus software. These registries are often smaller and lack a dedicated internal IT position.

▪ **Support for introducing HL7 reporting to laboratories**
− Registries are constantly working with laboratories to help them understand how to do HL7 reporting. Registries described this process as "a lot of handholding." They noted that support from CDC to produce an introductory packet on HL7 reporting for laboratories could reduce the training time spent.

▪ **Platform for sharing best practices between registries**
− Some registries said that a share site where tools, tool tips, instructional materials, and best practices are stored would facilitate better flow of ideas and improvements across registries. Registries said that better information sharing between registries would help them achieve their goals related to high-quality data. Five out of nine registries in the focus group expressed interest in joining a workgroup to identify improvements needed, and one interviewee suggested town halls with registries in neighboring states as a forum for registry collaboration and to discuss strategies for improving electronic reporting.

An evaluator reviewed every tenth helpdesk ticket request from January 4, 2018, to May 9, 2019, to identify the software technical assistance (TA) needs of state and territorial cancer registries. The Informatics, Data Science, and Applications (IDSAT) team receives TA requests through the helpdesk email box or directly to their CDC email, which is then put through the helpdesk email box for documentation. A total of 114 requests were reviewed and coded into one of three major themes: Operability Issues, General Inquiries, and Software Requests.[8] TA requests pertained to issues with software program operability (47%) or general inquiries for subject matter expert (SME) support (41%) to install or understand software.

The remainder of TA requests were related to software requests (11%). IDSAT categorized Helpdesk tickets by type of request and sorted tickets by software program type (NPCR Registry Plus suite only). Many of the requests were for CRS Plus (25%), Web Plus (22%) and eMaRC Plus (17%) software assistance. See Figure 6 for the types of software requests submitted to IDSAT.[8]

Figure 6. *Types of Software Program Requests*

Major Theme	*Description*	Type of Request
Software Program Operability	*Requests categorized in this theme includes any issues, error messages, and assistance regarding the operation of software programs.*	• Downloading Issues • Upgrade/Update Issues • Connection Issues • Bugs • Receiving Error Messages
Software Requests	*Requests categorized in this theme includes any requests for software or about software release dates and availability of upgrades/updates.*	• Request for Downloads • Enhancements • Upgrades/Updates • Release Dates
General Inquiries	*Requests categorized in this theme includes any questions in regards to software and informatics that do not meet the definition in the other themes.*	• Questions about Using a Program (Subject Matter Expert Support) • Requesting Contact Information for a Specific Program • Questions about Program Installation

One of the main challenges IDSAT faces is the time spent on resolving general inquiries and converting registries to specific software. A large portion of requests were related to error messages when using software programs and requesting SME support to better understand how to use software programs. These error messages typically indicated a user error and not an error with the software itself. Moreover, some requests involved simple responses, such as software release dates, downloading instructions, and contact information for TA on specific software programs; some of this information is already shared by the IDSAT team through newsletters, emails, and conference calls.[8]

Many of these requests may stem from changes implemented by standard setters, which subsequently caused reporting and processing delays. The time spent responding to these requests impedes IDSAT from focusing on more in-depth and complex enhancements to software programs.[8]

Out-of-State and CoC Facility Cancer Case Reporting

When CDC/NAACCR/NACDD asked recipients about approximate percent of cases coming from out-of-state, in 2017, only three states reported 10% or more of their cases were reported by out-of-state sources. Eight states reported 5–9% of their cases were reported by out-of-state sources. The remaining states received less than 5% of their cases from out-of-state sources (p. 61).[4] States were also asked what percentage of cases were reported by at least one CoC accredited facility in 2017.

All states answered that 60% or more of their cases were submitted by a CoC-accredited facility. Sixteen states noted 70% or more, and nine states responded that 80% or more were reported by CoC facilities (p. 60).[4]

CDC-Specific NPCR Challenges

During in-depth interviews conducted in 2019, CSB staff revealed some potential threats (Figure 5)[9] to CDC NPCR's sustainability as a cancer surveillance program. Some interviewees shared concerns that SEER's work overlapped with the work of NPCR. Staff suggested defining partnerships and further clarifying NCI SEER and CDC NPCR roles related to working with central cancer registries. Additionally, participants identified a few other partners as being challenging to work with due to each of these partners having different cancer surveillance needs, priorities, and agendas.

Almost all respondents identified the need for NPCR to clearly state their purpose so that each CSB team and staff member can move forward with projects that align with that purpose. Some staff desired a clear, focused strategic plan to help define NPCR's role in the field of cancer surveillance.[9] Illustrative quotes from CSB staff qualitative interviews are included below.

"NPCR needs to find a good niche in cancer surveillance"

"NCI doesn't have an interest in communicating or collaborating with CDC, [there's] a huge amount of duplication of effort."

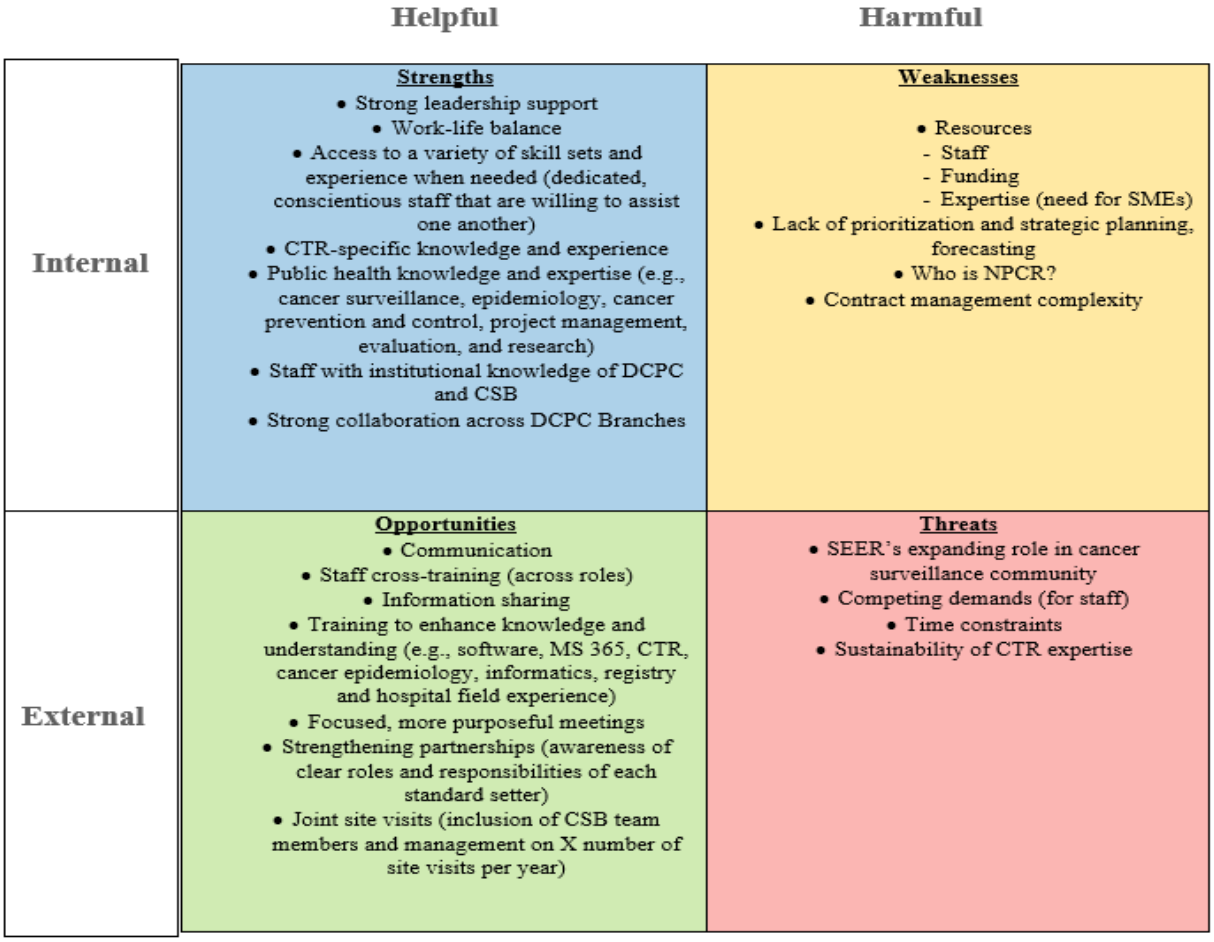
"We are in a hard spot with working with partners with different priorities."

"We always need the recognition that we are not a permanent program. We need to promote ourselves."

"NCI SEER is still in the driver's seat making decisions as far as changes to data requirements. This process needs to be more collaborative."

"We are a big fish in a pond, but [we] feel like a little fish sometimes."

Figure 7. *CSB Staff Interview SWOT Analysis*



CSB staff offered the following suggestions to improve NPCR[9]:

- Increased transparency
- Develop or revise CSB strategic plan
- Revisit staff work responsibilities
- Provide more cross-training opportunities for interested staff
- Continue supportive leadership style that promotes autonomy and Branch collaboration
- Ensure staff have training opportunities
- Ensure contracted CTR staff have very specific roles and responsibilities

Additionally, the CDC/NAACCR/NACDD Best Practices project[4,6] helped identify an assortment of challenges faced by NPCR. Registries discussed challenges with data completeness, timeliness, and quality, electronic reporting, facility reporting, and human

resources. All participants agreed that the biggest barrier to monitoring central registry completeness and progress toward 12- and 24-month data standards was the lack of transparent and consistent number of expected cases (in relation to actual cases reported) to use as the denominator. Although the group acknowledged that the CDC and NAACCR are working on revising the methodology for calculating the denominator, they recommended that the number of expected cases used to estimate 12- and 24-month completeness should be the same.

Furthermore, NPCR, as a state and territorial cancer surveillance program, encounters challenges related to timely information sharing with registries. Specifically, this includes generating completeness, timeliness, and data quality reports in the registry environment. Registry staff recommended that CDC develop a dashboard report within the central registry software that shows real-time progress toward the 12- and 24-month completeness benchmark using a consistent denominator and numerator. NPCR also encountered challenges with the current e-path reporting model used by most cancer registries.

Many of the e-path reporting challenges experienced by state registries were software-related. Overall, registries used varied processes, which required different software applications to process e-path reports. The available software programs neither reduced case processing time, nor improved data quality. In contrast, some programs created more manual work for registries to complete case processing.

Registry participants recommended that CDC NPCR invest in the development of an integrated cancer registry software program. Additionally, registries requested additional technical support and more timely software updates from CDC NPCR. NPCR also encountered barriers when trying to assist registries with facility reporting. Particularly for non-hospital

reporting, manuals and other materials from CDC were outdated and did not apply to the most recent version of the software.

Moreover, NPCR did not tailor onboarding and training materials to each state, which may be worth considering in the future due to the variety of processes used across recipients (p.134).[6] However, providing specific training to each state or territory would pose an additional challenge, as reporting requirements change frequently based on decision making by standard setters. Lastly, NPCR encountered a variety of human resources challenges indirectly as the federal fiduciary agent. There is a critical shortage of personnel, especially CTRs, trained to work in population-based cancer registries and the CDC could assess registry budgetary needs and allow for some flexibility with expenditures.

Furthermore, because exposure to careers in cancer surveillance is not common in most universities and community colleges, NPCR, NAACCR, and NACDD could implement a marketing plan at the national level. Standard setters/cancer surveillance experts could work together to develop a cancer registry basic training webinar series for CTR candidates or new CTRs that could be utilized by all NPCR-funded registries.[6]

Data Quality, Timeliness, Completeness and Security

Data Quality Assurance & Quality Control Procedures

Registries implemented several quality assurance/quality control (QA/QC) procedures to meet NPCR national and advanced national data standards. Specifically, states produced reports that compared case submissions by primary site, by diagnosis year, by class of case, and by region to identify facilities that are behind on reporting. Registry staff requested that management tools be built into current cancer registry software to facilitate ongoing data monitoring efforts. Additionally, registries shared that establishing reporting expectations, goals,

and timelines for reporting facilities to submit cancer data and following up with facilities by phone or email was a part of their routine QA/QC activities.

Target setting for 12-month reporting was another strategy used by some registries (p. 3-11).[5] Most registries sent monthly or quarterly letters to hospital registry staff and managers informing the facility of their current timeliness and completeness progress. Some registries monitored reporting from non-hospital sources and smaller facilities less often (e.g., quarterly or semi-annually), but established timeframes to track progress. Some registries implemented an annual "close-out" process where they established an annual closeout date for all cases (e.g., July 1st) and required submission of a closeout form from reporting facilities.

The closeout form provides the facility reporting status for the diagnosis year, explains any deficiencies in case submissions, provides the number of expected cases for the upcoming year, and includes updated facility personnel and contact information.[5] In some instances, states established reporting requirements, only accepted cases that pass edits, and promoted the use of electronic reporting to assist in timely case submission. CDC/NACCR/NACDD hosted a workshop in 2020 that focused on *Developing and Evaluating Management Reports* (29 registries participated). Workshop objectives were to: (1) Identify and assess the most important data management reports required to monitor completeness, timeliness, and quality of reporting facilities and central registries; (2) establish metrics and benchmarks for the management reporting of facilities and central registries around completeness, timeliness, and quality; and (3) suggest new or improved management reporting practices that would enhance central registries' ability to meet completeness, timeliness, and quality goals.

Registries recommended that management reports include the following data elements: completeness; percent of cases missing age, sex, race, and county; percent of cases from death

certificates only (DCO); percent of cases passing CDC-prescribed set of standards edits.[4] Registries also suggested the generation of management reports for each reporting hospital/facility that included timeliness of submissions, completeness of reporting, percent of cases missing age, sex, race, and county, and percent of cases passing standard edits (p.112-122).[6] As a result of recommendations generated from the Best Practices project and management reports workshop, CDC/NAACCR/NACDD created **five Tip Sheets** to help registries monitor completeness, timeliness, and data quality at CCR and facility levels, build and maintain strong relationships with hospital registries, and improve reporting from non-hospital sources (p. 149-151).[6] Additionally, registries performed remote or in-person facility (or reporting source) audits and participated in NPCR's data quality evaluation (DQE) as part of registry QA/QC efforts.

When asked about future innovative approaches to improving data quality, data processing, and electronic data adoption, some registries mentioned the importance of conducting more case finding audits and data linkages to improve data quality and completeness (p. 3-12).[5]

Barriers and Facilitators to Achieving Advanced National Data Quality Standards

CDC/NAACCR/NACDD Best Practices study participants identified several **barriers** to achieving NPCR advanced data standards or 12-month completeness[4]:

- **Lack of trained staff (CTRs) at hospitals**- caused high error rates for cases submitted and delayed or no cancer case reporting to registries.
    - Participants also mentioned staff turnover in hospital settings as one root cause of this barrier.
- **Late and incomplete reporting from hospitals-** related to barrier noted above, case-finding audits revealed partial reporting in many facilities for some registries and some facilities that were complacent about reporting.

- **The 2018 changes and delays significantly impacted timeliness of reporting**- changes in data items created delays in revisions to software; new rules, guidelines, and changes caused registrar fatigue due to steep learning curve (impacted productivity); participants mentioned delays and inefficiencies in CDC-provided software.
- **Understaffed state and territorial central cancer registries**- reduced program funding, staff turnover, retirements, and challenges with recruitment were identified as root causes of inadequate staffing by participants.
- **Insufficient IT support**- due to organizational restructure, staff unfamiliar with cancer registry or software, lack of staff assigned to assist.
- **Difficulty receiving e-path reports**- based on format of reports, resources available, software systems utilized
- **Non-hospital reporting sources**- increasing cases, but incomplete data, which causes registry staff to perform additional processing, consolidation, and edits.
- **Training new staff (hospital and cancer registry)-** resource intensive

Registry staff mentioned lack of enforceable penalties for non-reporting, lack of VA reporting, out of state reporting, work volume, and death clearance process as additional barriers to meeting NPCR's 12-month data quality standard. Participants identified the following **facilitators** to achieving 12-month data quality standards[4]:

- Provide management reports to reporting facilities reflecting progress
- Use weekly or bi-weekly management reports internally to track timeliness, case counts, missing data, overall data quality
- Send warning letters to senior management when hospitals are seriously behind
- Use laws and regulations to require e-path reporting and allow access to electronic medical records
- Implement quality measures
- Monitor cases using historical data
- Rely on electronic reporting of cases
- Use automated reports to provide metrics to reporting facility
- Perform robust edits to ensure good data
- Conduct re-abstracting and case-finding audits for facilities facing challenges with data submission

Frequency of Data QA/QC Activities

Central cancer registries (CCRs) varied greatly in the frequency, approach, and methodology of providing feedback to reporting facilities, and included data quality indicators tailored to their registry needs (p. 119).[6] While frequency of data quality feedback varies, feedback is usually provided monthly, bimonthly or quarterly. Additionally, the number of data items reviewed and included for feedback varies, but most registries included 6-10 data items. CCRs used an assortment of tools and resources to generate reports to monitor their data quality.

Most utilized software external to their database management system, including SAS, Crystal Reports, Tableau, and SQL queries (p. 121).[6] Some registries used weekly, bi-weekly, monthly, and quarterly management reports to track registry timeliness, the number of cancer cases in the queue waiting to be processed, and to examine reporting progress against quality control benchmarks (p. 51).[4] CDC/NAACCR/NACDD led a series of workshops for registries based on recommendations generated from the Best Practices project. One of the workshops in 2020 focused on registries' communication and relationships with hospitals (24 registries participated).

Depending on existing resources and facility caseload, all registries provided feedback to reporting hospitals at least quarterly, and many communicated by telephone or email monthly (p. 127).[6] Common topics during these routine communications included edit results, data quality (including visual editing and re-abstracting), timeliness, and completeness.

Electronic Reporting

CDC/NAACCR/NACDD Best Practices project team members asked 22 registries about the percentage of cases that are reported electronically by hospital, facility, pathology lab, physicians' office, and non-hospital treatment center. Sixteen states noted that they received

100% of their **hospital** cases electronically, four states stated 98–99%, and only two states mentioned that they received 80% or less electronic reporting from hospitals. Four states shared that 100% of their **pathology** lab cases were reported electronically, seven states stated 90–99%, and four states specified that none of their pathology reports were reported electronically. Five states reported 100% of their **physician** cases were reported electronically, three states reported 90–99%, and six states reported none of their physician office cases were reported electronically.

Eight states reported 100% of their **non-hospital treatment center** cases were reported electronically and seven reported none of their treatment center cases were reported electronically.[4]

Legislation and Electronic Reporting

Registries found laws and rules to positively influence timeliness. State laws vary in scope, but 16 of 22 (73%) states reported 100% electronic hospital reporting, and only two states noted less than 80% electronic reporting from hospitals. Though laws and regulations are perceived as highly influential on timely case reporting, registry staff shared that their own laws do not hold hospitals and facilities accountable. Penalties for no or late reporting to central cancer registries are not enforced even though regulations include language about fines or penalties.

Consequently, in practice, registry laws and regulatory rules had limited efficacy for some states. In fact, 68% of states reported that their laws do not require rapid path only reporting or rapid case ascertainment.[4]

Auto-consolidation and Automation

According to CDC/NAACCR/NACDD Best Practices project findings, most state registries implement some limited auto-consolidation of cases combined with manual review. One state's definition of auto-consolidation was "something that requires no human touch with complex logic," and noted that when automation is incorporated, registry staff can evaluate, follow back, and revise case records as warranted (p. 190-191).[4] Limited auto-consolidation used by most participating registries consisted of person-level and tumor-level matching of incoming records to those already housed on the CCR. Registries noted some data level auto-consolidation, but this was mostly limited to taking known values over unknown values for data items such as race, social security number, place of birth, date of last contact, and vital status (p. 191).[4]

Almost all states participating in focus groups and interviews indicated an interest for increased automation within their respective registries. Only two states reported that they were almost fully automated, with < 10% of cases requiring manual review. Two states did not utilize auto-consolidation as part of data review, cleaning, and consolidation processes. CDC/NAACCR/NACDD also asked registries to identify any processes that aren't automated that could be explored for future automation.

Registries shared the following suggestions for **automation**[4,6]:

- Data consolidation at data, patient, and tumor item levels
- Improved reportability screening with auto coding of e-path cases in eMaRC Plus
- Auto coding of DCO cases from death certificate
- Production and automation of management reports that track facility submissions, data timeliness, quality, and staff productivity

IT Infrastructure

Based on quantitative survey responses,[4] IT services were located outside of the cancer registry in 11 states while support was embedded within registry administrative units in eight states. Three states had IT embedded within program and outside of the registry. Many central cancer registries housed within the Department of Health experienced centralized IT systems that offered call centers and help desks. However, this centralized strategy resulted in significant delays and registry staff being assigned to IT professionals that lacked cancer registry experience.

When funding for IT staff was included in program budgets, staff became integrated into the centralized state system, which did not result in direct technical assistance to registries. Furthermore, this arrangement left registries with inadequate IT resources or support, which is essential to effective registry operations and data management.

Assessing NPCR data completeness, timeliness, and quality

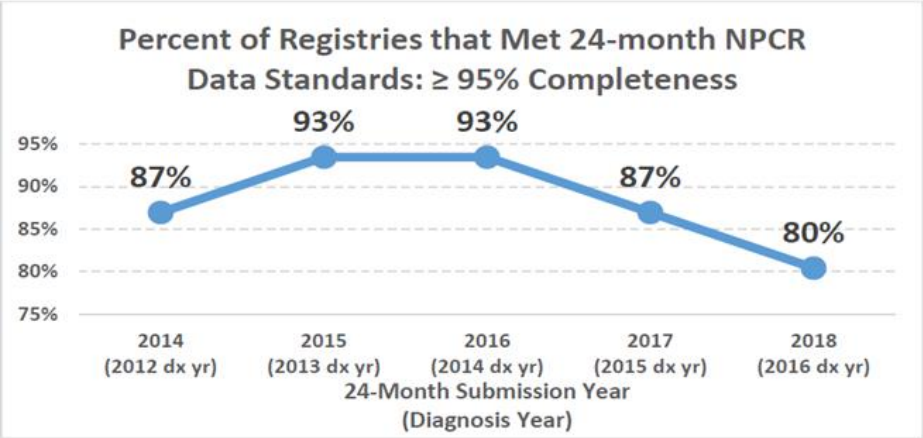
In this sub-section, we present findings from two analyses: an analysis of NPCR-CSS data submission compliance reports from 2014-2018 and an analysis of data submission compliance reports from 2017-2021.[10,11]

NPCR-CSS Compliance Report Data Analysis (2014-2018)[9]

A total of 46 NPCR-funded registries were included in this data completeness, timeliness, and quality analysis. Of the 46 NPCR-funded registries included in our analysis, 74% consistently met 24-month completeness for each of the 5 submission years from 2014 through 2018. Graph 3 shows the percent of registries that met completeness standards per year across the 5 years for 24-

month data submissions. During the 5-year timeframe, 26% of registries did not meet 24-month completeness for each of the 5 years.

Graph 3. *Percent of Registries Meeting 24-Month Completeness*



- All registries (100%) met the NPCR standards for **age and sex** for each of the 5 submission years.
- 91% met the NPCR standards for having **less than or equal to 3% of missing race** data for each of the 5 submission years.
- 96% met the standard for having **less than or equal to 2% of missing county** data.
- 83% met the standard for having **less than or equal to 3% for death clearance only** reporting across the 5 years.
- 93% of registries met the standard for having **less than or equal to 1% of unresolved duplicates (per 1,000)** across the 5 years.
- Almost all registries passed **a CDC-prescribed set of standard edits for core-single or inter-field edits (93%)** and all registries **passed core inter-record edits** (100%).

When evaluators reviewed 24-month completeness, all dual-funded registries met race, county, death-certificate-only cases, unresolved duplicates, and passing core-single or inter-field edits while a small number of NPCR-only funded registries did not meet these standards. See **tables 4-8** below. There were no differences between the NPCR-only funded and dual funded registries for meeting 24-month standards for age, sex, and passing core inter-record edits.

Table 4. *Count and Percent of Registries Meeting 24-Month Completeness: Race*

	Met standards	Did not meet standards	Total
NPCR-only funded	34 (74%)	4 (9%)	38 (83%)
SEER and NPCR funded	8 (17%)	0	8 (17%)
Total	42 (91%)	2 (4%)	46 (100%)

Table 5. *Count and Percent of Registries Meeting 24-Month Completeness: County*

	Met standards	Did not meet standards	Total
NPCR-only funded	36 (78%)	2 (4%)	38 (83%)
SEER and NPCR funded	8 (17%)	0	8 (17%)
Total	44 (96%)	2 (4%)	46 (100%)

Table 6. *Count and Percent of Registries Meeting 24-Month Completeness: Death Certificate Only Cases*

	Met standards	Did not meet standards	Total
NPCR-only funded	30 (65%)	8 (17%)	38 (83%)
SEER and NPCR funded	8 (17%)	0	8 (17%)
Total	38 (83%)	8 (17%)	46 (100%)

Table 7. *Count and Percent of Registries Meeting 24-Month Completeness: Unresolved Duplicates*

	Met standards	Did not meet standards	Total
NPCR-only funded	35 (76%)	3 (7%)	38 (83%)
SEER and NPCR funded	8 (17%)	0	8 (17%)
Total	43 (93%)	3 (7%)	46 (100%)

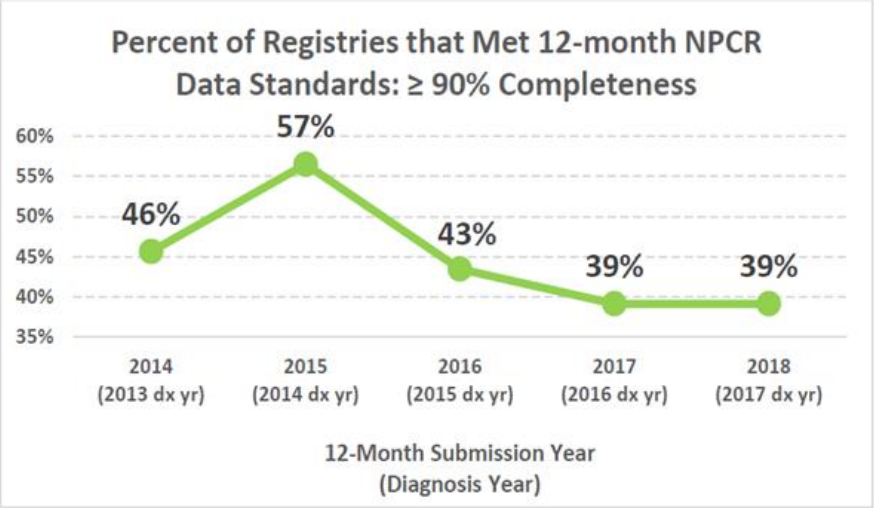
Table 8. *Count and Percent of Registries Meeting 24-Month Completeness: Passing Core-single or Inter-field Edits*

	Met standards	Did not meet standards	Total
NPCR-only funded	35 (76%)	3 (7%)	38 (83%)
SEER and NPCR funded	8 (17%)	0	8 (17%)
Total	44 (93%)	3 (7%)	46 (100%)

Assessing NPCR 12-month data completeness, timeliness, and quality[10]

Over the 2014 through 2018 timeframe, only **26% of registries** consistently met 12-month completeness for each of the 5 submission years. The graph below illustrates 12-month completeness trends based on 2014-2018 submission years.

Graph 4. *Percent of Registries Meeting 12-Month Completeness*



- All registries (100%) met the NPCR standards for **age, sex, and unresolved duplicate rates**.
- A large percentage of registries met the NPCR standard for **race** based on 12-month data submission (91%).
- Almost all registries (96%) met the standard for having **less than or equal to 2% of missing county** data.
- Almost all registries passed a **CDC-prescribed set of standard edits for core-single or inter-field edits** (93%).

Our analysis of 2014 through 2018 data did not show significant differences in meeting 12-month completeness between dual-funded (NPCR and SEER) and NPCR-only funded registries. The relationship between the two groups fell into 3 categories: both groups completely met data standards, both groups did not meet data standards, and dual-funded registries met specific data standards while NPCR-only funded registries did not meet these same data

standards. The latter was an interesting finding that emerged. SEER-funded registries met standards for county and passing core-single or inter-field edits while some NPCR-only funded registries did not meet these standards.

There were no differences in trends noted between the groups for meeting 12-month data standards for age, sex, and unresolved duplicates.

Table 9. *Count and Percent of Registries Meeting 12-Month Completeness*

	Met standards	**Did not meet standards**	**Total**
NPCR-only funded	8 (17%)	30 (65%)	38 (83%)
SEER and NPCR funded	4 (9%)	4 (9%)	8 (17%)
Total	12 (26%)	34 (74%)	46 (100%)

Table 10. *Count and Percent of Registries Meeting 12-Month Completeness: Race*

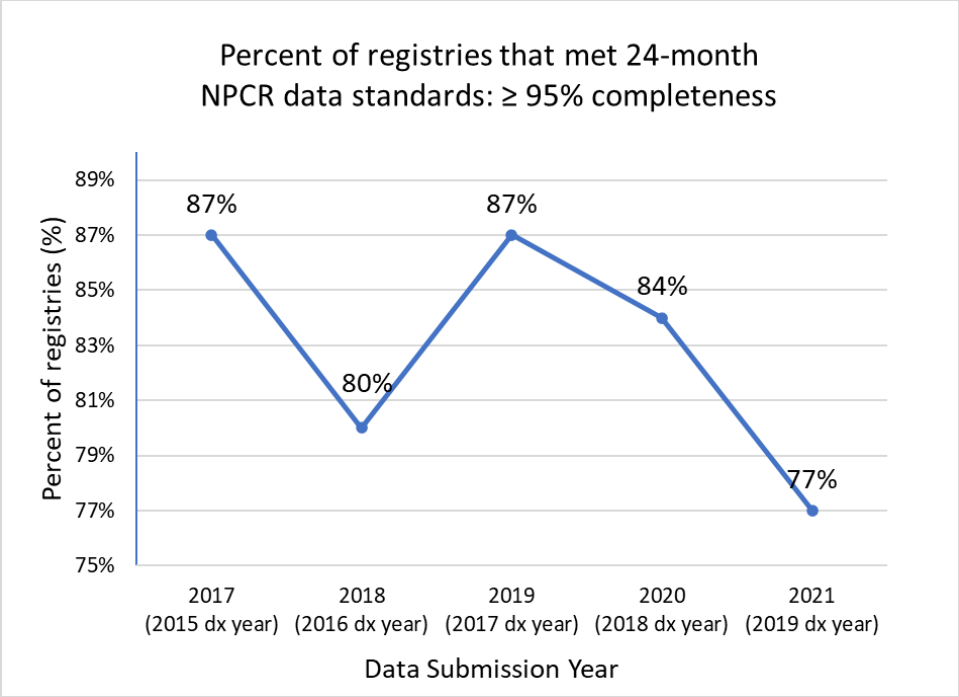
	Met standards	**Did not meet standards**	**Total**
NPCR-only funded	35 (76%)	3 (7%)	38 (83%)
SEER and NPCR funded	7 (15%)	1 (2%)	8 (17%)
Total	42 (91%)	4 (9%)	46 (100%)

NPCR-CSS Compliance Report Data Analysis (2017-2021)[10.11]

A subsequent analysis was performed by evaluators to determine the percent of registries meeting NPCR data quality standards for DP17-1701 funding cycle submission years. Evaluators reviewed NPCR-CSS Data Submission Compliance Reports from 2017 to 2021.[11] Graphs depicting the percent of registries that met 24-month (NPCR national data quality standards) and

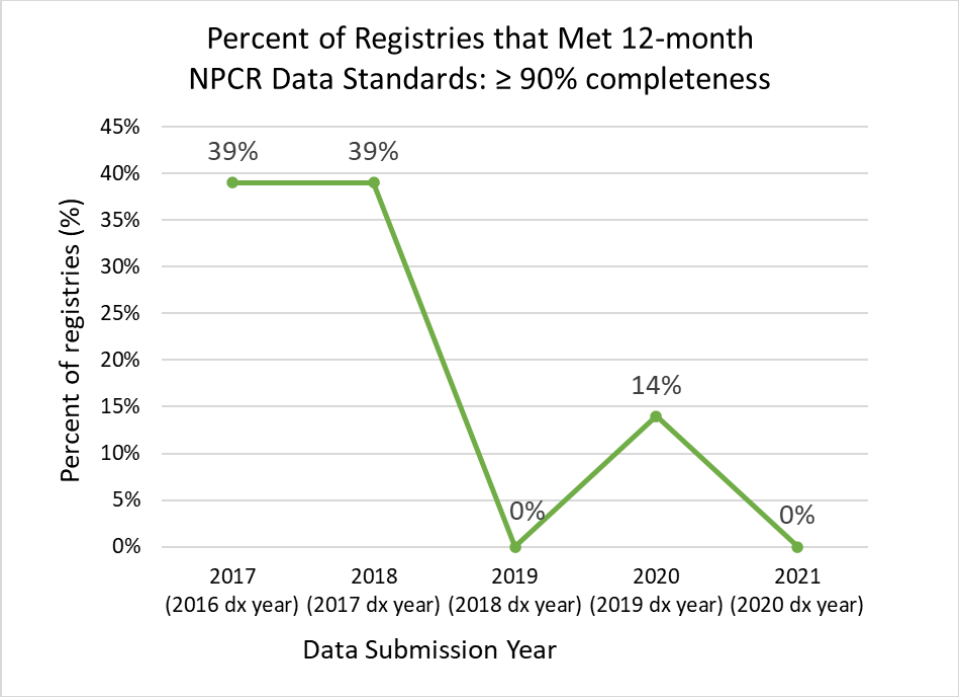
12-month (NPCR advanced national data quality standards) completeness per submission year across the 5-year funding cycle are included below. As indicated below, we examined and summarized information on additional data standards for submission years 2019-2021.

Graph 5. *Percent of Registries Meeting 24-month Completeness: DP17-1701 Submission Years*



- All registries (100%) met the NPCR standards for **age and sex** for each of the 3 submission years.
- 96% met the standard for having **less than or equal to 3% of missing race data**.
- 96% met the standard for having **less than or equal to 2% of missing county data.**
- 92% met the standard for having **less than or equal to 3% for death clearance only** reporting across the 3 years.
- All registries met the standard for having **less than or equal to 1% of unresolved duplicates (per 1000)** across the 3 years.
- Almost all registries passed a **CDC-prescribed set of standard edits for core-single or inter-field edits (96%)** and all registries **passed core inter-record edits (100%).**

Graph 6. *Percent of Registries Meeting 12-month Completeness: DP17-1701 Submission Years*



- All registries (100%) met the NPCR standards for **age, sex, and unresolved duplicate rates.**
- Most registries (90%) met the NPCR standard for **race** based on 12-month data submission.
- Almost all registries (94%) met the standard for having **less than or equal to 2% of missing county data.**
- Only one registry (2%) passed a **CDC-prescribed set of standard edits for core-single or inter-field edits** for 12-month data submission across the 3 years.
    - In 2018, only 4% of registries passed core-single or inter-field edits. These numbers were much higher for submission years 2019 (90%) and 2020 (88%).

Overall, trends from 2014-2021 suggest that completeness for 24-month and 12-month NPCR data quality standards has declined. Specifically, 2014-2017 were high performing submission years for 24-month data with 87%, 93%, 93%, and 87% of registries meeting 24-month completeness standards, correspondingly.[10,11] Furthermore, 2014-2016 submission years had high percentages of registries meeting 12-month completeness standards at 46%, 57%, and 43% respectively. However, in 2018, the percent of registries meeting 24-month completeness dropped to 80%, then decreased to 77% in 2021.[10]

This may be partially due to major implementation changes made by standard setters (NAACCR, CDC, NCI, etc.) to require data items, edits, rules for determining multiple primaries and histologies, and updates to histology codes for the 2018 diagnosis year. Moreover, changes impacted registry and facility software and data collection and consolidation processes. Hospitals and facilities experienced case reporting backlogs because some were waiting for software updates. The COVID-19 pandemic required some central and hospital registry staff to work from home and several states experienced furloughs, staff vacancies, and re-assignments at larger hospitals, which affected cancer case reporting.

Furthermore, states may have experienced a reduction in total cancers diagnosed and reported to cancer registries in diagnosis years 2020 (NPCR will get a better idea during the 2022 NPCR data submission) and 2021 (12-month data submitted in 2022, 24-month data in 2023 submission) due to a decrease in the number of patients visiting doctor's offices to receive cancer screening and general care. The consequences of the COVID-19 pandemic on case reporting may impact cancer registry processes, including number of cases submitted annually for several years. Additionally, low numbers for 24-month completeness may be attributed to low compliance with death clearance only reporting among registries in 2018 and 2021. The percent of registries meeting 12-month completeness decreased 39% in 2017 and 2018 and was as low as 0% in 2019 and 2021.[10,11]

Low achievement of 12-month completeness may be due to few registries passing a set of CDC-prescribed standard edits for core-single or inter-field edits. Consequently, the percentage of registries that met the NPCR race standard was lower for these years. As noted above, delays in NAACR 18 implementation changes may have contributed to low 12-month completeness percentages.[4]

In summary, gaining a better understanding of registry management, standard operating procedures, practices, and how each registry meets NPCR program standards may provide CSB with invaluable programmatic insight. Some trends in meeting data standards were apparent between dual funded and NPCR-only funded registries. Evaluating these differences in greater detail such as differences in software used, staffing footprint, data linkages, or specific quality assurance and quality control activities (e.g., management reports used) conducted may provide a better understanding of how dual funding may impact quality, completeness, and timeliness of NPCR data.

Data Use and Dissemination

How Cancer Registries and Their Partners Use Data

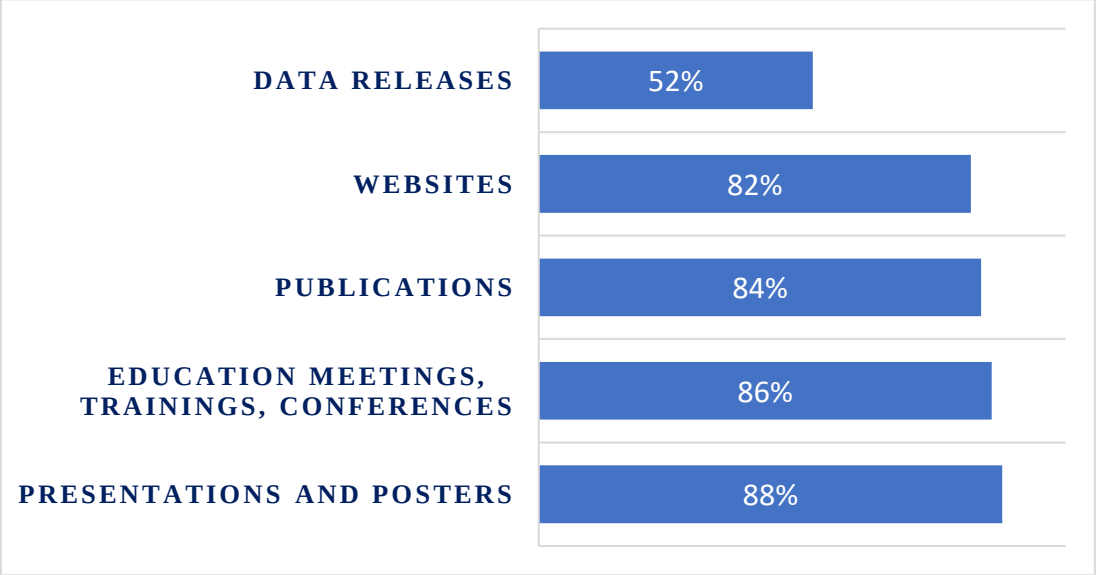
Central cancer registries, BCCEDP, CCCP, external programs, and collaborators used cancer surveillance data frequently to describe their state or territorial cancer burden. The cancer registry utilized data to: (1) calculate incidence/mortality estimates (94%); (2) calculate incidence/mortality by state and geographic area (94%); collaborate with colorectal, breast, and cervical cancer screening programs (94%); conduct epidemiologic studies (92%); facilitate program planning (90%); conduct health event investigations (88%); and perform program evaluation (84%).[12] Of these data uses, 58% of recipients reported including cancer data in journal publications. State and territorial BCCEDP and CCCP used cancer data for monitoring breast and cervical cancer screenings (e.g., data linkage) and creating comprehensive cancer control plans (e.g., to describe cancer burden, establish baselines for indicators, create targets, inform cancer plan priorities, etc.).

Externally, local health departments, county cancer coalitions, hospitals, and non-profit health agencies used cancer surveillance data for various public health activities. Researchers

used data most often, as all registries received numerous data requests for research studies. Furthermore, universities and colleges used cancer data by incorporating it into student training.[4] According to an analysis of PEI 2017 data and NPCR-SEER USCS Public Use Incidence Database User Requests, cancer data was mainly used by NPCR registries in presentations and posters (88%), meetings and trainings (86%), publications (84%), websites (82%), and data releases (52%) (Figure 8).[12]

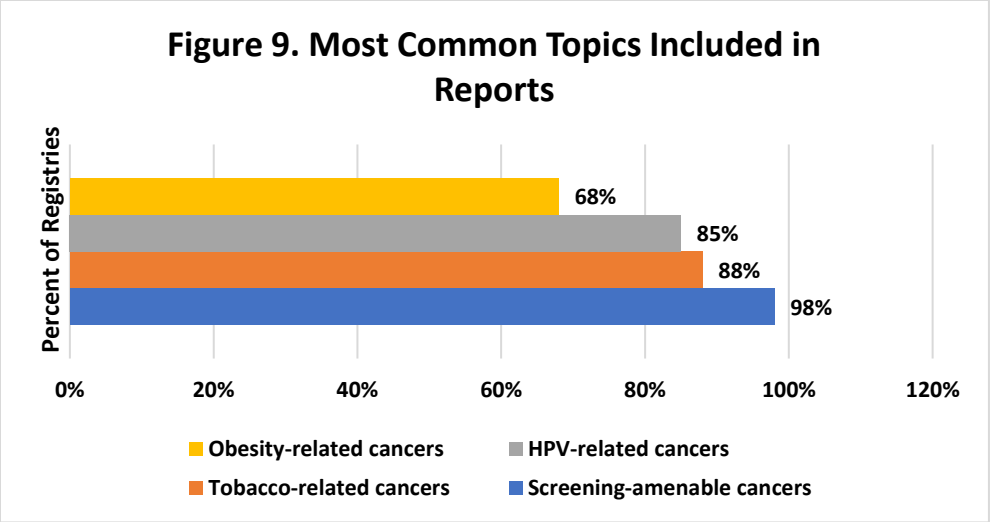
Less common data end products disseminated by recipients were requests-for-proposals/bid solicitations (22%) and press releases/statements (16%).

Figure 8. *Registry Data Dissemination Products*



Cancer Data Dissemination Focus Areas

Registry reports focused on screening-amenable cancers (98%), tobacco-related cancers (98%), HPV-related cancers (85%), and obesity-related cancers (68%) (Figure 9).[12] Less common topics included in recipient reports pertained to hepatitis B/liver cancer, betel nut/oral cancer, pediatric cancer and survival, UV-radiation, and melanoma.



Who Requests and Uses USCS Public Use Data?

About 40% of registries requested access to the USCS Public Use Database. Based on USCS Public Use Incidence Database user requests from 2017-2018 and 2018-2019, there were a total of 224 USCS users and 28 publications produced using this data.[13] USCS public use data was requested most frequently by academic institutions (44%) during the time periods above. The pharmaceutical industry (15%), medical institutions (13%), private sector organizations (5%), and other public sector organizations like NASA (<1%) represented organizations requesting USCS public use data. The following NPCR cancer partners also requested USCS public use data: central cancer registries (14%), American Cancer Society (2%), NCI (1%), other CDC offices (2%), and the American College of Surgeons (<1%).[13]

Lastly, several countries requested USCS data, which included: Australia, Belgium, Canada, China, Egypt, Korea, Saudi Arabia, Taiwan, and the United States (including Puerto Rico).

Funding-Related

Additional Financial and In-Kind Resources Available to Registries

States have a variety of non-CDC financial and in-kind resources to support CCR operations and management. State funds were a common source of non-CDC or supplemental funding for NPCR-funded registries. These funds are usually included in state general appropriation budgets, but also include general funds, revenue funds, and expenditures (p.6).[3] A few recipients reported that a percentage of state cigarette taxes and tobacco settlement funds were sourced for matching requirements.

State cancer registries reported receiving the required matching funds from their states, but in many cases, state support did not exceed these minimums. Many registries faced stagnant or decreased state funding during the 17-1701 funding period despite increasing costs, and many relied on in-kind support to meet federal matching requirements.[6] A few registries also reported a variety of funding sources outside of state funds. Nine of the 50 NPCR-funded recipients received additional funding from the Surveillance, Epidemiology, and End Results (SEER) Program and were designated as dual-funded registries.

A few states received funding from other sources such as block grants or earned funds from conducting research projects. One registry obtained funds from Medicaid Administrative Claiming (p. 57-58).[4] For in-kind resources, some recipients were provided with non-cash contributions from registries/reporting facilities (hospitals and medical centers) in the form of services, staff, and registry operations.[3]

An Exploration of Annual NPCR Recipient Spend Rates

NPCR performed spend rate analysis of available financial data from Years 1-3 (June 30, 2017 through June 29, 2020) for 36 recipients using data from Federal Financial Reports (FFR), internal budget recommendations and spreadsheets, and Notices of Awards. Of the 36 recipients, only 22 (61%) had FFRs available for review for all three years, and 4 (11%) did not have information needed to calculate NPCR spend rates for any of the years examined.[14] The average single year NPCR spend rate was higher than 92% for Years 1-3. Some recipients had a single year spend rate greater than 100% in Years 2 and 3 due to receiving and spending carryover funds from previous years.

The average single year spend rate increased from Year 1 to Year 2 and decreased in Year 3.[14] Table 11 shows the average spend rate for NPCR registries.

Table 11. *Average Individual Spend Rate by Year*

Year	**N**	**Average Spend Rate**	**Range**
Year 1	24	92.6%	(73.1%, 100.0%)
Year 2	21	95.1%	(69.4%, 104.6%)
Year 3	16	93.9%	(78.8%, 101.8%)
Cumulative (Years 1-3)	16	92.0%	(61.7%, 100.0%)

The annual spend rate for the NPCR program, based on the available FFRs, is shown in Table 12. Like the average individual spend rates, the annual NPCR spend rate increased from Year 1 to Year 2 and decreased in Year 3.[14]

Table 12. *Annual NPCR Spend Rate*

Year	N	Annual Spend Rate
Year 1	24	92.9%
Year 2	21	96.0%
Year 3	16	93.8%

An NPCR Evaluation Project in Progress

CDC and RTI NPCR COPE-QI

The NPCR Cost Optimization and Process Efficiency for Quality Improvement (NPCR COPE-QI) study objective entails: (1) reviewing practices that yield high-quality data; (2) identifying optimal processes to improve efficiency; and (3) quantifying resources and costs required to produce high-quality cancer surveillance data. This study includes 22 cancer registries who were purposively selected based on varying levels in meeting national and advanced national data quality standards. The study commenced in March 2020 and the completion timeline was extended to May 2023 due to the COVID-19 pandemic resulting in data collection and analysis delays. See Table 15 in the appendix to review the DP17-1701 evaluation questions *potentially answered* due to the successful implementation of this multi-pronged study.

The NPCR COPE-QI study focuses on **five critical domains**, which can also be described as **data elements**:

- *Contextual* (external and internal environment, funding, staffing, expertise, infrastructure)
- *Content* (caseload, data variables collected, software)
- *Process* (operations, data flow – acquisition, processing and reporting, quality review)
- *Outcomes* (National Data Quality Standards, Advanced National Data Quality Standards, Timeliness, data use)
- *Costs & resources* (Labor, facilities, IT systems, software purchases, overhead)- collecting cost information for FY21 (July 2020-June 2021)

Study methods and status of each COPE-QI study component are provided below:

- Prospective staffing survey (3 rounds)- completed (preliminary results shared with CDC 8/2022)
- Outcomes survey- 22 registries have provided data so far
- Retrospective costing tool- 22 registries have provided data so far
- Registry innovation (looking at common themes)- e-pathology and how implementation contributes to data quality (data collected from NC, ID, LA, PA, TX, and Los Angeles)

Conclusion

Based on secondary data analyses performed by a CSB staff member, most central cancer registries were housed within state health departments or academic institutions. Funding sources outside of NPCR for recipients included state funds, SEER program funding, block grants, research projects, and in-kind resources. Registries spent most of their funds on staffing and fringe benefits followed by contract line items. Several registries experienced staffing shortages for critical registry positions due to lack of qualified staff available, decreased or level federal funding, staff turnover, and retirements. This was especially evident for CTR positions.

Evaluators found that registries used a variety of software to support cancer surveillance data management including Registry Plus, the Rocky Mountain Cancer Day Systems, and SEER*DMS. When asked about software needs, registries requested software enhancements, bug fixes, timely software upgrades, and increased automation of registry processes to facilitate data cleaning, consolidation, and submission. Overall, participating states reported that software updates that offer better linkages, flexibility, auto-consolidation, and automated fill features would help registries achieve NPCR data quality standards.

When evaluators examined data quality, completeness, and timeliness, they found that very few registries met 12-month data standards during the 17-1701 funding cycle, and the percent meeting these standards decreased over time. We also found that the 2018 and 2020

diagnosis years were particularly challenging for registries to meet completeness standards because of NAACCR 18 delays, changing data elements, and changes needed within facility software systems. This caused backlogs in case review and reporting for many facilities. Additionally, the COVID-19 pandemic negatively impacted facility and hospital case reporting for the 2020 diagnosis year due to furloughs, a decrease in patients seeking care and being screened and diagnosed with cancer, and changes in registry operations due to a shift to remote work.

Moreover, registries encountered additional barriers that impact cancer registry management and operations. A lack of technical expertise, time consuming manual review processes for data consolidation, and limited capacity for evaluation planning were key barriers that emerged from our evaluation data. However, evaluation findings also identified a multitude of promising practices that registries implement to enhance their cancer registry operations. Program implementation facilitators entailed practices and processes related to interstate data exchange, IT systems/infrastructure, automated data consolidation, and management support.

Furthermore, registries implemented several quality assurance/quality control procedures to meet NPCR national and advanced national data standards, such as monthly and quarterly letters and reports to reporting facilities. Additionally, evaluation study results identified a variety of challenges faced by NPCR including timely information sharing with registries, software application issues, tailoring guidance to each state, and human resources. However, the NPCR program was successful in providing strong leadership support, CTR-specific knowledge and expertise, and public health knowledge and expertise.

As a cancer surveillance program, NPCR provided the opportunity for registries, internal, and external partners to utilize data in various ways. Registries used cancer data to create

incidence and mortality reports, reports on screening-amenable cancers, data briefs, presentations, for data releases, and for education and training purposes. Additionally, data was disseminated to a variety of partners including breast and cervical cancer screening and comprehensive cancer control programs, researchers, community-based organizations, and other public health programs.

Evaluation findings demonstrated high spend rates among NPCR recipients. Based on a review of fiscal data over a 3-year timeframe, a large percentage of registries had 92-95% annual spend rates and NPCR's annual spend rate peaked at 96% in year 2 based on fiscal data from 21 registries. We found that FFRs were often filled out incorrectly or missing information, including NPCR program-specific information. A refresher training focused on completing FFRs correctly and submitting them by the due date is warranted.

While 24-month data standards were achievable for many NPCR-funded registries, very few were able to meet national data standards. Registries that met national data standards were a combination of small, medium, and large volume registries and being dual-funded was not always associated with improved data quality, completeness, and timeliness. Based on interview and focus group findings, registries need increased funding, improved software with automation features, qualified CTR and PD candidates to fill vacant positions, implementation of routine QA/QC activities including generation of management reports via software, and registry tools, resources, and TA to successfully meet national and advanced national NPCR data standards.

Successes

CSB was able to partially or fully answer several questions (18 questions) outlined in the DP17-1701 evaluation plan, which focused on examining recipient staffing and registry infrastructure, data quality, timeliness, completeness, and security, program monitoring and

evaluation, data use and dissemination, and funding-related areas. CSB staff produced several manuscripts due to implementation of priority evaluation activities, most notably through CSB collaboration with EARB and RTI. This provided an opportunity to showcase NPCR evaluation efforts and share findings with recipients, standard setters, collaborators, partners, researchers, and other public health surveillance programs. Additionally, CSB was able to hire an evaluation fellow (for 1 year) during year 2 of the DP17-1701 funding cycle who led secondary data analyses and evaluation logic model development.

Having a staff member dedicated to NPCR evaluation activities allowed CSB to make progress on completing several evaluation questions via secondary analysis of available data sources. Furthermore, collaboration with external partners including NACDD and NAACCR provided additional resources to answer several evaluation questions through a variety of primary data collection methods. These sessions generated a variety of recommendations regarding cancer registry promising practices. Specifically, CDC/NAACCR/NACDD synthesized results and created 11 TIP sheets that can serve as a starting point for more in-depth discussions, development of tools, and the establishment of more innovative and efficient registry processes or practices.

Limitations

A key limitation of The Identify and Implement Best Practices for Cancer Registry Operations 2018-2021 evaluation project (CDC, NACDD, & NAACCR) was that it did not focus on answering the recommended NPCR evaluation questions from the evaluation plan exclusively. Several questions were added during initial project planning and implementation. Furthermore, project findings represented viewpoints from less than half of cancer registries (n = 17; n = 22), so results are not transferable to all NPCR-funded cancer registries. Some of the

project team conducting focus group discussions and in-depth interviews with participants served in state cancer registry roles, which may have reduced objectivity and reflexivity during data collection and potentially introduced interviewer bias.

Furthermore, less than half of registries participated in the Feasibility of E-Reporting Assessment, so results may not represent the viewpoints of all NPCR-funded registries. Some of the data sources we used to answer evaluation questions had limitations. Since we utilized PEI surveys, 17-1701 FOA applications, budget justifications, and FFRs, this meant that we relied on information collected and submitted by registries, which may have led to some variability in the completeness and accuracy of information gleaned from these sources.

Additionally, COVID-19 posed several barriers to NPCR data collection and registry data submission. Some states ended participation in Best Practices project activities early due to changing resource demands. Moreover, many workshops were hosted virtually due to the COVID-19 pandemic, which posed barriers to recipient engagement. This also hindered full development of vetted best practices, as consensus can be difficult to reach within the framework of a brief virtual workshop.

The COVID-19 pandemic may have also influenced registry data submission, as mandated office shutdowns of many state and university offices during the pandemic resulted in significant disruption to registry operations. Likewise, it is difficult to assess to what extent COVID-19 may have influenced or compounded the registry barriers identified in this report, particularly staff shortages, funding constraints, and other resource limitations.

Lessons Learned

- Too many overall evaluation questions to answer without conducting major primary data collection in one funding cycle (limited resources and staff available to answer all questions)

- Too many multi-part evaluation questions that were difficult to answer
- The inclusion of broad evaluation questions resulted in a variety of potential answers and interpretations
- Throughout evaluation plan implementation, priorities and resources shifted, which resulted in revisions to evaluation question priorities
- Collaboration with EARB provided staff, expertise, and resources needed to answer key evaluation questions
- Collaboration with external partners allowed for additional resources to answer evaluation questions, but at times strayed from NPCR-specific evaluation questions, thus affecting their interpretation and leaving questions unanswered
- Question results overlapped in the areas of *recipient staffing and infrastructure, data use and dissemination, and data quality, completeness, and timeliness.*
- Challenges arose in striking a balance between incorporating everyone's priorities while keeping the evaluation plan within the scope of its original intent
- As you are drafting the evaluation plan, explore opportunities for primary data collection

Recommendations and Action Items

For CSB

- Narrow the focus of DP22-2202 evaluation to **10-12 key questions** and ensure questions are distinct enough, so there is minimal overlap in questions and subsequent results
- Limit the number of multi-part evaluation questions to the extent possible
- Utilize NPCR Program Standards and DP22-2202 logic model to guide evaluation plan and evaluation logic model development (logic model draft completed 10/2022, presented to Branch by Sofia Huster 11/15/2022)
- Consider including priority DP17-1701 evaluation questions that were unanswered during the DP17-1701 funding cycle in the DP22-2202 evaluation plan (NPCR customer service, technical assistance (TA), guidance to recipients)
- Recruit and retain experienced evaluators to conduct CSB process and outcome evaluation with at least two full-time staff (PPEO evaluation fellow and a health scientist) dedicated to evaluation efforts (currently employ 1 full-time PPEO Evaluation Fellow)
- Identify POCs from SERT and IDSAT (e.g., by project) to ensure active engagement in priority evaluation activities from all CSB teams
- Host strategic planning sessions across DCPC and CSB as appropriate to discuss and share information on evaluation progress
- Continue collaborating with PSB, CCCB and EARB evaluation staff on priority evaluation activities
- Continue collaboration with EARB and RTI to conduct priority evaluation activities, including CBCP evaluation (if funded by OD as a special project)
- Seek out funding opportunities from DCPC, NCCDPHP, or other sources to support CSB evaluation efforts

- Consider providing supplemental funding (as available) to registries to conduct innovative projects focused on evaluation
- Create evaluation capacity strengthening resources for recipients (first DP22-2202 evaluation capacity strengthening webinar completed 10/27/22; create timely webinars, briefs, and/or evaluation-related guidance as warranted)
- Create or utilize an existing share site (e.g., Sharepoint or AMP) for evaluation tools, tips, instructional materials, and to disseminate registry promising practices in support of peer-to-peer learning and information sharing
- Consider sharing **key** State of Evaluation report findings with NPCR recipients
- Ensure evaluators have access to necessary qualitative and quantitative software to perform evaluation-specific data management and analysis activities (not provided during most of DP 17-1701 funding cycle)
- Seek out opportunities for short-term evaluation technical assistance via PPEO

For NPCR Recipients

- Consider cross-training staff, as this promising practice may provide coverage to conduct essential data management, consolidation, and quality improvement duties when critical staff retire or there are vacant positions within the registry (Note: some registries are doing this already based on evaluation findings)
- Continue to explore partnerships to develop and implement "Grow a CTR" program (Note: some registries are doing this already based on evaluation findings)
- Volunteer to participate on the NPCR Advisory Committee to provide input on cancer registry priorities and use forum to share promising practices, learn from peers, and propose viable solutions to registry challenges.
- Participate in cancer surveillance workgroups established by NAACCR, CDC, and NCI
- Inform NPCR Program Consultant about any major program challenges on at least a quarterly basis (Quarterly check-ins have provided a mechanism for registries to share program progress and challenges encountered)
- Consider serving as a presenter in upcoming evaluation capacity strengthening webinars to promote and strengthen proactive evaluation

NPCR Evaluation Next Steps

1. Share State of Evaluation Report with CSB management team, PSB PET, NCCCP PEP, EARB, and DCPC OD
2. Present findings at a future DCPC All Hands meeting
3. Use report as a resource during conceptualization and development of DP22-2202 Evaluation Plan, Cloud-based Computing Platform (CBCP) logic model and evaluation plan development
4. Include report as part of orientation resources for incoming CSB staff (ORTAT, IDSAT, SERT)

References

1. Pordell P. *National Program of Cancer Registries (NPCR) Evaluation Plan: DP17-1701 Cancer Prevention and Control Programs for State and Territorial Organizations.* 2018. Atlanta, GA: Centers for Disease Control and Prevention. National Center for Chronic Disease Prevention and Health Promotion. Division of Cancer Prevention and Control.

2. Milstein RL, Wetterhall SF. Framework for program evaluation in public health. *MMWR*. 1999;48(No.RR-11):1-58.

3. Trinh E, Pordell P, Pollack L. *NPCR Evaluation: National Cancer Prevention and Control Program Funding Opportunity CDC-RFA-DP17-1701. Grantee Funding and Resources Brief Report.* 2019. Atlanta, GA: Centers for Disease Control and Prevention. National Center for Chronic Disease Prevention and Health Promotion. Division of Cancer Prevention and Control.

4. National Association for Chronic Disease Directors (NACDD). North American Association for Central Cancer Registries (NAACCR). Centers for Disease Control and Prevention (CDC). *Identify and Implement Best Practices for Cancer Registry Operations. August 2019*.

5. Tangka F, Edwards P, Pordell P, Wilson R, Blumenthal W, Jones S, Jones M, Subramanian S. *NPCR Feasibility Assessment of Electronic Reporting and Automation of Registration: Summary of Results from Interviews and Focus Groups January 2019.* Research Triangle Institute. Centers for Disease Control and Prevention.

6. National Association for Chronic Disease Directors (NACDD). North American Association for Central Cancer Registries (NAACCR). Centers for Disease Control and Prevention (CDC). *Identify and Implement Best Practices for Cancer Registry Operations Year 2. March 2021*.

7. Trinh E, Pordell P, Pollack L. *NPCR Evaluation: National Cancer Prevention and Control Program Funding Opportunity CDC-RFA-DP17-1701. Grantee Software Use Report.* 2019. Atlanta, GA: Centers for Disease Control and Prevention. National Center for Chronic Disease Prevention and Health Promotion. Division of Cancer Prevention and Control.

8. Trinh E. *NPCR IDSAT Helpdesk Summary*. 2019. Atlanta, GA: Centers for Disease Control and Prevention. National Center for Chronic Disease Prevention and Health Promotion. Division of Cancer Prevention and Control.

9. Trinh E, Pordell P. *NPCR Evaluation: Results from CSB Staff Qualitative Interviews*. 2019. Atlanta, GA: Centers for Disease Control and Prevention. National Center for Chronic Disease Prevention and Health Promotion. Division of Cancer Prevention and Control.

10. Trinh E., Pordell P, Pollack L. *Summary of NPCR-funded Registries Meeting NPCR Data Standards*. 2019. Atlanta, GA: Centers for Disease Control and Prevention. National Center for Chronic Disease Prevention and Health Promotion. Division of Cancer Prevention and Control.

11. Cancer Surveillance Branch. *NPCR-CSS Data Submission Compliance Reports: 2019, 2020, 2021*. Atlanta, GA: Centers for Disease Control and Prevention. National Center for Chronic Disease Prevention and Health Promotion. Division of Cancer Prevention and Control.

12. Trinh E. *Data Use by NPCR Cancer Registries*. 2019. Atlanta, GA: Centers for Disease Control and Prevention. National Center for Chronic Disease Prevention and Health Promotion. Division of Cancer Prevention and Control.

13. Trinh E. *Data Use: US Cancer Statistics Database User Request Brief*. 2019. Atlanta, GA: Centers for Disease Control and Prevention. National Center for Chronic Disease Prevention and Health Promotion. Division of Cancer Prevention and Control.

14. Fukayama C, Nethercott E, Pordell P. *DP17-1701 Fiscal Analysis Brief: Years 1-3*. 2022. Atlanta, GA: Centers for Disease Control and Prevention. National Center for Chronic Disease Prevention and Health Promotion. Division of Cancer Prevention and Control.

15. National Cancer Registrar's Association. *Job Prospects & Salary*. 2017. Alexandria, VA: National Cancer Registrar's Association.

Appendices

Figure 10.

DP17-1701 NPCR Logic Model

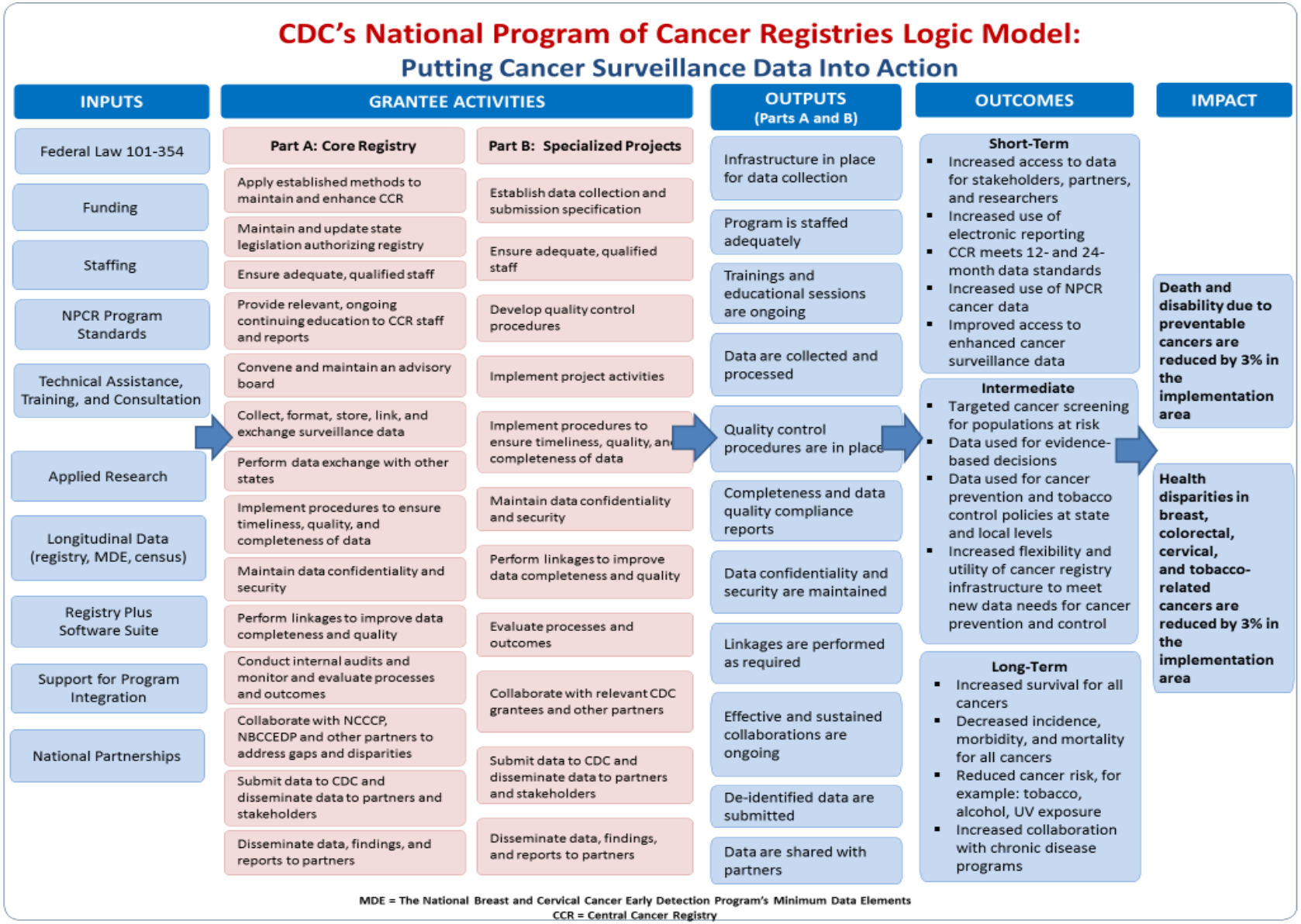


Figure 11.

2017 Map of State and Territorial Central Cancer Registries

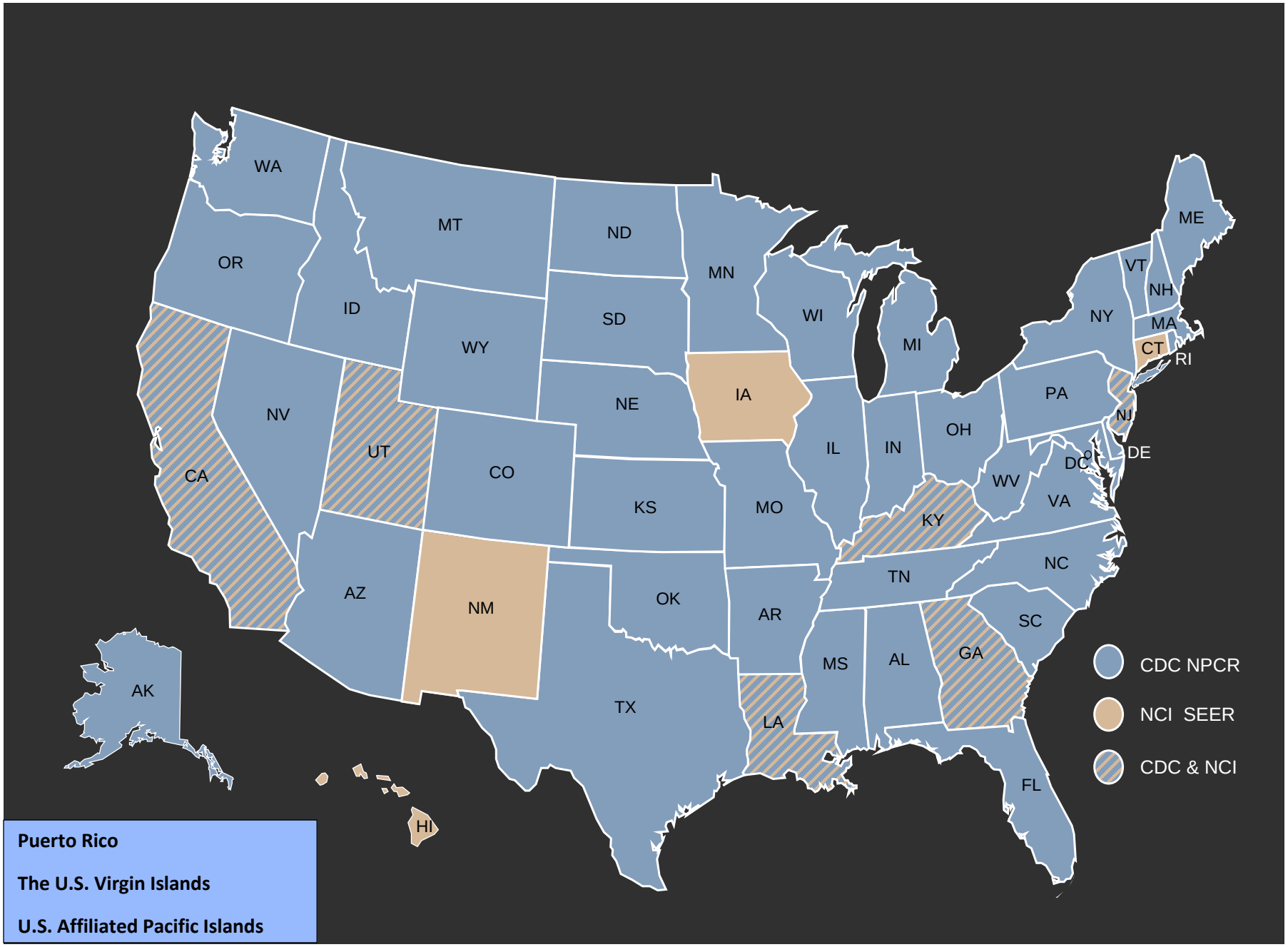
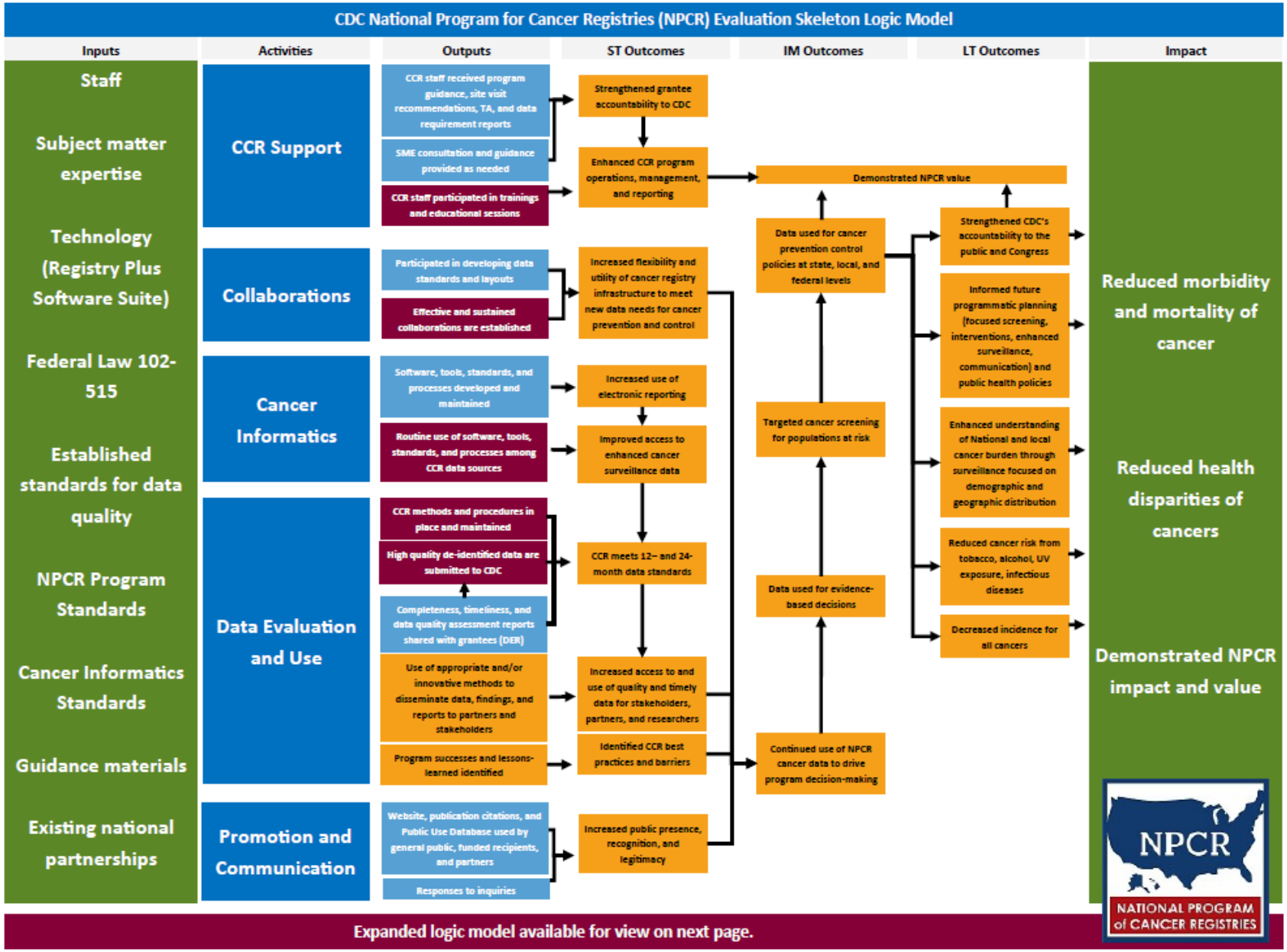


Figure 12.

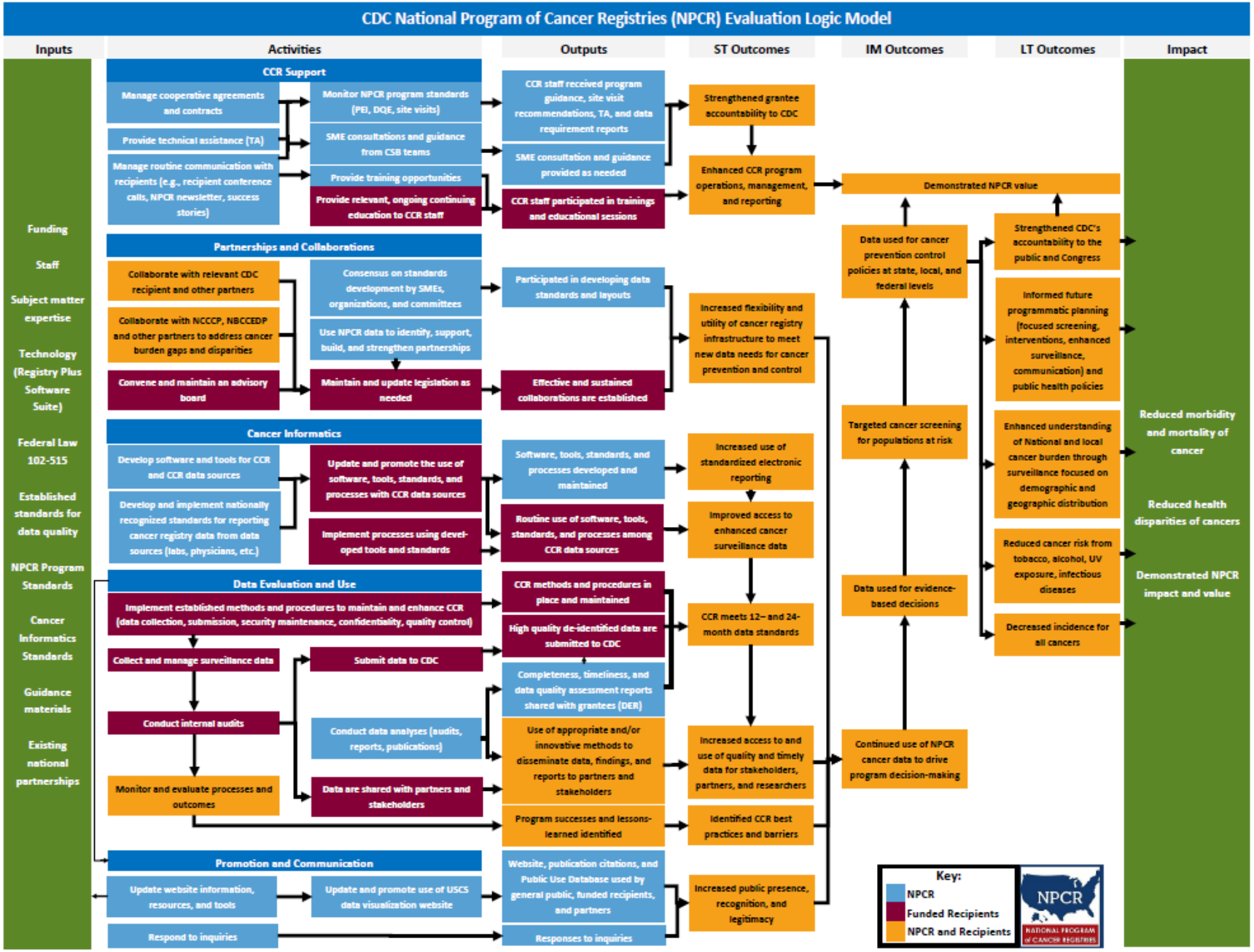
DP17-1701 NPCR Evaluation Logic Model (Skeleton)



10.17.2018

Figure 13.

DP17-1701 NPCR Evaluation Logic Model (Detailed)



National Program of Cancer Registries (NPCR) Program Standards, 2017 to 2022

A functional, NPCR-funded central cancer registry must be able to:

- Report cancer incidence trends by geographic area and provide cancer data to support cancer control programs.
- Collect and report incidence, burden, and stage data that can direct targeted interventions, guide research, and be used to evaluate the success of cancer prevention and screening programs.
- Identify disparities by age, gender, race, ethnicity, and geographic areas in cancer incidence, stage at diagnosis, and mortality.
- Create and maintain registry and state policies that support research uses of cancer registry data.

Goals of NPCR:

- Collection and dissemination of high-quality data on all reportable incident cancer cases in a timely manner for the purpose of public health cancer prevention and control
- Improved and enhanced electronic reporting to central cancer registries.

In addition to the goals stated above, the goal for any of the NPCR Component 2 pilot public health surveillance projects is to identify the feasibility of and/or barriers to collection of new information on cancer cases through cancer registries in one of three focus areas:

- Cervical cancer precursor data and outcomes directly related to cervical cancer prevention programs
- Cancer screening and diagnostic follow-up data on breast and cervical cancer cases
- New or emerging cancer prognostic factors or risk assessment models

NPCR Short, Intermediate, and Long-term Outcomes

Short Term Outcomes

- Increased access to quality and timely cancer data for stakeholders, partners and researchers
- Increased use of electronic reporting of cancer cases to the central cancer registry.
- Meet established NPCR's National Data Quality and Advanced National Data Quality standards
- Increased use of NPCR cancer data
- Improved access to enhanced cancer surveillance data

Intermediate Outcomes

- Targeted cancer screening for populations at risk
- Utilization of data for evidence-based decisions
- Utilization of data for cancer prevention and tobacco control strategies at state and local levels
- Increase in flexibility and utility of the cancer registry infrastructure to meet new data needs for cancer prevention and control

Long Term Outcomes

- Increased survival for all cancers
- Decreased incidence, morbidity, and mortality for all cancers
- Reduced cancer risk e.g. tobacco, alcohol, UV exposure
- Increased collaboration with Chronic Disease Programs at state and local levels

NPCR will monitor and assess progress, results, and overall impact through:

a. The NPCR performance measures, outputs and program outcomes from both the Integrated Cancer Logic Model as well as the NPCR Program specific logic model.
b. The annual cancer data submissions for progress in meeting NPCR Program Standards, as well as timelines and completeness requirements.
c. Results of the NPCR Program Evaluation Instrument, the Data Quality Evaluation in conjunction with annual progress reports for a comprehensive view of grantee performance.

Key Performance Measures for NPCR Component 1 and 2 will include the following outputs from the NPCR Logic Model:

- Activities to evaluate and improve timeliness, quality, and completeness of cancer data.
- Status of infrastructure for increased and electronic reporting of cases.
- Timeliness of capturing cancer cases from facilities.
- Successful submission of electronic data files, according to the timeframe and content established by CDC, to the NPCR Cancer Surveillance System (CSS).
- Meeting NPCR standards as outlined in NPCR Program Standards and evaluated by annual reports and Program Evaluation Instrument survey results.
- Creation and maintenance of registry and state policies supportive of research uses of central cancer registry data.
- Data dissemination and data use through the development of surveillance reports and other products that identify and report on the cancer burden and trends by age, gender, race/ethnicity and geographic area in support of health equity initiatives, cancer control programs, and public health practice.

NPCR Program Standards (Strategies)

The following strategies are defined as CDC's Program Standards for the National Program of Cancer Registries (NPCR). These standards are based on the legal authority provided to the CDC under the Public Health Service Act (Title 42, Chapter 6A, Sub-Chapter II, Part M, § 280e) and subsequent amendments, and apply to all reportable cancers as defined in the Act and amendments. These standards may change during the project period of the cooperative agreement.

Strategy 1: Program Collaboration

Support collaboration across CDC's NPCR, National Breast and Cervical Cancer Early Detection Program (NBCCEDP), and National Comprehensive Cancer Control Program (NCCCP) as well as other chronic disease programs.

- The central cancer registry actively collaborates in the state's comprehensive cancer control planning efforts.

- The central cancer registry establishes a working relationship with other cancer control programs, including cancer screening programs and tobacco control programs, to assess and implement cancer control activities.
- The central cancer registry establishes and regularly convenes an advisory committee to help build consensus, cooperation, and planning for the registry and to enhance chronic disease program coordination and collaboration. Representation should include key organizations and individuals within (such as representatives from all cancer prevention and control components and chronic disease programs) and outside the program (such as hospital cancer registrars, the American Cancer Society, American College of Surgeons liaison, clinical-laboratory personnel, pathologists, and clinicians). Advisory committees may be structured to meet the needs of the state or territory, such as the comprehensive cancer control program committee structure, an advocacy group, or a focus group.

Strategy 2: External Partnerships

Convene, support, and sustain partnerships and networks necessary to support implementation of cancer program priorities and activities.

- Establish and convene an advisory committee to help enhance and use the central cancer registry data for prevention and control of cancer and other chronic diseases, and coordinate and collaborate with other cancer programs.
- Use the advisory committee to develop and refine quality improvement initiatives.
- Establish and promote greater awareness and use of the cancer registry data.

Strategy 3: Cancer Data and Surveillance

Legislative Authority

- The state or territory has a law authorizing a population-based central cancer registry.
- The state or territory has legislation or regulations that support Public Health Service Act Title 42, Chapter 6A, Sub-Chapter II, Part M, 280e, authorizing the NPCR.

Administration and Operations

- Hire or retain staff sufficient in number and expertise to manage, implement, and evaluate the central cancer registry, as well as use and disseminate the data. Core staff must fill the roles of program director, project director, principal investigator, quality assurance or quality control manager, and education and training coordinator.
- The central cancer registry maintains an operations manual that describes registry operations, policies, and procedures. At a minimum, the manual contains—

1. The reporting laws and regulations.
2. A list of reportable diagnoses.
3. A list of required data items.
4. Procedures for data processing operations, including procedures for—
    a) Monitoring timeliness of reporting.
    b) Receipt of data.
    c) Database management, including a description of the registry operating system software. This may be accomplished by citing a software vendor's Web site and documentation.
    d) Conducting death certificate clearance.

e) Implementing and maintaining the quality assurance or quality control program, including procedures for—
i. Conducting follow-back to reporting facilities on quality issues. These procedures include rules for identifying when action or further investigation is needed.
ii. Conducting record consolidation.
iii. Maintaining detailed documentation of all quality assurance operations.
iv. Education and training.
f) Conducting data exchange, including a list of states with which case-sharing agreements are in place.
g) Conducting data linkages.
h) Ensuring confidentiality and data security, including disaster planning.
i) Data release, including access to and disclosure of information.
j) Maintaining and updating the operations manual.

5. Management reports that include processes and activities to monitor the registry operations and database.
6. An abstracting and coding manual that is made available to and used by reporting sources that abstract and report cancer cases.

Data Collection, Content, and Format

- Central cancer registries must collect and submit data for all reportable cancers and benign neoplasms, including at a minimum, primary site, histology, behavior, date of diagnosis, race and ethnicity, age at diagnosis, gender, stage at diagnosis, and first course of treatment, according to CDC specifications and other information required by CDC.
- For all CDC-required reportable cases, the central cancer registry collects or derives all required data items using standard codes prescribed by CDC.
- Regardless of residency, the central cancer registry collects data on patients who were diagnosed or received the first course of treatment in the registry's state or territory.
- The central cancer registry uses a standardized, CDC-recommended data exchange format to transmit data to other central cancer registries and CDC.

Data Quality Assurance and Education

- The central cancer registry has an overall program of quality assurance that is defined in the registry operations manual. The quality assurance program includes, but is not limited to—
    1. A designated certified tumor registrar (CTR) is responsible for the quality assurance program.
    2. Quality assurance activities should be conducted by qualified, experienced CTRs or CTR-eligible staff.
    3. Data consolidation procedures are performed according to the central cancer registry protocol and nationally accepted abstracting and coding standards.
    4. At least once every five years, case finding and re-abstracting audits are conducted from a sample of source documents for each hospital-based reporting facility. This may include external audits by CDC or SEER.

5. Routine audits of a sample of consolidated cases are performed by the central cancer registry.
6. Feedback is provided to reporting sources on data quality and completeness.

- The central cancer registry has an education program that is defined in the registry operations manual. The education program includes, but is not limited to—
    1. Training for central cancer registry staff and reporting sources to ensure high-quality data.
    2. A designated education and training coordinator who is a qualified, experienced CTR.
    3. Where feasible, the education and training coordinator may be regionally based, allowing applicants to collaborate to identify one applicant to provide the education and training coordinator activities to be carried out in a region.

Data Submission

- The central cancer registry annually submits data files to the NPCR Cancer Surveillance System (CSS) that meet the reporting requirements outlined in the NPCR CSS Submission Specifications document and meet criteria for publication in *United States Cancer Statistics.*
- In appropriate data submission years, when the central cancer registry data file meets specified data completeness and quality standards, the central cancer data are included in the *Cancer in Five Continents* publication.
- The central cancer registry participates in all CDC-created and hosted analytic datasets and Web-based data query systems, according to the annual NPCR CSS Data Release Policy.

Data Use and Data Monitoring

- Within 12 months of the end of the diagnosis year with data that are 90% complete, the central cancer registry produces preliminary pre-calculated data tables in an electronic data file or report of incidence rates, counts, or proportions for the diagnosis year by SEER site groups to monitor the top cancer sites within the state or territory.
- Within 24 months of the end of the diagnosis year with data that are 95% complete, the central cancer registry, in collaboration with local cancer control programs, produces the following electronic reports—
    1. Reports on age-adjusted incidence rates, stage at diagnosis, and age-adjusted mortality rates for the diagnosis year using SEER site groups and, where applicable, stratifying by sex, race, ethnicity, and geographic area.
    2. Biennial reports providing data on stage and incidence by geographic area, with an emphasis on screening-amenable cancers and cancers associated with modifiable risk factors, such as tobacco, obesity, and human papillomavirus (HPV).
- The central cancer registry ensures annual use of cancer registry data for public health and surveillance research purposes in at least five of the following ways—
    1. Comprehensive cancer control.
    2. Detailed incidence and mortality by stage and geographic area.
    3. Collaboration with cancer screening programs for breast, colorectal, or cervical cancer.
    4. Health event investigations.
    5. Needs assessment and program planning, such as Community Cancer Profiles.

6. Program evaluation.
7. Epidemiologic studies.

- The central cancer registry submits a success story to CDC at least annually detailing how registry data have been used to impact public health.

Electronic Data Exchange

- The central cancer registry is required to adopt and use standardized, CDC-recommended data transmission formats for the electronic exchange of cancer data (see CDC NPCR Electronic Reporting and Data Exchange Guidance). Registries should promote the use of these formats by reporting sources that transmit data to the registry electronically. CDC-recommended data exchange formats include—
    1. Hospital reporting: The NAACCR record layout version specified in year-appropriate *Standards for Cancer Registries Volume II: Data Standards and Data Dictionary*.
    2. Anatomic pathology laboratory reports: NAACCR's *Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting* (version 2.2 or higher).
    3. Non-hospital sources using electronic medical records: Integrating the Healthcare Enterprise (IHE) Provider Reporting to Public Health-Cancer Registry (PRPH-Ca) Profile.
- For hospitals reporting to the central cancer registry, increase the percentage reporting electronically every year to meet the standard of all hospitals reporting electronically by the end of the five-year project period to reach a goal of 100% of all hospitals.
- For non-hospital facilities reporting to the central cancer registry, increase the percentage reporting electronically every year to meet the standard of at least 80% of these facilities reporting electronically by the end of the five-year project period.
- The central cancer registry uses a secure Internet-based, FTP, https, or encrypted e-mail mechanism to receive electronic data from reporting sources.
- The central cancer registry has a plan in place for receiving and processing data from electronic medical records over the five-year project period in accordance with Meaningful Use practices.
- The central cancer registry should submit the NPCR Hospital, Pathology Lab, and Physician Reporting Progress Report form with the Annual Report.

Strategy 4: Community Level Interventions and Patient Support

Disseminate cancer surveillance data with NCCCP and NBCCEDP programs, and other organizations and agencies as identified by the registry's advisory committee, to support community-level and patient support interventions.

Strategy 5: Health Systems Change

Linkages

- The central cancer registry links with state death files at least every year and incorporates results on vital status and cause of death into the registry database.
- The central cancer registry should link with the National Death Index annually and incorporate results on vital status and cause of death into the registry database.

- The central cancer registry links with the state breast and cervical cancer early detection program at least once a year to identify potentially missed cases, reconcile differences between the two systems, and update appropriate data fields to capture post-linkage information.
- The central cancer registry links with the Indian Health Service (IHS) Administrative Database at least every five years. Central cancer registries with IHS Contract Health Service Delivery Area counties link their records with patient registration records from IHS annually.
- The central cancer registry uses linkages to address gaps identified in data quality and completeness or to improve the utility of the data. Potential sources of information include—
    1. Statewide electronic health files for casefinding and completeness of required data items.
    2. Claims data for casefinding and completeness of required data items.
    3. Census data (or similar) for socio-demographic variables.
    4. Birth records for demographic information.
    5. Department of Motor Vehicle records for demographic information.
    6. Voter registration files for demographic information.

Strategy 6: Program Monitoring and Evaluation

Data Completeness, Timeliness, and Quality

- Data being evaluated for the National Data Quality Standard (formerly known as the 24-Month Standard) must meet the following five data quality criteria—
    1. Data are 95% complete, based on observed-to-expected cases as computed by CDC.
    2. There are 3% or fewer death-certificate-only cases.
    3. There is a 1 per 1,000 or fewer unresolved duplicate rate.
    4. The maximum percentage missing for critical data elements are—
        a. 2% age.
        b. 2% sex.
        c. 3% race.
        d. 2% county.
    5. 99% pass a CDC-prescribed set of standard edits.
- Data being evaluated for the Advanced National Data Quality Standard (formerly known as the 12-Month Standard) must meet the following four data quality criteria—
    1. Data are 90% complete, based on observed-to-expected cases as computed by CDC.
    2. There is a 2 per 1,000 or fewer unresolved duplicate rate.
    3. The maximum percent missing for critical data elements are—
        a. 3% age.
        b. 3% sex.
        c. 5% race.
        d. 3% county.
    4. 97% pass a CDC-prescribed set of standard edits.
- Annually increase case reporting by urologists, dermatologists, and gastroenterologists, as required by state law, to demonstrate continuing progress and improvement by the end of the five-year project period.

- Annually increase case reporting by medical oncologists, radiation oncologists, and hematologists, as required by state law, to demonstrate continuing progress and improvement by the end of the five-year project period.
- The cancer registry participates in the National Interstate Data Exchange Agreement to the extent possible, and exchanges data with all bordering central cancer registries and other central registries most likely to yield missed cases. Data exchange must meet the following minimum criteria—
    1. Occurs within 12 months of the close of the diagnosis year.
    2. Occurs at least twice a year.
    3. Includes all cases not exchanged previously.
    4. Includes all CDC-required data items.
    5. 99% of data pass a CDC-prescribed set of standard edits.
- The central cancer registry is required to complete and submit the NPCR Program Evaluation Instrument (PEI) as directed.

Table 14.

DP17-1701 NPCR Evaluation Questions[1]

Evaluation Question	Data Source
Staffing and Grantee Infrastructure	
1. How is the Central Cancer Registry (CCR) Structured (Where does it sit, staff composition, are staff arranged by operational duties, is there cross training)? 1a. What type of organization is your cancer registry located in (e.g., health department, academic institution, private organization that serves as contractor for all registry operations, etc.)?	PEI 2015, 2017 17-1701 FOA application OFR-approved budgets (year 1-5, as available) Organizational chart Informal interviews
2. What expertise and skills are available in the registry or to the registry (Epi, CTR, IT, Evaluator, etc.)? • Average # of yrs. of experience, all staff • Staff turnover • Salary info • Vacant positions • Key positions fully staffed (PD, CTR, Epi, Data Mgr., etc.) • Qualifications of Registry Director • CTR caseload (Cases/CTR/Yr.)	DP 17-1701 FOA application 17-1701 Progress reports Organizational chart OFR-approved budgets (year 1-5, as available) PEI 2015, 2017
3. What proportion of NPCR funds are used for personnel, contracts, consultants, indirect, travel, supplies, equipment, and other?	OFR-approved budgets (year 1-5, as available) Eva Trinh, Lead with input from PSB Evaluation Team (Justin) PEI 2015, 2017
4. Does program have state support or support from their organization (e.g., Funds, staffing, etc.), or other sources (specify source)?	Informal interviews OFR-approved budgets
5. How has funding for 17-1701 cycle impacted activities and/or organizational structure of CCR? **LP**	17-1701 Progress reports Budget justification Site visit report Informal interviews
Education and Training	
6. What are the current education, training needs of NPCR grantees? (Priority Question) 6a. What professional development and education activities are grantees	Informal interviews Informal focus groups

participating in? **LP** • Level of training for reporting year • Were new reporting standards implemented? 6b. What are some examples of short and intermediate outcomes of providing training to registrars, program directors, epidemiologists, IT specialists? **LP** 6c. What education and training activities are grantees providing to CCR and hospital/facility staff (e.g., CTRs, data managers, epidemiologists, other cancer registry staff? **LP**	Informal focus groups Informal interviews 17-1701 Progress reports NPCR site visit reports
Building and Strengthening Partnerships	
7. Are partnerships with other federal agencies (e.g., VA, IHS, etc.), state, local and national partners (ACS, NAACCR, NCRA, etc.) formalized (e.g., MOU, IAA, etc.)? **LP**	Informal interviews 17-1701 Progress reports NPCR site visit reports
8. In collaboration with CCR, what types of activities are partners involved with? **LP**	Informal interviews 17-1701 Progress reports NPCR site visit reports
9. How are NPCR grantees developing, strengthening, and maintaining collaborations with NCCCP, NBCCEDP, and other chronic disease, infectious disease, or immunization programs? **LP**	Informal interviews 17-1701 progress reports NPCR site visit reports Cancer leadership plans Site visit reports
Program Monitoring and Evaluation	
10. What resources does the grantee have around evaluation and program monitoring efforts? **LP**	Grantee budget Informal interviews
11. To what extent are grantee evaluation plans consistent with the 17-1701 requirements, their overall program work plan, NPCR logic model, and NPCR Evaluation Guide? **LP**	Grantee evaluation plans Grantee evaluation results (starting in year 2 or 3)
12. What barriers and facilitators do grantees encounter when managing, implementing, and/or evaluating their cancer registry programs?	1701 site visit reports OT18-1802 cooperative agreement Informal interviews Informal focus group

13. To what extent do information technology and software tools maintain CCR software as well as facilitate data management (e.g., data collection, consolidation, and submission) processes? 13a. What IT resources does the grantee have? What software does the grantee use (Data management system used)? 13b. If using Registry Plus software suite, what are the TA needs with respect to updating software, troubleshooting, and data entry? 13c. What informatics enhancements would you propose for Registry Plus to make your registry operations more efficient?	IDSAT software list OFR-approved budget PEI 2015, 2017 Informal interviews
14. As part of routine cancer registry management, operations, and surveillance activities: 14a.What are grantees' technical assistance needs with respect to cancer registry management, operations? 14b. What is the distribution of type of reporting source at 12, 24, 36 months? 14c. What is average interval and range between DOD [390] and date case report received [2111] to get at reporting delays? 14d. What portion of cancer registry cases come from out of state? 14e. What percent of cancer registry cases from rural counties? 14f. What percent of cancer registry cases come from CoC- accredited facilities? • Percent of cases coming from a CoC-approved facility as the **only** data source for the tumor? • Percent of cases with at least one of multiple reports coming from a CoC-approved facility for the tumor?	Informal interviews Recorded IDSAT RPUG calls 17-1701 progress reports

15. How do NPCR grantees track program progress over the course of each year? **LP**	NPCR evaluation plans Informal interviews 17-1701 progress reports
16. What are the major challenges and barriers that the CDC NPCR program currently faces (Audience is internal, grantees, partners)?	Informal interviews among DCPC staff Funding trends over the last 5 years (OFR budgets) Informal interviews with grantees, partners
Data Quality, Timeliness, Completeness, and Security	
17. What are the barriers or challenges programs face with respect to CCR data quality? 17a.What types of quality control/assurance procedures do CCRs have in place? • 12-month completeness • 24-month completeness 17b. What barriers do CCRs face around reporting high quality, complete 12- month data?	17-1701 FOA application 17-1701 Progress report CCR policies and procedures manual 1701 Site Visit Reports 2017 onward DQE Reports Informal interviews
18. What is frequency (e.g., every week, bi-weekly, monthly, quarterly, 6 months, etc.) of quality control/assurance activities within the CCR (e.g., Edits, audits, etc.)?	Grantee evaluation plans 17-1701 Progress reports Informal interviews
19. To what extent does state policy and technology support cancer surveillance? 19a. What are the respective percentages of electronic reporting from hospitals, facilities, pathology labs, physicians' offices to CCR? Are rates of electronic reporting increasing among NPCR grantees? 19b. Does the registry have a State law in place that promotes rapid case ascertainment (Path only)? Can we check for record source? 19c. How much of your incoming data is automated, electronic, or in paper abstract format (standardize calculation)? 19d. How much of your CCR processes are automated vs. manual?	PEI 2015, 2017 17-1701 progress reports Informal interviews

19e. What CCR processes need to be automated? 19g. What type of IT infrastructure is in place to support your registry (is IT embedded within registry or consolidated elsewhere?)	
20. To what extent did the CCR meet NPCR data completeness, timeliness, and quality standards? 20a. Has the overall timeliness, completeness, and quality of NPCR data improved over time? 20b. With respect to data quality and completeness, how are grantees doing as far as case ascertainment completeness and percent passing required program edits? 20c. Are our SEER-only or dually funded cancer registries getting complete, quality 12-month data? If not, what are the issues?	NPCR-CSS submissions (2014-2018)/Data Evaluation Report (DER) 17-1701 Progress report (older reports) Informal interviews
Data Use and Dissemination	
21. Who currently uses NPCR Data, and in what ways (We are interested in its use in program planning, implementation, cancer-related communication, and research)? • How many publications? • Number of inquiries received? (Question for CDC internal)	NPCR grantee websites 17-1701 progress reports Cancer leadership plans 1701 Site visit reports Informal interviews
22. How are the cancer registry data used at Territorial, State and National levels to describe cancer burden, demonstrate progress with incidence reduction, and targeted health care service delivery, including cancer screening by geographic area (Please provide examples that demonstrate how data is used)?	NPCR grantee websites Cancer leadership plans 17-1701 progress reports Success Stories Informal interviews
Funding-related	
23. What non-CDC financial or in-kind resources do grantees have to support CCR operations and management?	17-1701 progress reports OFR-approved budget and 1701 FOA submission

	Informal interview Site visit reports
24. What is the annual spend rate for the NPCR program? For each of the 50 NPCR grantees?	OFR-approved budgets
NPCR Customer Service, Technical Assistance (TA), Guidance to Grantees	
25. To what extent are NPCR grantees satisfied with TA from NPCR PCs, Epidemiologists, IT staff and subject matter experts (SMEs) (e.g., Software, evaluation, staging and coding, etc.)? • TA and guidance provided by PCs? • Accessibility to SMEs, resources?	Informal interviews
26. To what extent is NPCR to grantee face-to-face, verbal, and written communication effective and timely?	Monthly conference calls Site visits Email communications
27. How effective are NPCR tools that are shared with grantees? • Ask for helpful examples	Informal interviews
28. To what extent are NPCR grantees satisfied with CDC-NPCR program leadership? • Direction of the program? • Emphasis placed on different strategies? • Accessibility to leaders?	Informal interviews

*LP= low priority

Table 15.

DP17-1701 NPCR Evaluation Project Table

Evaluation Project or Activity	NPCR Evaluation Category	Methods	Evaluation Question(s)	Question Fully or Partially Answered?	End Products (n)
Identify and Implement Best Practices for Cancer Registry Operations 2018-2021 (CDC, NACDD, & NAACCR)	• Staffing & recipient infrastructure • Education & training • Program monitoring & evaluation • Data quality, timeliness, completeness, and security • Funding	Qualitative- KIIs, FGDs Quantitative- Survey (n= 22 registries)	2, 4, 6, 12, 13, 16, 17, 18, 19, 20, 23	#2 partially; could not answer average # years of experience, salary info., vacant positions, and qualifications of registry director #4 partially; #6 partially; unable to answer 6b or c #12 partially #13 fully #16 partially #17 fully #18 partially	Workshops, 4 Presentations, 2 Reports, 2 TIP sheets, 11
Explore NPCR Evaluation Grantee Funding and Resources Report (Trinh et al.)	• Staffing & recipient infrastructure • Funding	Secondary data analysis of 17-1701 recipient (n= 50) applications and budgets (2017, 2018)	1, 2, 3, 4, 23	#1 fully #2 partially- qualifications of registry director, salary information not answered #3 fully #4 partially- could only answer which	Brief report, 1 CSB presentation, 1

				states had SEER, state funds, or in-kind #23 partially	
NPCR Feasibility Assessment of Electronic Reporting and Automation of Registration: Summary of Results from Interviews and Focus Groups, 2019 (CDC and RTI)	• Program monitoring & evaluation • Data quality, timeliness, completeness, and security	IDIs with registry data managers (n = 9) registry program directors (n= 9) FGDs focused on facilitators and barriers to e-reporting (n= 9) FGDs focused on process modifications and outcomes (n= 8)	12, 13, 19	For e-reporting and automation #12 fully #13 fully #19 partially	Report, 1 Presentation, 3 Manuscripts, 3- 2 completed, 1 (conceptual model) submitted to journal
NPCR Evaluation Grantee Software Use Report and Helpdesk Technical Assistance Needs Report (Trinh et al.)	• Program monitoring & evaluation	Evaluator reviewed an MS Excel file including content from every tenth helpdesk ticket request from 1/2018-5/2019	13	#13 partially	Report, 1
DCPC CSB Staff Qualitative Interviews (Trinh, Pordell)	• Program monitoring & evaluation	Key informant interviews with CSB staff (n= 15)	16	#16 partially, as we were unable to interview NPCR	Report, 1

				recipients and CSB partners	
National Program of Cancer Registries PEI 2015 and 2017 Analysis: Electronic Reporting (Duda)	• Data quality, timeliness, completeness, and security	Secondary data analysis using PEI 2015 and 2017 results and Identify and Implement Best Practices for Cancer Registry Operations Report, 2018-2019	19	#19a and b fully #19c, e, and g partially; could not answer #19d	Report, 1 Presentation, 2
Meeting NPCR Data Standards (Trinh et al.)	• Data quality, timeliness, completeness, and security	Secondary data analysis of 24-mth data for dx years 2012-2016 and 12-mth data for dx years 2013-2017 (Used NPCR-CSS DERs, DP17-1701 APRs)	20	#20 fully	Report, 1
USCS Public Use Data Brief Report and Data Use by NPCR Cancer Registries Brief Report (Trinh)	• Data use and dissemination	Secondary data analysis using PEI 2017, NPCR SEER USCS public use incidence database user requests.	21	#21 fully- we answered who uses USCS data, # of USCS data users and # of publications using USCS data (from 8/2017 through	Infographic, 1 Brief Report, 2

				6/2018 and 6/2018-6/2019) as a result of USCS public use data report. How NPCR data is used by cancer registries answered as a result of data use by NPCR cancer registries report.	
Calculate spend rate per registry using a combination of low, medium, and high case count registries (n=36) (Fukayama, Nethercott, Pordell)	• Funding	Secondary data analysis using year 1-3 GMM budget recommendation sheets, internal NPCR budget spreadsheet, available FFRs (n= 36 recipients)	24	#24 partially; we were unable to calculate overall NPCR spend rate for 50 recipients	Report, 1
COPE-QI Project (CDC and RTI) Ongoing (August 2019- May 2023)	• Program monitoring and evaluation • Data quality, timeliness, completeness, and security • Potentially funding-related via costing tool	Staffing survey- 3 rounds- examine staff time spent on different activities within data acquisition, processing and reporting buckets. (n=22)	Potentially 12, 15, 17, 18, 19d, e, 20a, 23	To be decided as this project is ongoing	Preliminary findings from staffing surveys (Excel workbook); Preliminary data from special studies (October-November 2022)

		Outcomes survey- data completeness, quality, timeliness (3m, 6m, 12m, 18m, 24m) (n=22) Mixed methods Costing tool- examine labor and non-labor cancer registry costs (n=22) Special studies (n=6)- examine electronic reporting process for pathology/lab data			