A Qualitative Analysis of Cancer Registry Program Evaluation and Technical Assistance

Overview

This project is part of the program evaluation of the National Program of Cancer Registries (NPCR) 2022-2027 funding cycle. As outlined in the program evaluation plan, the overarching evaluation goals for the NPCR program are 1. to increase completeness, timeliness, and quality of recipient data and 2. understand promising practices, facilitators, and barriers to effective cancer surveillance program implementation. To address these overarching evaluation goals, this project sought to understand recipients' experience with CDC NPCR offered training and technical assistance (TA) and registry program evaluation – essential areas for effective cancer surveillance program implementation.

Specific evaluation questions this project sought to answer were:
1. To what extent do trainings provided by NPCR meet the needs of NPCR recipient staff?
2. What are recipients' TA needs?
3. How effectively do NPCR staff resolve NPCR recipients' TA requests?
4. What barriers and facilitators have NPCR recipients encountered related to program evaluation?

This report is part of a multi-part effort to address these evaluation questions. These questions are aligned with the NPCR program evaluation plan (Appendix 2). This multi-part effort included an analysis of AMP TA requests[1], an assessment of CDC NPCR trainings[2], and informal interviews during registry monthly check-in calls. This report focuses on qualitative findings from informal interviews focused on understanding cancer registry's current experience with program evaluation and technical assistance.

Methods

Evaluators held 23 informal interviews with program recipients from October 2023 through January 2024. Interviews focused on recipients' program evaluation barriers and facilitators, technical assistance (TA) needs, and satisfaction with TA.

Qualitative data was coded and analyzed to identify themes in NVivo 14. In NVivo, a CDC evaluator led initial coding and went line by line through the data and coded relevant text by question. After their initial review, the evaluator conducted second level coding in which they reviewed initial themes, removed any repeated codes, and reduced them to more focused codes. A secondary evaluator then quality checked the coding from the lead evaluator and provided any suggestions. The lead evaluator then incorporated those suggestions to identify final codes. Once codes were finalized for each of the evaluation questions, the CSB evaluation sub-group met to aggregate the

codes into themes by grouping related codes into respective columns and labeling them appropriately.

Findings

Interviews with recipients included questions focused on five key areas: program evaluation barriers, program evaluation facilitators, program evaluation TA needs, general TA needs, and TA satisfaction.

Research Question 1: Barriers

We identified five main themes from the analysis as barriers to registry program evaluation: (1) lack of resources, (2) lack of evaluation competency, (3) data reporting and submission, (4) leadership in transition, and (5) insufficient training (Appendix 3).

Lack of Resources

Participants identified several areas where lack of resources were barriers to program evaluation at their registry, including time constraints, competing priorities, insufficient staff, and lack of funding. Many emphasized that their primary focus was on data collection and quality control efforts, which deprioritized program evaluation activities to some degree. One participant encapsulated this challenge, stating,

> *"If any one element of the ecosystem gets thrown out of sorts, evaluation becomes the thing that may have to fall off the plate."*

Others echoed this sentiment, noting that consistently prioritizing evaluation is difficult amid other pressing tasks. Another registry elaborated,

> *"Time is a really big barrier. With everything else we are doing, finding time to actually devote to an evaluation plan and process is difficult."*

Staffing challenges, such as insufficient staff, high turnover rates, and difficulties in hiring were frequently cited as significant contributors to these competing priorities. These issues result in a lack of available staff to focus on program evaluation, as staff are preoccupied with more urgent responsibilities.

Although lack of funding was mentioned briefly by a few registries, it contributes to the overarching theme of resource shortages. This lack of resources, stemming from insufficient funding, inadequate staffing, and time constraints, forces registries to prioritize other tasks over evaluation, thereby hindering their ability to conduct thorough program evaluation activities.

Lack of Evaluation Competency

Another theme that emerged among 11 of the 23 interviewed registries was a lack of evaluation competency. Registries reported that internal staff without program evaluation education or experience face significant barriers. One participant noted,

"We don't have anyone on our team who is specifically trained in program evaluation."

This deficiency forces registries to either contract out evaluation tasks or assign them to program directors, who are already overwhelmed with other responsibilities.

The general lack of evaluation competency leads to a gap in understanding the critical role program evaluation plays in cancer registry program improvement. As one participant stated,

"[I] feel the newcomers need to understand the importance of program evaluation".

However, this awareness can be difficult to achieve. One participant expressed,

"Another challenge is getting staff trained without having staff versed in evaluation".

Data Reporting and Submission

Data reporting and submission was another theme, identified in **8 of the 23 interviews.** Registries described how access to specific data, necessary to perform program monitoring and evaluation, can be difficult to obtain. Participants described race data being affected when pathology reports increase, with one registry stating:

"One of our biggest barriers right now is that we have increased our pathology, e-path reporting, so with that, our race percentages are getting worse because pathology reports don't have race".

Additionally, several registries described a delay in reporting from reporters affecting their internal program monitoring and evaluation metrics. One registry explained

"[We] have encountered challenges with having facilities sending timely 2021 and 2022 data".

Leadership in Transition

Leadership in transition was reported to impact program monitoring and evaluation in 6 out of the 23 registries interviewed. Five registries indicated that new program directors, who were still acclimating to their roles and managing multiple priorities, contributed to delays in focusing on evaluation tasks. Furthermore, many registries experienced prolonged vacancies that postponed essential tasks. When questioned about barriers to program evaluation activities, one registry cited:

"…being a new PD" as a challenge.

Additionally, other leadership changes were noted to hinder progress in evaluation efforts.

Insufficient Training

Lastly, three registries identified insufficient training as a barrier to effective program monitoring and evaluation.

One registry specifically highlighted the need for Diversity, Equity, and Inclusion (DEI) training, emphasizing its importance in aligning efforts:

> "...before we can accomplish equity initiatives, everyone needs to have the same education/foundation" about DEI.

Moreover, several participants expressed a lack of understanding regarding CDC Performance Measures and how to use the Award Management System (AMP). One registry indicated they are:

> "…waiting for a training session [on AMP] where we can ask questions and get responses".

Research Question 2: Facilitators

Five main themes were identified from the analysis as facilitators for registry program evaluation: (1) partnerships and collaborations, (2) adequate resources, (3) training and technical assistance, (4) effective operations and management, and (5) evaluation competency (Appendix 2).

Partnerships and Collaborations

There was a strong theme of partnerships and collaborations as a facilitator for registry program evaluation (identified by **12 of 23 registries**). Participants mentioned how partnerships allow them to have program evaluation discussions and brainstorm solutions. As one participant described when talking about their registry evaluation workgroups,

> "the way we began the workgroups was from the cancer plan to advance those goals but also to identify gaps (what's not working, issues with data access ...). There were a lot of discussions about gaps and areas of improvement".

They explained that these workgroups help them have conversations about the registry program, its operations, and program evaluation to identify gaps and ways to improve going forward. Other registries also described workgroups, and specific forms of collaboration as helpful to conduct program evaluation. Further, registries mentioned cancer coalitions, evaluation committees, and advisory committees as specific partnerships and collaborations that serve as facilitators to program evaluation. One registry elaborated,

"The Cancer Advisory Committee has also been a great help in identifying areas of health equity that could use focus".

Registries also mentioned how partnerships and collaborations with other registries are useful to discuss challenges and share strategies to address program evaluation.

Adequate Resources

Partly related to building and maintaining successful partnerships and collaborations, **ten registries** described having adequate resources as essential to their success in conducting registry program monitoring and evaluation. Most frequently, registries referenced additional funding as a facilitator, as this was related to their ability to maintain other adequate resources such as internal staffing and contractors for evaluation-related activities. One registry described how

"when there was extra funding available during COVID years, [we] engaged a professional development firm. ... The evaluation firm had time and resources".

Another registry explained how supplemental funding from CDC's data modernization initiative

"helped them to focus on e-path reporting and improve that process and put some effort and student workers in that area".

Effective Operations and Management

Effective operations and management was one of the main facilitators of program evaluation for registries **(9 interviewees)**. Various components of registry operations and management were found to facilitate registry's ability to plan for and implement program evaluation activities. Most notably, having quality assurance and quality control practices in place allows registries to, as one registry described "bake" evaluation into "what we do".

Registries with regular monitoring mechanisms, timely completion of linkages, and successful completion of facility compliance reports found that these QA/QC practices facilitated their collection of data and ability to evaluate their cancer registry program. As one participant described,

"[we have] regular monitoring mechanisms established. We hold monthly production meetings to ensure the timely completion of data linkages and high follow-up rates for cases".

Additionally, effective software (SAS) and enhanced IT infrastructure were aspects of effective registry operations and management that facilitated program evaluation implementation. A participant elaborated,

"We have a database where we track data requests, info requests, projects we work on, and where our data gets used."

Lastly, registries mentioned that supportive leadership and supportive legislation facilitate program evaluation. One registry described,

>*"They set up the law so people are required to report, but in addition to that they can fine people for not reporting".*

Training and Technical Assistance

Training and technical assistance (TA) around program evaluation was a prominent theme, identified in **8 of the 23 interviews**. Registries described how TA and resources provided by CDC were helpful. Specifically, they mentioned the targeted support and office hours offered by program consultants and guidelines, webinars, and toolkits created by CDC staff on program evaluation. One registry stated,

>*"toolkits and webinars are real facilitators to give jumpstart and real examples".*

As described in this quote, one aspect of CDC training webinars that registries enjoyed was real life examples. Another registry shared

>*"[we] have seen a couple evaluation webinars like examples from the other states was really helpful".*

As seen in the partnerships and collaborations theme, registries enjoy collaborating with one another and sharing promising practices.

Evaluation Competency

Lastly, one theme that emerged among **7 of the 23** interviewed registries was the importance of evaluation competency. Registries with internal staff that have program evaluation education and/or experience described how beneficial it was to have this knowledge inside the registry. One participant explained,

>*"[we are] really fortunate to have [name] and he has a lot of evaluation experience".*

Another described, they have

>*"skilled people to get the data that they need to answer the [evaluation] questions".*

Having staff with evaluation competency allows registries to save time and resources as they do not need to depend on external contractors to obtain evaluation services.

Research Question 3: Program Evaluation TA Needs

NPCR registries identified **seven types of TA and resources** needed to help address barriers encountered in program evaluation. These included (1) targeted support, (2) addressing organizational challenges, (3) guidance, (4) technical resources, (5) learning from other registries, (6) training, and (7) increasing evaluation capacity (Appendix 5).

Targeted Support

Eleven registries would like more tailored assistance to help address their unique needs. While trainings and webinars are essential, registries expressed having additional questions and considerations specific to their context. Personalized

assistance in the form of one-on-one support and connections with NPCR SMEs were requested for program evaluation and other aspects of registry operations:

"Most helpful is one to one. Being able to ask all the questions. On webinars it is difficult to get questions answered"

"Another resource would be getting in contact with people that specialize in a certain area (For ex. Mary O'Neil with NDI)."

Registries appreciated NPCR evaluation office hours and recommend that this form of targeted support continues. Further, prompt feedback from PCs and NPCR evaluators continues to be an integral form of targeted evaluation support.

Addressing Organizational Challenges

Eleven registries mentioned that organizational challenges hinder CCR program evaluation. Assistance such as increasing funding, providing better timing of deadlines, strengthening internal collaboration, and advocacy for legislation were all identified as means of addressing organizational challenges.

For timing on deadlines, one registry elaborated, "The timing of evaluation trainings is important", they suggested to offer them "in the spring after APR".

Regarding strengthening internal collaboration, one registry captures this sentiment eloquently:

"Unless someone can provide technical assistance on how to better incorporate the different programs into the registry... everyone sees the registry as the resource. That would be an area of improvement. We talk monthly with the other cancer programs but its more "this is what we've done" rather incorporating registry into what's being done. We are the resource; we are the data to be used."

Guidance

Eight registries indicated that guidance and resources continue to be a need. As two registries similarly explained, guidance covering cancer registry evaluation would be helpful:

"NPCR might want to consider the program evaluation piece and have people refocus on it on what they are here to do – they are here to produce a dataset. So have people focus on that basic component if there are barriers."

Another guidance need appears to be related to the NPCR evaluation plan:

"Not having any formal feedback on the evaluation plan but would be helpful to hear suggestions. Maybe not things that need to be changed but things to consider."

Importantly, knowing where to find NPCR evaluation guidance might be key to helping address this need.

Technical Resources

Seven registries need assistance leveraging technology both for program evaluation and other aspects of registry operations. Registries are looking for ways to streamline registry data to address evaluation needs and increase public awareness of the cancer data. Specific technical resources for creating data dashboards and using specific software were requested, including LexisNexis, SAS, Web Plus, MS Excel, and MS Access. One registry explained:

"Having TA that could help with advanced Excel knowledge, Access knowledge, SAS expertise. This would help them streamline and improve the data quality and monitoring expertise."

Learning from Other Registries

Seven registries asked for examples from other registries. It appears registries want to learn more about what other registries are doing, how they are implementing their evaluation plan, and what techniques they are using to make evaluation progress. Improving collaboration by providing a forum for registries to share promising practices and lessons learned would address this need. As stated by one registry:

"Improved collaboration and insight into other states/border states ... would help us to set a foundation of our own to model after, as well as help supplement."

One participant provided ideas for this information sharing forum. They described,

"It would be good to have an evaluation call or evaluation community of practice to hear other states' best practices for evaluation".

Training

Five registries requested ongoing evaluation trainings and standalone trainings dedicated to specific topics in program evaluation. Of importance is listing available and upcoming NPCR evaluation trainings, specifying the audience, and ensuring this information can be easily located. There appears to be some difficulty identifying specific trainings needed, as one registry explained:

"Continuous training throughout the period because ... you almost already need to know how to do the evaluation. So continuing education on how to do that and maybe offer CEs for it too."

However, trainings on AMP and how to conduct evaluation were suggested.

Increasing Evaluation Capacity
Two registries expressed needing to build capacity internally to perform program evaluation, including culturally sensitive program evaluation. As one registry noted:

"The most important piece from an evaluation perspective is not only quality metrics but how do we build some of the efficiencies into the processes, given that we are still learning."

Research Question 4: TA Needs

Based on analysis results, NPCR recipients identified **six areas** (themes) as cancer registry technical assistance needs: (1) Sharing promising practices; (2) Award Management Platform (AMP) support; (3) NOFO requirements; (4) DMI; (5) Registry management and operations; and (6) Training (Appendix 6).

Sharing Promising Practices
Nine registries discussed sharing promising practices from other cancer registries as an area for additional technical assistance. This was the most prominent theme uncovered under recipient TA needs based on informal interviews.

A participant highlighted the importance of fostering peer-to-peer learning opportunities for NPCR-funded registries, as *"information sharing across registries (Awardees Networking Forum, Community of Practice),"* and having *"opportunities to learn from other registries to share lessons learned"* would be beneficial to all registries.

Several participants had the desire to learn more about how states use SAS, perform linkages, use linkages and data sharing opportunities to better understand health equity, and include advisory boards in evaluation. One participant shared *"[I'm] curious what other linkages registries are working on, maybe [having] some case studies."*

Another registry talked about the need to learn more about how other registries secure state resources since registries struggle with the reality of being flat funded by federal agencies. A participant added

"what would be helpful is if [we] could access what funding other states are getting from the state level...ensuring [we] meet federal requirements for the cancer registry is keeping sufficient state resources for it."

AMP Support
Nine registries cited the need for additional AMP support (training and technical assistance). Several registries noted that learning how to use and navigate through AMP takes time and effort, and that additional training would be helpful. A participant noted

"When you're updating something in AMP, it is hard to see if you should just be adding to what you are updating or do it over."

A few registries talked about how training should be conducted by NPCR staff instead of contractors focused on the technical (system front or back end) aspects of AMP. Moreover, trainers should be familiar with NPCR and recipient needs, as one participant stressed,

"The only thing that comes to mind is AMP…putting progress report and other stuff [into AMP- have someone walk through [this process]." Additionally, they added that *"the Deloitte people should not be the ones training [us]."*

Another participant shared the same sentiment about AMP training when she shared that *"they are technical [people] without expertise of cancer registry."*

Notice of Funding Opportunity (NOFO) Requirements

Technical assistance needs grouped under the NOFO requirement's theme consisted of requests focused on assistance with performing NDI linkage, APR, and data submission. **Four registries discussed** needing help with NDI linkage and APR submission, respectively, while **two registries** identified TA needs related to NPCR data submission. Participants mentioned that the NDI application and linkage process was not easy, and that *"a webinar [to review] would be helpful for a first-time person completing the [NDI] application."* Another participant added *"NDI was a beast- having those webinars to go back [to] has been really helpful."*

Registries requested more APR training and guidance to ensure good understanding of requirements, as one participant shared *"the annual performance report is coming up and [we] may have some questions with that."* Another participant emphasized the importance of *"getting guidance much earlier in terms of reporting for APR,"* since guidance was provided by CDC in November and December.

A few registries discussed the need for TA on data submission requirements and specifications, as they seemed unclear about the timing of specific activities. A participant elaborated *"what are the steps for data submission…what reports do we need to run, what linkages do we need to do, and what is the timing…logging into website, and uploading data, etc."*

Data Modernization Initiative (DMI)

Four registries mentioned having TA needs related to DMI. Specifically, registries talked about establishing or increasing electronic reporting, needing access to cloud-based Registry Plus software (e.g., eMaRC Plus, Nimbus), access to LexisNexis, and implementing artificial intelligence (AI) and Natural language Processing (NLP) technologies hosted by CDC. A participant commented on experiencing e-reporting challenges, and noted

"our biggest limitations are establishing electronic reporting (improving significantly as WebPlus continues to be adopted) which consumes most, if not all available time and resources…"

Lastly, one participant brought up the need to implement AI and NLP technology to move DMI forward within cancer registries, as they shared *"… that CDC can implement AI and NLP…[we] are really interested in something like this and don't have technology resources to do this on our own."* They added *"pooling CDC resources would be much more efficient than trying to have each state trying to implement that on their own."*

Registry Management and Operations

Nine registries discussed technical assistance needs related to effective registry management and operations. Specifically, participants talked about IT or infrastructure, registry staff expertise, and operations resources needs. **Two registries** mentioned having insufficient IT staff, as one participant shared *"[we] don't have dedicated IT staff in our state the way other registries do…. [it] can be hard to find this support since we lost staff in this area."*

One registry talked about their need for a stronger registry infrastructure, as they mentioned that *"[we] are trying to get our infrastructure straight…it is more infrastructure support."*

Moreover, **three registries** discussed needing subject matter experts to meet NPCR requirements. One participant said that "*losing the person that has been doing our data submission for 40 years"* will result in having to hire or train someone else to take over this role. **Two registries** talked about the importance of employing staff with epidemiology skills and experience, as one registry had no epidemiologist on staff. Another participant shared *"[our] cancer epi has taken a new role in the state…will probably need some assistance regaining [this] knowledge."*

Registries asked for additional operations resources such as a deadlines calendar, resource list, manuals, and budget assistance. One participant shared *"[our] TA need would be stretching and rearranging the budget, as our state got a cost-of-living increase…some TA and support in how to budget better."* Another participant discussed the need for a deadlines calendar, as they requested a resource that included *"specific tasks that are due at specific times…due as part of registry function."*

Training

Eight registries requested more training opportunities as part of their TA needs. Suggested topics included a new NPCR program manager orientation, webinars on SSDI, NDI, fundamentals of SAS, QA/QC, and linkages or data sharing to help understand health equity.

A participant shared it would be great if there were *"more detailed trainings [on] dashboards, how to do better QA, [including] QA tool options (abstracting and casefinding)."* Another participant desired training focused on performing cancer data analysis, as they emphasized *"…very specific types of training to help with specific analyses for incidence…provide fundamentals of SAS or something that registries did not have to pay for."*

Two registries discussed the ongoing need for training and registry support opportunities, as one participant stated, *"continued training and support…previous training courses have been helpful."*

Research Question 5: TA Satisfaction

Four key areas were identified as themes related to registry's satisfaction with TA provided by CDC: (1) positive TA experience, (2) timely response, (3) cancer registry resources and (4) TA challenges (Appendix 7).

Positive TA Experience

When asked about their satisfaction with technical assistance provided by CDC, **twelve registries** expressed a positive TA experience. Specifically, they elaborated that they were very satisfied with TA from CDC NPCR program consultants (PCs). One registry expressed,

> *"I don't have any issues, anytime I've made a request I've gotten a response."*

This feedback was not only specific to PCs, however. Registries also expressed general satisfaction from CDC TA more broadly, notably TA provided by staff within CSB, including TA for IT and software support, data quality, and general information gathering.

Another registry elaborated more broadly to express their satisfaction with TA received across the board:

> *"our vendors and partners have performed excellent service to assistance requests".*

Timely Response

Additionally, **12 registries** described satisfaction with the timeliness of TA responses. Registries described how their PCs respond "right away" or "within a day" to their TA requests. Overall, CCRs highlighted general satisfaction, quick response turnaround times from NPCR PCs, and shared that staff monitoring the Cancer Informatics Inboxes also responded in a prompt manner. Lastly, one registry expressed that they were,

> *"very satisfied with the response time to any of our technical assistance requests. The prompt and efficient handling of our inquiries has been greatly appreciated".*

Cancer Registry Resources

Four registries described their satisfaction with cancer registry resources. They listed the deadlines calendar, orientation for new Program Directors, NPCR webinars and NPCR townhalls as useful TA resources.

TA Challenges

Two registries identified dissatisfaction with CDC NPCR technical assistance. For one registry, they had a bit of a problem with one TA request where it did not go through the AMP platform. Another registry did not receive a prompt response to their TA request submitted to the AMP platform. They described that the TA request was advanced to a

person other than the PC, and they did not receive a response for three months. They suggested,

"PCs can check TA requests [in AMP] to see if they were followed up on to make sure requests are closed out".

Summary

The word cloud below displays the **30 most frequent words** mentioned by registries during informal interviews. Looking at these words provides some context for the overarching themes and topics we heard about across our interviews. Top referenced words including, "evaluators, timing, resources, activities, training, data, staff, funds", etc. were topics that are captured within our four overarching themes. The four overarching themes identified across questions and interviews include: (1) resources, (2) training, (3) collaboration and partnerships, and (4) registry operations.

Resources

Cancer registry resources emerged as an overarching theme. Registries described how a lack of resources (time, staff, funding, etc.) contributed to program evaluation barriers, while registries with adequate resources felt that this was a program facilitator. Most notably, **funding** was a frequently mentioned area that posed either a barrier (lack of funding) or facilitator (adequate or supplemental funding) to cancer registry program evaluation. Specifically, registries with additional funding had more resources that allowed for internal staffing and contractors for evaluation-related activities. Furthermore, one registry mentioned how DMI funding helped them leverage technical resources to improve electronic reporting. The need for **technical resources** was

another area that emerged under this theme, as registries also noted a desire to increase access to software and IT infrastructure.

Training

Training was a prominent theme across all research questions. Sufficient training was found to be a facilitator for registry program evaluation activities, while insufficient training was identified as a barrier. Registries acknowledged training as a program evaluation and general TA need, although interviewees also expressed satisfaction with existing CDC trainings and resources. Registries shared that trainings in **program evaluation** were helpful, and they enjoyed trainings focused on having registries share promising practices with each other.

Areas where registries identified a desire for additional training include **AMP**, **foundational evaluation trainings,** and **diversity, equity and inclusion**. AMP was a topic that came up many times across research questions throughout interviews. Registries identified a need for additional AMP support such as how to use and navigate through AMP and a desire for AMP trainings to be led by someone with cancer registry knowledge. Another cross-cutting area that emerged was the need for foundational evaluation trainings. In cancer registries with limited resources, participants emphasized a need to build capacity on how to perform program evaluation. Therefore, providing more foundational trainings, ongoing evaluation trainings, and trainings on incorporating cultural sensitivity and diversity, equity and inclusion were desired.

Training is an area that can significantly impact a registries' program evaluation competency and overall cancer registry program implementation and TA needs. Providing trainings that are clear, foundational, led by subject matter experts, and focused on registry needs will aid registries' program implementation and program evaluation throughout the current and future NPCR funding cycles.

Collaboration and Partnerships

Registries mentioned the importance of collaboration and partnerships as a program evaluation facilitator, program evaluation TA need, and general TA need. Registries identified how partnerships and collaborations allow them to have program evaluation discussions and brainstorm solutions. Registries feel that **leveraging relationships with each other** contributes to increased evaluation capacity.

Registries expressed an interest in collaborating with each other when discussing their program evaluation TA and general TA needs. Registries stated that learning from the examples of other registries, particularly in how they are implementing their evaluation plan, is a TA area of interest. Additionally, interviewees expressed an interest in having NPCR host a **forum** for lessons learned and **peer-to-peer learning** opportunities to discuss challenges, brainstorm solutions, and share lessons learned.

Providing a space for registries to collaborate with each other may contribute further to facilitated program evaluation, as collaborations and partnerships were identified as the

strongest facilitator for registry program evaluation. Registries discussed how working with their workgroups, cancer coalitions, evaluation committees and advisory committees allowed them to discuss challenges and brainstorm solutions. Therefore, providing a space for registries to share knowledge may help them discuss and address evaluation and cancer surveillance program implementation gaps.

Registry Operations and Management

The last overarching theme identified in registry interviews was registry operations and management. This theme was mentioned as a program evaluation barrier, facilitator, TA need, and general TA need. Registries that were undergoing **transitions in leadership** encountered barriers as new staff and prolonged vacancies led to delays focusing on evaluation tasks. Alternatively, registries with effective operations and management (such as supportive leadership and legislation) were able to implement regular monitoring mechanisms that made it easier for them to evaluate their program.

Registries mentioned the need for **stronger internal collaboration** and **advocacy for legislation** as a program evaluation TA need related to their registry operations and management. Registries also listed registry operations and management as a general TA need and described how there was a need for subject matter experts and additional operations resources due to staff vacancies and a lack of knowledgeable staff.

Another significant area mentioned across questions under registry operations and management was **registry IT infrastructure.** Registries listed effective software and IT infrastructure as an aspect of registry operations that served as a program evaluation facilitator. Other registries noted that this was a program evaluation TA need, as they wanted assistance leveraging technology to streamline registry data to address evaluation needs. Registries also expressed a general TA need for technical resources to establish or increase e-reporting, access cloud-based software, and improve IT infrastructure overall.

Many aspects of registry operations and management **overlaps with the resources theme**. Registries with more resources (staff, funding, etc.) tend to have the time and ability to maintain high quality collaboration, monitoring practices, and successful IT infrastructure and software. Addressing resource limitations and TA needs in registries is likely to contribute to an improvement in registry operations and management as well.

Strengths and Limitations

This analysis comes with notable limitations. Our sample included 23 NPCR recipients of varying size and geography. However, these findings are not generalizable to all NPCR-funded recipients. Additionally, the results may be subject to interviewer and participant bias or participant social desirability bias, due to the relationship between the interviewer and interviewees (funding organization and recipient). Moreover, researcher bias may have been introduced during data analysis as what was identified as relevant

to one researcher in the coding and report writing process may not be the same for others.

Despite these limitations, there were several strengths associated with the approach used in this project. Interviews were primarily conducted by a CDC Cancer Surveillance Branch Evaluation Fellow, to minimize any power dynamics between program consultants and cancer registries. Additionally, the qualitative interview guide was shared with registries in advance of informal interviews, so interviewees were aware of and prepared for the questions. Evaluators used a structured approach to conduct interviews, analyze data, generate themes, and write results. A quality check reviewer process was implemented during qualitative data analysis to minimize researcher bias. This analysis is the first to our knowledge to explore registry program evaluation barriers, facilitators and technical assistance needs in depth, and provides important findings to improve cancer registry program implementation and evaluation going forward.

Conclusion and Recommendations

Our qualitative analysis of program evaluation barriers, facilitators, TA needs, and TA satisfaction yielded important results for understanding the variety of factors that go into successful cancer registry program implementation and program evaluation. Identifying key themes such as the availability of resources, trainings, and opportunities for collaboration helps inform NPCR program improvement. Our findings confirmed the importance of understanding registry barriers, facilitators, and technical assistance needs to guide CDC NPCR resources, priorities and decision-making. Compiling and discussing these results helped evaluators generate specific recommendations for CDC NPCR and CCRs, presented below.

CDC NPCR

- Present qualitative analysis findings to NPCR recipients (NPCR Community of Practice, July 2024)
- Further leverage AMP as a resource hub for recipients where they can share resources (i.e., evaluation plans, data dashboards)
- Update the CDC NPCR resource list for recipients and identify where resources can be found
- Continue to provide targeted support (as needed) and office hours on program evaluation and implementation
- Continue to provide evaluation webinars that include real world examples (e.g., from NPCR registries)
- Continue providing webinars on NOFO requirements including NDI application and linkage process, APR, SSDI, and timing of data submission requirements and specifications
- Continued information sharing about DMI (electronic reporting, eMaRc Plus, Nimbus, LexisNexis, CBCP, AI and NLP)

- Use findings to inform CDC NPCR technical assistance including
  - Additional training on AMP from a cancer registry subject matter expert
  - DEI training
  - Foundational evaluation trainings
  - Trainings focused on QA/QC (e.g., how to perform better QA, sharing registry-specific QA tools, abstracting and casefinding)
  - Trainings or individual TA on specific software needs (data dashboards, fundamentals of SAS)
  - Information sharing on strategies to strengthen internal collaboration with registries and other chronic disease programs
  - Case studies on registries (e.g., other linkages registries are working on)
- PCs continue to familiarize themselves with AMP functionality and routinely check TA requests in AMP to see if they were followed up on and closed out
- Include need for additional NPCR funding in documents or testimony shared with US Congress

CCRs

- Review existing NPCR resources including new PD orientation presentation, evaluation trainings, and deadlines and CCR calendars
- Attend existing forums to connect with other cancer registries (NPCR Community of Practice, Awardees Networking Forum)
- Incorporate regular monitoring mechanisms that facilitate data collection and evaluation (e.g., timely completion of linkages and facility compliance reports)
- Consider hiring program staff with evaluation experience (e.g., PD, data analyst, or epidemiologist with evaluation experience)
- Identify legislation from other registries and advocate for similar legislation that improves/facilitates registry operations and management
- Review existing budget and meet with PC to discuss how best to allocate federal funds for upcoming funding year to maximize program dollars
- Utilize CDC IT support and IDSAT help desk to address IT gaps and limitations in IT infrastructure

References

1. DP 22-2202 AMP TA Requests: June 2022-September 2023. November 17, 2023**.** [DP22-2202 TA Requests_AMP Report_11.17.23.docx](#)

2. Results from an assessment of CDC NPCR Trainings. July 5, 2024. [CDC NPCR Training Assessment Results_Edits.docx](#)

Appendices

Appendix 1: Abbreviations

AI: Artificial Intelligence
AMP: Award Management Platform
APR: Annual Progress Report
CBCP: Cloud Based Computing Platform
CCRs: Central Cancer Registries
DEI: Diversity, Equity, Inclusion
DMI: Data Modernization Initiative
IT: Information Technology
NDI: National Death Index
NLP: Natural Language Processing
NOFO: Notice of Funding Opportunity
NPCR: National Program of Cancer Registries
QA/QC: Quality Assurance/Quality Control
SSDI: Site-Specific Data Item
TA: Technical Assistance

Appendix 2: Project Questions and Evaluation Questions

Project Evaluation Question	NPCR Evaluation Question (#)	NPCR Evaluation Question
To what extent do trainings provided by NPCR meet the needs of NPCR recipient staff?	1.1	To what extent do trainings provided by NPCR, NAACCR, NCRA and other standard setters meet the needs of NPCR recipient staff?
What are recipients' TA needs?	N/A	N/A
How effectively do NPCR staff resolve NPCR recipients' TA requests?	1.2	How effectively do NPCR staff resolve NPCR recipients' TA requests?

| What barriers and facilitators have NPCR recipients encountered related to program evaluation? | 5.1 | | | |

Appendix 3: Summary Table of Themes for Program Evaluation Barriers

Summary Table 1: Program Evaluation Barriers				
Theme	**Definition**	**Number of Participants Mentioning Theme**	**Number of References Under Theme**	**Illustrative Quote(s)**
Lack of resources	A lack of resources noted as barriers to conducting program evaluation within the registry. These barriers included time constraints, competing priorities, insufficient staff, and lack of funding	**22**	**71**	*"If any one element of the ecosystem gets thrown out of sorts, evaluation becomes the thing that may have to fall off the plate."* *"Time is a really big barrier. With everything else we are doing, finding time to actually devote to an evaluation plan and process is difficult."*
Lack of evaluation competency	A lack of knowledge and competency within the registries' internal staff regarding program evaluation.	**11**	**14**	*"We don't have anyone on our team who is specifically trained in program evaluation."* *"[I] feel the newcomers need to understand the importance of program evaluation".* *"Another challenge is getting staff trained*

				without having staff versed in evaluation".
Data reporting and submission	Difficulty in accessing specific data needed for program monitoring and evaluation.	7	8	*"One of our biggest barriers right now is that we have increased our pathology, e-path reporting, so with that, our race percentages are getting worse because pathology reports don't have race".* "[We] have encountered challenges with having facilities sending timely 2021 and 2022 data".
Leadership in transition	Changes in leadership at the Program Director level or higher.	6	7	*"…being a new PD"* as a challenge."
Insufficient training	Insufficient training in areas that affect program evaluation and monitoring activities.	3	8	*...before we can accomplish equity initiatives, everyone needs to have the same education/foundation"* *"…waiting for a training session [on AMP] where we can ask questions and get responses".*

Appendix 4: Summary Table of Themes for Program Evaluation Facilitators

Summary Table 2: Program Evaluation Facilitators				
Theme	**Definition**	**Number of Participants Mentioning Theme**	**Number of References Under Theme**	**Illustrative Quote(s)**
Partnerships and collaboration	This theme encompasses all relationships that registries have within and outside of their organizations, that they work with on program evaluation activities.	12	20	"our partners and coalition members have been helpful" "it's been helpful to talk with other registries in our region"
Adequate resources	This is about the resources the registry has, including funding and staffing, that facilitate their implementation of program evaluation.	10	11	"We used infrastructure funding for a CTR and stat-analyst" "Staffing available to conduct evaluation activities"
Effective operations and management	This represents aspects of effective registry operations and management, including quality assurance and quality control and infrastructure, that facilitate program evaluation.	9	17	"Regular monitoring mechanisms are established" "The hardware and software systems supporting various registry activities ... have been maintained and enhanced"
Training and technical assistance	This depicts one-on-one support, resources received, and trainings attended by registries in the area of program evaluation.	8	12	"Value program consultants and all calls from [PC name] and CDC NPCR" "Targeted TA on evaluation" "The templates for the evaluation plan and report"
Evaluation competency	This includes the knowledge and competency that	7	9	"[staff member] has a professional

| | registries' have with their internal staff. | | | background in evaluation"

"Skilled people to get the data that we need to answer the questions" |

Appendix 5: Summary Table of Themes for Program Evaluation Technical Assistance Needs

Summary Table 3: Program Evaluation Technical Assistance Needs				
Technical Assistance (TA) Need	**Definition**	**Number of Participants Mentioning Theme**	**Number of References Under Theme**	**Illustrative Quote(s)**
Training	Ongoing evaluation trainings and standalone trainings dedicated to program evaluation topics.	**5**	**11**	"Ongoing trainings that are made available."

"Types of trainings." "List of trainings and training description, purpose of training; identify audience." |
| **Guidance** | Written resources and guidance, suggestions on the evaluation plan, and assistance locating evaluation resources produced by NPCR. | **8** | **9** | "Availability of resources and knowing where to seek support."

"Resources like the toolkit that help provide more detail especially written down so it is easier to reference."

"Before we submit our evaluation plan, could I send that in for advanced type review?" |
| **Targeted Support** | Tailored assistance and prompt feedback via one-on-one support, office hours, and | **11** | **12** | "...Skilled and knowledgeable personnel with experience in program evaluation." |

	connection with NPCR SMEs.			"Office hours are really helpful."
Increasing Evaluation Capacity	Building internal capacity for CCR program evaluation and culturally sensitive program evaluation.	2	4	"For registry staff there are cultural considerations they have to take." "But when dealing with lack of data, infrastructure, processes, etc. and also have staff that don't have a lot of background knowledge in things that would help with evaluation."
Technical Resources	Assistance leveraging data through data dashboards and specific software.	7	11	"How can we leverage data we have to expand and build on to help programs as well..." "...only able to complete so much because they don't have any data dashboards..." "Technology to support the evaluation activities"
Learning from Other Registries	A forum for information-sharing on promising practices and lessons learned.	7	7	"It is always interesting to share what other registries are doing because it generates ideas for own registry." "Providing more examples of evaluation plans or techniques that other states are implementing. What are the foci of evaluation for other states."

Addressing Organizational Challenges	Increased funding, better timing, enhanced internal collaboration, and advocacy support.	11	19	"Additional funding as a resource" "Have met a lot of their goals on their evaluation plan but have met them because we've changed our timelines – revisiting the plan and revising timelines." "Lack of transparency and communication between registry, IT and internal leadership." "Some advocacy for how to revise legislation or messaging around making changes..."

Appendix 6: Summary Table of Themes for Technical Assistance Needs

Technical Assistance (TA) Need	Definition	Number of Participants Mentioning Theme	Number of References Under Theme	Illustrative Quote(s)
Summary Table 4: Technical Assistance Needs				
Sharing Promising Practices	Having a forum to share ideas and information among registries, so registries can learn from each other and have tangible examples or models to work with. This could also be defined as having a cancer registry community of practice.	9	13	"Opportunities to learn from other registries to share lessons learned." "Knowledge sharing about software." "…how other registries are using SAS and what people are using SAS…knowing who is doing what in other registries…"
AMP Support	Any mention of TA needs specific to the Award Management Platform used by DCPC to communicate with recipients, provide resources, receive TA requests, and submit NOFO deliverables.	9	12	"AMP navigation, training on this." "Mostly just AMP." "Appreciating AMP more, takes a little while getting used to compared to usual [APR] narratives." "Deloitte people should not be the ones that are training."
NOFO Requirements	Any mention of TA needs related to performing NDI linkage, preparing APR, or NPCR data submission.	10	12	"Getting guidance much earlier in terms of reporting for APR…" "What are steps for data submission, what do we need to do to make sure it happens…what reports…linkages…what is the timing…uploading data."

				"NDI was a beast- having those webinars to go back to have been really helpful."
Data Modernization Initiative (DMI)	This includes any mention of access to Registry Plus developed software, LexisNexis, AI, NLP, challenges with electronic reporting, current IT infrastructure, interoperability, etc.	4	6	"Waiting anxiously for CDC to have their cloud version of eMaRC, Nimbus." "…getting data faster." "LexisNexis…this is helpful...need this." "…process that CDC can implement AI and NLP…interested in something like this…don't have technology or resources to do this on our own."
Registry Management and Operations	1. IT or infrastructure support- having dedicated IT staff for registry. Infrastructure support from CDC. 2. Operations resources- resources that will help operate and manage the registry such as manuals, job aids, resource lists, calendars, trainings, etc. Registry staff expertise- any reference to staff turnover, retirement, lack of staff with epi or NPCR data submission	8	10	"Don't have dedicated staff for [state registry] the way other registries do…can be hard to find this kind of support." "More introductory or manuals readily available for operations resources." "TA need would be stretching and rearranging the budget…some TA and support in how to budget better." "Registries have epis, and [our state registry] doesn't have an epi." "Losing the person that has been doing our data

	expertise, for example.			submission for 40 years."
Training	Any mention of the need or desire for more or continued CDC training and TA in the form of resources, webinars, etc.	8	8	"…detailed trainings on specific topics…dashboards, how to do better QA, QA tool options (reabstracting and casefinding)." "Get new webinars (NDI,SSDI, etc.)." "Continued training and support…previous training courses have been helpful."

Appendix 7: Summary Table of Themes for Registry TA Satisfaction

Summary Table 5: Registry TA Satisfaction				
Theme	**Description (What it represents)**	**Number of Participants Mentioning Theme**	**Number of References Under Theme**	**Illustrative Quote(s)**
Positive TA Experience	This theme captures registries' satisfaction with TA from CDC program consultants, CDC NPCR staff, and other partners/vendors.	12	14	"Very satisfied with TA" "Had great technical assistance from CDC people" "Had a couple little glitches upgrading to v23 and [name] got on and got those straightened out right away"
Timely Response	This includes references that described registries' satisfaction with the timeliness of CDC or others' response to their TA requests.	12	14	"Any time we have required technical assistance it has been provided very timely" "From the very beginning, [PC] was

				great - responded right away" "Good, have never gone more than a day without a response"
Cancer Registry Resources	Cancer registry resources that have been helpful TA resources for registries (such as the CCR calendar, NPCR webinars and townhalls) are captured under this theme.	4	5	"The deadlines calendar was really helpful. Orientation provided for new PDs was really helpful" "Appreciate webinars"
TA Challenges	Challenges identified by registries that affect their satisfaction with TA from CDC are described under this theme.	2	2	"With the last one [AMP TA request] there was a bit of a problem where it did not go through" "Handling follow-up in AMP when advancing TA requests"