

Summary of NPCR Evaluation Activities

Background: In FY2019, DCPC is engaged in multiple activities focused on increasing the completeness, timeliness, and quality of 12- and 24-month cancer surveillance data submitted by NPCR grantees.

Workgroups focused on NPCR Evaluation:

- 1) The **NPCR Evaluation Working Group** focuses on implementing a strategic approach to learn about and share NPCR best practices. This group, led by Paran Pordell and supported by a PPEO Evaluation Fellow (Eva Trinh) ensures inclusion, coordination and branch collaboration across relevant projects and activities. Two key products serve as a road map for NPCR evaluation activities, bringing together the multiple DCPC projects focused on understanding what facilitates grantee success and addressing barriers to effective NPCR program implementation. An academic, senior evaluation expert (Dr. Jim Emshoff) provided consultative advice during evaluation planning.
- 2) The **CSB Data Quality and Quality Control Workgroup**, led by Denise Duran and David Bang, evaluates NPCR program operations and data quality control through activities such as PEI, DER, DQE, and special QC projects (CDC/NCI grade analysis). One of the workgroup's main activities is to develop standardized criteria to identify and provide technical assistance and guidance to struggling recipients to enhance program operations and improve the quality of central cancer registry data submissions.

NPCR Evaluation Framework: A Roadmap for Program Improvement and Efficiency

- **NPCR Evaluation Plan.** Building from the NPCR 17-1701 logic model, NPCR-EWG defined 28 priority evaluation questions, which will be answered using a mixed-methods, phased approach over five years.
- **NPCR Evaluation Logic Model.** Created by NPCR-EWG September 2018 based on NPCR 17-1701 LM
- **Phase I** (November 1, 2018 – September 30, 2019): Secondary analyses of PEI, DER, DQE, recipient 17-1701 NOFO submissions, budgets, and end of year recipient progress reports will help answer evaluation questions focused on staffing and grantee infrastructure, funding, education, training, program monitoring and evaluation as well as data quality, timeliness, and completeness.
- **Phase II** (February 1, 2019 – December 31, 2019): Primary data collection from NPCR registries and stakeholders to collect quantitative and qualitative data.
- **Phase III** (January 1, 2020-January 31, 2021): Continue to answer evaluation questions aligned with NPCR Program Standards, which include cancer surveillance sub-areas such as data use and dissemination, building and strengthening partnerships, NPCR's customer service, types of technical assistance, and guidance to funded 17-1701 recipients.
- **Phase IV** (February 1, 2021-July 1, 2021) Write up Evaluation Report with Recommendations for next steps and present to external and internal stakeholders. Modify NPCR documents and processes due to recommendations and offer program and software-related training and technical assistance.

DCPC Funded Projects supporting NPCR Evaluation Framework

- 1) **Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health** (OSTLTS OT18-1802, Collaboration with NACDD and NAACCR; POC: Trevia Brooks)
 - *Summary:* Assess operations through focus group discussions, in-depth interviews, and surveys of selected registries to identify best practices; convene expert panels; and beta-test effective solutions with registries that have difficulty meeting NPCR standards.
 - *Relation to NPCR Evaluation:* Project will provide qualitative data for Phase II.
- 2) **Feasibility Assessment on the Costs and Process of Electronic Cancer Registry Reporting and Automation of Registration** (EARB Task Order; POC: Florence Tangka)
 - *Summary:* Perform formative assessment on barriers and facilitators, conduct process evaluation, derive cost of registry operation, and assess cost-efficiency of electronic data reporting and automation of cancer registry operations to inform optimal implementation of electronic reporting.
 - *Relation to NPCR Evaluation:* Phase 1 will identify approaches, both internally within the registries in terms of processes and externally in terms of support activities, to enhance electronic reporting to generate high quality data efficiently.

NPCR Evaluation Progress to Date (April 2019)

CSB has completed several secondary data analyses of grantee funding applications, continuation applications, and internal documents to answer priority evaluation questions in relation to grantee infrastructure, funding, and software use.

- Findings show that most grantees (46 states and 4 territories) are organized by the state health department (84%). The remaining registries are organized by academic institution (14%) or hospital association (2%).
- Grantees requested the majority of their funds for personnel costs.
- The majority of NPCR-funded staff consist of coordinators, auditors, geocoders, field representatives, and certified tumor registrars (CTRs) to implement registry operation duties.
- More than half of NPCR grantees utilize funds for contract costs, which is the second largest amount of funding requested by grantees.
 - Contracts include costs for CTRs, research, IT support, evaluation, education and training, software and licenses, and personnel at a second organization to implement registry operations.
- Dual funded grantees who receive funding from SEER and NPCR have greater numbers of total CCR staff.
- More than 80% of grantees use eMaRC Plus software for data abstraction, file upload, and follow-back.
- All 50 grantees use at least one component of the Registry Plus Software Suite.

DCPC Funded Projects supporting NPCR Evaluation Framework

1) **Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health-** will utilize primary data collection strategies using mixed methods

- Select cancer registries identified and notified by CDC and NAACCR.
- 22 in-depth interviews completed with participating cancer registry representatives.
- Participants received questions prior to the interviews, which resulted in enlightened, well-rounded and candid feedback.
- Two-three focus groups for next round of cancer registry input scheduled with additional focus groups planned.
- Statistical Summit convened to identify possible ways to measure completeness completed April 8-9, 2019, in Gaithersburg, MD.
- Operations Summit scheduled for May 6-8, 2019 in Atlanta, GA to identify ways to operationalize cancer registry best practices.

2) **Feasibility Assessment on the Costs and Process of Electronic Cancer Registry Reporting and Automation of Registration**

- 18 CCRS completed in-depth interviews in February and March 2019.
- Questions included self-described adoption of the level of electronic reporting by CCR, how CCR staff define electronic reporting, facilitators and barriers experienced with electronic reporting in the field, and overall feedback on the approach used.
- Interoperability of software (Registry Plus Suite), staffing, and infrastructure required to maintain software were cited by CCR staff as some challenges experienced with electronic reporting activities.
- Future work includes two virtual focus group discussions with a small group of central cancer registry staff in May and June 2019 to gather more information about cancer registry operations, infrastructure, barriers, and successes as well as electronic reporting cost implications and sustainability; and feedback on the value of electronic reporting.
- Report of preliminary findings expected by September 2019.

For more information about NPCR Evaluation Framework activities, please contact Ms. Paran Pordell at either (404) 639-8497 or ppordell@cdc.gov.