2019 NPCR NORTH CAROLINA SUCCESS STORY

North Carolina Cancer Registry:
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Facilitating Cancer Research in North Carolina- A Successful Partnership

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: Built on decades of strong collaborative relationship between Rapid Case Ascertainment (RCA), N.C. Central Cancer Registry (CCR), and UNC Lineberger Comprehensive Cancer Center, RCA has been in operation since 1992. RCA is an acceleration of the CCR's reporting process for quick identification of cancer patients throughout the state, with cases being identified within 30 days of diagnosis.

North Carolina is one of the first central cancer registries and is one of the few in the nation to provide RCA. We support population-based epidemiologic behavioral, clinical, health services and other cancer research. We facilitate research to advance knowledge of causes, treatment, and prevention of cancer. Without RCA, research involving timely patient contact would not be possible, and peer reviewed grant proposals might not be funded.

CHALLENGE: Researchers in North Carolina needed a mechanism to quickly identify and enroll newly diagnosed cancer cases, in order to conduct large epidemiologic cancer studies exploring risk factors and/or possible causes of cancer (especially interaction of genes and environment), including diet, medication use, and family history, as well as knowledge, attitudes, beliefs, and practices about screening and treatment. Some studies compare data between cases and controls. No studies offer treatments. To investigate and research options to provide this service, the North Carolina Central Cancer Registry partnered with the University of North Carolina-Chapel Hill. Leaders from the two organizations worked together to devise a unit devoted solely to facilitating rapid identification of newly diagnosed cancer cases.

RCA PROCESS: Researchers actively engaged in the research first obtain IRB approval from their institution(s). Once researchers obtain IRB approval, they submit their request for data to the CCR for review and approval. Once those approvals are in place, the case identification process begins.

Registrars provide pathology reports, demographics, and physician contact information to RCA for patients meeting eligibility criteria. This information is usually provided within one month of diagnosis via mailing or electronic reporting (contact us to learn more about how your facility can implement electronic case reporting to RCA). RCA mails a CCR brochure to all potentially eligible participants, outlining CCR's role in research and providing notification of possible contact by researchers. Patients may opt-out by calling CCR and requesting that their information not be shared with researchers. Eligible patient data is entered into the RCA database and sent to studies each week.

RESULTS: The RCA has experienced staff who facilitate research that requires early contact with cases. They review all pathology reports for each specific study case and will select reports that meet a study's selection criteria. RCA staff work with hospitals across the state to educate and engage cancer registrars to participate in RCA. As each study is approved, RCA staff contact area hospital registrars and enlist their help in case identification. While earlier studies utilized only a subset of North Carolina counties, more recent studies have expanded to statewide case ascertainment, and hospitals and registrars in all 100 N.C. counties are now participating.

SUSTAINING SUCCESS: RCA has helped enroll more than 20,000 cancer patients in research studies in North Carolina and beyond. Since 1992, RCA has identified and reviewed over 200,000 path reports for 30 studies spanning 15 cancer sites. This research may help find cancer causes and cures.

Hospital cancer registrars across the state who participate in RCA are contributing to important cancer research studies. Their hard work is reflected in the research being done to help find causes and cures for cancer. The studies reimburse hospital registrars in the amount of $15 per eligible pathology report submitted. This money is sometimes earmarked for educational purposes or supplies for the hospital registry department. Some studies request help from RCA to obtain cancer patient data even sooner – within 1 to 2 weeks of diagnosis (which we call SUPER-RCA studies). These studies may need to contact participants before they receive treatment or before they are too sick to take part due to an aggressive cancer such as liver or pancreatic. For SUPER-RCA studies, registrars are reimbursed $20 per eligible pathology report. Registrars receive annual accrual reports from each facility for all studies utilizing RCA. Reports to their hospital's cancer committee demonstrate a registrar's active participation and cooperation with the CCR. The inclusion of enrolled cases in annual reports may support a hospital's accreditation. RCA is a valuable resource that is making continued research possible in North Carolina and other states.

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https://unclineberger.org/research/core-facilities/rapid-case-ascertainment

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