SIDEBAR

The North Carolina Tissue Consortium: Ensuring Equitable Representation and Accessibility to Cancer Specimens from Eastern North Carolina

Moses A. McDaniel, Nasreen A. Vohra, Kathryn M. Verbanac

The North Carolina Tissue Consortium (NCTC) is an IRB-approved tissue bank established at East Carolina University (ECU) in 2008 [1]. The objective of the NCTC is to facilitate cancer-related research by providing a means through which normal and malignant tissue specimens are procured, processed, stored, and distributed to researchers while protecting the rights and confidentiality of participants. The NCTC is supported by the University Cancer Research Fund (UCRF), which was established by the North Carolina General Assembly in 2007 and has been continually funded with the goals of improving the quality of life of cancer patients in North Carolina, increasing the ability to discover and disseminate cancer information, and improving prevention and early detection [2–4]. UCRF funds were allocated to the UNC-Chapel Hill School of Medicine and the Lineberger Comprehensive Cancer Center to support cancer research throughout the state. At the time of the UCRF's creation, there were 41,000 new cancer cases and 17,000 deaths annually in North Carolina and more than 560,000 annual deaths nationally [4]. Although the state cancer mortality rate (annual cancer deaths per 100,000 people) has since decreased, projected numbers in 2023 are significantly higher, with 67,358 new cases and 22,052 deaths [5], evidence of the continued importance of this initiative.

In addition to providing a means for procuring, processing, storing, and distributing tissue, the NCTC also provides consultations to help identify and target specimen collection to meet the specific research needs of investigators at ECU. Researchers must have an IRB-approved study, or a study verified as exempt by the IRB. Although challenges and lapses in acquisition have been encountered (e.g., intermittent staff vacancies and the COVID-19 pandemic), from January 2021 to October 2023 1,103 patients have consented to participate (> 99% consent rate), with 663 samples collected. The NCTC currently contains 3,271 tissue samples (20% colon, 15% breast, 11% lung, 8% kidney, 7% liver, 3% ovary, and 1% brain) stored as frozen and formalin-fixed paraffin-embedded (FFPE) specimens. NCTC clinical specimens have been used by ECU researchers for a variety of studies, leading to significant published insights into cancer signaling pathways, biomarkers, bioenergetics, and potential therapeutic targets [6–9].

ECU is located in the heart of rural Eastern North Carolina (ENC), a racially and ethnically diverse region with significant health disparities and adverse social determinants of health. Cancer disparities in our region are well documented; the 29-county region of ENC has higher cancer incidence and mortality rates compared to the rest of the state and the nation [10–13]. ENC has a higher proportion of Black residents compared to the remainder of the state and nation and a high percentage of residents living below the federal poverty threshold [14].

Historically, certain demographic groups such as racial and ethnic minorities, women, elderly individuals, and people from low socioeconomic backgrounds have been underrepresented in clinical trials, large scale clinical studies, registries, and biobanks. This has led to insufficient data from which to draw definitive conclusions about how different research findings are applicable and beneficial to a diverse population [15–17]. The ECU NCTC has enrolled 60% female participants and a diverse patient population representative of our region: 61% White, 38% Black, 1% Hispanic. To expand the participant population and specimen use, the NCTC consent form and protocol have been modified over time, including the addition of a Spanish version of the consent form and provision of de-identified specimens to extramural collaborators (with IRB approval). We are currently addressing the challenge of expanding the consent form and protocol to enable sample distribution to researchers who wish to conduct multi-ancestry cancer genetic studies. Most publicly available genomics data sources are derived from White populations, impairing the ability of underrepresented groups to benefit fully from recent advances in risk scores, precision oncology, and immunotherapy [15, 18, 19]. Conducting genomic research in diverse populations is critical to increase our understanding of differences in cancer biology, drug metabolism, and biomarkers, and to better address disparities in cancer outcomes.

The NCTC strives to provide every cancer patient undergoing surgery with the opportunity to contribute their specimens to research. The true intent and value of this bank and the donations from numerous patients will only be realized when these specimens are utilized to further cancer research. We hope this article will increase awareness of the availability of cancer specimens for research from a disparate and underrepresented region of North Carolina. Researchers who wish to obtain tissue samples from the NCTC may contact the Director and Principal Investigator, the Co-PI, or the NCTC Study Coordinator. NCMJ

Moses A. McDaniel, MS Research Specialist, Division of Surgical Oncology, Department of Surgery, Brody School of Medicine, East Carolina University, Greenville, North Carolina.
Nasreen A. Vohra, MD Associate Professor and Chief, Division of Surgical Oncology, Department of Surgery, Brody School of Medicine, East Carolina University, Greenville, North Carolina.
Kathryn M. Verbanac, PhD Professor, Division of Surgical Oncology, Department of Surgery; Interim Director, Center for Health Disparities, Brody School of Medicine, East Carolina University, Greenville, North Carolina.

Acknowledgments

The NCTC acknowledges the critical collaboration of the Department of Pathology and Laboratory Management at ECU Health for facilitation of optimal specimen procurement.

No conflicts of interest were disclosed.

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Electronically published January 8, 2024.

Address correspondence to Kathryn M. Verbanac, Department of Surgery, Brody School of Medicine, East Carolina University, 600 Moye Blvd, Mail Stop 639, Greenville, NC 27834 (verbanack@ecu.edu).

N C Med J. 2024;85(1):15-17. 0029-2559/2024/85108