Catchment-Specific Identification of Adult T-Cell Leukemia/Lymphoma Using Population-Based Cancer Registry Data

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1. Background
Adult T-cell leukemia/lymphoma (ATLL) is a rare and aggressive hematologic malignancy etiologically linked to human T-cell lymphotropic virus type 1 (HTLV-1). In the United States, surveillance of ATLL is challenging due to its rarity, heterogeneous clinical presentation, and limitations in routinely collected cancer registry data. These challenges are particularly relevant for cancer center catchment areas shaped by migration, ancestry, and population diversity.

2. Goals
Our goals were to determine population-based incidence and survival analysis.

3. Solutions and Methods
Using population-based cancer registry data from across the U.S., we evaluated national patterns of ATLL occurrence while examining geographic concentration within specific metropolitan catchment areas.

4. Outcomes
Although cases were identified nationally, ATLL diagnoses were highly concentrated in South Florida and New York City – regions characterized by large Caribbean and immigrant populations with elevated HTLV-1 prevalence. This pattern highlights substantial heterogeneity in disease burden that is diluted in national summaries but becomes apparent when data are interpreted through a catchment area lens.

5. Lessons Learned and Future Directions
Our findings underscore how reliance on national averages and limited demographic detail may underestimate or obscure risk in specific populations and geographic areas. For rare, infection-associated malignancies such as ATLL, standard registry approaches may fail to fully capture the local context needed for accurate surveillance, prevention, and early detection efforts. This work demonstrates the value of catchment-focused analyses using population-based registry data to identify high-risk populations, inform targeted public health strategies, and strengthen cancer surveillance infrastructure. Enhanced capture of ancestry, migration history, and infection-related risk factors is critical to advancing data excellence and addressing inequities in rare cancer burden within diverse U.S. catchment areas.