ACS Study Finds Individuals With Rare Cancers in the U.S. Present Distinct Diagnosis Patterns and Many Experience Treatment Delays

CHICAGO, October 11, 2025 — Rare cancers, defined as fewer than 6 cases per 100,000 people per year, are understudied in the United States. Patients with rare cancers may experience unique challenges. In a new, large study led by the American Cancer Society (ACS), scientists found that patients diagnosed with rare cancers exhibit distinct diagnosis patterns and more than one-third did not initiate treatment within 30 days of diagnosis. The findings will be presented at the annual American Society of Clinical Oncology (ASCO) Quality Care Symposium in Chicago, October 10-11, 2025.

Researchers, led by Nova Yang, MSPH, at the American Cancer Society, analyzed data from patients of all ages who were diagnosed with first primary rare cancers between 2015 and 2022 across 50 U.S. states and the District of Columbia using the National Cancer Database (NCDB). Scientists provided descriptive statistics to characterize individuals with rare cancers, their diagnosis and treatment patterns, and the timing of treatment initiation.

Study results identified 1,922,105 individuals diagnosed with rare cancers, representing 23.4% of all cancer diagnoses during the study period. One-quarter of patients (25.6%) were aged 55 years old and younger; 43.8% of patients were treated at academic facilities. The most common sites of rare cancers were the digestive system (35.3%), hematopoietic system (18.3%), nervous system (7.6%), and head & neck (5.4%); these sites represented about 10% of common cancers. Notably, early-stage diagnoses were less common for rare than common cancers (32.3% vs. 59.9%), and 28.6% of rare cancer diagnoses (vs. 3.8% of common cancers) did not have applicable staging. Treatment patterns for patients with rare cancers varied by stage. Nearly one-quarter of patients with early-stage rare cancers (24.3%) did not receive any surgical treatment, and over one-third of patients with stage IV cancers (37.9%) did not receive systemic therapy. The median days to receive treatment after diagnosis was 35 days, with variation by age, cancer site, and other characteristics. Shorter times to treatment initiation were observed among younger individuals and those with private insurance, while delays were more common among patients aged 75 years and older, racialized as Non-Hispanic Black, living in poorer areas, with unknown stage, and with greater comorbidity burden.

Researchers emphasized that targeted efforts are warranted to improve access to care and health outcomes for patients diagnosed with rare cancers.

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About the American Cancer Society
The American Cancer Society is a leading cancer-fighting organization with a vision to end cancer as we know it, for everyone. For more than 110 years, we have been improving the lives of people with cancer and their families as the only organization combating cancer through advocacy, research, and patient support. We are committed to ensuring everyone has an opportunity to prevent, detect, treat, and survive cancer. To learn more, visit cancer.org or call our 24/7 helpline at 1-800-227-2345. Connect with us on Facebook, X, and Instagram.

For further information: FOR MORE INFORMATION, CONTACT: American Cancer Society, Anne.Doerr@cancer.org

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