



Central Brain Tumor Registry of the United States Statistical Report: Adolescent and Young Adult Primary Brain and Other Central Nervous System Tumors, 2016–2020

Introduction

The data analyzed in the report is from the largest population-based dataset available for characterizing brain and other central nervous system (CNS) tumor incidence, prevalence, and survival in the United States, reported by the Central Brain Tumor Registry of the United States (CBTRUS) from data collected by the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI) of the U.S. National Institutes of Health.

The report defines adolescents and young adults (AYAs) as people between the ages of 15 and 39 years old.

An accurate statistical assessment of primary brain and other CNS tumors in the AYA population is vital to understand the impact of these tumors within this population. AYAs often experience a difficult adjustment between pediatric and adult brain and other CNS tumor care. Furthermore, research has shown primary brain and other CNS tumors impacting this age group have unique molecular features distinct from pediatric and adult tumors, posing challenges for diagnosis and treatment. This report serves as a reference for the AYA patient community, researchers investigating new therapies, and clinicians treating these patients.

Key Takeaways

- Primary brain and other CNS tumors are the second most common cancer type in AYAs.
- There are an estimated 208,620 AYAs living with a primary brain or other CNS tumor diagnosis in 2024.
- Mortality rates for AYAs with brain and other CNS tumors have not changed since 2007, unlike other common cancer types, which have seen decreased mortality.
- Primary malignant (cancerous) brain and other CNS tumors are the leading cause of death for those between 15 and 24 years old.

Incidence: Newly Diagnosed Primary Brain and Other CNS Tumors

- Roughly 12 in 100,000 AYAs were diagnosed with a malignant or non-malignant primary brain or other CNS tumor per year, averaging 12,848 newly diagnosed cases annually, making it the second most common cancer in this age range. About one quarter (3,457) of those tumors were malignant.
- In 2024, an estimated 13,350 new cases of malignant and non-malignant (benign) primary brain and other CNS tumors will be diagnosed in AYAs.
- Female AYAs were more likely to develop primary CNS tumors than males (14.67 vs. 9.38 per 100,000, respectively). However, males were more likely to be diagnosed with malignant primary CNS tumors.



- Incidence was slightly higher in AYAs who were non-Hispanic American Indian/Alaska Native (12.75 per 100,000) compared with AYAs who were non-Hispanic White, non-Hispanic Black, non-Hispanic Asian or Pacific Islander, or Hispanic AYAs of all races.
- Incidence increased with age and was highest in AYAs between 35 and 39 years old.
- Non-malignant pituitary tumors were the most common CNS tumors in AYAs overall and accounted for 36.5 percent of cases, followed by meningioma and nerve sheath tumors.
- The most common malignant tumor type was adult-type diffuse gliomas (glioblastoma, diffuse astrocytoma, and anaplastic astrocytoma).

Prevalence: Total AYAs Living with a Primary Brain or Other CNS Tumor

- An estimated 208,620 AYAs are living with a primary brain or CNS tumor diagnosis. This is approximately 50 percent higher than the estimated 132,620 AYAs who are living with leukemia or a related disorder.
- The most common CNS tumors in 2024 are expected to be tumors of the sellar region, including pituitary gland tumors, which are mostly non-malignant. However, about a quarter of the CNS tumors diagnosed in AYAs in 2024 will be malignant.

Five-Year Survival

- Over 90 percent of AYAs diagnosed with a primary brain or other CNS tumors lived for at least five years.
- Five-year relative survival for AYAs with malignant primary brain or other CNS tumors was 72.7 percent.
- Survival after diagnosis was highest in adolescents ages 15–19 years (92.0 percent) and lowest in young adults ages 35–39 years (89.9 percent).

Mortality: Deaths Due to Primary Brain and Other CNS Tumors

- Roughly one in 100,000 AYAs died due to a primary malignant brain or other CNS tumor each year, averaging 1,018 deaths annually.
- Primary malignant brain and other CNS tumors were the second most common cause of cancer-related death in AYAs—and the leading cause of death for those between 15 and 24 years old.
- While cancer survival overall has been improving, there has been no significant change in brain and other CNS tumor mortality in AYAs since 2007.



About the Report

- The incidence and survival data spanned cases diagnosed from 2016 to 2020, and represent ~99.9% of newly diagnosed brain and CNS tumor cases reported to US cancer registries during this time period. These data are provided by the CDC’s National Program of Cancer Registries and the NCI’s Surveillance, Epidemiology, and End Results program.
- Prevalence was estimated as of December 31, 2024.
- This is the first statistical report to analyze the unique AYA population while incorporating current tumor classification based on recent molecular data.

American Brain Tumor Association AYA Resources & Support

- Online and in-person [webinars](#), [Patient & Family Meetings](#), and a [National Conference](#) with sessions pertaining to AYAs.
- An [online support community](#).
- A [Patient and Caregiver Mentor Support Program](#).
- A [Financial Assistance Program](#).

NCI AYA Resources

- [AYAs with Cancer](#) includes cancer types, finding a doctor, treatments, coping and support, survivorship, end-of-life care, and more resources.
- [Coping with Cancer for Young Adults](#) from MyPart (My Pediatric and Adult Rare Tumor Network).
- [NCI-CONNECTions](#): A rare brain and spine tumor blog with news and information for AYAs.