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CBTRUS Statistical Report: American Brain Tumor Association & NCI Neuro-Oncology Branch Adolescent and Young Adult Primary Brain and Other Central Nervous System Tumors Diagnosed in the United States in 2016–2020

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Abstract

Recent analyses have shown that, whereas cancer survival overall has been improving, it has not improved for adolescents and young adults ages 15–39 years (AYA). The clinical care of AYA with primary brain and other central nervous system (CNS) tumors (BT) is complicated by the fact that the histopathologies of such tumors in AYA differ from their histopathologies in either children (ages 0–14 years) or older adults (ages 40+ years). The present report, as an update to a 2016 publication from the Central Brain Tumor Registry of the United States and the American Brain Tumor Association, provides in-depth analyses of the epidemiology of primary BT in AYA in the United States and is the first to provide biomolecular marker-specific statistics and prevalence by histopathology for both primary malignant and non-malignant BT in AYA. Between 2016 and 2020, the annual average age-specific incidence rate (AASIR) of primary malignant and non-malignant BT in AYA was 12.00 per 100,000 population, an average of 12,848 newly diagnosed cases per year. During the same period, an average of 1,018 AYA deaths per year were caused by primary malignant BT, representing an annual average age-specific mortality rate of 0.96 per 100,000 population. When primary BT were categorized by histopathology, pituitary tumors were the most common (36.6%), with an AASIR of 4.34 per 100,000 population. Total incidence increased with age overall; when stratified by sex, the incidence was higher in females than males at all ages. Incidence rates for all primary BT combined and for non-malignant tumors only were highest for non-Hispanic American Indian/Alaska Native individuals, whereas malignant tumors were more frequent in non-Hispanic White individuals, compared with other racial/ethnic groups. On the basis of histopathology, the most common molecularly defined tumor was diffuse glioma (an AASIR of 1.51 per 100,000). Primary malignant BT are the second most common cause of cancer death in the AYA population. Incidence rates of primary BT overall, as well as specific histopathologies, vary significantly by age. Accordingly, an accurate statistical assessment of primary BT in the AYA population is vital for better understanding the impact of these tumors on the US population and to serve as a reference for afflicted individuals, for researchers investigating new therapies, and for clinicians treating these patients.

Executive Summary

The Central Brain Tumor Registry of the United States (CBTRUS), developed in collaboration with the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI) of the US National Institutes of Health, is the largest population-based registry focused exclusively on primary brain and other central nervous system (CNS) tumors (BT) in the United States. As such, CBTRUS represents the entire US population. The *CBTRUS Statistical Report: American Brain Tumor Association & NCI Neuro-Oncology Branch Adolescent and Young Adult Primary Brain and Other Central Nervous System Tumors Diagnosed in the United States in 2016–2020* contains the most up-to-date population-based data on primary BT in adolescents and young adults ages 15–39 years (AYA) available through the US surveillance system and supersedes all previous reports in terms of completeness and accuracy. This age range is used by the NCI's SEER Program, the 2023 CBTRUS Statistical Report, and many other cancer reporting agencies.[1,2] Accordingly, this report represents a current, comprehensive source for the descriptive epidemiology of these tumors.

Incidence: Newly Diagnosed Primary Brain and Other CNS Tumors in AYA, 2016–2020

- Between 2016 and 2020, the annual average age-specific incidence rate of all primary malignant and non-malignant BT in AYA was 12.00 per 100,000 population. The incidence for malignant tumors only (ICD-O-3 behavior code of /3) was 3.21 per 100,000 population versus 8.79 per 100,000 population for non-malignant tumors (ICD-O-3 behavior code of /0 or /1).
- The rate of all primary malignant and non-malignant BT in AYA was higher in females than males (14.67 vs 9.38 per 100,000, respectively). Primary malignant BT were more frequent in males than females (3.66 vs 2.75 per 100,000, respectively).
- Incidence was slightly higher in AYA who were non-Hispanic American Indian/Alaska Native (12.75 per 100,000) compared with AYA who were non-Hispanic White (12.71 per 100,000), non-Hispanic Black (11.50 per 100,000), non-Hispanic Asian or Pacific Islander (6.55 per 100,000), or Hispanic AYA of all races (10.44 per 100,000).
- Incidence was higher in young adults ages 35–39 years (18.05 per 100,000) than in all other age groups in the AYA spectrum at diagnosis.
- In 2024, an estimated 13,350 new cases of primary malignant or non-malignant BT will be diagnosed in AYA in the United States.

Mortality: Deaths Due to Primary Brain and Other CNS Tumors in AYA, 2016–2020

- Overall, 5,090 deaths were attributed to primary malignant BT in AYA ages 15–39 years at death. This represents an annual average age-specific mortality rate of 0.96 per 100,000 population and an average of 1,018 deaths per year caused by primary malignant BT.
- Although overall mortality due to primary BT decreased by 1.6% between 1969 and 1981 (95% CI: –2.2% to –1.0%) and by 1.8% from 1994 to 2007 (95% CI: –2.4% to –1.3%), AYA mortality related to these tumors has not changed significantly since 2007.
- Primary BT are the second most significant contributors to cancer death in AYA overall and the leading contributor in those who die at 15–24 years of age.

Survival: From Diagnosis to 5 Years Beyond in AYA, 2016–2020

- The 5-year relative survival rate after diagnosis of a primary malignant or non-malignant BT tumor was 91.1%.
- Survival after diagnosis of a primary BT was highest in adolescents ages 15–19 years (92.0%) and lowest in young adults ages 35–39 years (89.9%).
- Among AYA with malignant tumors, the 5-year relative survival rate was 72.7%.

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

- An estimated 208,620 AYA will be living with a primary BT diagnosis in 2024. This number is approximately 50% higher than the estimated 132,620 AYA who will be living with a leukemia or a related disorder.
- In 2024, the most prevalent histopathological group is expected to be tumors of the sellar region (an estimated 57,850 cases).

Introduction

Primary brain and other central nervous system (CNS) tumors (BT) found in adolescents and young adults ages 15–39 years (AYA) are a distinct group of tumors that pose challenges not only for treatment, but also for reporting. Overall, tumors in the AYA age group are biologically distinct from tumors in both younger children (ages 0–14 years) and older adults (ages 40+ years),[3,4] and they produce different histopathologies.[1,5,6] Prognosis and expected survival also vary between younger and older adults, with longer survival generally observed in those who are younger at the time of diagnosis.[1,7–9] Despite this survival advantage, recent analyses have shown that, although cancer survival has been improving overall, it has not improved for AYA.[6,9]

The present report, as an update to a 2016 publication from the CBTRUS and the American Brain Tumor Association,[6] provides in-depth analyses of the epidemiology of primary BT in AYA in the United States and is the first to provide biomolecular marker-specific statistics and prevalence by histopathology for both malignant and non-malignant primary BT in AYA.

Background

CBTRUS is a population-based site-specific registry in the United States that works in partnership with a public cancer surveillance organization, the US Centers for Disease Control and Prevention (CDC)'s National Program of Central Registries (NPCR), and with the Surveillance, Epidemiology and End Results (SEER) Program of the National Cancer Institute (NCI) of the US National Institutes of Health. The SEER program was established for national cancer surveillance in the early 1970s.[10] Collection of central cancer data was mandated in 1992 by Public Law 102-515, the Cancer Registries Amendment Act.[11] With the passage of Public Law 107-260 in 2002, this mandate was expanded to include non-malignant BT as of January 1, 2004.[12] The CBTRUS database represents the largest aggregation of population-based data on the incidence of primary BT in the United States and serves as a global resource.

The SEER data are received directly under a special agreement[1] that permits data transfer through the NPCR Cancer Surveillance System (NPCR-CSS) submission specifications mechanism. CBTRUS researchers combine the NPCR data with data from the NCI's SEER Program. As noted above, the SEER data on non-malignant tumors included in the current report were available only from years 2004 onward (2006 for trends analyses, due to significant variability in first 2 years of collection).

All data from NPCR and SEER originate from tumor registrars who report these data to the central cancer registry (CCR) in their state. Tumor registrars adhere to the Uniform Data Standards for malignant and non-malignant primary BT, as directed by the North American Association of Central Cancer Registries (NAACCR) (http://www.naaccr.org). Along with the Uniform Data Standards, various quality control checks and a system for rating each CCR further ensure that these data are reported as accurately and completely as possible. These measures permit CBTRUS, as a surveillance partner, to obtain high-quality data with histopathological specificity that is useful to the communities it serves. Aggregate information on all cancers, including primary BT, from all US CCRs is available from the *United States Cancer Statistics (USCS)* Working Group.[13,14]

Data Collection and Classification

Incidence Data

CBTRUS contains deidentified incidence data from 52 independent CCRs (48 NPCR and 4 SEER registries) representing the entire US population for the time period examined in this report.[15] The population-based CCRs represent all 50 states plus the District of Columbia and Puerto Rico. See the 2023 CBTRUS Statistical Report[1] for additional information about how these data are obtained and processed. In the United States, cancer registries and surveillance groups collect data on primary BT only (meaning tumors that originate within the brain and spinal cord) and do not collect data on tumors that metastasize to the brain or spinal cord from other primary sites. As a result, **only primary BT are included in this report.**

In 2006, the National Institutes of Health, the NCI, and the LiveStrong Young Adult Alliance conducted a progress review of AYA oncology. Their publication, entitled *Research and care imperatives for adolescents and young adults with cancer: a report of the Adolescent and Young Adult Oncology Progress Review Group*,[16] established the standard age range for AYA as 15–39 years. This age range is used by the NCI's SEER Program, CBTRUS (2023 CBTRUS Statistical Report), and many other cancer reporting agencies.[1,2]

Incidence data for selected other cancers common in AYA were obtained from the USCS, produced by the CDC and NCI, for the purpose of comparison with incidence rates for primary BT in AYA.[17] This database includes both NPCR and SEER data and represents the entire US population. Comparison cancers are classified by using the SEER *AYA Site Recode 2020 Revision* grouping system, which only includes malignant behavior.[18] Incidence data for trends were collected from 2004 through 2019.

Impact of the COVID-19 Pandemic on 2020 Cancer Incidence Data

Health care disruptions caused by the COVID-19 pandemic significantly affected cancer incidence data through diagnosis delays and new case abstraction.[1,19] The 2020 data were included in all calculated incidence rates but were excluded from trends analyses.

Survival Data

Deidentified USCS survival data for malignant and non-malignant primary BT were obtained from 39 NPCR registries.[20] This dataset provides population-based information for 84% of the US population for the years 2004 to 2019 and is a subset of the data used for the incidence calculations presented in this report. Survival information is derived from both active and passive follow-up. Secondary or later primary tumors (in AYA, approximately 3% of newly diagnosed primary BT), cases diagnosed at autopsy, cases in which either race or sex was coded as other or unknown, and persons known to be alive but for whom follow-up time could not be calculated, were excluded from survival data analyses.

Mortality Data

Mortality data used in this report were derived from the National Vital Statistics System (NVSS), which includes death certification data for individuals from all 50 states and the District of Columbia. NVSS data are not collected through the cancer registration system; rather, they represent the primary cause of death listed on each individual death certificate. As a result, deaths in persons with cancer could be recorded as noncancer deaths. For the current report, the NVSS data were limited to deaths in which a primary malignant BT was listed as the primary cause of death on the death certificate. Comparison data on malignant BT and other comparison cancers were obtained using SEER*Stat.[21]

International estimates of malignant primary BT incidence and mortality were obtained from GLOBOCAN, a project of the International Agency for Research on Cancer (https://gco.iarc.fr/today/).[22] These estimates are generated using estimates from regional and national cancer registries worldwide.

Classification by Tumor Site and Histopathology

The primary malignant and non-malignant tumors reported herein were classified according to the following *International Classification of Diseases for Oncology, Third Edition* (ICD-O-3)[23] anatomical sites: brain, meninges, spinal cord, cranial nerves, and other parts of the CNS; pituitary and pineal glands; and nasal cavity (ICD-O-3 site code C30.0 and histopathology codes 9522–9523 only) (**Supplementary Table 1**). Note that the statistics for lymphomas and hematopoietic neoplasms contained in this report refer only to those that arise in the brain and other CNS ICD-O-3 topography codes.

For histopathology groupings, CBTRUS is using histopathology groupings according to *2016 World Health Organization Classification of Tumours of the Central Nervous System* (**Supplementary Table 2**).[24,25] As there is no standard definition for glioma, CBTRUS defines glioma as ICD-O-3 histopathology codes 9380–9384 and 9391–9460, as starred in **Supplementary Table 2**.

Classification by Behavior

Primary BT can be broadly classified as non-malignant (ICD-O-3 behavior codes /0 for benign and /1 for uncertain) or malignant (ICD-O-3 behavior code /3). In 2002, the Cancer Registries Amendment Act (Public Law 102-515) mandated collection of central (state) cancer data for all primary malignant tumors (**Supplementary Table 2**).[11] With the passage of Public Law 107–260 a decade later, this mandate was expanded to include non-malignant BT as of January 1, 2004.[26]

Pilocytic astrocytoma is clinically considered and classified as a grade I non-malignant tumor by the WHO guidelines for BT.[27] For the purposes of cancer registration, these tumors have historically been reported as malignant tumors (9421/3), both in the United States and worldwide by the International Agency for Research on Cancer and the International Association of Cancer Registries.[28,29] Accordingly, CBTRUS classifies these tumors as malignant in its reporting unless otherwise stated. It should be noted that cases of pilocytic astrocytoma or juvenile pilocytic astrocytoma diagnosed in, or after, 2023 (and therefore not available for analysis until 2026) will no longer be considered as malignant (/3), but uncertain (/1); ICD-O code 9421/3 will be reserved for high-grade astrocytoma with piloid features. The effects of this reclassification on cancer incidence and survival reporting are being discussed.[5,30]

CBTRUS is currently engaged in ongoing collaborations with other cancer registry reporting groups, including SEER, to harmonize brain tumor reporting definitions. See the 2023 *CBTRUS Statistical Report: Primary Brain and Other Central Nervous System Tumors Diagnosed in the United States in 2016-2020* for further information on differences in brain tumor definitions.[1]

Classification by Brain Molecular Markers

Given the growing recognition of the value of biomarkers for classifying specific brain tumor histopathologies, the *WHO Classification of Tumours of the Central Nervous System* included biomarkers in its 2016 revision.[31] Starting with diagnosis year 2018, the US cancer registry system began collecting information on multiple BT biomarkers, including isocitrate dehydrogenase 1/2 (*IDH1/2*) mutation, 1p/19q co-deletion, medulloblastoma molecular subtypes, and all biomarkers in the 2016 WHO classification that use the brain molecular marker variable (see **Supplementary Table 3** for an overview of applicable histopathologies and coding schemes). Additional molecularly defined histopathologies from the 2016 WHO classification were added using their new ICD-O-3 codes, for which collection also began in 2018. These data were first available to CBTRUS with the 2021 NPCR and SEER data releases. As a result, the data included in this report are for the 2018–2020 diagnosis years only. CBTRUS evaluated the completeness of these markers in 2021, the first year these data were available in the NPCR and SEER combined dataset.[32]

New molecularly defined histopathologies introduced in the 2021 WHO classification have been incorporated into a revised brain molecular marker variable. These will be collected for the first time starting in diagnosis year 2024 and will be available for analysis in reporting year 2027.

Statistical Methods

This report presents the following population-based measures: incidence rates, prevalence, mortality rates, observed survival (median survival time and hazard ratios), and relative survival rates (for more information on definitions of terms and measures used, see https://cbtrus.org/cbtrus-glossary/). Counts, means, medians, rates, ratios, proportions, and other relevant statistics were calculated using R 4.3.2 statistical software[33] and/or SEER*Stat 8.4.2.[34] Figures and tables were created in R 4.3.2 using the following packages: flextable, officer, orca, ggplot2, plotly, SEER2R, sf, tigris, and tidyverse.[35–43]

Incidence and mortality rates were suppressed when counts were fewer than 16 within a cell but were included in totals, except when data were suppressed from only one cell to prevent identification of the number in the suppressed cell. Survival estimates were suppressed when beginning counts were fewer than 50 or when fewer than 16 individuals in the cohort remained alive during the period for which survival was being estimated. **NOTE: Reported percentages may not add up to 100% due to rounding.**

Estimation of Incidence and Mortality Rates

Incidence

Incidence is the number of newly diagnosed primary BT in a given time period.

Average annual age-specific incidence rates (AASIR), incidence rate ratios (IRR), and 95% confidence intervals (CI) per 100,000 population were estimated using the CBTRUS analytic dataset[15] for years 2016–2020 and were based on 5-year age groups and were standardized to the 2000 US

standard population. Population data for each geographic region were obtained from the SEER program website.[44] *P*-values for incidence rate ratios were calculated using previously described method[45] and were considered statistically significantly different when less than 0.05.

Estimates are presented by histopathology, age group at diagnosis, tumor behavior, sex, race/ethnicity, urbanicity, and brain molecular markers. Sex categories in this report are male and female; cases in which sex was coded as other or unknown were excluded from data analyses. Racial/ethnic categories are non-Hispanic White, non-Hispanic Black, non-Hispanic American Indian/Alaska Native, non-Hispanic Asian or Pacific Islander, and Hispanic (all races). Hispanic ethnicity was defined using the NAACCR Hispanic Identification Algorithm, version 2, data element, which utilizes a combination of cancer registry data fields (Spanish/Hispanic Origin data element, birthplace, race, and surnames) to directly and indirectly classify cases as Hispanic or non-Hispanic.[46] The categories other race, unspecified, and unknown race were included in statistics that are not race-specific.

The NAACCR regional scheme (http://faststats.naaccr.org/usregions.php) was used for statistics reported by region of the United States. Urbanicity was defined according to an individual's residence at time of diagnosis and by using the 2013 US Department of Agriculture Rural-Urban Continuum code (RUCC) classifications, which categorize all US counties as either metropolitan or nonmetropolitan.[47] The metropolitan counties (RUCC 1 to 3) are distinguished by the population size of their metro area, and nonmetropolitan counties (RUCC 4 to 9) are distinguished by population size, the degree of urbanization and adjacency to a metropolitan area.

Mortality, Relative Survival, Overall Survival, and Adjusted Hazard Ratios

Mortality is the number of deaths due to primary BT within a given time period.

Average annual age-specific mortality rates (AASMR) for deaths resulting from all primary malignant BT were calculated per 100,000 population by using NVSS mortality data available in the SEER*Stat online database for years 2016–2020.[48] These data were available for 50 states and the District of Columbia. Mortality estimates are presented as the age of death due to a primary BT. Rates are presented by 5-year age group at death, sex, race/ethnicity, and state. AASMR for single-year ages at death were generated using CDC Wonder.[49]

As mortality estimates herein are presented as age at death, they may include individuals who were diagnosed with a primary BT as a child aged 0–14 years and survived into adolescence or young adulthood before dying from their illness. To estimate the proportion of these deaths that occurred in these pediatric brain tumor survivors, we calculated age at diagnosis for those who died in the AYA age group of a primary BT in SEER between 2016 and 2020.

The 1-, 5-, and 10-year relative survival rates for malignant and non-malignant primary BT cases diagnosed between 2004–2019 and registered at 39 NPCR CCRs were estimated using SEER*Stat.[50] Median survival time for all primary BT diagnosed between 2001–2019 (2004–2019 for non-malignant tumors) reported to the 39 NPCR CCRs was calculated by histopathology and tumor site by using the Kaplan-Meier method, as well as by 5-year age group.

Cox proportional hazard models were used to test associations between demographic factors and overall survival by histopathology for primary malignant BT diagnosed in 2001–2020. All models were adjusted for sex (reference group: male), and race/ethnicity (reference group: non-Hispanic White). These models were used to estimate hazard ratios associated with each group and corresponding 95% CI and *P*-values. Adjusted estimates included all covariates (sex and race/ethnicity) a priori, regardless of individual significance level. The proportional hazards assumption was tested separately by histopathology, and residuals were examined for all variables. Hazard ratios were considered statistically significantly different when the *P*-value was less than 0.05 or the 95% CI did not include the null.

Incidence and Mortality Time Trends

Joinpoint 5.0.2.0[51] was used to estimate incidence and mortality time trends and to generate annual percentage changes (APCs) and 95% CIs. Rather than calculating a single, consistent slope of change over an entire period of time, Joinpoint allows for points where the slope of the trend can change during the time period (joinpoints). This method starts with a model that assumes one consistent trend over time, and tests whether the addition of these 'joinpoints' results in a model whose fit represents a statistically significant improvement over the model with no joinpoints. These models are tested using Monte Carlo permutations—that is, the program repeats the same analysis multiple times and uses random samples to identify the "true" proportion of times that a comparison is statistically significant.[52] The models allowed for a maximum of three joinpoints (two for non-malignant tumors), a minimum of 3 years from a joinpoint to either end of the time period, and a minimum of 3 years between joinpoints.[53,54]

Histopathologies for the five most incident and five most mortality-causing comparison cancers and primary BT are presented by age group. Trends for the year 2020 were excluded in accordance with current SEER guidelines in response to the COVID-19 pandemic's effect on cancer reporting and survival.

Future Cases

Estimated numbers of expected malignant and non-malignant primary BT were calculated for 2024–2026. To project estimates of newly diagnosed primary BT, age-specific annual tumor incidence rates were generated for 2001–2019 for malignant tumors and for 2006–2019 for non-malignant tumors (excluding years 2004–2005, the first few years of data collection for non-malignant tumors, when incidence increased significantly). Incidence data from the year 2020 were excluded due to noted data quality issues during the first year of the COVID-19 pandemic.

Incidence rates were generated by age and histopathological type. Joinpoint 5.0.2.0[51] was used to fit regression models to these incidence rates,[52] which were used to predict numbers of cases in future years by using the parameter from the selected models. Modified Bayesian

Information Criterion procedures included in Joinpoint were used to select the best-fitting model. The overall totals presented are based on total malignant and non-malignant tumor incidence; when stratified, these rates may not add up to the overall totals. Estimated numbers of cases are highly dependent on input data.

Different patterns of incidence within strata can significantly affect the projected estimates, especially when the number of cases within a stratum is low. Estimates are generated with the assumption of consistent trends in cases and population. **Caution should be exercised when using these estimates.**

Estimation of Prevalence

Prevalence is the number of individuals living with a primary BT at a given point in time, regardless of when the diagnosis was made.

For estimating the prevalence of primary BT, new case counts for malignant and non-malignant BT were extracted by histopathology and age at diagnosis from CBTRUS[15] for 2000–2020 (2004–2020 for non-malignant tumors) and from SEER 8[55] for 1975–2020. For comparison cancers, new case counts by International Classification of Childhood Cancer–defined histopathology and age at diagnosis were extracted from USCS for 2001–2020 and from SEER 8 for 1975–2020. Survival data for 1975–2019 were obtained from SEER 8 (2020 survival rates were presumed equal to 2019 rates). Projected new diagnosis numbers and survival for 2021–2024 were estimated on the basis of data from 2010–2019 (2020 was excluded due to known data quality issues in the first year of the COVID-19 pandemic). The total number of cases by histopathology and age as of December 31, 2024 was estimated using *prevEst*.[51,53,56]

Prevalence estimates were based on age in 2024. **As a result, prevalence estimates may include individuals diagnosed as a child who survived into adolescence or young adulthood.** Prevalence estimates were further stratified by age at diagnosis (0–14 vs 15–39) to assess proportion of cases representing pediatric brain tumor diagnoses.

Results

Overall, the AASIR of all malignant and non-malignant primary BT in AYA was 12.00 per 100,000 population between 2016 and 2020, for an average of 12,848 newly diagnosed cases per year (**Table 1**, **Figure 1**). During the same period, 5,090 AYA deaths were attributed to malignant primary BT. This represents an AASMR of 0.96 per 100,000 population and an average 1,018 deaths per year caused by primary malignant BT (**Table 1**, **Figure 1**).

Central Cancer (State) Registry-Specific Regional and Global Brain Tumor Incidence and Mortality, 2016–2020

The overall incidence and mortality rates for all primary BT in AYA by CCR are shown in **Figure 2** and **Supplementary Table 4**. See **Supplementary Figure 1** and **Supplementary Figure 2** for incidence and mortality by AYA age group at diagnosis (15–19, 20–24, 25–29, 30–34, and 35–39 years).

- Incidence of (**Figure 2A**) and mortality from (**Figure 2B**) primary BT varied by CCR. **Regional variations among CCRs probably reflect differences in reporting and case ascertainment practices, along with demographic differences in the underlying population that are associated with variations in BT risk.**
- Internationally, incidence (**Figure 3A**) and mortality (**Figure 3B**) due to primary BT in AYA varied by country and region.
- Higher-income countries have higher average annual incidence than their counterparts, with the United States, Canada, and some European countries representing the highest incidence of primary BT.

Frequency of Primary Brain and Other CNS Tumors, by Histopathology and WHO Grade Completeness, 2016–2020

The distribution of primary BT in AYA by tumor site is shown in **Figure 4A**. Frequencies for each site by age group are presented in **Supplementary Figures 3A–7A**.

- The most common site was the pituitary and craniopharyngeal duct (38.0%), followed by the meninges (16.3%).
- The least common site, the brain stem, accounted for 2.4% of tumors.
- "Other brain" is a designation used in cancer registry data when the location of a tumor is not identified in a patient's record or when a tumor involves multiple locations in the brain. See **Supplementary Table 1** for information about the specific sites included in these groups.
- Among adolescents ages 15–19 years, tumors of the pituitary and craniopharyngeal duct (36.8%) were the most common, followed by other brain tumors (7.7%), which includes miscellaneous and diagnoses that do not fit other histopathologies.
- Among young adults ages 20–24 years, tumors of the pituitary (43.7%) were the most common, followed by tumors of the frontal lobe (8.9%) and the meninges (8.6%).
- Among young adults ages 25–29, 30–34, and 35–39 years, tumors of the pituitary were the most common, followed by tumors of the meninges and the frontal lobe.

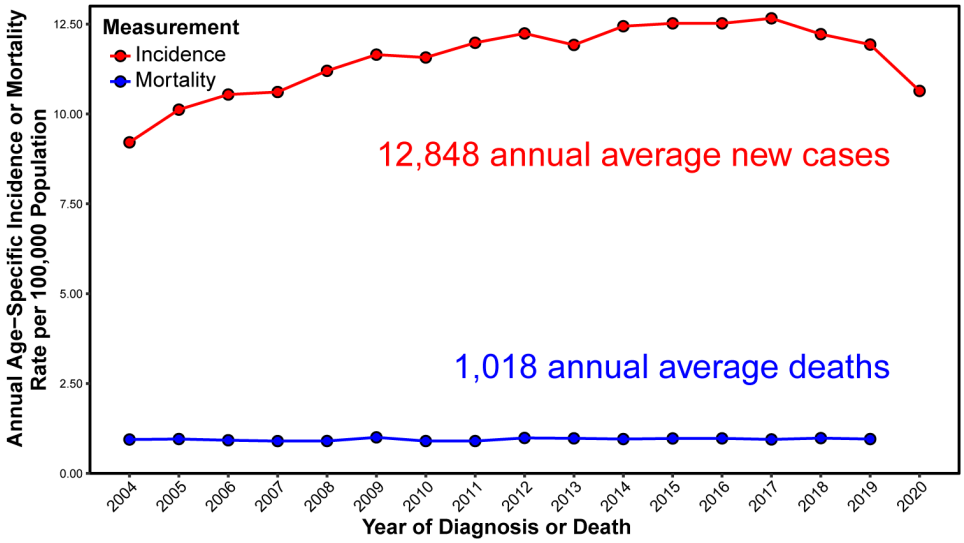
The distribution in AYA of primary BT is shown by histopathology in **Figure 4B** and by behavior in **Figure 5**. Frequencies for each histopathology are presented in **Table 2**. Frequencies by age group are presented in **Supplementary Table 6** and **Supplementary Figures 3B–7B**.

- The most frequent histopathology was non-malignant tumors of the pituitary (36.5%).
- The most frequently reported malignant tumors included glioblastoma (17.9% of malignant BT), and adult-type lower grade astrocytomas (diffuse astrocytoma and anaplastic astrocytoma, 15.3% and 11.7% of malignant BT, respectively).

Table 1. 2016–2020 Annual Average Case Counts[a], Age-Specific Incidence Rates[b], Annual Average Death Counts[c], and Age-Specific Mortality Rates[b], and 2004–2019 5-Year Relative Survival for Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years, by Behavior, Sex, Race/Ethnicity, and Age Group

Group	Incidence (2016-2020)						Mortality (2016-2020)		5-Year Relative Survival (2004-2019)		
	Total		Malignant[d]		Non-Malignant[e]		Malignant Only		Total	Malignant	Non-Malignant
	Annual Average[f]	Rate (95% CI)	Annual Average	Rate (95% CI)	Annual Average	Rate (95% CI)	Annual Average	Rate (95% CI)	RS (95% CI)	RS (95% CI)	RS (95% CI)
Total	**12,848**	**12.00 (11.90-12.09)**	**3,457**	**3.21 (3.16-3.26)**	**9,391**	**8.79 (8.71-8.87)**	**1,018**	**0.96 (0.93-0.98)**	**91.1 (90.9-91.2)**	**72.7 (72.2-73.1)**	**98.4 (98.3-98.4)**
Male	5,076	9.38 (9.26-9.50)	1,996	3.66 (3.58-3.73)	3,081	5.72 (5.63-5.82)	619	1.15 (1.11-1.20)	86.5 (86.2-86.8)	70.6 (70.0-71.2)	97.5 (97.3-97.7)
Female	7,771	14.67 (14.53-14.82)	1,461	2.75 (2.69-2.81)	6,310	11.93 (11.79-12.06)	399	0.76 (0.72-0.79)	94.1 (93.9-94.2)	75.5 (74.8-76.2)	98.7 (98.6-98.8)
Race/ethnicity											
Non-Hispanic White	7,659	12.71 (12.58-12.84)	2,324	3.84 (3.77-3.91)	5,335	8.87 (8.76-8.98)	707	1.18 (1.14-1.22)	90.7 (90.5-90.9)	73.9 (73.3-74.4)	98.5 (98.3-98.6)
Non-Hispanic Black	1,737	11.50 (11.26-11.75)	339	2.19 (2.08-2.30)	1,398	9.31 (9.09-9.54)	108	0.70 (0.64-0.77)	90.6 (90.2-91.1)	65.8 (64.3-67.3)	97.4 (97.1-97.7)
Non-Hispanic American Indian/Alaska Native	123	12.75 (11.75-13.82)	26	2.69 (2.25-3.20)	97	10.06 (9.17-11.01)	6	0.67 (0.46-0.95)	91.9 (90.1-93.4)	71.6 (66.2-76.3)	98.6 (97.3-99.3)
Non-Hispanic Asian/Pacific Islander	516	6.55 (6.30-6.81)	125	1.63 (1.50-1.76)	391	4.93 (4.71-5.15)	48	0.62 (0.54-0.71)	91.3 (90.5-92.0)	70.9 (68.5-73.1)	98.7 (98.3-99.0)
Hispanic (all races)	2,376	10.44 (10.25-10.63)	545	2.37 (2.28-2.46)	1,832	8.07 (7.91-8.24)	147	0.64 (0.60-0.69)	91.9 (91.5-92.2)	71.9 (70.7-73.0)	98.5 (98.3-98.7)
Age group[g]											
15-19 years	1,573	7.51 (7.34-7.68)	536	2.56 (2.46-2.66)	1,037	4.95 (4.82-5.09)	118	0.56 (0.51-0.61)	92.0 (91.6-92.4)	80.1 (79.1-81.1)	99.0 (98.8-99.2)
20-24 years	1,792	8.20 (8.03-8.37)	501	2.30 (2.21-2.39)	1,291	5.90 (5.76-6.05)	115	0.53 (0.48-0.57)	91.8 (91.4-92.2)	76.7 (75.6-77.8)	98.5 (98.3-98.7)
25-29 years	2,468	10.69 (10.50-10.88)	693	3.00 (2.90-3.10)	1,775	7.69 (7.53-7.85)	162	0.69 (0.65-0.74)	91.3 (90.9-91.6)	74.5 (73.5-75.4)	98.4 (98.1-98.6)
30-34 years	3,183	14.41 (14.19-14.64)	828	3.75 (3.63-3.86)	2,354	10.67 (10.48-10.86)	260	1.17 (1.11-1.24)	91.3 (91.0-91.6)	72.1 (71.1-73.1)	98.4 (98.2-98.6)
35-39 years	3,832	18.05 (17.79-18.30)	899	4.23 (4.10-4.35)	2,933	13.82 (13.60-14.05)	363	1.69 (1.62-1.77)	89.9 (89.6-90.2)	64.3 (63.3-65.3)	98.0 (97.8-98.2)

[a]Annual average case counts are calculated by dividing the 5-year total by 5.
[b]Rates are per 100,000 population.
[c]Annual average death counts are calculated by dividing the 5-year total by 5.
[d]Assigned an ICD behavior code of /3 (see **Supplementary Table 3**).
[e]Assigned an ICD behavior code of /0 or /1 (see **Supplementary Table 3**).
[f]Subgroup averages may not sum to total due to rounding.
[g]For incidence and survival data, age group at diagnosis; for mortality data, age group at death.
Data Source: CBTRUS Adolescent and Young Adult Report: incidence data provided by CDC's NPCR and NCI's SEER, 2016–2020; mortality data provided by NCHS's NVSS Program, 2016–2020; survival data provided by CDC's NPCR Program, 2004–2019.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; ICD-O-3, *International Classification of Diseases for Oncology, Third Edition*; NCI, National Cancer Institute; NCHS, National Center for Health Statistics; NPCR, National Program of Cancer Registries; NVSS, National Vital Statistics System; RS, relative survival; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.



a Rates are per 100,000 population.
b For incidence data, age at diagnosis; for mortality data, age at death.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS – CDC's NPCR and NCI's SEER, 2016–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

Fig. 1 2016–2020 Average Annual Age-Specific Incidence and Mortality[a] for Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years[b]

- Meningiomas accounted for 16.0% of all new primary BT diagnoses (21.7% of all non-malignant tumors).
- In adolescents ages 15–19 years, the most common histopathology was tumors of the pituitary (34.5%), followed by neuronal and mixed neuronal-glial tumors (8.8%) and pilocytic astrocytoma (8.0%).
- Among young adults ages 20–39 years, tumors of the pituitary were the most common histopathology, followed by meningiomas and nerve sheath tumors.

The distribution of primary BT in AYA by WHO grade is shown in **Supplementary Table 6**.

- Overall, 58.1% of primary BT were confirmed histopathologically. A larger proportion of malignant tumors were confirmed histopathologically (90.6%), compared with non-malignant tumors (46.2%).
- Of histopathogically confirmed tumors, the largest proportion of primary BT was assigned a CNS WHO grade of 1/I (44.7%).

Age-Specific Incidence Rates, 2016–2020

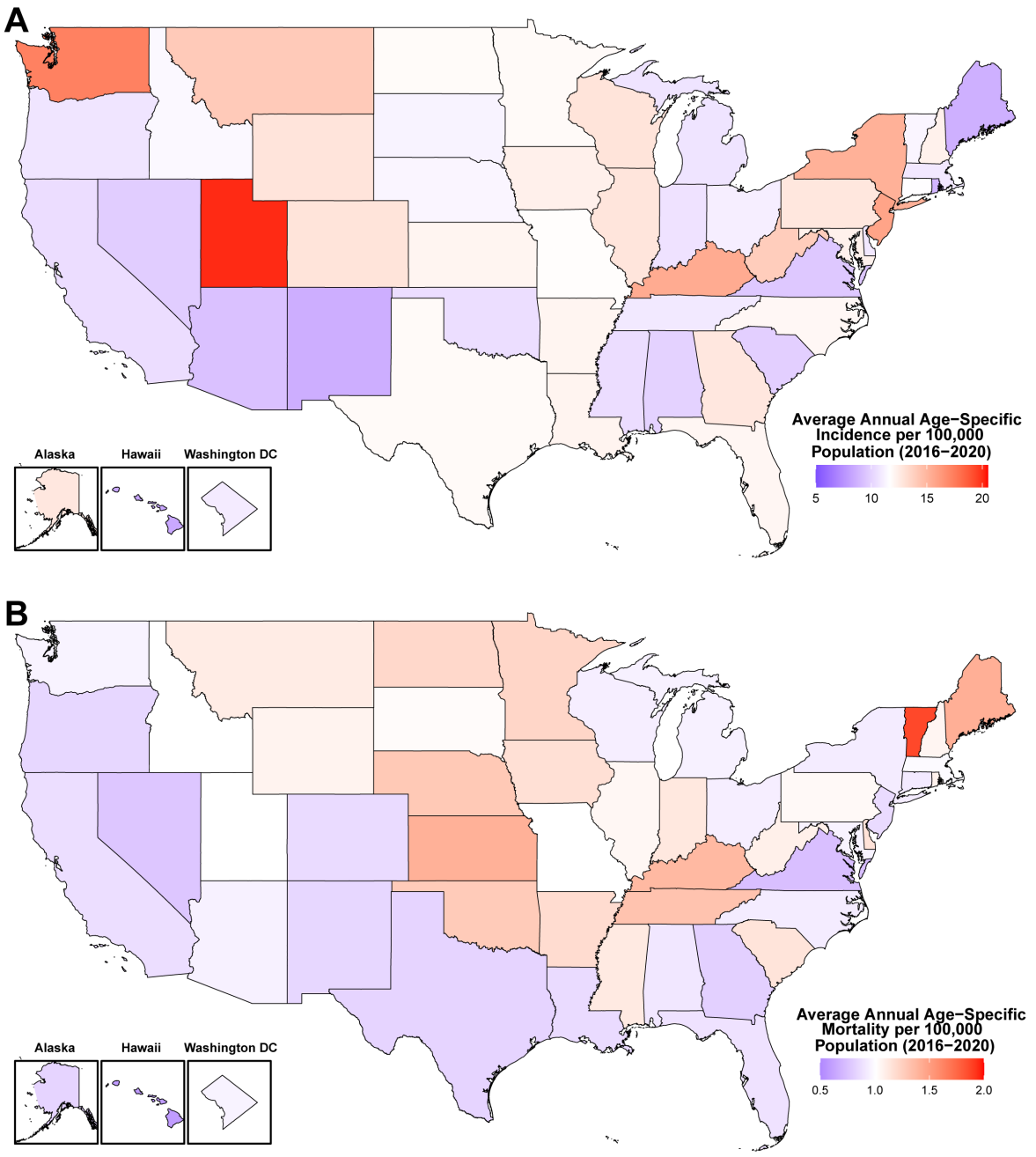
The overall AASIR for all primary BT in AYA was 12.00 per 100,000 population; non-malignant tumors were more frequent than malignant tumors in all age groups (**Table 1**). Histopathological AASIR is shown by behavior and single-year age at diagnosis in **Figure 6** and overall by single-year age in **Supplementary Figure 8**. AASIRs overall by histopathology grouping are shown in **Table 2** and by age group in **Table 3**.

- Total incidence increased with increasing age overall and when stratified by sex and behavior.
- Overall incidence was higher in females than males at all ages, however, when stratified by behavior, incidence was higher in males than females in all ages when restricted to malignant tumors.
- Among CBTRUS major histopathology groupings, incidence rates were highest for tumors of the sellar region (4.47 per 100,000), followed by tumors of meninges (2.29 per 100,000), diffuse astrocytic and oligodendroglial tumors (1.81 per 100,000), and tumors of cranial and spinal nerves (1.03 per 100,000).
- Among CBTRUS specific histopathology groupings, incidence rates were highest for tumors of the pituitary (4.34 per 100,000), meningiomas (2.00 per 100,000), glioblastoma (0.58 per 100,000), and diffuse astrocytoma (0.48 per 100,000).

Median Age at Diagnosis

Among AYA, median age for diagnosis varied by tumor type. The median age at diagnosis for a primary BT among those in the AYA age group was 31 years, slightly older than the predicted median (27 years) if the age distributions were equal (**Table 2**).

- The histopathology-specific median ages ranged from 20 years for germ cell tumors to 34 years for meningioma.
- The median age for pilocytic astrocytoma, unique astrocytoma variants, neuronal and mixed neuronal-glial tumors, and germ cell tumors was less than 25 years of age at diagnosis.



a Rates are per 100,000 population.
b For incidence data, age at diagnosis; for mortality data, age at death.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS – CDC's NPCR and NCI's SEER, 2016–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

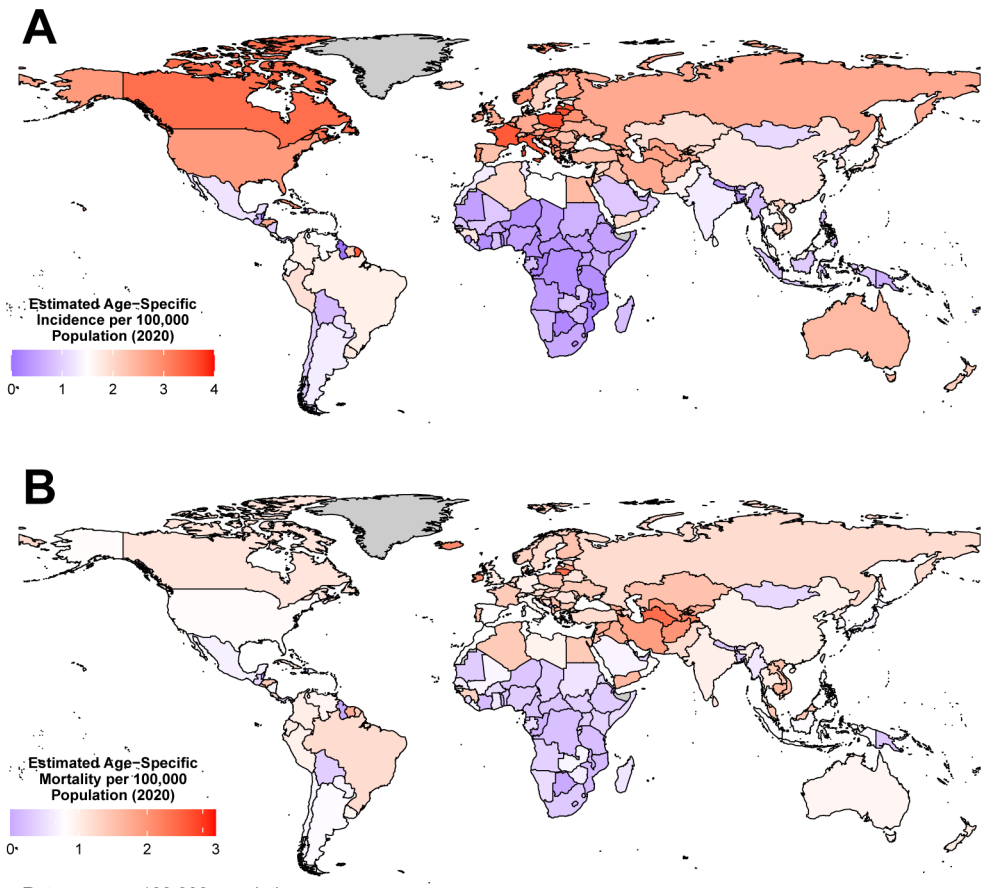
Fig. 2 2016–2020 Average Annual Age-Specific (A) Incidence and (B) Mortality[a] due to Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years[b], by Central Cancer Registry

- The median age for embryonal tumors was 25 years.
- The median ages at diagnosis for malignant and non-malignant tumors were 29 and 31 years, respectively.
- The median ages for glioblastomas and other gliomas were 32 and 26 years, respectively.

Incidence Rates by Age at Diagnosis and Histopathology

AASIR by age at diagnosis and histopathology in AYA are shown in **Table 3**.

- For both malignant and non-malignant tumors, the incidence rate was highest for young adults ages 35–39 years (4.23 and 13.82 per 100,000, respectively). When



a Rates are per 100,000 population.
b For incidence data, age at diagnosis; for mortality data, age at death.
Data Source: CBTRUS Adolescent and Young Adult Report: International Agency for Research on Cancer's GLOBOCAN, 2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States.

Fig. 3 2020 Country- and Age-Specific (A) Incidence and (B) Mortality[a] due to Malignant Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years[b]

compared by age group at diagnosis, as age decreased, incidence also decreased.
- Incidence rates of most histopathologies increased with age, with the exception of other astrocytic tumors, other gliomas, neuronal and mixed neuronal-glial tumors, embryonal tumors, and germ cell tumors.
- Glioblastoma became more frequent as age increased, with an incidence rate of 1.10 per 100,000 population in young adults ages 35–39 years.
- Other gliomas (including glioma malignant, not otherwise specified and other neuroepithelial tumors) were most frequent in adolescents ages 15–19 years (0.48 per 100,000).
- The incidence of medulloblastoma decreased with increasing age. The incidence rate in adolescents ages 15–19 years was 0.15 per 100,000 population.

Age-Specific Incidence Rates by Site Within Diagnosis Group

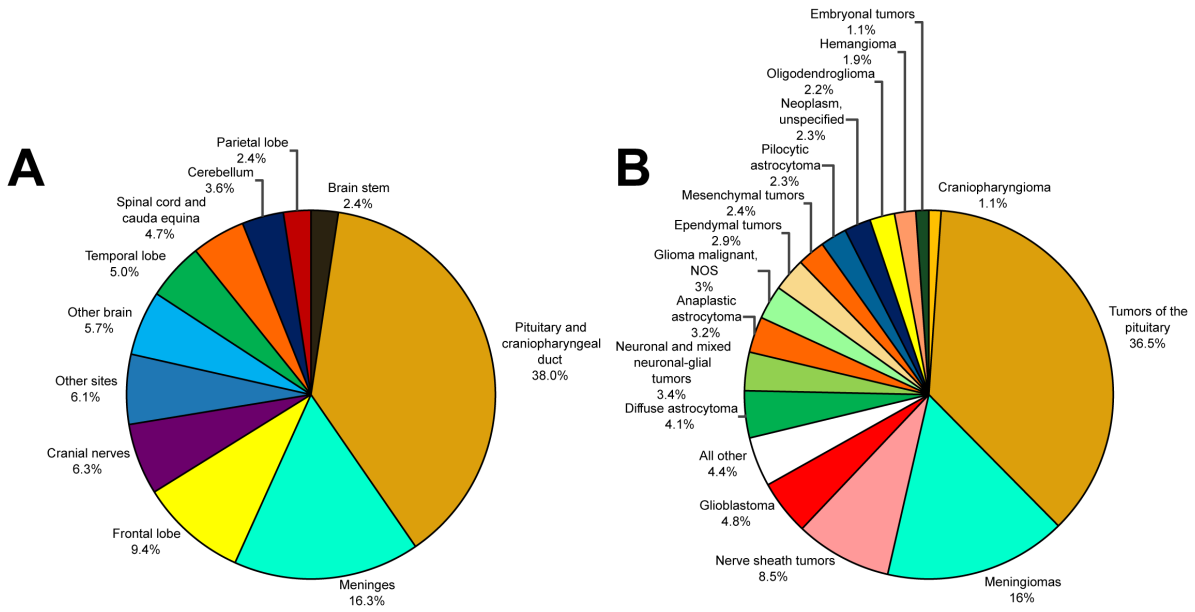
Incidence rates in AYA for each tumor site by age group at diagnosis are shown in **Table 4**.

- In adolescents ages 15–19 years, the site with the highest incidence was the pituitary gland (2.68 per 100,000), followed by the temporal lobe (0.55 per 100,000).
- In young adults ages 20–24 and 25–29 years, the site with highest incidence was the pituitary gland (3.52 and 4.44 per 100,000, respectively), followed by the frontal lobe (0.73 and 1.10 per 100,000, respectively).
- In young adults ages 30–34 and 35–39 years, the sites with highest incidence were the pituitary gland (5.35 and 5.96 per 100,000, respectively) and the cerebral meninges (2.13 and 3.92 per 100,000, respectively).

Sex- and Race/Ethnicity-Specific Incidence Rates, 2016–2020

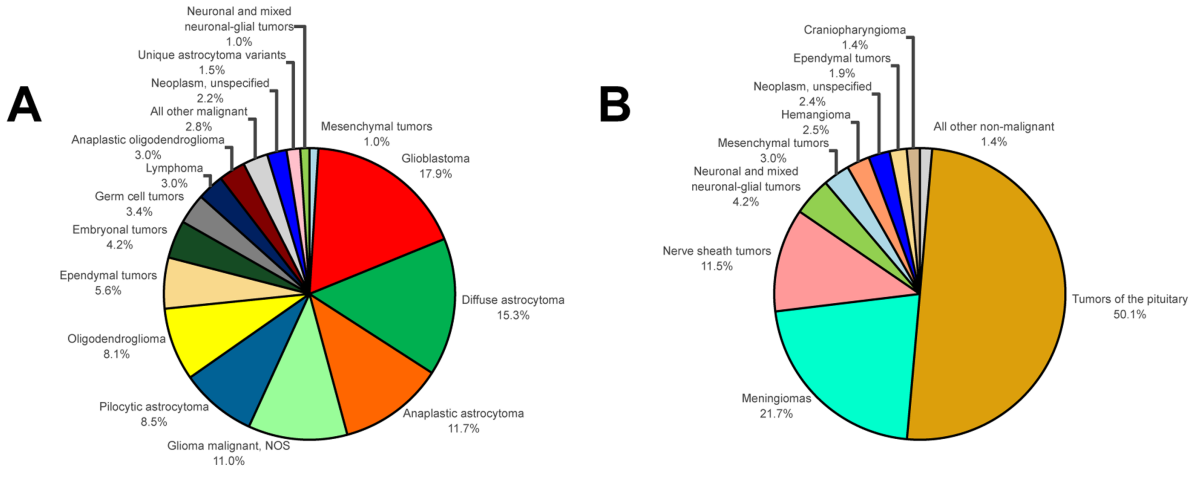
Distribution and Incidence by Sex, Behavior, and Histopathology

Incidence rates, total cases, and annual average case counts in AYA by sex and histopathology are shown in



a Percentages may not sum to 100% due to rounding.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS – CDC's NPCR and NCI's SEER, 2016–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

Fig. 4 2016–2020 Distribution[a] of All Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years (5-Year Total=64,238; Annual Average Case Count=12,848), by (A) Tumor Site and (B) Histopathology



a Percentages may not sum to 100% due to rounding.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS – CDC's NPCR and NCI's SEER, 2016–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

Fig. 5 2016–2020 Distribution[a] of (A) Malignant and (B) Non-Malignant Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years (5-Year Total=64,238; Annual Average Case Count=12,848), by Histopathology

Table 2 and **Figure 7** and are further stratified by age group at diagnosis in **Supplementary Table 5**.

- Overall, among all primary BT diagnosed in AYA, 39.5% occurred in males (25,381 tumors) and 60.5% occurred in females (38,857 tumors).
- Among primary malignant BT diagnosed in AYA, 57.7% occurred in males (9,978 tumors) and 42.3% occurred in females (15,403 tumors).
- Incidence rates for all primary BT combined were higher among females (14.67 per 100,000) than males (9.38 per 100,000).

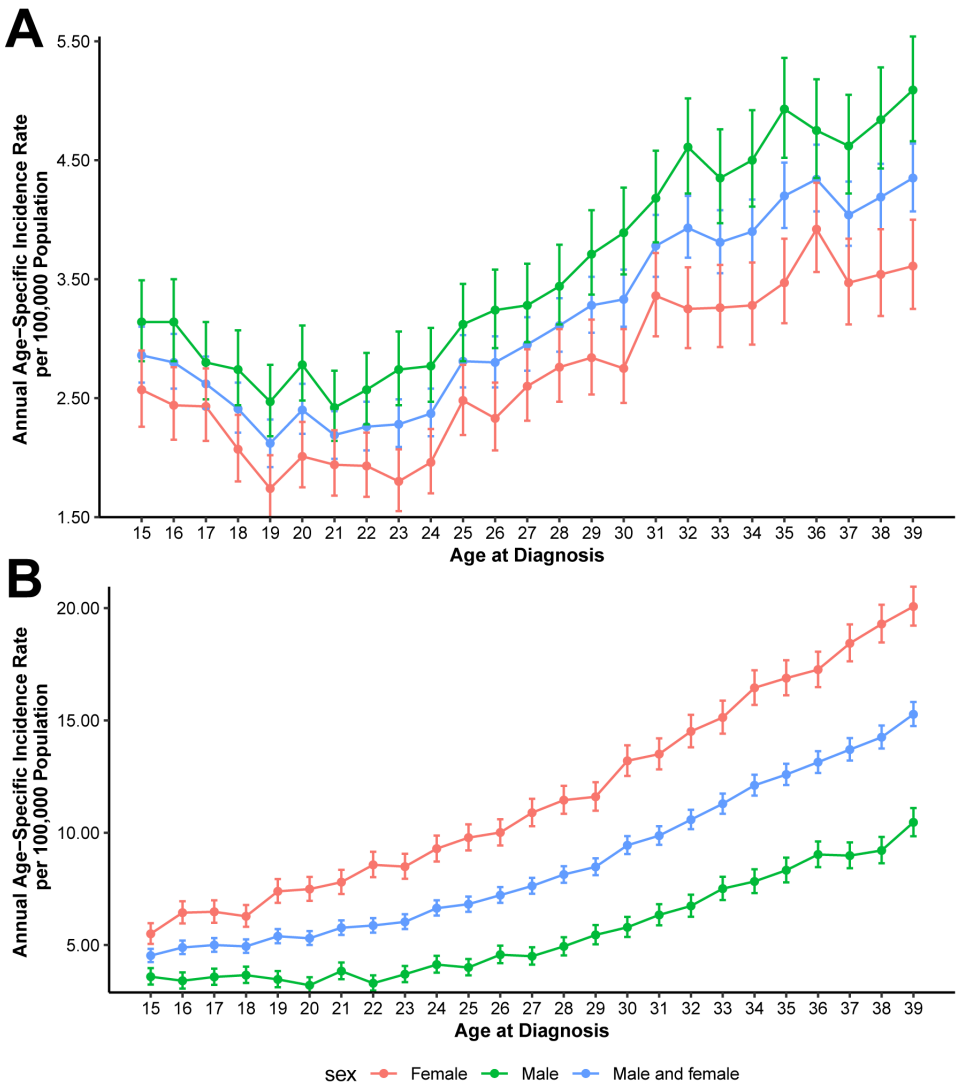
Table 2. 2016–2020 Total Cases, Annual Average Case Counts[a], Median Age, and Annual Average Age-Specific Incidence Rates[b] for Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years, by Sex and Histopathology

Histopathology	Total					Male			Female		
	Total Cases	Annual Average[c]	Median Age	% of All Tumors[d]	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)
Diffuse astrocytic and oligodendroglial tumors	**9,733**	**1,947**	**31**	**15.2**	**1.81 (1.78-1.85)**	**5,686**	**1,137**	**2.10 (2.04-2.15)**	**4,047**	**809**	**1.52 (1.48-1.57)**
Diffuse astrocytoma	2,637	527	30	4.1	0.48 (0.47-0.50)	1,521	304	0.55 (0.52-0.58)	1,116	223	0.42 (0.39-0.44)
Anaplastic astrocytoma	2,023	405	31	3.1	0.37 (0.35-0.39)	1,172	234	0.42 (0.40-0.45)	851	170	0.32 (0.29-0.34)
Glioblastoma	3,089	618	32	4.8	0.58 (0.56-0.61)	1,878	376	0.71 (0.67-0.74)	1,211	242	0.46 (0.44-0.49)
Oligodendroglioma	1,398	280	32	2.2	0.26 (0.25-0.28)	782	156	0.29 (0.27-0.31)	616	123	0.23 (0.22-0.25)
Anaplastic oligodendroglioma	513	103	33	0.8	0.10 (0.09-0.11)	291	58	0.11 (0.10-0.12)	222	44	0.08 (0.07-0.10)
Oligoastrocytic tumors	73	15	31	0.1	0.01 (0.01-0.02)	42	8	0.02 (0.01-0.02)	31	6	0.01 (0.01-0.02)
Other astrocytic tumors	**1,874**	**375**	**22**	**2.9**	**0.34 (0.33-0.36)**	**1,016**	**203**	**0.37 (0.34-0.39)**	**858**	**172**	**0.32 (0.30-0.34)**
Pilocytic astrocytoma	1,497	299	21	2.3	0.28 (0.26-0.29)	818	164	0.29 (0.27-0.32)	679	136	0.26 (0.24-0.28)
Unique astrocytoma variants	377	75	23	0.6	0.07 (0.06-0.08)	198	40	0.07 (0.06-0.08)	179	36	0.07 (0.06-0.08)
Ependymal tumors	1,869	374	30	2.9	0.35 (0.33-0.36)	1,041	208	0.38 (0.36-0.41)	828	166	0.31 (0.29-0.33)
Other gliomas	**1,936**	**387**	**26**	**3.0**	**0.36 (0.34-0.37)**	**984**	**197**	**0.36 (0.34-0.38)**	**952**	**190**	**0.36 (0.33-0.38)**
Glioma malignant, NOS	1,904	381	26	3.0	0.35 (0.34-0.37)	—	—	—	—	—	—
Other neuroepithelial tumors	32	6	26	0.0	0.01 (0.00-0.01)	—	—	—	—	—	—
Neuronal and mixed neuronal-glial tumors	**2,166**	**433**	**24**	**3.4**	**0.40 (0.38-0.42)**	**1,170**	**234**	**0.42 (0.40-0.45)**	**996**	**199**	**0.37 (0.35-0.40)**
Choroid plexus tumors	**208**	**42**	**27**	**0.3**	**0.04 (0.03-0.04)**	**95**	**19**	**0.03 (0.03-0.04)**	**113**	**23**	**0.04 (0.04-0.05)**
Tumors of the pineal region	**269**	**54**	**26**	**0.4**	**0.05 (0.04-0.06)**	**117**	**23**	**0.04 (0.03-0.05)**	**152**	**30**	**0.06 (0.05-0.07)**
Embryonal tumors	**726**	**145**	**25**	**1.1**	**0.13 (0.12-0.14)**	**457**	**91**	**0.16 (0.15-0.18)**	**269**	**54**	**0.10 (0.09-0.11)**
Medulloblastoma	624	125	25	1.0	0.11 (0.10-0.12)	404	81	0.14 (0.13-0.16)	220	44	0.08 (0.07-0.09)
Tumors of cranial and spinal nerves	**5,445**	**1,089**	**32**	**8.5**	**1.03 (1.00-1.06)**	**2,607**	**521**	**0.97 (0.94-1.01)**	**2,838**	**568**	**1.08 (1.04-1.12)**
Nerve sheath tumors	—	—	—	—	—	—	—	—	—	—	—
Other tumors of cranial and spinal nerves	—	—	—	—	—	—	—	—	—	—	—

Table 2. Continued

Histopathology	Total					Male			Female		
	Total Cases	Annual Average[c]	Median Age	% of All Tumors[d]	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)
Tumors of meninges	**11,845**	**2,369**	**34**	**18.4**	**2.29 (2.25-2.33)**	**3,651**	**730**	**1.38 (1.33-1.42)**	**8,194**	**1,639**	**3.21 (3.14-3.28)**
Meningiomas	10,264	2,053	34	16.0	2.00 (1.96-2.04)	2,865	573	1.09 (1.05-1.13)	7,399	1,480	2.91 (2.85-2.98)
Mesenchymal tumors	1,557	311	29	2.4	0.29 (0.27-0.30)	—	—	—	—	—	—
Primary melanocytic lesions	24	5	27	0.0	0.00 (0.00-0.01)	—	—	—	—	—	—
Lymphomas and hemopoietic neoplasms	**526**	**105**	**32**	**0.8**	**0.10 (0.09-0.11)**	**319**	**64**	**0.12 (0.10-0.13)**	**207**	**41**	**0.08 (0.07-0.09)**
Lymphoma	—	—	—	—	—	—	—	—	—	—	—
Other hematopoietic neoplasms	—	—	—	—	—	—	—	—	—	—	—
Germ cell tumors	**627**	**125**	**20**	**1.0**	**0.11 (0.11-0.12)**	**534**	**107**	**0.19 (0.18-0.21)**	**93**	**19**	**0.03 (0.03-0.04)**
Tumors of the sellar region	**24,202**	**4,840**	**30**	**37.7**	**4.47 (4.41-4.52)**	**6,415**	**1,283**	**2.38 (2.32-2.44)**	**17,787**	**3,557**	**6.62 (6.52-6.71)**
Tumors of the pituitary	23,522	4,704	30	36.6	4.34 (4.29-4.40)	6,066	1,213	2.25 (2.19-2.31)	17,456	3,491	6.49 (6.40-6.59)
Craniopharyngioma	680	136	27	1.1	0.13 (0.12-0.14)	349	70	0.13 (0.11-0.14)	331	66	0.12 (0.11-0.14)
Unclassified tumors	**2,812**	**562**	**29**	**4.4**	**0.52 (0.50-0.54)**	**1,289**	**258**	**0.48 (0.45-0.50)**	**1,523**	**305**	**0.57 (0.54-0.60)**
Hemangioma	1,196	239	29	1.9	0.22 (0.21-0.23)	560	112	0.20 (0.19-0.22)	636	127	0.24 (0.22-0.26)
Neoplasm, unspecified	1,484	297	30	2.3	0.28 (0.26-0.29)	657	131	0.25 (0.23-0.27)	827	165	0.31 (0.29-0.33)
All other	132	26	26	0.2	0.02 (0.02-0.03)	72	14	0.03 (0.02-0.03)	60	12	0.02 (0.02-0.03)
Total	**64,238**	**12,848**	**31**	**100.0**	**12.00 (11.90-12.09)**	**25,381**	**5,076**	**9.38 (9.26-9.50)**	**38,857**	**7,771**	**14.67 (14.53-14.82)**
Malignant	**17,285**	**3,457**	**29**	**26.9**	**3.21 (3.16-3.26)**	**9,978**	**1,996**	**3.66 (3.58-3.73)**	**7,307**	**1,461**	**2.75 (2.69-2.81)**
Non-malignant	**46,953**	**9,391**	**31**	**73.1**	**8.79 (8.71-8.87)**	**15,403**	**3,081**	**5.72 (5.63-5.82)**	**31,550**	**6,310**	**11.93 (11.79-12.06)**

[a]Annual average case counts are calculated by dividing the 5-year total by 5.
[b]Rates are per 100,000 population.
[c]Subgroup averages may not sum to total due to rounding.
[d]Percentages may not add to 100% due to rounding.
— Data are not presented when fewer than 16 cases were reported for the specific category. Counts and associated rates cannot be provided when Total Cases are fewer than 16 cases or when a value based on less than 16 cases can be back-calculated using a cell. Suppressed cases are included in the total count.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS - CDC's NPCR and NCI's SEER, 2016–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NOS, not otherwise specified; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.



a Rates are per 100,000 population.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS – CDC's NPCR and NCI's SEER, 2016–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

Fig. 6 2016–2020 Age-Specific Incidence Rates[a] with 95% CIs for All (A) Malignant and (B) Non-Malignant Primary Brain and Other CNS Tumor Histopathologies in AYA Ages 15–39 Years, by Sex

- Incidence was significantly higher in females than males for the following histopathologies: tumors of the pineal region (35% higher), nerve sheath tumors (11% higher), meningioma (167% higher), tumors of the pituitary (188% higher), and hemangioma (17% higher).
- Incidence was significantly higher in males than females for the following histopathologies: all glioma histopathologies, embryonal tumors (56% higher), lymphomas and hemopoietic neoplasms (45% higher), and germ cell tumors (450% higher).
- Glioblastoma (0.71 vs 0.46 per 100,000), anaplastic oligodendroglioma (0.11 vs 0.08 per 100,000), and medulloblastoma (0.14 vs 0.08 per 100,000) were more frequent among males than females, respectively.

Incidence Rates by Race/Ethnicity, Behavior, and Histopathology

Overall incidence of primary BT by race/ethnicity and behavior in AYA are shown in **Table 1**. Incidence rates, total cases, and annual average case counts by race/ethnicity and histopathology are shown in **Table 5** and **Figure 8** and are further stratified by age group at diagnosis in **Supplementary Table 7**.

- Incidence rates for all primary BT combined and non-malignant tumors only were highest for non-Hispanic American Indian/Alaska Native individuals compared with non-Hispanic White individuals, non-Hispanic Black individuals, non-Hispanic Asian or Pacific

Table 3. 2016–2020 Total Cases, Annual Average Case Counts[a], and Annual Average Age-Specific Incidence Rates[b] for Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years, by Age Group at Diagnosis and Histopathology

Histopathology	15–19 years			20–24 years			25–29 years			30–34 years			35–39 years		
	Total Cases	Annual Average[c]	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)
Diffuse astrocytic and oligodendroglial tumors	**651**	**130**	**0.62 (0.58-0.67)**	**1,150**	**230**	**1.05 (0.99-1.11)**	**2,076**	**415**	**1.81 (1.73-1.88)**	**2,773**	**555**	**2.51 (2.42-2.61)**	**3,083**	**617**	**2.90 (2.80-3.00)**
Diffuse astrocytoma	245	49	0.23 (0.21-0.27)	388	78	0.36 (0.32-0.39)	612	122	0.53 (0.49-0.58)	713	143	0.65 (0.60-0.69)	679	136	0.64 (0.59-0.69)
Anaplastic astrocytoma	105	21	0.10 (0.08-0.12)	235	47	0.21 (0.19-0.24)	535	107	0.47 (0.43-0.51)	601	120	0.54 (0.50-0.59)	547	109	0.51 (0.47-0.56)
Glioblastoma	216	43	0.21 (0.18-0.24)	331	66	0.30 (0.27-0.34)	547	109	0.47 (0.43-0.51)	833	167	0.75 (0.70-0.81)	1,162	232	1.10 (1.03-1.16)
Oligodendroglioma	71	14	0.07 (0.05-0.09)	145	29	0.13 (0.11-0.16)	279	56	0.24 (0.22-0.28)	421	84	0.38 (0.35-0.42)	482	96	0.45 (0.41-0.49)
Anaplastic oligodendroglioma	—	—	—	—	—	—	—	—	—	184	37	0.17 (0.14-0.19)	190	38	0.18 (0.15-0.21)
Oligoastrocytic tumors	—	—	—	—	—	—	—	—	—	21	4	0.02 (0.01-0.03)	23	5	0.02 (0.01-0.03)
Other astrocytic tumors	**744**	**149**	**0.71 (0.66-0.76)**	**384**	**77**	**0.36 (0.32-0.40)**	**306**	**61**	**0.26 (0.23-0.29)**	**249**	**50**	**0.22 (0.20-0.25)**	**191**	**38**	**0.18 (0.15-0.21)**
Pilocytic astrocytoma	630	126	0.60 (0.56-0.65)	293	59	0.27 (0.24-0.31)	243	49	0.21 (0.18-0.23)	188	38	0.17 (0.15-0.19)	143	29	0.13 (0.11-0.16)
Unique astrocytoma variants	114	23	0.11 (0.09-0.13)	91	18	0.08 (0.07-0.10)	63	13	0.05 (0.04-0.07)	61	12	0.06 (0.04-0.07)	48	10	0.05 (0.03-0.06)
Ependymal tumors	**258**	**52**	**0.25 (0.22-0.28)**	**275**	**55**	**0.25 (0.22-0.28)**	**370**	**74**	**0.32 (0.29-0.35)**	**460**	**92**	**0.42 (0.38-0.46)**	**506**	**101**	**0.48 (0.44-0.52)**
Other gliomas	**501**	**100**	**0.48 (0.44-0.52)**	**321**	**64**	**0.30 (0.26-0.33)**	**373**	**75**	**0.32 (0.29-0.36)**	**397**	**79**	**0.36 (0.32-0.40)**	**344**	**69**	**0.32 (0.29-0.36)**
Glioma malignant, NOS	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Other neuroepithelial tumors	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Neuronal and mixed neuronal-glial tumors	**692**	**138**	**0.66 (0.61-0.71)**	**448**	**90**	**0.41 (0.38-0.45)**	**369**	**74**	**0.32 (0.29-0.35)**	**358**	**72**	**0.32 (0.29-0.36)**	**299**	**60**	**0.28 (0.25-0.31)**
Choroid plexus tumors	**44**	**9**	**0.04 (0.03-0.06)**	**39**	**8**	**0.04 (0.03-0.05)**	**42**	**8**	**0.04 (0.03-0.05)**	**42**	**8**	**0.04 (0.03-0.05)**	**41**	**8**	**0.04 (0.03-0.05)**
Tumors of the pineal region	**61**	**12**	**0.06 (0.04-0.07)**	**49**	**10**	**0.05 (0.03-0.06)**	**68**	**14**	**0.06 (0.05-0.08)**	**46**	**9**	**0.04 (0.03-0.06)**	**45**	**9**	**0.04 (0.03-0.06)**

Table 3. Continued

Histopathology	15–19 years			20–24 years			25–29 years			30–34 years			35–39 years		
	Total Cases	Annual Average[c]	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)
Embryonal tumors	**190**	**38**	**0.18 (0.16-0.21)**	**170**	**34**	**0.16 (0.14-0.18)**	**150**	**30**	**0.13 (0.11-0.15)**	**127**	**25**	**0.11 (0.10-0.14)**	**89**	**18**	**0.08 (0.07-0.10)**
Medulloblastoma	161	32	0.15 (0.13-0.18)	147	29	0.14 (0.12-0.16)	134	27	0.12 (0.10-0.14)	110	22	0.10 (0.08-0.12)	72	14	0.07 (0.05-0.08)
Tumors of cranial and spinal nerves	**466**	**93**	**0.45 (0.41-0.49)**	**624**	**125**	**0.57 (0.53-0.62)**	**975**	**195**	**0.85 (0.80-0.91)**	**1,469**	**294**	**1.33 (1.26-1.40)**	**1,911**	**382**	**1.80 (1.72-1.88)**
Nerve sheath tumors	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Other tumors of cranial and spinal nerves	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Tumors of meninges	**587**	**117**	**0.56 (0.52-0.61)**	**972**	**194**	**0.88 (0.83-0.94)**	**1,725**	**345**	**1.50 (1.43-1.57)**	**3,208**	**642**	**2.91 (2.81-3.02)**	**5,353**	**1,071**	**5.07 (4.93-5.21)**
Meningiomas	362	72	0.35 (0.31-0.38)	740	148	0.67 (0.62-0.72)	1,376	275	1.20 (1.14-1.27)	2,818	564	2.56 (2.47-2.66)	4,968	994	4.71 (4.58-4.84)
Mesenchymal tumors	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Primary melanocytic lesions	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Lymphomas and hemopoietic neoplasms	**39**	**8**	**0.04 (0.03-0.05)**	**66**	**13**	**0.06 (0.05-0.08)**	**95**	**19**	**0.08 (0.07-0.10)**	**145**	**29**	**0.13 (0.11-0.15)**	**181**	**36**	**0.17 (0.15-0.20)**
Lymphoma	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Other hematopoietic neoplasms	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Germ cell tumors	**292**	**58**	**0.28 (0.25-0.31)**	**165**	**33**	**0.15 (0.13-0.18)**	**99**	**20**	**0.08 (0.07-0.10)**	**45**	**9**	**0.04 (0.03-0.05)**	**26**	**5**	**0.02 (0.02-0.04)**
Tumors of sellar region	**2,863**	**573**	**2.74 (2.64-2.84)**	**3,876**	**775**	**3.54 (3.43-3.65)**	**5,159**	**1,032**	**4.46 (4.34-4.59)**	**5,939**	**1,188**	**5.38 (5.24-5.51)**	**6,365**	**1,273**	**5.98 (5.83-6.13)**
Tumors of the pituitary	2,717	543	2.60 (2.50-2.70)	3,757	751	3.43 (3.32-3.54)	5,030	1,006	4.35 (4.23-4.47)	5,801	1,160	5.25 (5.12-5.39)	6,217	1,243	5.84 (5.70-5.99)
Craniopharyngioma	146	29	0.14 (0.12-0.16)	119	24	0.11 (0.09-0.13)	129	26	0.11 (0.09-0.13)	138	28	0.12 (0.10-0.15)	148	30	0.14 (0.12-0.16)
Unclassified tumors	**475**	**95**	**0.45 (0.41-0.50)**	**421**	**84**	**0.39 (0.35-0.43)**	**534**	**107**	**0.46 (0.42-0.50)**	**655**	**131**	**0.59 (0.55-0.64)**	**727**	**145**	**0.68 (0.64-0.74)**
Hemangioma	206	41	0.20 (0.17-0.23)	198	40	0.18 (0.16-0.21)	227	45	0.20 (0.17-0.22)	270	54	0.24 (0.22-0.28)	295	59	0.28 (0.25-0.31)

Table 3. Continued

Histopathology	15–19 years			20–24 years			25–29 years			30–34 years			35–39 years		
	Total Cases	Annual Average[c]	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)
Neoplasm, unspecified	237	47	0.23 (0.20-0.26)	202	40	0.19 (0.16-0.21)	277	55	0.24 (0.21-0.27)	359	72	0.33 (0.29-0.36)	409	82	0.39 (0.35-0.43)
All other	32	6	0.03 (0.02-0.04)	21	4	0.02 (0.01-0.03)	30	6	0.03 (0.02-0.04)	26	5	0.02 (0.02-0.03)	23	5	0.02 (0.01-0.03)
Total	**7,863**	**1,573**	**7.51 (7.34-7.68)**	**8,960**	**1,792**	**8.20 (8.03-8.37)**	**12,341**	**2,468**	**10.69 (10.50-10.88)**	**15,913**	**3,183**	**14.41 (14.19-14.64)**	**19,161**	**3,832**	**18.05 (17.79-18.30)**
Malignant	**2,679**	**536**	**2.56 (2.46-2.66)**	**2,504**	**501**	**2.30 (2.21-2.39)**	**3,464**	**693**	**3.00 (2.90-3.10)**	**4,142**	**828**	**3.75 (3.63-3.86)**	**4,496**	**899**	**4.23 (4.10-4.35)**
Non-malignant	**5,184**	**1,037**	**4.95 (4.82-5.09)**	**6,456**	**1,291**	**5.90 (5.76-6.05)**	**8,877**	**1,775**	**7.69 (7.53-7.85)**	**11,771**	**2,354**	**10.67 (10.48-10.86)**	**14,665**	**2,933**	**13.82 (13.60-14.05)**

[a]Annual average case counts are calculated by dividing the 5-year total by 5.
[b]Rates are per 100,000 population.
[c]Subgroup averages may not sum to total due to rounding.
— Data are not presented when fewer than 16 cases were reported for the specific category. Counts and associated rates cannot be provided when Total Cases (2018–2020) are fewer than 16 cases or when a value based on less than 16 cases can be back-calculated using a cell. Suppressed cases are included in the total count.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS - CDC's NPCR and NCI's SEER, 2016–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NOS, not otherwise specified; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

Table 4. 2016–2020 Total Cases, Annual Average Case Counts[a], and Annual Average Age-Specific Incidence Rates[b] for Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years, by Age at Diagnosis and Tumor Site[c]

Tumor Site	15–19 years			20–24 years			25–29 years			30–34 years			35–39 years		
	Total Cases	Annual Average[d]	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)
Olfactory tumors of the nasal cavity (C30.0)[e]	—	—	—	—	—	—	17	3	0.01 (0.01-0.02)	19	4	0.02 (0.01-0.03)	55	11	0.05 (0.04-0.07)
Meninges (cerebral and spinal) (C70.0-C70.9)	393	79	0.38 (0.34-0.41)	775	155	0.70 (0.65-0.75)	1,413	283	1.23 (1.17-1.30)	2,873	575	2.61 (2.52-2.71)	5,041	1,008	4.77 (4.64-4.91)
Cerebral meninges (C70.0)	310	62	0.30 (0.26-0.33)	632	126	0.57 (0.53-0.62)	1,148	230	1.00 (0.94-1.06)	2,343	469	2.13 (2.04-2.22)	4,132	826	3.92 (3.80-4.04)
Spinal meninges (C70.1)	36	7	0.03 (0.02-0.05)	46	9	0.04 (0.03-0.06)	79	16	0.07 (0.05-0.09)	129	26	0.12 (0.10-0.14)	176	35	0.17 (0.14-0.19)
Meninges, NOS (C70.9)	47	9	0.04 (0.03-0.06)	97	19	0.09 (0.07-0.11)	186	37	0.16 (0.14-0.19)	401	80	0.37 (0.33-0.40)	733	147	0.69 (0.64-0.75)
Cerebrum (C71.0)	302	60	0.29 (0.26-0.32)	195	39	0.18 (0.16-0.21)	228	46	0.20 (0.17-0.23)	285	57	0.26 (0.23-0.29)	264	53	0.25 (0.22-0.28)
Frontal, temporal, parietal, and occipital lobes of the brain (C71.1-C71.4)	1,410	282	1.35 (1.28-1.42)	1,549	310	1.42 (1.35-1.49)	2,268	454	1.97 (1.89-2.05)	2,859	572	2.59 (2.49-2.69)	3,077	615	2.89 (2.79-3.00)
Frontal lobe (C71.1)	547	109	0.52 (0.48-0.57)	793	159	0.73 (0.68-0.78)	1,265	253	1.10 (1.04-1.16)	1,675	335	1.52 (1.44-1.59)	1,752	350	1.64 (1.57-1.72)
Temporal lobe (C71.2)	579	116	0.55 (0.51-0.60)	493	99	0.45 (0.41-0.49)	616	123	0.53 (0.49-0.58)	729	146	0.66 (0.61-0.71)	811	162	0.76 (0.71-0.82)
Parietal lobe (C71.3)	196	39	0.19 (0.16-0.22)	205	41	0.19 (0.16-0.22)	322	64	0.28 (0.25-0.31)	379	76	0.34 (0.31-0.38)	438	88	0.42 (0.38-0.46)
Occipital lobe (C71.4)	88	18	0.08 (0.07-0.10)	58	12	0.05 (0.04-0.07)	65	13	0.06 (0.04-0.07)	76	15	0.07 (0.05-0.09)	76	15	0.07 (0.06-0.09)
Ventricle (C71.5)	280	56	0.27 (0.24-0.30)	229	46	0.21 (0.18-0.24)	250	50	0.21 (0.19-0.24)	211	42	0.19 (0.17-0.22)	184	37	0.17 (0.15-0.20)
Cerebellum (C71.6)	541	108	0.52 (0.47-0.56)	426	85	0.39 (0.36-0.43)	470	94	0.40 (0.37-0.44)	469	94	0.42 (0.39-0.46)	431	86	0.41 (0.37-0.45)
Brain stem (C71.7)	376	75	0.36 (0.32-0.40)	256	51	0.24 (0.21-0.27)	286	57	0.25 (0.22-0.28)	300	60	0.27 (0.24-0.30)	306	61	0.29 (0.26-0.32)
Other brain (C71.8-C71.9)	610	122	0.58 (0.54-0.63)	514	103	0.47 (0.43-0.51)	709	142	0.61 (0.57-0.66)	848	170	0.77 (0.72-0.82)	958	192	0.90 (0.84-0.96)

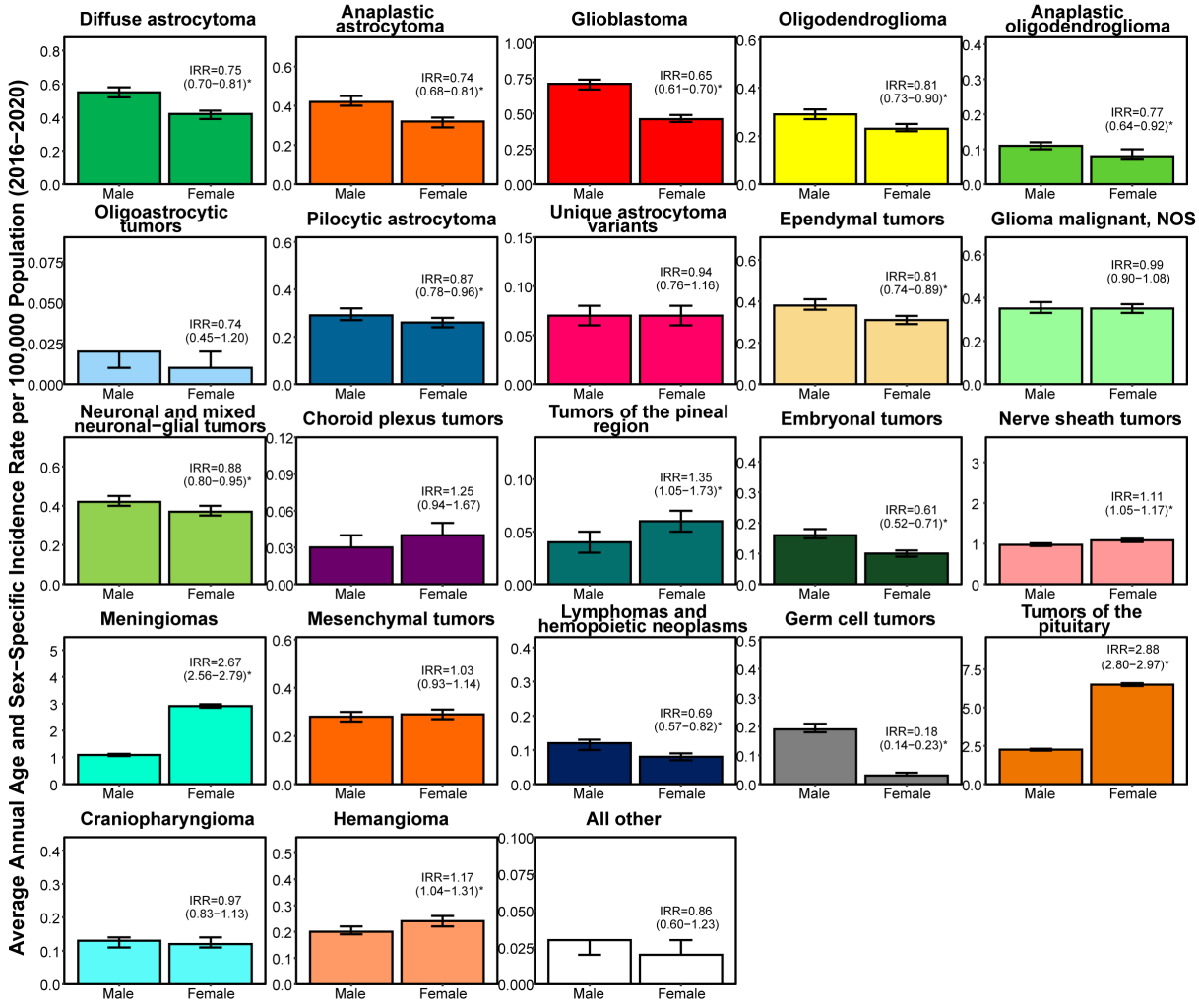
Table 4. Continued

Tumor Site	15–19 years			20–24 years			25–29 years			30–34 years			35–39 years		
	Total Cases	Annual Average[d]	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)
Overlapping lesion of brain (C71.8)	182	36	0.17 (0.15-0.20)	170	34	0.16 (0.13-0.18)	236	47	0.21 (0.18-0.23)	333	67	0.30 (0.27-0.34)	330	66	0.31 (0.28-0.34)
Brain, NOS (C71.9)	428	86	0.41 (0.37-0.45)	344	69	0.31 (0.28-0.35)	473	95	0.41 (0.37-0.45)	515	103	0.47 (0.43-0.51)	628	126	0.59 (0.54-0.64)
Spinal cord and cauda equina (C72.0-C72.1)	403	81	0.38 (0.35-0.42)	424	85	0.39 (0.35-0.43)	575	115	0.50 (0.46-0.54)	775	155	0.70 (0.65-0.75)	839	168	0.79 (0.74-0.84)
Spinal cord (C72.0)	—	—	—	—	—	—	—	—	—	755	151	0.68 (0.64-0.73)	809	162	0.76 (0.71-0.82)
Cauda equina (C72.1)	—	—	—	—	—	—	—	—	—	20	4	0.02 (0.01-0.03)	30	6	0.03 (0.02-0.04)
Cranial nerves (C72.2-C72.5)	351	70	0.33 (0.30-0.37)	462	92	0.42 (0.38-0.46)	717	143	0.63 (0.58-0.67)	1,089	218	0.99 (0.93-1.05)	1,410	282	1.33 (1.26-1.40)
Olfactory nerve (C72.2)	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Optic nerve (C72.3)	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Acoustic nerve (C72.4)	160	32	0.15 (0.13-0.18)	272	54	0.25 (0.22-0.28)	472	94	0.41 (0.38-0.45)	765	153	0.69 (0.65-0.75)	1,012	202	0.95 (0.89-1.01)
Cranial nerve, NOS (C72.5)	103	21	0.10 (0.08-0.12)	144	29	0.13 (0.11-0.15)	209	42	0.18 (0.16-0.21)	284	57	0.26 (0.23-0.29)	362	72	0.34 (0.31-0.38)
Other nervous system (C72.8-C72.9)	46	9	0.04 (0.03-0.06)	49	10	0.04 (0.03-0.06)	65	13	0.06 (0.04-0.07)	91	18	0.08 (0.07-0.10)	88	18	0.08 (0.07-0.10)
Overlapping lesion of brain & CNS (C72.8)	—	—	—	—	—	—	—	—	—	17	3	0.02 (0.01-0.02)	—	—	—
Nervous system, NOS (C72.9)	—	—	—	—	—	—	—	—	—	74	15	0.07 (0.05-0.08)	—	—	—
Pituitary (C75.1- C75.2)	2,899	580	2.77 (2.67-2.87)	3,922	784	3.58 (3.47-3.70)	5,208	1,042	4.51 (4.38-4.63)	6,006	1,201	5.44 (5.30-5.58)	6,438	1,288	6.05 (5.90-6.20)
Pituitary gland (C75.1)	2,801	560	2.68 (2.58-2.78)	3,850	770	3.52 (3.41-3.63)	5,135	1,027	4.44 (4.32-4.57)	5,913	1,183	5.35 (5.22-5.49)	6,344	1,269	5.96 (5.81-6.11)

Table 4. Continued

Tumor Site	15–19 years			20–24 years			25–29 years			30–34 years			35–39 years		
	Total Cases	Annual Average[d]	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)
Craniopharyngeal duct (C75.2)	98	20	0.09 (0.08-0.11)	72	14	0.07 (0.05-0.08)	73	15	0.06 (0.05-0.08)	93	19	0.08 (0.07-0.10)	94	19	0.09 (0.07-0.11)
Pineal (C75.3)	241	48	0.23 (0.20-0.26)	150	30	0.14 (0.12-0.16)	135	27	0.12 (0.10-0.14)	88	18	0.08 (0.06-0.10)	70	14	0.07 (0.05-0.08)
Total	**7,863**	**1,573**	**7.51 (7.34-7.68)**	**8,960**	**1,792**	**8.20 (8.03-8.37)**	**12,341**	**2,468**	**10.69 (10.50-10.88)**	**15,913**	**3,183**	**14.41 (14.19-14.64)**	**19,161**	**3,832**	**18.05 (17.79-18.30**

[a] Annual average cases are calculated by dividing the 5-year total by 5.
[b] Rates are per 100,000 population.
[c] The tumor sites referred to in this table are loosely based on the categories and site codes defined in the SEER site/histology validation list.
[d] Subgroup averages may not sum to total due to rounding.
[e] ICD-O-3 histopathology codes 9522–9523 only.
— Data are not presented when fewer than 16 cases were reported for the specific category. Counts and associated rates cannot be provided when Total Cases are fewer than 16 cases or when a value based on less than 16 cases can be back-calculated using a cell. Suppressed cases are included in the total count.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS - CDC's NPCR and NCI's SEER, 2016–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; ICD-O-3, *International Classification of Diseases for Oncology, Third Edition*; NCI, National Cancer Institute; NOS, not otherwise specified; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.



a Rates are per 100,000 population.
* Significant at P<0.05.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS – CDC's NPCR and NCI's SEER, 2016–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

Fig. 7 2016–2020 Age-Specific Incidence Rates[a] and Incidence Rate Ratios with 95% CIs for Selected Primary Brain and Other CNS Tumor Histopathologies in AYA Ages 15–39 Years, by Sex

Islander individuals, and Hispanic individuals of all races.

- Incidence rates for primary malignant BT were highest in non-Hispanic White individuals.
- In Hispanic individuals, incidence rates were 0.44 per 100,000 for glioblastoma, 1.61 per 100,000 for meningioma, and 4.69 per 100,000 for tumors of the sellar region.

In comparison with their non-Hispanic White counterparts:

- Non-Hispanic Black individuals had significantly higher incidence rates for meningiomas (12% higher), lymphomas and hemopoietic neoplasms (195% higher), tumors of the pituitary (32% higher), and craniopharyngioma (46% higher);
- Non-Hispanic Asian or Pacific Islander individuals had significantly higher incidence rates for lymphomas and hemopoietic neoplasms (59% higher) and germ cell tumors (58% higher);
- Non-Hispanic American Indian/Alaska Native individuals had significantly higher incidence rates for tumors of the pituitary (36% higher) (*Data not shown*); and
- Non-Hispanic American Indian/Alaska Native individuals had significantly higher incidence rates for embryonal tumors (19% higher), tumors of the pituitary (15% higher), and craniopharyngioma (23% higher) (*Data not shown*).

Incidence Rates by Urbanicity and Histopathology

In recent years, urbanicity has become a suspected predictor of BT incidence and outcomes due to the difference in demographics between metropolitan and non-metropolitan areas, including less access to care for

Table 5. 2016–2020 Total Cases, Annual Average Case Counts[a], and Annual Average Age-Specific Incidence Rates[b] for Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years, by Race/Ethnicity[c] and Histopathology

Histopathology	Non-Hispanic White			Non-Hispanic Black			Non-Hispanic American Indian/Alaska Native			Non-Hispanic Asian/Pacific Islander			Hispanic (All Races)		
	Total Cases	Annual Average[d]	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)
Diffuse astrocytic and oligodendroglial tumors	**7,003**	**1,401**	**2.31 (2.25-2.36)**	**704**	**141**	**0.93 (0.86-1.00)**	**73**	**15**	**1.50 (1.17-1.90)**	**337**	**67**	**0.85 (0.76-0.94)**	**1,366**	**273**	**1.21 (1.15-1.28)**
Diffuse astrocytoma	1,956	391	0.64 (0.61-0.67)	180	36	0.23 (0.20-0.27)	23	5	0.46 (0.29-0.70)	69	14	0.18 (0.14-0.22)	338	68	0.30 (0.26-0.33)
Anaplastic astrocytoma	1,520	304	0.49 (0.47-0.52)	122	24	0.16 (0.13-0.19)	—	—	—	64	13	0.16 (0.12-0.21)	271	54	0.24 (0.21-0.27)
Glioblastoma	2,092	418	0.70 (0.67-0.73)	285	57	0.38 (0.34-0.43)	19	4	0.39 (0.23-0.62)	141	28	0.35 (0.30-0.42)	488	98	0.44 (0.40-0.48)
Oligodendroglioma	1,017	203	0.34 (0.32-0.36)	80	16	0.11 (0.08-0.13)	17	3	0.35 (0.20-0.56)	42	8	0.10 (0.08-0.14)	185	37	0.16 (0.14-0.19)
Anaplastic oligodendroglioma	365	73	0.12 (0.11-0.13)	—	—	—	—	—	—	—	—	—	—	—	—
Oligoastrocytic tumors	53	11	0.02 (0.01-0.02)	—	—	—	—	—	—	—	—	—	—	—	—
Other astrocytic tumors	**1,253**	**251**	**0.42 (0.39-0.44)**	**217**	**43**	**0.27 (0.23-0.30)**	—	—	—	—	—	—	**284**	**57**	**0.23 (0.21-0.26)**
Pilocytic astrocytoma	1,022	204	0.34 (0.32-0.36)	174	35	0.21 (0.18-0.25)	—	—	—	—	—	—	210	42	0.17 (0.15-0.20)
Unique astrocytoma variants	231	46	0.08 (0.07-0.09)	43	9	0.05 (0.04-0.07)	—	—	—	—	—	—	74	15	0.06 (0.05-0.08)
Ependymal tumors	**1,262**	**252**	**0.42 (0.40-0.44)**	**176**	**35**	**0.22 (0.19-0.26)**	—	—	—	—	—	—	**314**	**63**	**0.27 (0.24-0.31)**
Other gliomas	**1,259**	**252**	**0.42 (0.39-0.44)**	**252**	**50**	**0.32 (0.28-0.36)**	—	—	—	—	—	—	**279**	**56**	**0.24 (0.21-0.27)**
Glioma malignant, NOS	1,243	249	0.41 (0.39-0.43)	—	—	—	—	—	—	—	—	—	—	—	—
Other neuroepithelial tumors	16	3	0.01 (0.00-0.01)	—	—	—	—	—	—	—	—	—	—	—	—
Neuronal and mixed neuronal-glial tumors	**1,436**	**287**	**0.48 (0.45-0.50)**	**228**	**46**	**0.28 (0.25-0.32)**	—	—	—	—	—	—	**343**	**69**	**0.29 (0.26-0.32)**
Choroid plexus tumors	**140**	**28**	**0.05 (0.04-0.05)**	**18**	**4**	**0.02 (0.01-0.04)**	—	—	—	—	—	—	**33**	**7**	**0.03 (0.02-0.04)**
Tumors of the pineal region	**179**	**36**	**0.06 (0.05-0.07)**	**35**	**7**	**0.04 (0.03-0.06)**	—	—	—	—	—	—	**37**	**7**	**0.03 (0.02-0.04)**

Table 5. Continued

Histopathology	Non-Hispanic White			Non-Hispanic Black			Non-Hispanic American Indian/Alaska Native			Non-Hispanic Asian/Pacific Islander			Hispanic (All Races)		
	Total Cases	Annual Average[d]	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)
Embryonal tumors	**411**	**82**	**0.13 (0.12-0.15)**	**80**	**16**	**0.10 (0.08-0.12)**	—	—	—	—	—	—	**191**	**38**	**0.16 (0.14-0.18)**
Medulloblastoma	346	69	0.11 (0.10-0.12)	74	15	0.09 (0.07-0.11)	—	—	—	—	—	—	169	34	0.14 (0.12-0.16)
Tumors of cranial and spinal nerves	**3,609**	**722**	**1.21 (1.17-1.25)**	**400**	**80**	**0.53 (0.47-0.58)**	**56**	**11**	**1.20 (0.90-1.56)**	**333**	**67**	**0.84 (0.75-0.94)**	**823**	**165**	**0.73 (0.68-0.79)**
Nerve sheath tumors	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Other tumors of cranial and spinal nerves	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Tumors of meninges	**7,065**	**1,413**	**2.41 (2.35-2.46)**	**1,872**	**374**	**2.60 (2.48-2.73)**	**110**	**22**	**2.37 (1.94-2.86)**	**453**	**91**	**1.15 (1.05-1.27)**	**1,995**	**399**	**1.85 (1.77-1.93)**
Meningiomas	6,099	1,220	2.09 (2.04-2.14)	1,670	334	2.35 (2.23-2.46)	96	19	2.09 (1.68-2.55)	388	78	0.99 (0.89-1.09)	1,715	343	1.61 (1.53-1.68)
Mesenchymal tumors	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Primary melanocytic lesions	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Lymphomas and hemopoietic neoplasms	**190**	**38**	**0.06 (0.05-0.07)**	**138**	**28**	**0.19 (0.16-0.22)**	—	—	—	—	—	—	**135**	**27**	**0.12 (0.10-0.14)**
Lymphoma	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Other hematopoietic neoplasms	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Germ cell tumors	**351**	**70**	**0.12 (0.10-0.13)**	**62**	**12**	**0.08 (0.06-0.10)**	—	—	—	—	—	—	**136**	**27**	**0.11 (0.09-0.13)**
Tumors of sellar region	**12,448**	**2,490**	**4.08 (4.01-4.16)**	**4,125**	**825**	**5.42 (5.26-5.60)**	**274**	**55**	**5.68 (5.02-6.41)**	**1,014**	**203**	**2.53 (2.37-2.69)**	**5,394**	**1,079**	**4.69 (4.56-4.81)**
Tumors of the pituitary	12,111	2,422	3.97 (3.90-4.04)	4,000	800	5.26 (5.10-5.43)	—	—	—	—	—	—	5,234	1,047	4.55 (4.43-4.67)
Craniopharyngioma	337	67	0.11 (0.10-0.12)	125	25	0.16 (0.14-0.19)	—	—	—	—	—	—	160	32	0.14 (0.12-0.16)
Unclassified tumors	**1,689**	**338**	**0.56 (0.53-0.59)**	**379**	**76**	**0.50 (0.45-0.56)**	**24**	**5**	**0.47 (0.30-0.71)**	**72**	**14**	**0.18 (0.14-0.23)**	**551**	**110**	**0.48 (0.44-0.52)**
Hemangioma	732	146	0.24 (0.22-0.26)	—	—	—	—	—	—	—	—	—	239	48	0.20 (0.18-0.23)
Neoplasm, unspecified	878	176	0.29 (0.27-0.31)	—	—	—	—	—	—	—	—	—	281	56	0.25 (0.22-0.28)

Table 5. Continued

Histopathology	Non-Hispanic White			Non-Hispanic Black			Non-Hispanic American Indian/Alaska Native			Non-Hispanic Asian/Pacific Islander			Hispanic (All Races)		
	Total Cases	Annual Average[d]	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)	Total Cases	Annual Average	Rate (95% CI)
All other	79	16	0.03 (0.02-0.03)	—	—	—	—	—	—	—	—	—	31	6	0.03 (0.02-0.04)
Total	**38,295**	**7,659**	**12.71 (12.58-12.84)**	**8,686**	**1,737**	**11.50 (11.26-11.75)**	**615**	**123**	**12.75 (11.75-13.82)**	**2,581**	**516**	**6.55 (6.30-6.81)**	**11,881**	**2,376**	**10.44 (10.25-10.63)**
Malignant	**11,621**	**2,324**	**3.84 (3.77-3.91)**	**1,696**	**339**	**2.19 (2.08-2.30)**	**132**	**26**	**2.69 (2.25-3.20)**	**625**	**125**	**1.63 (1.50-1.76)**	**2,723**	**545**	**2.37 (2.28-2.46)**
Non-malignant	**26,674**	**5,335**	**8.87 (8.76-8.98)**	**6,990**	**1,398**	**9.31 (9.09-9.54)**	**483**	**97**	**10.06 (9.17-11.01)**	**1,956**	**391**	**4.93 (4.71-5.15)**	**9,158**	**1,832**	**8.07 (7.91-8.24)**

[a]Annual average case counts are calculated by dividing the 5-year total by 5.
[b]Rates are per 100,000 population.
[c]Individuals with unknown race were excluded.
[d]Subgroup averages may not sum to total due to rounding.
— Data are not presented when fewer than 16 cases were reported for the specific category. Counts and associated rates cannot be provided when Total Cases are fewer than 16 cases or when a value based on less than 16 cases can be back-calculated using a cell. Suppressed cases are included in the total count.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS - CDC's NPCR and NCI's SEER, 2016–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCHS, National Center for Health Statistics; NCI, National Cancer Institute; NOS, not otherwise specified; NPCR, National Program of Cancer Registries; NVSS, National Vital Statistics System; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

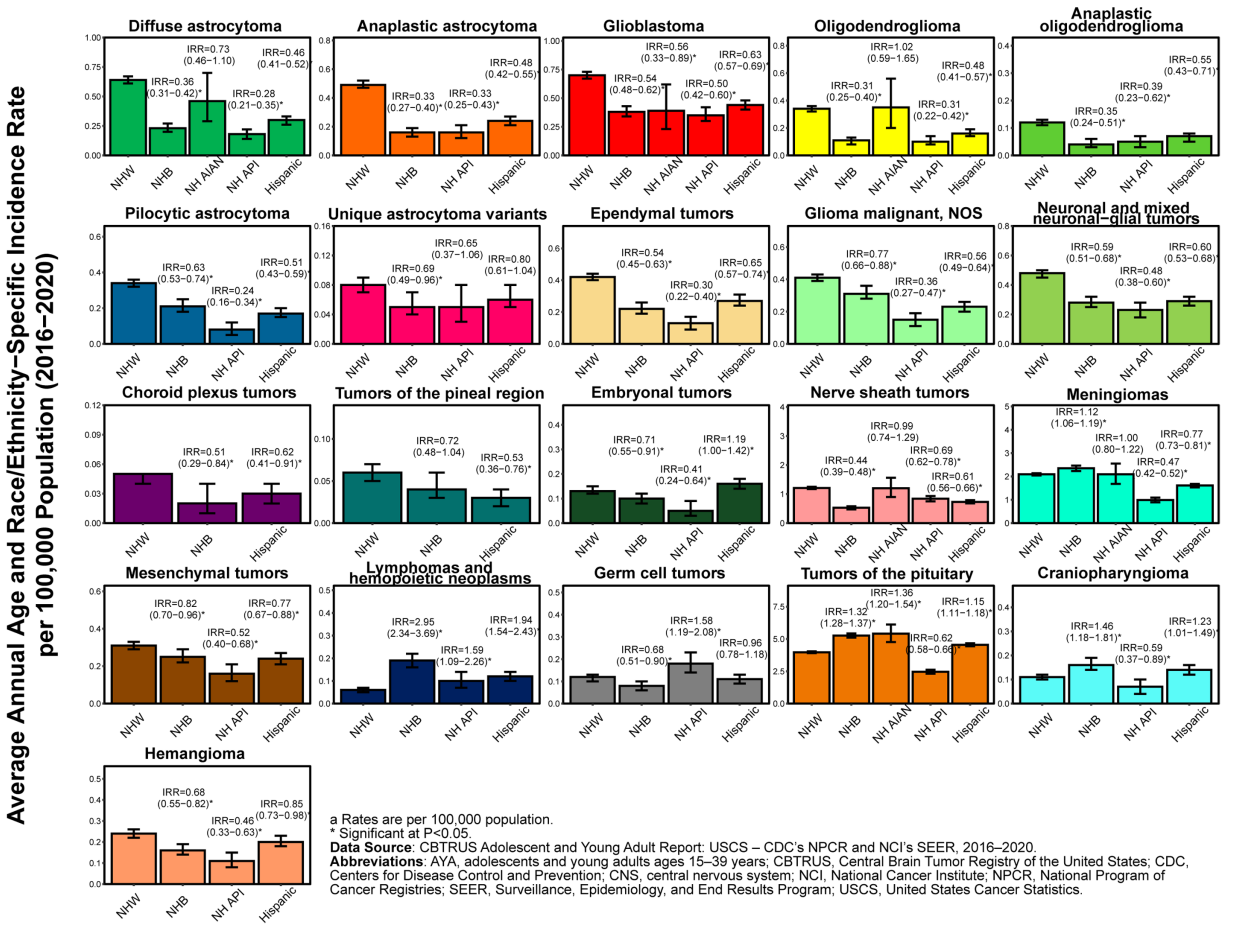


Fig. 8 2016–2020 Age-Specific Incidence Rates[a] and Incidence Rate Ratios with 95% CIs by Race/Ethnicity for Selected Primary Brain and Other CNS Tumor Histopathologies in AYA Ages 15–39 Years

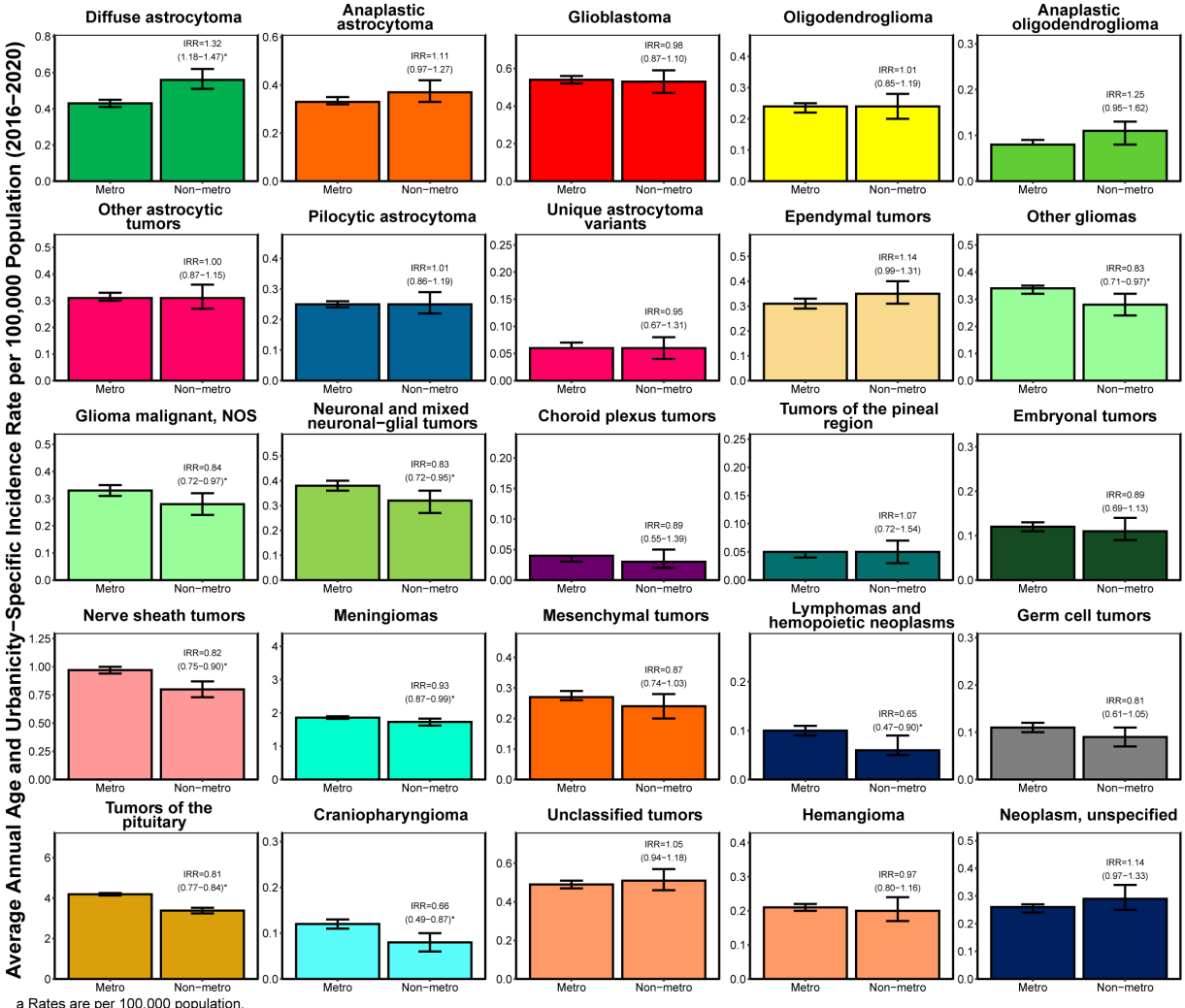
those in non-metropolitan areas.[57] Overall incidence and incidence rate ratios for primary BT in AYA are shown by urbanicity and histopathology in **Figure 9**.

- Among AYA ages 15–39 years, the incidence of diffuse astrocytoma was significantly higher (32% higher) in non-metropolitan dwellers than their metropolitan counterparts.
- Compared with metropolitan areas, non-metropolitan areas had significantly lower incidence rates for other gliomas (17% lower), glioma malignant, not otherwise specified (16% lower), neuronal and mixed neuronal-glial tumors (17% lower), nerve sheath tumors (18% lower), meningiomas (7% lower), lymphomas and hemopoietic neoplasms (35% lower), tumors of the pituitary (19% lower), and craniopharyngioma (34% lower).

Frequency and Incidence of Molecularly Defined Primary Brain and Other CNS Tumors, 2018–2020

Total cases and AASIR for molecularly (histopathologically) defined primary BT diagnosed in AYA in 2018–2020, along with median age at diagnosis and distribution by sex and racial/ethnic group are shown in **Table 6**. Most of these entities began being reported only in 2018, and as a result some may have occurred too infrequently to report.

- The most common cancer was molecularly defined adult-type diffuse glioma (1.51 per 100,000). Molecularly defined diffuse gliomas were less common in females (40.9%) than males and more common in non-Hispanic White individuals (73.4%), compared with all other racial/ethnic groups. The overall median age at diagnosis for these tumors was 32 years.
- The most common medulloblastoma subtype was SHH-activated & *TP53* wildtype, which had an incidence rate of 0.04 per 100,000 population and a median age at diagnosis of 26 years. Non-WNT/non-SHH medulloblastoma was the second most commonly occurring subtype, with an incidence rate of 0.01 per 100,000 and a median age at diagnosis of 19 years.
- Diffuse midline glioma, H3 K27M-mutant had an incidence rate of 0.05 per 100,000 population and a median age at diagnosis of 25 years.
- Papillary glioneuronal tumors were the only newer histopathology that was more common in females (52.1%) than males. The *PRKCA* gene fusion was not included in reporting during this period so it is not possible to state definitively that this marker present.



a Rates are per 100,000 population.
* Significant at P<0.05.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS – CDC's NPCR and NCI's SEER, 2016–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

Fig. 9 2016–2020 Age-Specific Incidence Rates[a] and Incidence Rate Ratios with 95% CIs by Urbanicity for Selected Primary Brain and Other CNS Tumor Histopathologies in AYA Ages 15–39 Years

- When stratified by WHO grade, 78.1% of WHO grade 2/II astrocytoma were *IDH1/2* mutant, while 76.3% of WHO grade 3/III and 23.7% of WHO grade 4/IV astrocytoma were *IDH1/2*-mutant (**Figure 10**).

Changes in Incidence Over Time, 2004–2019

Time trends in cancer incidence are important measures of the changing burden of cancer in a population over time. **Many factors can cause rates to fluctuate over time, and all of these must be considered when interpreting time-trends results.** Delays in reporting can produce small fluctuations in incidence, making it imperative that the most recent data available are used when assessing trends in incidence over time. Time-trends analysis methods can be used to estimate if the APC is significantly different from 0% (meaning no change in incidence from year to year).

In addition to the statistical significance of changes in incidence over time, the size of this change also must be considered. With large datasets such as CBTRUS, very small fluctuations in incidence over time could be statistically significant but may not represent a truly large change in the proportion of individuals over time.

Incidence Time Trends for Primary Brain and Other CNS Tumors by Histopathology

AASIR for all primary BT was highest in young adults ages 35–39 years for the entire trend period (**Figure 11A**). AASIR and APC for selected histopathologies overall and by age group at diagnosis are shown in **Figure 11B**. Complete APC results are available in **Supplementary Table 8**.

- Among AYA ages 15–39 years, overall incidence of primary BT increased significantly from 2004–2009

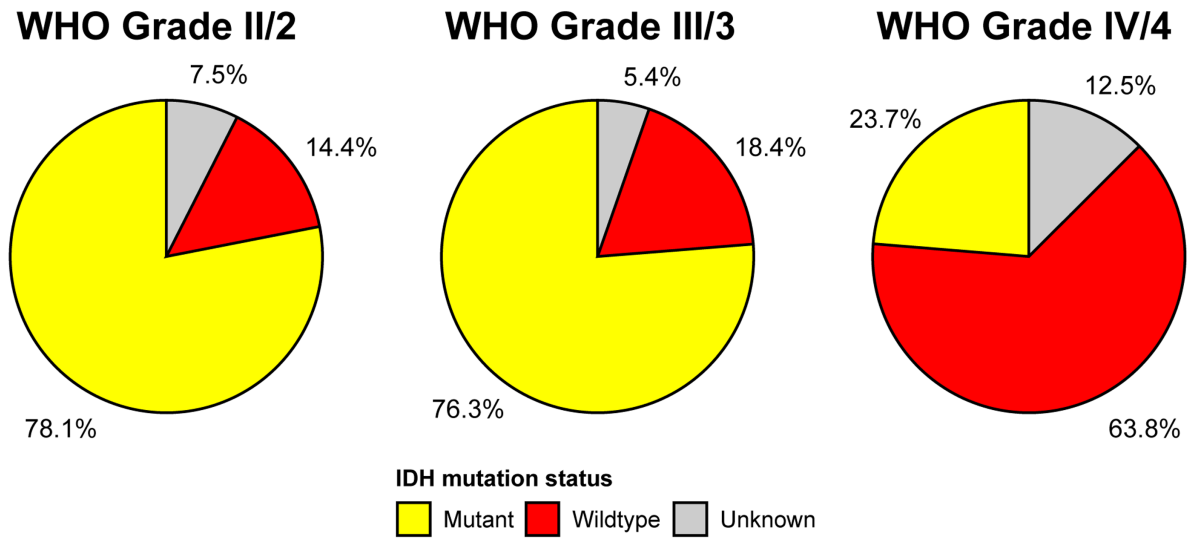
Table 6. 2018–2020 Total Cases, Annual Average Age-Specific Incidence[a], Median Age, and Percentages[b] by Sex and Race/Ethnicity for Molecularly Defined Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years

Tumor Type	ICD-O-3 Histopathology Codes[c]	Total Cases (2018-2020)	Age-Specific Incidence Rate	Age (Median, Interquartile Range)	Female (%)	Non-Hispanic White (%)	Non-Hispanic Black (%)	Hispanic (All Races) (%)
Molecularly defined diffuse glioma		*4,883*	*1.51 (1.47-1.55)*	*32 (27-36)*	*40.9*	*73.4*	*6.7*	*13.4*
IDH1/2 mutant - astrocytoma[d]	9400/3, 9401/3, 9445/3	2,196	0.67 (0.64-0.70)	31 (26-35)	40.4	76.5	5.7	12.7
IDH1/2 wildtype - astrocytoma and glioblastoma[e]	9400/3, 9401/3, 9440/3	1,682	0.53 (0.50-0.55)	32 (26-36)	40	69.6	8.6	14.7
IDH1/2 mutant & 1p/19q–co-deleted oligodendroglioma[f]	9450/3, 9451/3	1,005	0.31 (0.29-0.33)	33 (28-36)	43.3	73.1	5.6	12.5
Medulloblastoma		335	0.10 (0.09-0.11)	24 (20-31)	37	55.5	10.1	29.0
SHH-activated & *TP53* wildtype[g]	9471/3	116	0.04 (0.03-0.04)	26 (21-32)	38.8	54.3	—	31.0
SHH-activated & *TP53* mutant	9476/3	—	—	25 (19-35)	—	—	—	—
WNT-activated	9475/3	—	—	21 (20-27)	—	—	—	—
Non-WNT/non-SHH	9477/3	34	0.01 (0.01-0.01)	19 (16-24)	—	52.9	—	—
Embryonal tumor with multilayered rosettes, C19MC-altered[h]	9478/3	—	—	27 (24-30)	—	—	—	—
Ependymoma, *RELA* fusion	9396/3	—	—	18 (15-32)	—	—	—	—
Diffuse midline glioma, H3 K27M-mutant	9385/3	168	0.05 (0.04-0.06)	25 (19-32)	49.4	63.7	10.7	15.5
Papillary tumor of pineal region	9395/3	—	—	30 (25-34)	—	—	—	—
Pilomyxoid astrocytoma	9425/3	—	—	21 (17-32)	—	—	—	—
Angiocentric glioma	9431/1	—	—	31 (28-36)	—	—	—	—
Papillary glioneuronal tumor	9509/1	73	0.02 (0.02-0.03)	23 (19-31)	52.1	74.0	—	—

[a]Rates are per 100,000 population.
[b]Percentages may not add to 100% due to rounding.
[c]Assigned using the ICD-O-3 histopathology codes and a behavior code of /1 or /3.
[d]ICD-O-3 histopathology code of 9400/3 or 9401/3 and a BMM value of 1 or 3, or ICD-O-3 histopathology code of 9445/3.
[e]ICD-O-3 histopathology code of 9400/3, 9401/3, or 9440/3 and a BMM value of 2, 4, or 5.
[f]ICD-O-3 histopathology code of 9450/3 or 9451/3 and a BMM of 6 or7.
[g]ICD-O-3 histopathology code of 9471/3 and a BMM value of 8.
[h]ICD-O-3 histopathology code of 9478/3 and a BMM value of 9.
— Data are not presented when fewer than 16 cases were reported for the specific category. Counts and associated rates cannot be provided when Total Cases (2018–2020) are fewer than 16 cases or when a value based on less than 16 cases can be back-calculated using a cell. Suppressed cases are included in the total count.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS - CDC's NPCR and NCI's SEER, 2018–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; BMM, brain molecular marker variable; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; ICD-O-3, *International Classification of Diseases for Oncology, Third Edition*; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology and End Results Program; SHH, sonic hedgehog; WNT, wingless; USCS, United States Cancer Statistics.

(APC=4.2%; 95% CI: 2.6% to 5.8%) and from 2009–2017 (APC=1.1%; 95% CI: 0.2% to 1.9%), followed by an insignificant decrease from 2017–2019.

- Among adolescents ages 15–19 years, overall incidence of primary BT increased significantly from 2004–2009 (APC=4.0%; 95% CI: 2.3% to 5.7%) and remained relatively steady thereafter.
- Among young adults ages 20–24 years, overall incidence of primary BT increased significantly from 2004–2012 (APC=3.8%; 95% CI: 2.6% to 5.0%) and remained relatively steady thereafter.
- Among young adults ages 25–29 years, overall incidence of primary BT increased significantly from 2004–2008 (APC=5.1%; 95% CI: 2.0% to 8.2%).



a Molecular marker data collected via the NAACCR Site-Specific Data Item #3816: Brain Molecular Marker variable (see Supplementary Table 2 for included sites and coding schemes).
b Includes ICD-O-3 codes 9400/3, 9401/3 9440/3, and 9445/3.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS – CDC's NPCR and NCI's SEER, 2018–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; ICD-O-3, International Classification of Diseases for Oncology, Third Edition; IDH, Isocitrate dehydrogenase; WHO, World Health Organization; CBTRUS, Central Brain Tumor Registry of the United States; USCS, United States Cancer Statistics; CDC, Centers for Disease Control and Prevention; NPCR, National Program of Cancer Registries; NCI, National Cancer Institute; SEER, Surveillance, Epidemiology, and End Results Program.

Fig. 10 2018–2020 Frequency of *IDH* Mutations[a] in AYA Ages 15–39 Years, by WHO Grade for Selected Astrocytoma Histopathologies[b]

- Among young adults ages 30–34 years, overall incidence of BT increased significantly from 2004–2006 (APC=7.5%; 95% CI: 1.1% to 14.4%) and 2006–2016 (APC=1.7%; 95% CI: 1.2% to 2.2%), followed by a significant decrease from 2016–2019 (APC=–2.7%; 95% CI: –5.2% to –0.1%).
- Among young adults ages 35–39 years, overall incidence of primary BT increased significantly from 2004–2011 (APC=3.9%; 95% CI: 2.6% to 5.2%) and remained relatively steady thereafter.
- The incidence of tumors of the sellar region increased significantly from 2004–2009 (APC=7.8%; 95% CI: 5.9% to 9.8%) and 2009–2017 (APC=2.8%; 95% CI: 1.9% to 3.8%) for all AYA ages combined. This increase was greatest in 2004–2007 for pituitary tumors in young adults ages 35–39 years (APC=14.5%; 95% CI: 6.4% to 23.2%).
- **The increases in incidence for tumors frequently diagnosed by imaging alone, such as pituitary tumors, are partially attributable to improvements in the collection of radiographically diagnosed cases and non-malignant cases in general over time.**

Incidence Time Trends for Primary Brain and Other CNS Tumors and Common Cancers

Comparisons of AASIR trends and APC between all primary BT and other common AYA cancers are shown in **Figure 12**.

- Overall, the incidence of malignant and non-malignant primary BT increased significantly from 2004–2009 (APC=4.2%; 95% CI: 2.6% to 5.8%) and from 2009–2017 (APC=1.1%; 95% CI: 0.2% to 1.9%), followed by a period of no significant change from 2017–2019 (APC=–3.2%; 95% CI: –9.0% to 2.9%).
- In comparison, during the same time period, the incidence of malignant melanoma and female uterine cervix cancer decreased, and incidence of female breast cancer increased.

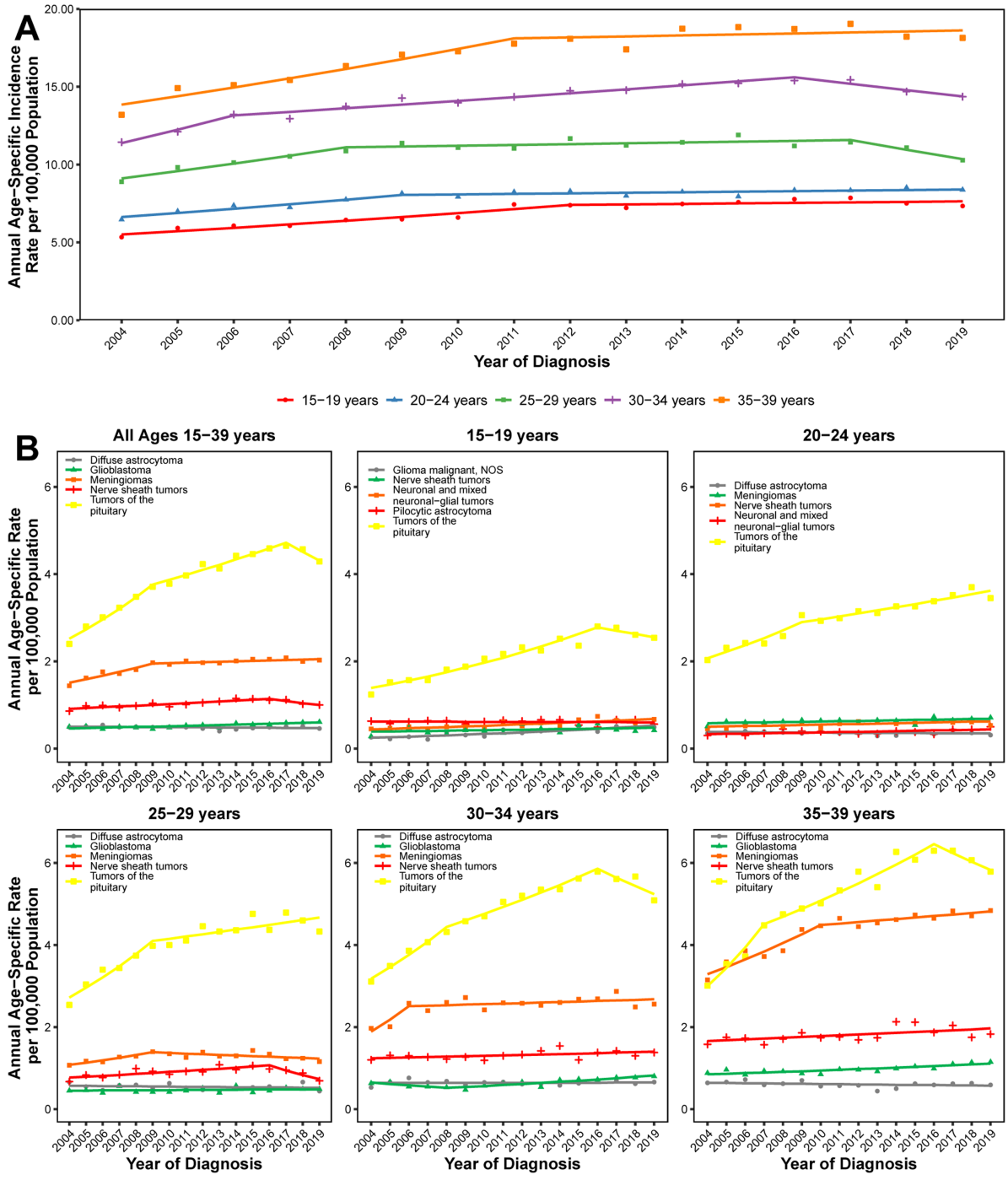
Incidence Time Trends for Primary Brain and Other CNS Tumors by Race/Ethnicity

AASIR for all malignant and non-malignant primary BT in AYA by racial/ethnic groups are shown in **Figure 13**.

- Among non-Hispanic White individuals, the overall incidence of primary BT increased significantly from 2004–2012 (APC=3.4%; 95% CI: 2.7% to 4.1%) and remained relatively steady thereafter.
- Among non-Hispanic Asian or Pacific Islander Individuals, the overall incidence of primary BT increased significantly from 2004–2019 (APC=1.3%; 95% CI: 0.6% to 1.9%).
- Among Hispanic individuals of all races, the incidence of primary BT held steady from 2004–2006 and then increased significantly from 2006–2019 (APC=1.3%; 95% CI: 0.6% to 1.9%).

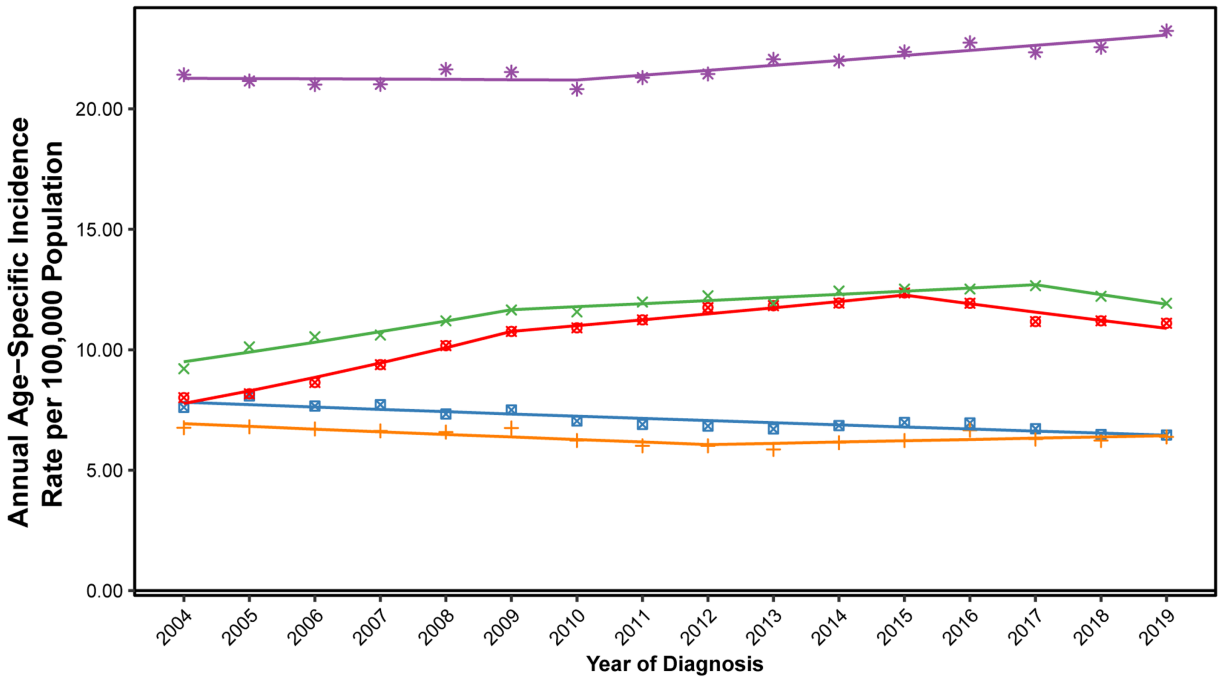
Age-, Sex-, and Race/Ethnicity-Specific Brain Tumor Mortality Rates, 2016–2020

The overall 2016–2020 AASMR for malignant primary BT in AYA was 0.96 per 100,000 population (**Table 1**). AASMR by



a Rates are per 100,000 population.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS – CDC's NPCR and NCI's SEER, 2004–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

Fig. 11 2004–2019 Trends by AYA Age Group at Diagnosis for (A) Annual Average Age-Specific Incidence Rates[a] of All Primary Brain and Other CNS Tumors; and (B) Annual Average Age-Specific Incidence Rates and Annual Percent Change for the Five Most Common Primary Brain and Other CNS Tumor Histopathologies



Legend	Histopathology	Years	APC (95% CI)	Years	APC (95% CI)	Years	APC (95% CI)
	Thyroid carcinoma	2004–2009	6.7(5,8.5)*	2009–2015	2.2(0.7,3.7)*	2015–2019	−2.9(−4.8,−1)*
	Breast (female only)	2004–2010	−0.1(−0.7,0.6)	2010–2019	0.9(0.6,1.3)*		
	Melanoma – malignant	2004–2019	−1.3(−1.6,−0.9)*				
	Brain and Other Nervous System	2004–2009	4.2(2.6,5.8)*	2009–2017	1.1(0.2,1.9)*	2017–2019	−3.2(−9,2.9)
	Uterine Cervix (female only)	2004–2012	−1.7(−2.7,−0.6)*	2012–2019	0.9(−0.5,2.2)		

a Rates are per 100,000 population.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS – CDC's NPCR and NCI's SEER, 2004–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

Fig. 12 2004–2019 Annual Age-Specific Incidence Rate[a] Trends and Annual Percent Change for All Malignant and Non-Malignant Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years, Compared with Other Common Cancers

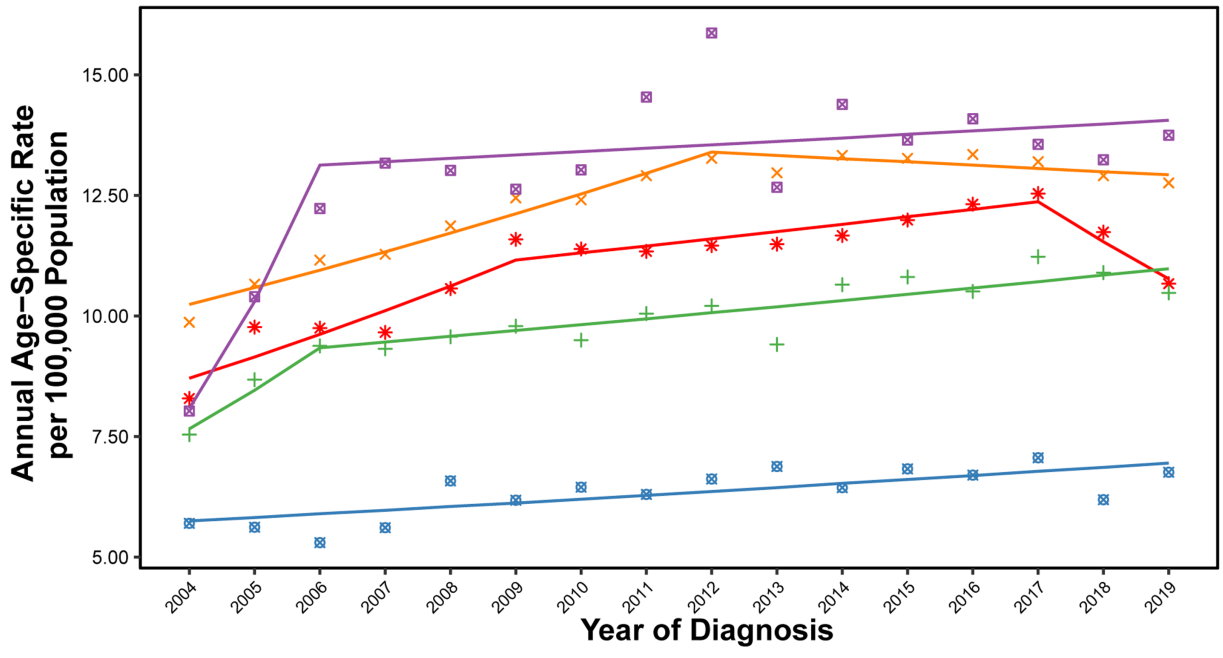
sex, race and Hispanic ethnicity, and age group at death are shown in **Table 1**. Crude mortality rates by individual age at death are shown in **Figure 14**.

- Mortality due to malignant primary BT was higher in males than females (1.15 vs 0.76 per 100,000, respectively).
- Young adults ages 35–39 years had the highest mortality of any age group (1.69 per 100,000), whereas young adults ages 20–24 years had the lowest mortality of any age group (0.53 per 100,000).
- Mortality was highest in non-Hispanic White individuals (1.18 per 100,000) and lowest in non-Hispanic Asian or Pacific Islander individuals (0.62 per 100,000), compared with other racial/ethnic groups.
- Overall mortality increased with increasing age, especially after 29 years of age.

Changes in Mortality Due to Malignant Tumors Over Time, 1969–2019

Time trends in cancer mortality are another important measures of the changing burden of cancer in a population over time. As with incidence time trends, **many factors can lead to fluctuations in mortality rates over time and must be considered when interpreting time trends.** It is critical to use the most recent data available when assessing mortality trends over time, as reporting delays can cause small fluctuations. Time-trends analysis methods can be used to estimate if the APC is significantly different from 0% (meaning no change in mortality from year to year).

AASMRs for primary malignant BT and other selected major causes of cancer death in AYA from 1969–2019 are shown in **Figure 15**. AASMRs for primary malignant BT are



Race and Ethnicity	Years	APC (95% CI)	Years	APC (95% CI)	Years	APC (95% CI)
Non−Hispanic White	2004−2012	3.4(2.7,4.1)*	2012−2019	−0.5(−1.3,0.2)		
Non−Hispanic Black	2004−2009	5.1(2.4,7.8)*	2009−2017	1.3(−0.1,2.7)	2017−2019	−6.7(−15.5,3.1)
Non−Hispanic American Indian/Alaska Native	2004−2006	27.5(−1.9,65.7)	2006−2019	0.5(−0.6,1.6)		
Non−Hispanic Asian or Pacific Islander	2004−2019	1.3(0.6,1.9)*				
Hispanic All Races	2004−2006	10.4(−4.1,27.2)	2006−2019	1.3(0.6,1.9)*		

a Rates are per 100,000 population.
Data Source: CBTRUS Childhood and Adolescent Report: USCS – CDC's NPCR and NCI's SEER, 2004–2020
Abbreviations: APC, annual percent change; AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

Fig. 13 2004–2019 Average Annual Age-Specific Incidence Rate[a] Trends and Annual Percent Change for All Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years, by Race/Ethnicity Group

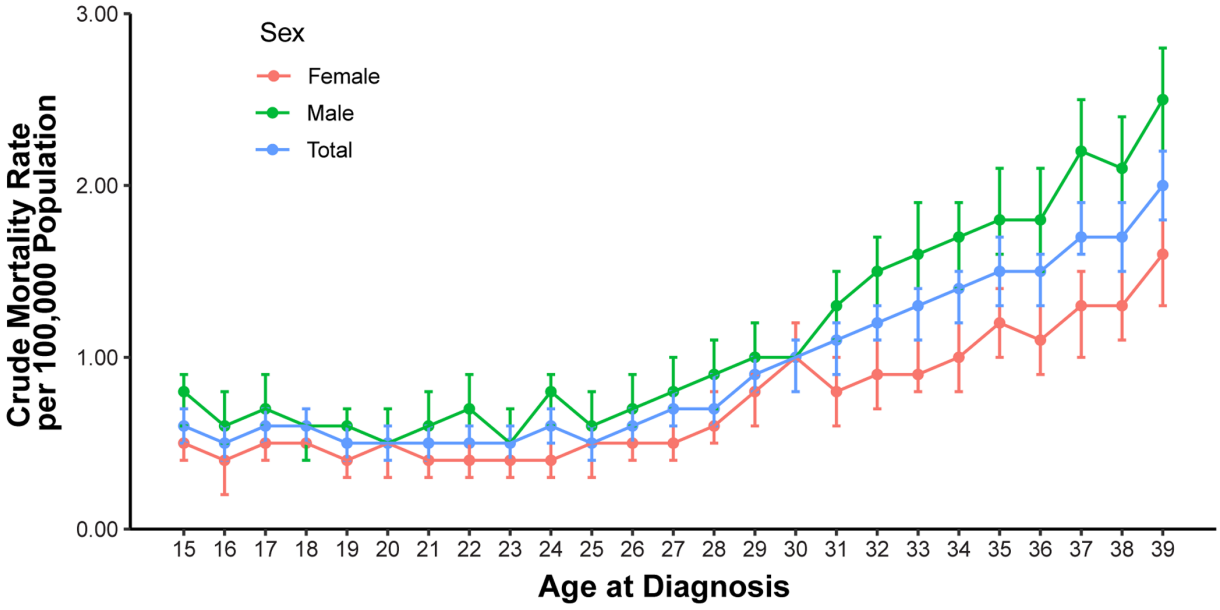
shown by age group at death in **Figure 16**. Complete APC results are available in **Supplementary Table 9**.

- Overall, mortality due to cancer has decreased since 1969.
- Some of the biggest decreases in mortality have come in breast cancer (female only), where mortality decreased by 0.2% per year from 1969–1987 (95% CI: –0.6% to –0.1%) and by 2.9% per year from 1987–2010 (95% CI: –3.1% to –2.6%), and in cervix uteri (female only), where mortality decreased by 6.0% from 1969–1978 (95% CI: –7.2 to –4.8) and 4.2% from 1996–2004 (95% CI: –5.9 to –2.4%).
- Although mortality due to primary BT decreased by 1.6% between 1969 and 1981 (95% CI: –2.2% to –1.0%) and by 1.8% from 1994 to 2007 (95% CI: –2.4% to –1.3%), AYA mortality from primary BT has not changed significantly since 2007.
- Mortality reflects age at death; thus, counts and rates may include those diagnosed at less than 15 years of age.

Comparing Primary Brain and Other CNS Tumors to Other Common AYA Cancers, 1969–2020

AASMRs for AYA overall and by age group at death are shown in **Figure 16**. AASIRs for the five most common causes of AYA death overall are shown in **Figure 17**, and AASMRs for the five most common causes of cancer death by AYA age group at death are shown in **Figure 18**.

- **All BT were the most significant contributor to cancer incidence in AYA age groups 15-29 years and the second most incident cancer overall. These tumors were the third highest contributor to incidence in young adults ages 30-39 years.**
- Female breast cancer was the highest incident cancer overall and among ages at diagnosis groups 30-39 years.
- When compared with other causes of death in AYA ages 15–39 years, all cancers combined contributed 9,108 deaths annually and was the fourth-leading cause of death. Death by cancer was among the top five causes



a Rates are per 100,000 population.
Data Source: CBTRUS Adolescent and Young Adult Report: NCHS's NVSS, 2016–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years at death; CBTRUS, Central Brain Tumor Registry of the United States; CNS, central nervous system; NCHS, National Center for Health Statistics; NVSS, National Vital Statistics System.

Fig. 14 2016–2020 Crude Mortality Rates[a] for Malignant Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years at Death, by Sex and Age at Death

of death in all age groups at diagnosis and was second highest in young adults ages 35–39 years.

Age-, Sex-, and Race/Ethnicity-Specific Relative Survival, 2004–2019

Five-year relative survival estimates for malignant and non-malignant primary BT in the United States during 2004–2019 in AYA overall, by sex, race/ethnicity, and age group at diagnosis are shown in **Table 1**.

- Overall, 5-year relative survival was 91.1% and was higher in females (94.1%) than males (86.5%). When stratified by behavior, 5-year survival estimates were slightly higher in females for both malignant and non-malignant tumors.
- Adolescents ages 15–19 years had the highest 5-year relative survival (92.0%) of any age group.
- Five-year relative survival was highest in non-Hispanic American Indian/Alaska Native individuals and Hispanic individuals of all races (both were 91.9%) and lowest in non-Hispanic Black individuals (90.6%). When stratified by behavior, 5-year relative survival for malignant tumors was highest in non-Hispanic White individuals (73.9%); for non-malignant tumors, 5-year relative survival was highest among non-Hispanic Asian or Pacific Islander individuals (98.7%).
- Adolescents ages 15–19 years had higher 5-year relative survival overall (92.0%) and when stratified by behavior, compared with the other age groups. Young adults ages 35–39 years had the lowest 5-year survival (89.9%) overall and stratified by behavior.

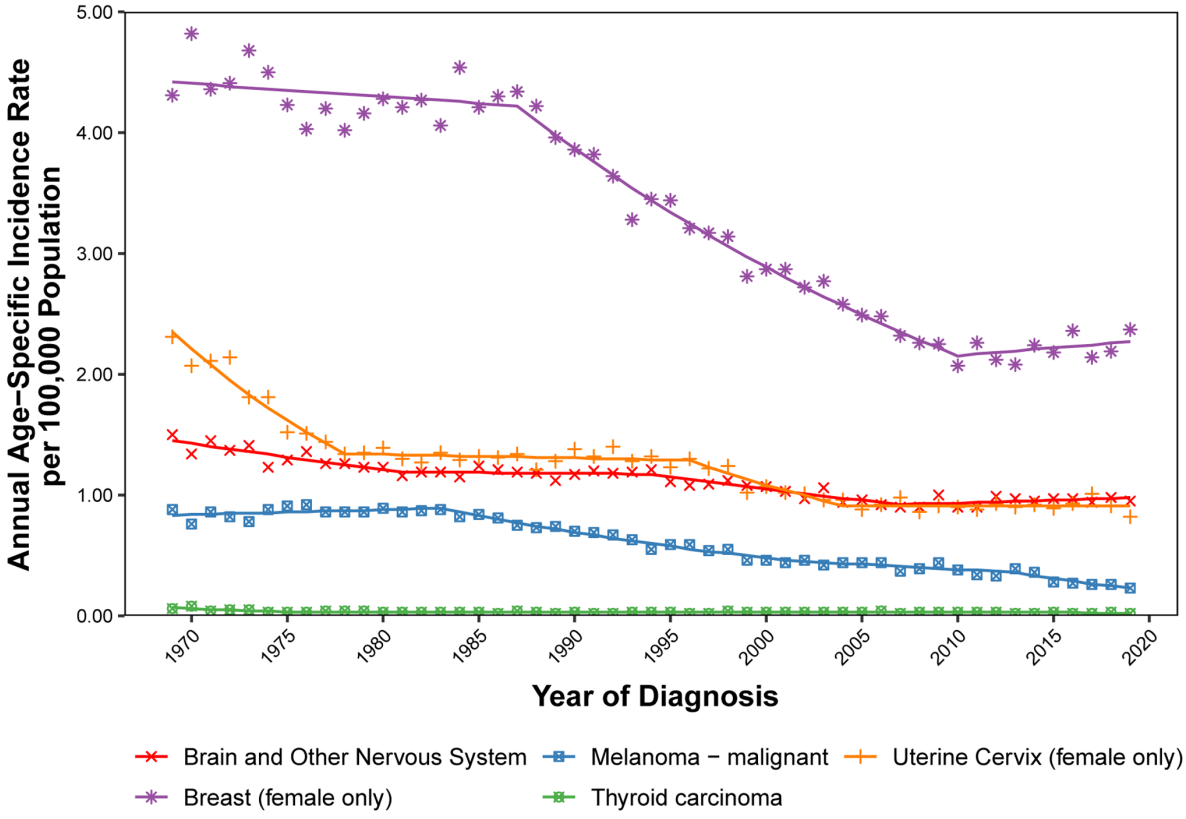
Age-, Histopathology-, and Site-Specific Relative Survival, 2004–2019

Relative survival estimates for primary BT in AYA by histopathology and age at diagnosis are shown in **Table 7** and **Supplementary Table 10**, respectively.

- Overall, 1-year survival for all primary BT was 97.0%; this rate declined to 91.1% for 5-year survival and 87.1% for 10-year survival.
- There was large variation in survival estimates depending upon tumor histopathology; 5-year survival rates ranged from 99.4% for pituitary tumors to 27.3% for glioblastoma.
- Relative survival in anaplastic astrocytoma was 92.3% 1 year after diagnosis but declined to 63.0% 5 years after diagnosis and 46.8% at 10 years after diagnosis.
- For embryonal tumors, the 1-year relative survival rate of 91.4% declined to 71.9% 5 years after diagnosis and 61.7% 10 years after diagnosis.
- For pilocytic astrocytoma, survival was high across all estimates: 1-year relative survival was 98.5%, while 5- and 10-year relative survival were 94.7% and 93.0%, respectively.
- Within each histopathology, relative survival estimates varied substantially by age group.

Relative survival estimates for primary BT in AYA by tumor site and age group at diagnosis are shown in **Table 8** and **Supplementary Table 11**.

- The highest 5-year relative survival rate was for tumors occurring in the pituitary gland (99.3%).



a Rates are per 100,000 population.
Data Source: CBTRUS Childhood and Adolescent Report: USCS – CDC's NPCR and NCI's SEER, 2004–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

Fig. 15 1969–2019 Annual Average Age-Specific Mortality Rates[a] and Mortality Trends for Malignant Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years at Death, Compared with Other Common AYA Cancers

- The lowest 5-year survival rate was for tumors occurring in the cerebrum (63.2%).
- Within each site, relative survival estimates varied substantially by age group at diagnosis.

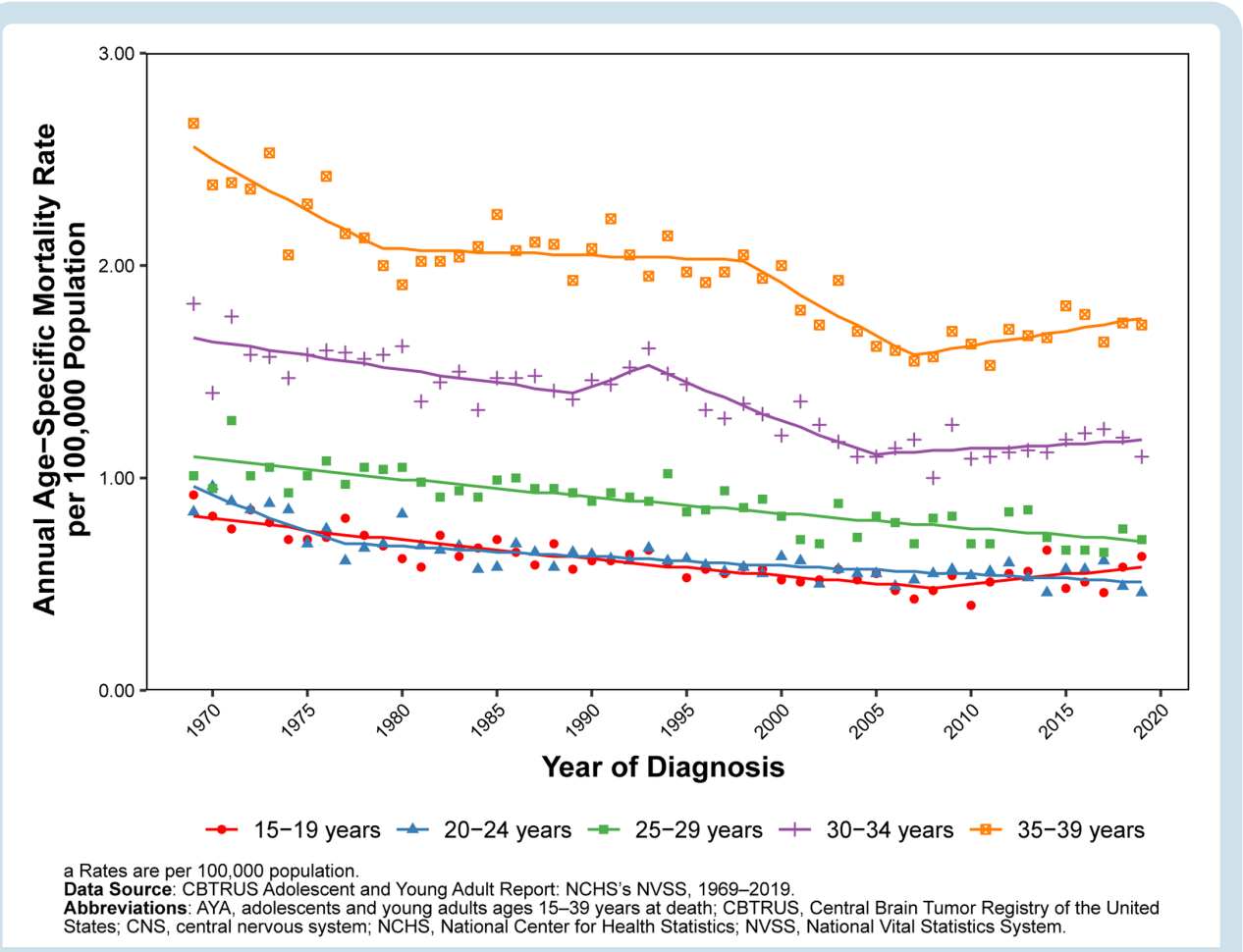
Overall Survival and Relative Survival, 2001–2019

Estimates of median survival in months for primary malignant BT tumors in AYA as determined by histopathology, irrespective of whether individuals received any treatment for their tumor, are shown in **Table 9**. Survival curves for the five most common malignant histopathologies are shown in **Figure 19A**.

- Median survival was shortest for glioblastoma (24 months) and highest for other neuroepithelial tumors (215 months, or approximately 18 years).
- Median survival could not be estimated for many non-malignant histopathologies because more than 50% of individuals remained alive during the 16-year follow up period.

Demographic factors such as age at diagnosis, sex, and race/ethnicity are known to have a significant effect on survival time after diagnosis of primary BT. Hazard ratios for the effect of sex and race/ethnicity in AYA are shown in **Table 10** for all individuals irrespective of whether they received any treatment for their tumor. Hazard ratio estimates for demographic factors in the five most common malignant histopathologies are shown in **Figure 19B**.

- Females had significantly better overall survival than males in half of the histopathologies evaluated.
- Non-Hispanic Black individuals had poorer survival outcomes compared with non-Hispanic White individuals, apart from unique astrocytoma variants (including subependymal giant cell astrocytoma, pleomorphic xanthoastrocytoma, and angiocentric glioma).
- Non-Hispanic American Indian/Alaska Native individuals had poorer survival compared with non-Hispanic White individuals in many histopathologies, although the small size of this population meant that many of these associations were nonsignificant.
- Being a non-Hispanic Asian or Pacific Islander individual was associated with better survival in almost half of the histopathologies as compared with non-Hispanic White individuals, although many of these associations were nonsignificant. Survival was significantly improved



a Rates are per 100,000 population.
Data Source: CBTRUS Adolescent and Young Adult Report: NCHS's NVSS, 1969–2019.
Abbreviations: AYA, adolescents and young adults ages 15–39 years at death; CBTRUS, Central Brain Tumor Registry of the United States; CNS, central nervous system; NCHS, National Center for Health Statistics; NVSS, National Vital Statistics System.

Fig. 16 1969–2019 Annual Average Age-Specific Mortality Rates[a] and Mortality Trends for Malignant Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years at Death, by Age Group at Death

in glioblastoma, oligodendroglioma, and ependymal tumors.
- Being Hispanic (all races) was associated with better survival in many of the histopathologies, including diffuse astrocytoma, glioblastoma, oligodendroglioma, and embryonal tumors.
- Other published survival estimates, including those previously published by CBTRUS, incorporate treatment patterns, which may explain differences between these population-level estimates and other published estimates.

When interpreting these results, it is important to remember that these models do not incorporate factors that may be associated with the demographic factors reported here and could affect overall survival, such as treatment patterns, health insurance, and type of facility at which an individual received treatment.

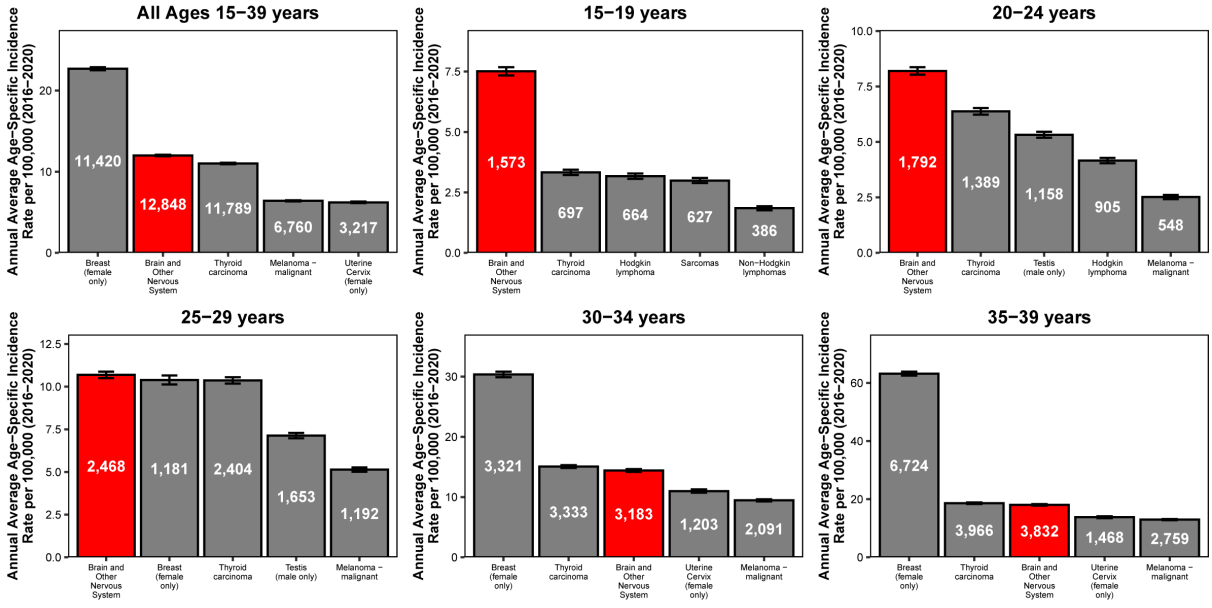
Age- and Histopathology-Specific Annual Case Projections, 2024–2026

The estimated number of cases of all primary BT among AYA for 2024, 2025, and 2026 are shown by selected histopathology and behavior in **Table 11**. Estimated numbers of cases are highly dependent on input data. Different patterns of incidence within strata can substantively affect the projected estimates, and strata-specific estimates may not equal the total estimate presented. **Caution should be exercised when using these estimates.**

- Tumors of the sellar region were expected to be the largest group of new cases for 2024, 2025, and 2026 (estimated cases expected: 4,520, 4,440, and 4,350, respectively).
- Meningiomas were expected to be the second-largest group of new cases, with an estimated 2,350 cases to be diagnosed in 2024.
- Among malignant tumors, most new cases were expected to be pilocytic astrocytoma (310 cases), followed by ependymal tumors (180 cases).

Primary Brain and other CNS Tumors Compared with Other Common AYA Cancers, 1975–2020

Prevalence estimates for primary BT among AYA ages 15–39 years in the United States in 2024 are shown in **Figure 20**, **Table 12**, and **Supplementary Table 12**.



a Rates are per 100,000 population.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS – CDC's NPCR and NCI's SEER, 2016–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

Fig. 17 2016–2020 Annual Average Age-Specific Incidence Rates[a] and Annual Average Case Counts for the Primary Brain and Other CNS Tumors and other Common Cancers in AYA Ages 15–39 Years, Overall and by Age Group at Diagnosis

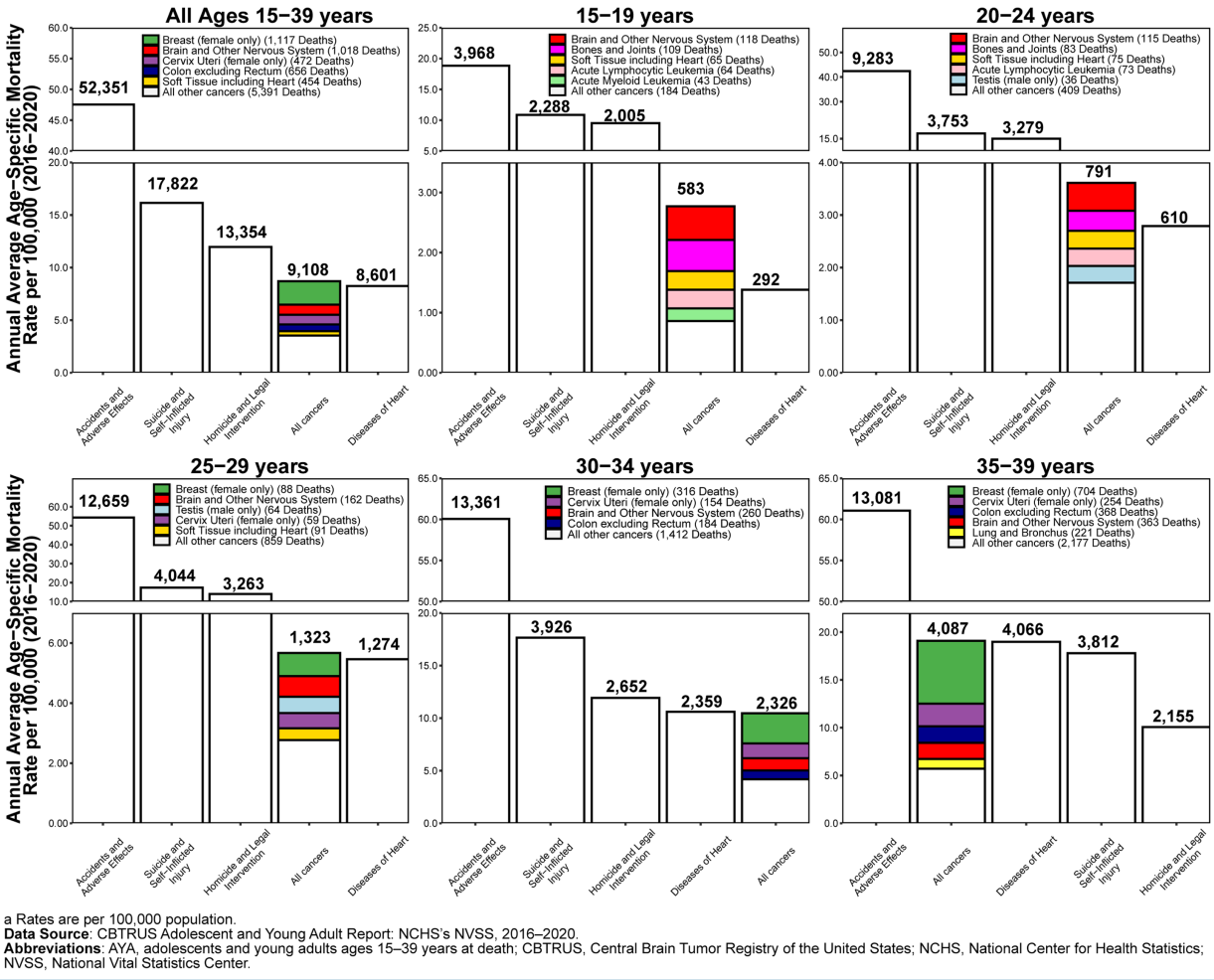
- An estimated 208,620 AYA ages 15–39 years will be living with a primary BT in 2024, making it the most prevalent cancer in this age range. It is also the most prevalent in those ages 15–19 years, 20–24 years, and 25–29 years.
- Primary BT are the third-most-prevalent cancer type among those ages 30–34 years and 35–39 years.
- The most-prevalent histopathology was tumors of the sellar region, with 57,850 cases.
- The next most prevalent histopathological groups are pilocytic astrocytoma (19,880 cases), other gliomas (16,830 cases), and meningioma (16,320 cases).
- **As these estimates include only AYA ages 15–39 years at the time prevalence was estimated (2024), the total population of AYA survivors with primary BT, including those who are now adults, is significantly larger. Additionally, these estimates include pediatric cases (individuals who were diagnosed at age 0–14 years) who were still alive at the time of estimation.**

Summary of Incidence Patterns in AYA

AYA with primary BT are transitioning from the rarer tumor types more common in children to the tumor types more common in older adults. The incidence of germ cell tumors, which are more common in children and younger AYA, declines rapidly with increasing age, such that the AASIR is more than an order of magnitude larger in the youngest ages compared with the oldest. Apart from pilocytic astrocytoma and other gliomas, the incidence rate of most adult-type gliomas increases steadily with age in AYA (**Table 3**), with the oldest AYA age group (35–39 years) having more than double the incidence seen in the youngest AYA age group (15–19). Despite this finding, in this age group overall, tumors of the pituitary tend to account for almost half of all tumors diagnosed, with this being especially apparent for those younger than 30 years of age; beyond age 30, incidence of meningioma becomes more comparable to that of pituitary tumors (**Figure 10**). Moreover, as AYA age increases, the proportion of lower-grade gliomas that progress to high-grade gliomas also increases.[58]

Whereas the incidence of primary BT generally increases with age, the proportion of tumors that are non-malignant increases much more rapidly than the proportion that is malignant. Accordingly, much of the increase in primary BT in this population may be attributable to the relative increase in non-malignant tumors, especially meningiomas and pituitary tumors (**Table 3**). Disparities in tumor behavior across AYA age groups become more apparent with increasing age, with non-malignant tumors accounting for three-quarters (76.5%) of all primary BT diagnosed in the oldest AYA age groups, versus about two-thirds (66.0%) in the youngest ages.

Adolescence also marks a time of growth and critical change in the brain and body, which may contribute to a shift away from tumors found at sites formed earlier in development, like the cerebellum and brain stem, toward tumors in the meninges, the four lobes of the brain, and the pituitary gland. This difference is most striking at the interface between those ages 15–19 years and those ages 20–24 years, when the contribution of primary BT



a Rates are per 100,000 population.
Data Source: CBTRUS Adolescent and Young Adult Report: NCHS's NVSS, 2016–2020.
Abbreviations: AYA, adolescents and young adults ages 15–39 years at death; CBTRUS, Central Brain Tumor Registry of the United States; NCHS, National Center for Health Statistics; NVSS, National Vital Statistics Center.

Fig. 18 2016–2020 Annual Average Age-Specific Mortality Rates[a] and Annual Average Death Counts for the Top Five Causes of Death Among AYA Ages 15–39 Years at Death, Overall, and by AYA Age Group at Death

diagnosed in the ventricles, cerebellum, and brain stem drops sharply, although this difference tapers off thereafter (**Table 4**). Inversely, tumors of the meninges, the four lobes of the brain, and pituitary increase steadily from the youngest ages to the oldest ages in AYA.

Risk Factors for Primary Brain and Other CNS Tumors

Known and suspected risk factors for developing tumors vary by cancer type. In most cases of primary BT, little is known about their origin or cause, even though many studies are investigating the causes and risk factors of these tumors.[59] Nonetheless, most brain tumors form in people without any known risk factors. The following is a brief summary of the current knowledge about risk factors for the primary BT types common in AYA.

Most primary BT are sporadic and develop in individuals with no family history of such tumors. In those with a family history, these tumors will most likely be diagnosed at a younger age.[60] Numerous Mendelian cancer syndromes have been found to increase risk for primary BT, including neurofibromatosis types 1 and 2, tuberous sclerosis, and Li Fraumeni syndrome (see **Supplementary Table 13** for a review of syndromes that may enhance predisposition to primary BT in AYA).[59,61] Several genetic factors appear to lead to primary BT; however, these instances are rare. Although no genome-wide association studies have been conducted specifically in AYA, studies in children and adults who lack family history have identified common inherited genetic polymorphisms related to genetic risk factors for these tumors.[5,62,63] Previous work by CBTRUS and others found that the risks associated with developing a primary BT vary according to region of the world and race/ethnicity.[64–67] This suggests that population-specific sources of genetic risk may contribute to risk for primary BT. However, this association needs further exploration in future studies.[68,69] Despite promising advancements in identifying sources of genomic risk that would inform the identification, and treatment of these tumors, significant gaps in the research remain to be filled, particularly in individuals who are in early adulthood when diagnosed.

Table 7. 2004–2019 Total Cases and 1-, 5-, and 10-Year Relative Survival Rates[a,b] for Selected Malignant[c] and Non-Malignant[d] Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years, by Histopathology

Histopathology	All				Malignant				Non-Malignant			
	Total Cases (2004-2019)	1-year RS (95% CI)	5-year RS (95% CI)	10-year RS (95% CI)	Total Cases (2004-2019)	1-year RS (95% CI)	5-year RS (95% CI)	10-year RS (95% CI)	Total Cases (2004-2019)	1-year RS (95% CI)	5-year RS (95% CI)	10-year RS (95% CI)
Diffuse astrocytic and oligodendroglial tumors	**24,994**	**90.9 (90.5-91.2)**	**65.5 (64.8-66.1)**	**51.2 (50.5-52.0)**	**24,979**	**90.9 (90.5-91.2)**	**65.5 (64.8-66.1)**	**51.2 (50.4-52.0)**	—	—	—	—
Diffuse astrocytoma	6,663	95.7 (95.1-96.1)	78.2 (77.1-79.3)	61.5 (59.9-63.0)	6,648	95.7 (95.1-96.1)	78.2 (77.0-79.3)	61.4 (59.9-62.9)	—	—	—	—
Anaplastic astrocytoma	4,138	92.3 (91.4-93.1)	63.0 (61.3-64.6)	46.8 (44.7-48.8)	4,138	92.3 (91.4-93.1)	63.0 (61.3-64.6)	46.8 (44.7-48.8)	—	—	—	—
Glioblastoma	6,567	76.9 (75.9-78.0)	27.3 (26.1-28.5)	19.0 (17.8-20.2)	6,567	76.9 (75.9-78.0)	27.3 (26.1-28.5)	19.0 (17.8-20.2)	—	—	—	—
Oligodendroglioma	3,949	98.6 (98.1-98.9)	92.7 (91.7-93.5)	79.0 (77.3-80.7)	3,949	98.6 (98.1-98.9)	92.7 (91.7-93.5)	79.0 (77.3-80.7)	—	— —	—	—
Anaplastic oligodendroglioma	1,277	95.9 (94.6-96.9)	80.4 (77.8-82.7)	64.5 (60.9-67.8)	1,277	95.9 (94.6-96.9)	80.4 (77.8-82.7)	64.5 (60.9-67.8)	—	—	—	—
Oligoastrocytic tumors	2,400	97.5 (96.8-98.1)	81.2 (79.5-82.7)	61.0 (58.7-63.2)	2,400	97.5 (96.8-98.1)	81.2 (79.5-82.7)	61.0 (58.7-63.2)	—	—	—	—
Other astrocytic tumors	**4,945**	**98.2 (97.8-98.5)**	**93.2 (92.4-93.9)**	**90.9 (89.9-91.9)**	**4,584**	**98.3 (97.8-98.6)**	**93.1 (92.2-93.9)**	**90.9 (89.8-91.9)**	**361**	**97.2 (94.7-98.5)**	**94.3 (90.9-96.5)**	**91.1 (86.4-94.3)**
Pilocytic astrocytoma	3,977	98.5 (98.1-98.9)	94.7 (93.9-95.4)	93.0 (91.9-94.0)	3,958	98.5 (98.1-98.9)	94.7 (93.9-95.4)	93.0 (91.9-93.9)	—	—	—	—
Unique astrocytoma variants	968	96.8 (95.4-97.7)	86.8 (84.2-89.0)	82.0 (78.8-84.8)	626	96.6 (94.8-97.8)	82.7 (79.1-85.7)	76.9 (72.5-80.8)	—	—	—	—
Ependymal tumors	**5,029**	**98.4 (97.9-98.7)**	**94.8 (94.0-95.5)**	**91.8 (90.7-92.7)**	**2,777**	**97.4 (96.7-98.0)**	**91.4 (90.2-92.5)**	**87.1 (85.5-88.6)**	**2,252**	**99.5 (99.1-99.8)**	**99.1 (98.3-99.5)**	**97.8 (96.5-98.7)**
Other gliomas	**3,891**	**91.5 (90.5-92.3)**	**78.9 (77.4-80.3)**	**72.4 (70.6-74.1)**	**3,863**	**91.4 (90.4-92.3)**	**78.8 (77.3-80.2)**	**72.2 (70.4-73.9)**	—	—	—	—
Glioma malignant, NOS	3,805	91.3 (90.4-92.2)	78.7 (77.2-80.1)	72.1 (70.3-73.9)	3,805	91.3 (90.4-92.2)	78.7 (77.2-80.1)	72.1 (70.3-73.9)	—	—	—	—
Other neuroepithelial tumors	86	96.5 (89.2-98.9)	88.2 (78.1-93.8)	83.9 (70.9-91.4)	58	94.8 (84.5-98.3)	84.5 (70.9-92.1)	77.5 (59.9-88.1)	—	—	—	—
Neuronal and mixed neuronal-glial tumors	**5,109**	**98.4 (98.0-98.8)**	**95.6 (94.9-96.2)**	**92.7 (91.7-93.7)**	**516**	**94.3 (91.9-96.0)**	**78.2 (74.0-81.8)**	**68.1 (62.8-72.9)**	**4,593**	**98.9 (98.5-99.2)**	**97.6 (97.0-98.1)**	**95.6 (94.7-96.4)**
Choroid plexus tumors	**593**	**98.2 (96.7-99.0)**	**95.9 (93.7-97.4)**	**92.7 (89.3-95.0)**	—	—	—	—	**554**	**98.2 (96.6-99.1)**	**97.0 (95.0-98.2)**	**95.5 (92.4-97.4)**
Tumors of the pineal region	**712**	**95.5 (93.6-96.8)**	**87.2 (84.1-89.7)**	**81.9 (78.0-85.2)**	**373**	**94.0 (91.0-96.0)**	**77.8 (72.5-82.2)**	**68.7 (62.1-74.4)**	**339**	**97.1 (94.5-98.5)**	**96.8 (93.8-98.3)**	**94.9 (90.6-97.3)**
Embryonal tumors	**2,133**	**91.4 (90.1-92.6)**	**71.9 (69.8-73.9)**	**61.7 (59.2-64.2)**	**2,133**	**91.4 (90.1-92.6)**	**71.9 (69.8-73.9)**	**61.7 (59.2-64.2)**	—	—	—	—
Medulloblastoma	1,689	94.1 (92.8-95.1)	80.6 (78.4-82.6)	69.9 (67.0-72.5)	1,689	94.1 (92.8-95.1)	80.6 (78.4-82.6)	69.9 (67.0-72.5)	—	—	—	—
Tumors of cranial and spinal nerves	**13,563**	**99.3 (99.1-99.4)**	**98.4 (98.1-98.7)**	**97.6 (97.1-98.0)**	**143**	**78.6 (70.8-84.5)**	**65.6 (56.9-73.0)**	**59.4 (49.7-67.9)**	**13,420**	**99.5 (99.3-99.6)**	**98.8 (98.5-99.0)**	**98.0 (97.6-98.4)**

Table 7. Continued

Histopathology	All				Malignant				Non-Malignant			
	Total Cases (2004-2019)	1-year RS (95% CI)	5-year RS (95% CI)	10-year RS (95% CI)	Total Cases (2004-2019)	1-year RS (95% CI)	5-year RS (95% CI)	10-year RS (95% CI)	Total Cases (2004-2019)	1-year RS (95% CI)	5-year RS (95% CI)	10-year RS (95% CI)
Tumors of meninges	**28,754**	**98.7 (98.5-98.8)**	**96.8 (96.5-97.0)**	**94.6 (94.2-95.0)**	**798**	**91.4 (89.2-93.2)**	**80.4 (77.2-83.2)**	**72.8 (68.8-76.4)**	**27,956**	**98.9 (98.7-99.0)**	**97.3 (97.0-97.5)**	**95.3 (94.9-95.6)**
Meningiomas	24,273	98.8 (98.6-98.9)	97.0 (96.8-97.3)	94.9 (94.5-95.3)	328	92.9 (89.5-95.3)	83.5 (78.6-87.3)	75.6 (69.3-80.8)	23,945	98.9 (98.7-99.0)	97.2 (97.0-97.5)	95.2 (94.8-95.6)
Mesenchymal tumors	4,428	98.2 (97.7-98.6)	95.8 (95.0-96.4)	93.6 (92.5-94.5)	—	—	—	—	—	—	—	—
Primary melanocytic lesions	53	80.3 (66.4-88.9)	66.1 (50.2-78.0)	52.7 (34.8-67.7)	—	—	—	—	—	—	—	—
Lymphomas and hemopoietic neoplasms	**1,570**	**68.0 (65.6-70.3)**	**59.7 (57.1-62.2)**	**55.6 (52.7-58.3)**	**1,570**	**68.0 (65.6-70.3)**	**59.7 (57.1-62.2)**	**55.6 (52.7-58.3)**	—	—	—	—
Germ cell tumors	**1,548**	**95.4 (94.2-96.4)**	**89.6 (87.7-91.1)**	**87.1 (85.0-89.0)**	**1,421**	**95.0 (93.7-96.1)**	**89.2 (87.3-90.9)**	**86.7 (84.4-88.7)**	**127**	**99.3 (93.4-99.9)**	**93.3 (86.2-96.8)**	**91.1 (83.0-95.4)**
Tumors of sellar region	**57,149**	**99.6 (99.5-99.7)**	**99.1 (99.0-99.2)**	**98.5 (98.3-98.6)**	**75**	**100.0 (**-**)**	**88.8 (77.9-94.5)**	**86.6 (73.5-93.5)**	**57,074**	**99.6 (99.5-99.7)**	**99.1 (99.0-99.2)**	**98.5 (98.3-98.7)**
Tumors of the pituitary	55,229	99.7 (99.7-99.8)	99.4 (99.3-99.5)	98.9 (98.7-99.0)	—	—	—	—	55,156	99.7 (99.7-99.8)	99.4 (99.3-99.5)	98.9 (98.7-99.1)
Craniopharyngioma	1,920	96.3 (95.3-97.0)	91.5 (90.0-92.8)	87.6 (85.6-89.3)	—	—	—	—	1,918	96.2 (95.3-97.0)	91.6 (90.1-92.9)	87.7 (85.7-89.4)
Unclassified tumors	**7,362**	**96.0 (95.5-96.4)**	**93.5 (92.8-94.1)**	**91.4 (90.6-92.2)**	**747**	**80.6 (77.5-83.3)**	**69.8 (66.2-73.2)**	**65.5 (61.4-69.3)**	**6,615**	**97.7 (97.3-98.0)**	**96.2 (95.6-96.7)**	**94.4 (93.6-95.1)**
Hemangioma	2,725	99.6 (99.2-99.8)	98.7 (97.9-99.1)	97.1 (95.8-98.0)	—	—	—	—	2,719	99.6 (99.3-99.8)	98.7 (98.0-99.2)	97.1 (95.8-98.0)
Neoplasm, unspecified	4,269	93.5 (92.7-94.2)	90.2 (89.2-91.1)	87.9 (86.7-89.0)	708	80.3 (77.1-83.1)	70.2 (66.5-73.7)	65.7 (61.5-69.6)	3,561	96.1 (95.4-96.7)	94.1 (93.2-94.9)	92.3 (91.1-93.3)
All other	368	98.1 (96.0-99.1)	94.5 (91.2-96.6)	92.9 (88.7-95.7)	—	—	—	—	335	99.2 (97.1-99.8)	97.9 (94.9-99.1)	96.2 (91.7-98.3)
Total[e]	**157,634**	**97.0 (96.9-97.1)**	**91.1 (90.9-91.2)**	**87.1 (86.9-87.3)**	**44,026**	**91.3 (91.1-91.6)**	**72.7 (72.2-73.1)**	**62.3 (61.8-62.9)**	**113,608**	**99.3 (99.2-99.3)**	**98.4 (98.3-98.4)**	**97.2 (97.0-97.3)**

[a] Cohort analysis of survival rates was used to calculate the survival estimates presented in this table. Long-term cohort-based survival estimates reflect the survival of individuals diagnosed over the time period and may not necessarily reflect the long-term survival outlook of newly diagnosed cases.
[b] Rates are an estimate of the percentage of patients alive at 1, 5, and 10 years.
[c] Assigned an ICD behavior code of /3 (see **Supplementary Table 3**).
[d] Assigned an ICD behavior code of /0 or /1 (see **Supplementary Table 3**).
[e] Includes histopathologies not listed in this table.
— Counts and associated rates cannot be provided when Total Cases are fewer than 50 cases or when a value based on less than 50 cases can be back-calculated using a cell.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS - CDC's NPCR, 2004–2019.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; ICD-O-3, *International Classification of Diseases for Oncology, Third Edition*; NOS, not otherwise specified; NPCR, National Program of Cancer Registries; RS, relative survival; USCS, United States Cancer Statistics.

Table 8. 2004–2019 Total Cases and 1-, 5-, and 10-Year Relative Survival Rates[a,b] for Selected Malignant[c] and Non-Malignant[d] Primary Brain and Other CNS Tumors[e] in AYA Ages 15–39 Years, by Tumor Site

Tumor Site	All				Malignant				Non-Malignant			
	Total Cases (2004-2019)	1-year RS (95% CI)	5-year RS (95% CI)	10-year RS (95% CI)	Total Cases (2004-2019)	1-year RS (95% CI)	5-year RS (95% CI)	10-year RS (95% CI)	Total Cases (2004-2019)	1-year RS (95% CI)	5-year RS (95% CI)	10-year RS (95% CI)
Olfactory tumors of the nasal cavity (C30.0)[f]	**290**	**94.0 (90.4-96.3)**	**83.9 (78.5-88.0)**	**73.7 (66.1-79.8)**	—	—	—	—	—	—	—	—
Meninges (cerebral and spinal) (C70.0-C70.9)	**24,703**	**98.8 (98.6-98.9)**	**97.0 (96.7-97.2)**	**94.8 (94.4-95.2)**	**482**	**91.6 (88.7-93.8)**	**83.3 (79.4-86.6)**	**74.9 (69.6-79.4)**	**24,221**	**98.9 (98.8-99.0)**	**97.3 (97.0-97.5)**	**95.2 (94.8-95.6)**
Cerebral meninges (C70.0)	19,952	98.8 (98.6-98.9)	97.1 (96.8-97.3)	94.9 (94.4-95.3)	322	92.2 (88.6-94.7)	84.7 (79.9-88.4)	75.6 (69.0-81.0)	19,630	98.9 (98.7-99.0)	97.3 (97.0-97.6)	95.2 (94.7-95.6)
Spinal meninges (C70.1)	1,287	99.5 (98.8-99.8)	97.5 (96.2-98.4)	95.6 (93.6-96.9)	65	93.9 (84.3-97.7)	83.8 (71.2-91.2)	81.3 (66.5-90.0)	1,222	99.8 (99.0-99.9)	98.3 (97.0-99.0)	96.3 (94.4-97.6)
Meninges, NOS (C70.9)	3,464	98.4 (97.9-98.8)	96.3 (95.4-97.0)	94.2 (93.0-95.2)	95	88.0 (79.3-93.2)	78.3 (67.6-85.8)	67.5 (53.8-78.0)	3,369	98.7 (98.2-99.0)	96.8 (96.0-97.4)	94.9 (93.7-95.9)
Cerebrum (C71.0)	**3,130**	**86.3 (85.0-87.5)**	**63.2 (61.3-65.0)**	**57.6 (55.5-59.6)**	**2,285**	**81.8 (80.1-83.3)**	**51.3 (49.1-53.5)**	**45.2 (42.8-47.6)**	**845**	**98.4 (97.2-99.1)**	**95.8 (94.0-97.2)**	**92.6 (89.7-94.7)**
Frontal, temporal, parietal, and occipital lobes of the brain (C71.1-C71.4)	**28,545**	**94.8 (94.6-95.1)**	**77.9 (77.4-78.4)**	**66.3 (65.6-67.0)**	**22,665**	**93.8 (93.4-94.1)**	**73.0 (72.3-73.6)**	**59.0 (58.2-59.8)**	**5,880**	**99.0 (98.7-99.2)**	**97.3 (96.8-97.8)**	**95.3 (94.5-96.1)**
Frontal lobe (C71.1)	15,163	95.0 (94.6-95.3)	77.5 (76.8-78.3)	64.6 (63.6-65.6)	13,077	94.4 (94.0-94.8)	74.5 (73.6-75.3)	59.9 (58.9-61.0)	2,086	98.6 (98.0-99.1)	96.9 (95.8-97.6)	94.2 (92.6-95.5)
Temporal lobe (C71.2)	8,259	95.6 (95.1-96.0)	80.0 (79.0-80.9)	69.2 (67.9-70.4)	5,747	94.0 (93.4-94.6)	72.5 (71.2-73.8)	57.9 (56.3-59.5)	2,512	99.2 (98.7-99.5)	97.8 (97.0-98.4)	96.6 (95.3-97.5)
Parietal lobe (C71.3)	4,041	93.2 (92.3-93.9)	73.7 (72.2-75.2)	63.7 (61.8-65.5)	3,174	91.4 (90.4-92.4)	67.4 (65.6-69.2)	55.4 (53.2-57.5)	867	99.5 (98.6-99.8)	96.9 (95.2-98.1)	95.0 (92.3-96.7)
Occipital lobe (C71.4)	1,082	93.4 (91.8-94.8)	82.5 (79.9-84.8)	77.3 (74.1-80.1)	667	90.2 (87.7-92.3)	73.2 (69.4-76.7)	66.8 (62.4-70.8)	415	98.6 (96.8-99.4)	97.5 (95.0-98.7)	94.6 (90.2-97.1)
Ventricle (C71.5)	**3,093**	**94.6 (93.7-95.3)**	**89.1 (87.8-90.2)**	**86.2 (84.7-87.6)**	**1,188**	**91.1 (89.3-92.6)**	**79.7 (77.1-82.0)**	**74.5 (71.5-77.3)**	**1,905**	**96.8 (95.8-97.5)**	**95.1 (93.9-96.1)**	**93.8 (92.2-95.0)**
Cerebellum (C71.6)	**5,968**	**95.8 (95.2-96.3)**	**88.7 (87.7-89.5)**	**84.6 (83.4-85.7)**	**3,511**	**93.7 (92.9-94.5)**	**82.5 (81.1-83.8)**	**76.4 (74.7-78.1)**	**2,457**	**98.8 (98.2-99.2)**	**97.6 (96.8-98.3)**	**96.6 (95.4-97.5)**
Brain stem (C71.7)	**3,904**	**89.5 (88.5-90.4)**	**76.7 (75.3-78.1)**	**70.7 (68.9-72.4)**	**2,762**	**86.2 (84.8-87.4)**	**68.9 (67.0-70.7)**	**61.7 (59.5-63.8)**	**1,142**	**97.6 (96.4-98.3)**	**96.0 (94.4-97.1)**	**93.1 (90.7-94.9)**
Other brain (C71.8-C71.9)	**9,592**	**89.8 (89.1-90.4)**	**75.4 (74.4-76.3)**	**68.6 (67.4-69.6)**	**6,308**	**85.6 (84.7-86.5)**	**64.8 (63.5-66.0)**	**55.6 (54.2-57.1)**	**3,284**	**97.8 (97.2-98.3)**	**95.7 (94.8-96.4)**	**93.5 (92.3-94.6)**
Overlapping lesion of brain (C71.8)	3,233	88.6 (87.4-89.7)	64.5 (62.7-66.3)	54.0 (51.9-56.1)	2,760	87.0 (85.6-88.2)	58.9 (56.9-60.9)	47.0 (44.7-49.3)	473	98.1 (96.3-99.1)	97.3 (94.9-98.5)	95.0 (91.3-97.1)
Brain, NOS (C71.9)	6,359	90.4 (89.6-91.1)	80.8 (79.7-81.8)	75.9 (74.7-77.2)	3,548	84.6 (83.3-85.7)	69.2 (67.6-70.8)	62.3 (60.4-64.2)	2,811	97.7 (97.1-98.2)	95.4 (94.5-96.2)	93.3 (91.9-94.4)
Spinal cord and cauda equina (C72.0-C72.1)	**7,614**	**97.7 (97.3-98.0)**	**94.1 (93.5-94.7)**	**92.3 (91.4-93.0)**	**2,304**	**93.6 (92.4-94.5)**	**83.7 (82.0-85.2)**	**80.1 (78.1-82.0)**	**5,310**	**99.5 (99.3-99.7)**	**98.7 (98.3-99.1)**	**97.7 (96.9-98.3)**

Table 8. Continued

Tumor Site	All				Malignant				Non-Malignant			
	Total Cases (2004-2019)	1-year RS (95% CI)	5-year RS (95% CI)	10-year RS (95% CI)	Total Cases (2004-2019)	1-year RS (95% CI)	5-year RS (95% CI)	10-year RS (95% CI)	Total Cases (2004-2019)	**1-year RS (95% CI)**	**5-year RS (95% CI)**	10-year RS (95% CI)
Spinal cord (C72.0)	7,361	97.7 (97.3-98.0)	94.0 (93.4-94.6)	92.1 (91.3-92.9)	—	—	—	—	—	—	—	—
Cauda equina (C72.1)	253	98.5 (95.7-99.5)	96.7 (92.7-98.5)	96.0 (91.2-98.2)	—	—	—	—	—	—	—	—
Cranial nerves (C72.2-C72.5)	**10,090**	**99.4 (99.2-99.6)**	**98.7 (98.4-99.0)**	**98.2 (97.7-98.6)**	**453**	**97.1 (95.0-98.3)**	**90.8 (87.4-93.4)**	**89.2 (85.0-92.2)**	**9,637**	**99.5 (99.3-99.7)**	**99.1 (98.8-99.3)**	**98.6 (98.1-99.0)**
Olfactory nerve (C72.2)	—	—	—	—	—	—	—	—	—	—	—	—
Optic nerve (C72.3)	—	—	—	—	—	—	—	—	—	—	—	—
Acoustic nerve (C72.4)	7,150	99.5 (99.3-99.7)	99.2 (98.8-99.4)	98.8 (98.3-99.2)	—	—	—	—	—	—	—	—
Cranial nerve, NOS (C72.5)	2,406	99.2 (98.7-99.5)	98.0 (97.1-98.6)	96.9 (95.6-97.9)	53	84.6 (71.4-92.0)	78.6 (64.4-87.7)	72.4 (55.1-84.0)	2,353	99.5 (99.1-99.8)	98.4 (97.6-98.9)	97.5 (96.2-98.4)
Other nervous system (C72.8-C72.9)	**934**	**91.3 (89.3-93.0)**	**86.1 (83.5-88.3)**	**82.6 (79.5-85.3)**	**317**	**77.6 (72.5-81.9)**	**65.2 (59.4-70.4)**	**63.9 (57.9-69.2)**	**617**	**98.3 (96.8-99.1)**	**96.6 (94.4-97.9)**	**92.0 (88.6-94.4)**
Overlapping lesion of brain & CNS (C72.8)	136	93.3 (87.5-96.5)	86.4 (78.9-91.3)	82.2 (73.2-88.4)	56	85.4 (72.8-92.5)	69.6 (54.9-80.3)	69.6 (54.9-80.3)	80	98.8 (90.5-99.9)	97.7 (88.5-99.6)	90.9 (78.6-96.3)
Nervous system, NOS (C72.9)	798	91.0 (88.7-92.8)	86.0 (83.2-88.4)	82.7 (79.3-85.5)	261	75.9 (70.2-80.8)	64.3 (57.8-70.0)	62.6 (55.9-68.5)	537	98.2 (96.6-99.1)	96.3 (93.9-97.8)	92.2 (88.4-94.7)
Pituitary (C75.1- C75.2)	**57,951**	**99.6 (99.5-99.7)**	**99.1 (99.0-99.2)**	**98.5 (98.3-98.6)**	**266**	**95.8 (92.5-97.7)**	**90.1 (85.4-93.4)**	**84.7 (78.0-89.5)**	**57,685**	**99.6 (99.6-99.7)**	**99.2 (99.1-99.3)**	**98.5 (98.3-98.7)**
Pituitary gland (C75.1)	56,787	99.7 (99.6-99.7)	99.3 (99.2-99.4)	98.7 (98.6-98.9)	—	—	—	—	—	—	—	—
Craniopharyngeal duct (C75.2)	1,164	96.0 (94.6-97.0)	90.2 (88.2-92.0)	85.2 (82.4-87.6)	—	—	—	—	—	—	—	—
Pineal (C75.3)	**1,820**	**95.1 (94.0-96.0)**	**89.1 (87.4-90.5)**	**85.2 (83.1-87.1)**	**1,195**	**93.8 (92.2-95.1)**	**85.0 (82.6-87.1)**	**80.3 (77.4-82.9)**	**625**	**97.6 (96.1-98.6)**	**96.4 (94.3-97.7)**	**94.1 (91.0-96.1)**

[a] Cohort analysis of survival rates was used to calculate the survival estimates presented in this table. Long-term cohort-based survival estimates reflect the survival of individuals diagnosed over the time period and may not necessarily reflect the long-term survival outlook of newly diagnosed cases.
[b] Rates are an estimate of the percentage of patients alive at 1, 5, and 10 years.
[c] Assigned an ICD behavior code of/3 (see **Supplementary Table 3**).
[d] Assigned an ICD behavior code of/0 or/1 (see **Supplementary Table 3**).
[e] The tumor sites referred to in this table are loosely based on the categories and site codes defined in the SEER site/histology validation list.
[f] ICD-O-3 histopathology codes 9522–9523 only.
— Counts and associated rates cannot be provided when Total Cases are fewer than 50 cases or when a value based on less than 50 cases can be back-calculated using a cell.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS - CDC's NPCR, 2004–2019.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; ICD, *International Classification of Diseases for Oncology, Third Edition*; NOS, not otherwise specified; NPCR, National Program of Cancer Registries; RS, relative survival; USCS, United States Cancer Statistics.

Table 9. 2001–2019 Total Deaths and Median Survival in Months for Malignant Primary Brain and Other CNS Tumor Histopathologies in AYA Ages 15–39 Years[a]

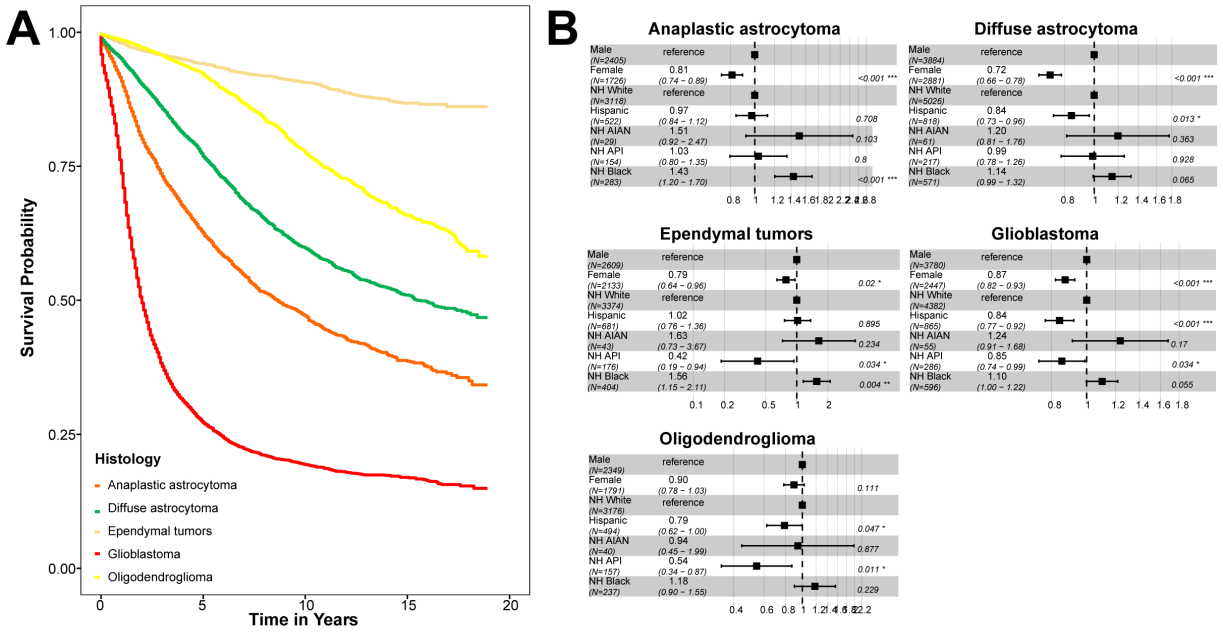
Histopathology	N	Deaths	Median Survival, Months (95% CI)
Diffuse astrocytoma	6,765	2,274	186 (174-212)
Anaplastic astrocytoma	4,131	1,741	104 (93-116)
Glioblastoma	6,227	4,371	24 (23-25)
Oligodendroglioma	4,140	860	** (**-**)
Anaplastic oligodendroglioma	1,332	425	185 (165-**)
Oligoastrocytic tumors	2,563	1,040	169 (159-202)
Pilocytic astrocytoma	3,978	295	** (**-**)
Unique astrocytoma variants	917	139	** (**-**)
Ependymal tumors	4,742	400	** (**-**)
Glioma malignant, NOS	3,507	890	** (**-**)
Choroid plexus tumors	498	30	** (**-**)
Other neuroepithelial tumors	78	11	215 (201-**)
Neuronal and mixed neuronal-glial tumors	4,589	284	** (**-**)
Tumors of the pineal region	662	111	** (**-**)
Embryonal tumors	2,181	743	** (**-**)
Nerve sheath tumors	11,295	348	** (**-**)
Other tumors of cranial and spinal nerves	—	—	—
Meningiomas	20,592	1,035	** (**-**)
Mesenchymal tumors	3,790	274	** (**-**)
Primary melanocytic lesions	—	—	—
Lymphoma	1,560	701	163 (132-**)
Other hemopoietic neoplasms	—	—	—
Tumors of the pituitary	44,611	755	** (**-**)
Craniopharyngioma	1,626	179	** (**-**)
Hemangioma	2,188	64	** (**-**)
Neoplasm, unspecified	3,019	405	** (**-**)
All other	312	15	** (**-**)

[a] For mortality data, age at death; for survival data, age at diagnosis.
— Counts and associated rates cannot be provided when Total Cases are fewer than 50 cases or when a value based on less than 50 cases can be back-calculated using a cell.
** Could not be calculated.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS - CDC's NPCR, 2001–2019.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NOS, not otherwise specified; NPCR, National Program of Cancer Registries; USCS, United States Cancer Statistics.

Few environmental factors have been definitively associated with brain tumor development. The only well-established environmental risk factor thus far is exposure of the head or neck to therapeutic doses of ionizing radiation, given the linear dose-response relationship between radiation exposure and risk for brain tumors.[70] Children and adolescents are at greater risk than adults for developing a radiation-induced primary BT, because their developing brains are more radiosensitive.[71]

Other factors thought to elevate risk for primary BT have not been specifically explored in AYA. Studies have consistently reported inverse associations between glioma susceptibility in adults and a history of atopic conditions like allergies (**Supplementary Table 14**)[72,73]. A particularly strong inverse association between respiratory allergies and gliomas has been reported.[72,74] These appear to be protective to other BT types, such as meningioma[75], although to a lesser extent than glioma. The effects of other comorbid diseases also have been investigated. A history of varicella, or chicken pox infection, has been shown to be protective against glioma.[76] Diabetes, especially long-term diabetes, has been correlated with lower risk for both glioblastoma and glioma.[77] Whereas autoimmune diseases are negatively correlated with risk for glioma, one study found a greater risk for these tumors in AYA with inflammatory bowel disease.[77]

Other factors have been explored without establishing definitive associations. One of these is exposure to pesticides, which have been classified as carcinogenic by the International Agency for Research on Cancer.[78] Studies



Data Source: CBTRUS Adolescent and Young Adult Report: USCS – CDC's NPCR, 2001–2019.
Abbreviations: AIAN, American Indian/Alaska Native; AYA, adolescents and young adults ages 15–39 years at diagnosis; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; NCI, National Cancer Institute; NH, Non-Hispanic; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

Fig. 19 2001–2019 (A) Kaplan-Meier Survival Curve for the Five Most Common Malignant Histopathologies in AYA Ages 15–39 Years at Diagnosis and (B) Hazard Ratios and 95% CIs for Sex, and Race/Ethnicity for the Five Most Common Histopathologies in AYA Ages 15–39 Years

analyzing agricultural workers have found a positive association between several agricultural activities and the incidence of primary BT, which might be attributable to these workers' proximity to pesticide toxins.[79] Some studies even found an association between parental work exposure to pesticides and the occurrence of primary BT in their offspring, as observed in a meta-analysis of children and AYA from North America.[80]

Primary BT in AYA are more common in males than females, with the exception of meningiomas (**Supplementary Table 15**) and pituitary tumors (**Supplementary Table 16**). Researchers have explored several factors that may contribute to this sex difference. Older age at menarche and having been pregnant have been associated with lower risk for glioma, whereas a history of breastfeeding has been associated with greater risk.[81,82]

Studies have shown that higher birth weight and size for gestational age also correlated with an increased chance of developing CNS tumors in both childhood and in young adulthood, although these associations were mixed.[68,83] The researchers in these studies hypothesized that the underlying mechanisms might involve the growth factors IGF-1 and IGF-2, which are commonly known to be overexpressed in many brain tumors.

Potential Disparities and Other Issues Affecting Diagnosis, Treatment, and Survival in AYA

In recent years, increasing attention has been paid to the role of disparities in BT incidence and outcomes. However, these disparities have not been characterized or well-documented relevant to AYA, despite the unique epidemiological considerations for this population. Patient-level factors, such as employment and socioeconomic status, healthcare status, and various psychosocial factors, have a significant impact on the AYA population.[84,85] This time period is marked by changes in these factors that often have far-reaching and unpredictable consequences. Many AYA in the United States lose critical access to their parents' health insurance at age 26,[86] which, combined with the unstable employment and lower income common in younger AYA, may result in healthcare access issues that can persist into adulthood. Research has highlighted the significant impact of health care access on both diagnosis and outcomes for individuals with a primary BT.

Of particular importance in the AYA population is the heightened potential for financial toxicity and related economic issues associated with a cancer diagnosis and treatment.[72,87,88] In a survey of AYA cancer survivors, almost half reported decreases in credit scores and increases in debt collection efforts, and nearly a quarter lacked money for necessities. Similarly, a recent meta-analysis showed that annual monetary losses were doubled in AYA with cancer versus without cancer. In particular, CNS tumors are among the highest-risk cancers for AYA in terms of increased usage of public benefits like Social Security and lower overall income postdiagnosis, compared with similarly aged individuals in the general population.[89,90]

Various barriers affect AYA access to care and access to neuro-oncology clinical trials.[91] This age group is particularly susceptible to diagnostic delay, given the unique

Table 10. Hazard Ratios for Malignant Primary Brain and Other CNS Tumor Histopathologies in AYA Ages 15–39 Years, by Sex and Race/Ethnicity[a]

Histopathology	N	Deaths	Sex		Race & Ethnicity							
			Female		Non-Hispanic Black		Hispanic (All Races)		Non-Hispanic American Indian/Alaska Native		Non-Hispanic Asian/ Pacific Islander	
			HR (95% CI)	*P*-value	HR (95% CI)	*P*-value	HR (95% CI)	*P*-value	HR (95% CI)	*P*-value	HR (95% CI)	*P*-value
Diffuse astrocytoma	6,765	2,274	0.72 (0.66-0.78)	<0.0001	1.14 (0.99-1.32)	0.065	0.84 (0.73-0.96)	0.013	1.20 (0.81-1.76)	0.362	0.99 (0.78-1.26)	0.929
Anaplastic astrocytoma	4,131	1,741	0.81 (0.74-0.89)	<0.0001	1.43 (1.20-1.70)	<0.0001	0.97 (0.84-1.12)	0.709	1.51 (0.92-2.47)	0.102	1.03 (0.80-1.35)	0.8
Glioblastoma	6,227	4,371	0.87 (0.82-0.93)	<0.0001	1.10 (1.00-1.22)	0.055	0.84 (0.77-0.92)	0.0002	1.24 (0.91-1.68)	0.17	0.85 (0.74-0.99)	0.034
Oligodendroglioma	4,140	860	0.90 (0.78-1.03)	0.111	1.18 (0.90-1.55)	0.229	0.79 (0.62-1.00)	0.047	0.94 (0.45-1.99)	0.877	0.54 (0.34-0.87)	0.011
Anaplastic oligodendroglioma	1,332	425	0.83 (0.68-1.01)	0.063	1.04 (0.67-1.62)	0.864	0.85 (0.63-1.16)	0.306	1.59 (0.59-4.27)	0.356	1.10 (0.70-1.71)	0.683
Oligoastrocytic tumors	2,563	1,040	0.77 (0.68-0.88)	<0.0001	1.40 (1.10-1.77)	0.006	0.79 (0.64-0.99)	0.038	1.13 (0.64-2.00)	0.67	0.92 (0.66-1.29)	0.629
Pilocytic astrocytoma	3,978	295	0.92 (0.73-1.15)	0.453	1.42 (1.01-1.99)	0.043	1.05 (0.74-1.51)	0.779	** (**-**)	**	1.44 (0.74-2.80)	0.287
Unique astrocytoma variants	917	139	0.81 (0.57-1.13)	0.209	0.61 (0.36-1.03)	0.066	0.54 (0.31-0.95)	0.032	1.37 (0.34-5.55)	0.662	0.99 (0.43-2.25)	0.974
Ependymal tumors	4,742	400	0.79 (0.64-0.96)	0.02	1.56 (1.15-2.11)	0.004	1.02 (0.76-1.36)	0.895	1.63 (0.73-3.67)	0.234	0.42 (0.19-0.94)	0.034
Glioma malignant, NOS	3,507	890	0.71 (0.62-0.81)	<0.0001	1.48 (1.24-1.78)	<0.0001	1.34 (1.10-1.63)	0.004	1.21 (0.54-2.70)	0.645	1.34 (0.96-1.88)	0.087
Other neuroepithelial tumors	—	—	—	—	—	—	—	—	—	—	—	—
Neuronal and mixed neuronal-glial tumors	4,589	284	0.72 (0.56-0.91)	0.007	1.69 (1.22-2.35)	0.002	1.54 (1.11-2.14)	0.010	0.84 (0.21-3.38)	0.803	1.69 (1.00-2.87)	0.051
Choroid plexus tumors	498	30	0.77 (0.37-1.59)	0.476	1.90 (0.64-5.65)	0.248	1.57 (0.68-3.65)	0.291	** (**-**)	**	** (**-**)	**
Tumors of the pineal region	662	111	0.50 (0.34-0.73)	0.0003	2.22 (1.45-3.41)	0.0003	0.99 (0.55-1.81)	0.987	** (**-**)	**	** (**-**)	**
Embryonal tumors	2,181	743	0.99 (0.86-1.15)	0.937	1.04 (0.83-1.29)	0.756	0.73 (0.60-0.88)	0.001	0.32 (0.10-1.01)	0.051	0.82 (0.50-1.35)	0.43
Nerve sheath tumors	11,295	348	0.63 (0.51-0.78)	<0.0001	2.19 (1.60-3.01)	<0.0001	1.44 (1.07-1.94)	0.016	2.06 (0.92-4.64)	0.08	0.58 (0.32-1.06)	0.078
Other tumors of cranial and spinal nerves	—	—	—	—	—	—	—	—	—	—	—	—
Meningiomas	20,592	1,035	0.56 (0.50-0.64)	<0.0001	1.39 (1.20-1.62)	<0.0001	0.79 (0.64-0.96)	0.017	1.16 (0.62-2.17)	0.637	0.51 (0.33-0.80)	0.003
Mesenchymal tumors	3,790	274	0.51 (0.40-0.66)	<0.0001	1.73 (1.24-2.42)	0.001	1.74 (1.29-2.35)	0.0003	0.85 (0.21-3.43)	0.818	1.14 (0.65-2.01)	0.643
Primary melanocytic lesions	—	—	—	—	—	—	—	—	—	—	—	—
Germ cell tumors	1,525	198	0.83 (0.55-1.26)	0.388	1.01 (0.64-1.59)	0.977	1.04 (0.70-1.53)	0.861	** (**-**)	**	1.48 (0.96-2.31)	0.079
Lymphoma	1,560	701	0.93 (0.80-1.09)	0.400	2.16 (1.82-2.57)	<0.0001	1.10 (0.89-1.35)	0.388	1.44 (0.74-2.80)	0.288	0.43 (0.24-0.77)	0.004
Other hemopoietic neoplasms	—	—	—	—	—	—	—	—	—	—	—	—
Tumors of the pituitary	44,611	755	0.48 (0.42-0.56)	<0.0001	1.35 (1.14-1.61)	0.001	0.68 (0.55-0.85)	0.001	1.70 (1.02-2.85)	0.043	0.60 (0.38-0.95)	0.031
Craniopharyngioma	1,626	179	0.73 (0.55-0.99)	0.041	2.63 (1.88-3.68)	<0.0001	1.12 (0.74-1.70)	0.600	2.40 (0.88-6.55)	0.088	0.55 (0.20-1.49)	0.239
Hemangioma	2,188	64	0.62 (0.38-1.03)	0.063	2.16 (1.14-4.10)	0.019	0.85 (0.40-1.81)	0.676	** (**-**)	**	** (**-**)	**
Neoplasm, unspecified	3,019	405	0.60 (0.49-0.73)	<0.0001	1.39 (1.08-1.78)	0.01	0.93 (0.70-1.24)	0.604	1.13 (0.50-2.55)	0.761	1.21 (0.68-2.16)	0.525
All other	312	15	0.80 (0.29-2.21)	0.66	2.15 (0.66-7.03)	0.205	0.74 (0.16-3.41)	0.696	** (**-**)	**	** (**-**)	**

[a] Reference categories are male for sex and non-Hispanic White for race/ethnicity.
— Counts and associated rates cannot be provided when Total Cases are fewer than 50 cases or when a value based on less than 50 cases can be back-calculated using a cell.
** Could not be calculated.
Data source: CBTRUS Adolescent and Young Adult Report: USCS - CDC's NPCR, 2001–2019.
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; HR, hazard ratio; NOS, not otherwise specified; NPCR, National Program of Cancer Registries; USCS, United States Cancer Statistics.

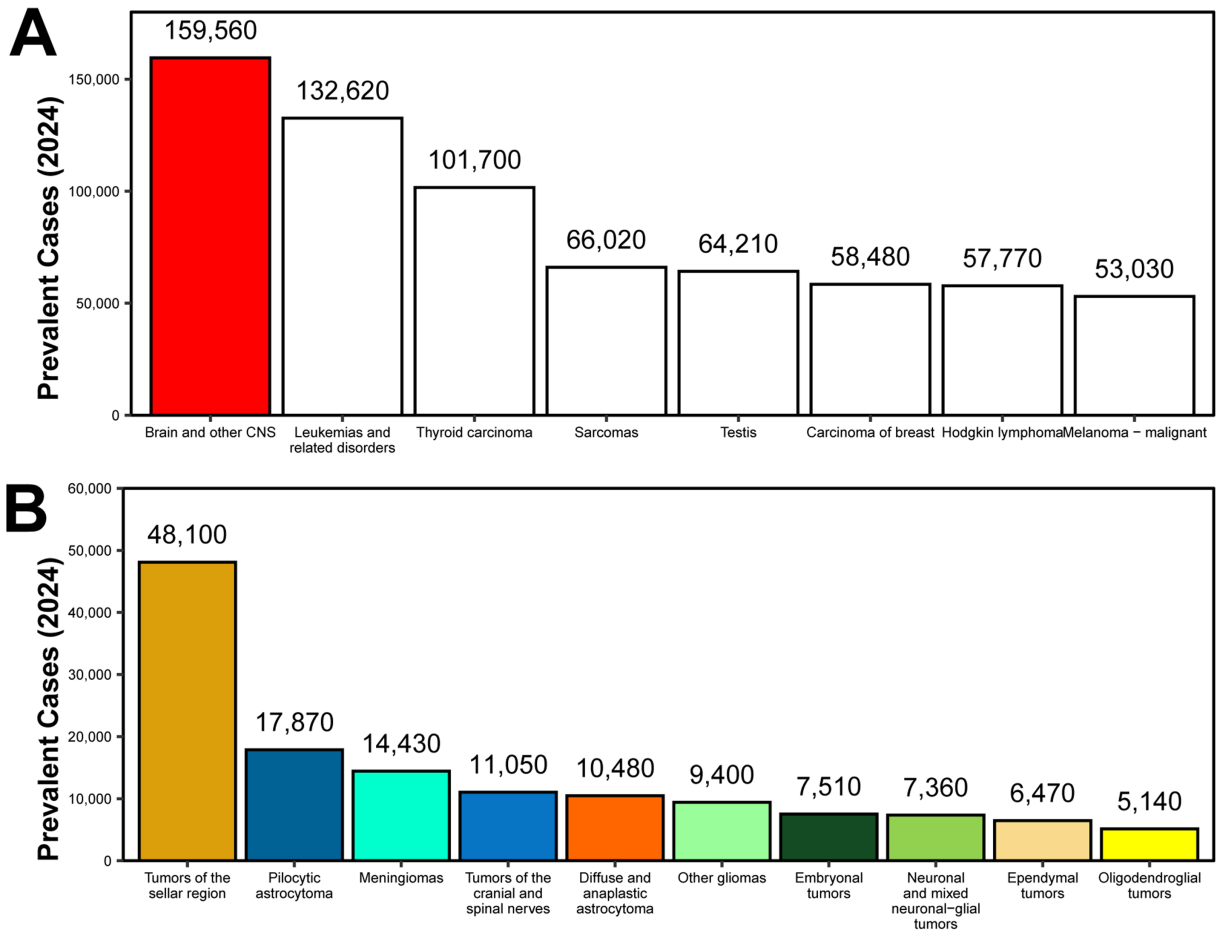
Table 11. 2024, 2025, and 2026 Estimated New Cases[a,b] of Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years, by Behavior and Histopathology

Histopathology	2024			2025			2026		
	All	Malignant	Non-Malignant	All	Malignant	Non-Malignant	All	Malignant	Non-Malignant
Diffuse astrocytic and oligodendroglial tumors	**2,030**	—	—	**2,050**	—	—	**2,060**	—	—
Diffuse and anaplastic astrocytoma	1,170	—	—	1,200	—	—	1,230	—	—
Glioblastoma	680	—	—	690	—	—	710	—	—
Oligodendroglial tumors	190	—	—	150	—	—	120	—	—
Other astrocytic tumors	**490**	**380**	**110**	**500**	**380**	**120**	**520**	**390**	**140**
Pilocytic astrocytoma	390	310	80	410	310	100	420	310	110
Unique astrocytoma variants	90	70	20	100	70	20	100	70	20
Ependymal tumors	**380**	**180**	**190**	**380**	**180**	**200**	**380**	**180**	**200**
Other gliomas	**510**	—	—	**530**	—	—	**540**	—	—
Neuronal and mixed neuronal-glial tumors	**520**	**40**	**470**	**530**	**40**	**480**	**540**	**40**	**490**
Choroid plexus tumors	**40**	—	—	**40**	—	—	**40**	—	—
Tumors of the pineal region	**70**	**40**	**20**	**70**	**50**	**20**	**70**	**50**	**20**
Embryonal tumors	**140**	—	—	—	—	—	**140**	—	—
Tumors of cranial and paraspinal nerves	**1,270**	—	—	**1,280**	—	—	**1,300**	—	—
Tumors of meninges	**2,680**	**50**	**2,630**	**2,720**	**50**	**2,670**	**2,750**	**50**	**2,710**
Meningiomas	2,350	20	2,340	2,390	20	2,370	2,430	—	—
Other tumors of the meninges	330	30	300	330	30	290	330	30	290
Lymphomas and hematopoietic neoplasms	**80**	—	—	**80**	—	—	**80**	—	—
Germ cell tumors	**130**	—	—	**130**	—	—	**130**	—	—
Tumors of the sellar region	**4,520**	—	—	**4,440**	—	—	**4,350**	—	—
Unclassified tumors	**490**	**60**	**420**	**480**	**60**	**410**	**460**	**60**	**400**
Total	**13,350**	3,670	**9,680**	**13,360**	**3,700**	**9,660**	**13,370**	**3,720**	**400**

[a] Estimation based on CBTRUS, NPCR, and SEER 2001–2019 data for malignant tumors, and NPCR and SEER 2006–2019 data for non-malignant tumors.
[b] Rounded to the nearest 10. Numbers may not add up due to rounding.
— Counts and associated rates cannot be provided when Total Cases are fewer than 20 cases or when a value based on less than 16 cases can be back-calculated using a cell.
Data Source: CBTRUS Adolescent and Young Adult Report: USCS - CDC's NPCR and NCI's SEER, 2001–2019 (varying).
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology and End Results Program; USCS, United States Cancer Statistics.

symptomology of primary BT in this group compared with older adults, the lack of physician awareness of cancer risk in this age group, and the insurance and economic issues discussed above. The unique needs and histopathologies of AYA may result in these patients not being appropriately served by either pediatric or adult neuro-oncology programs. These factors, along with exclusionary age-eligibility criteria, contribute to AYA being disproportionately excluded from clinical trials.

Racial/ethnic differences in incidence and outcomes have previously been reported in primary BT,[65] and these differences are consistent among AYA.[92,93] Across all histopathologies and regardless of age, overall incidence rates are similar for AYA who identify as non-Hispanic White, non-Hispanic Black, or non-Hispanic American Indian/Alaska Native, whereas those who identify as non-Hispanic Asian or Pacific Islander or Hispanic (all races) have lower overall incidence (**Table 5**). The incidence of



Data Source: CBTRUS Adolescent and Young Adult Report: USCS – CDC's NPCR and NCI's SEER, 1975–2020 (varying)
Abbreviations: AYA, adolescents and young adults ages 15–39 years in 2024; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NOS, not otherwise specified; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

Fig. 20 2024 Estimated US Cases of (A) the Eight Most Prevalent Cancers in Children and Adolescents, and (B) by the Ten Most Prevalent Primary Brain and Other CNS Histopathologies in AYA Ages 15–39 Years in 2024

specific tumor types varies substantially by race/ethnicity. Many factors affect whether a newly diagnosed case is reported to cancer registries, and cases diagnosed in some groups, especially non-Hispanic American Indian/Alaska Native groups, are likely underreported due to data-reporting or misclassification issues.[94] After diagnosis, race/ethnicity can significantly affect treatment timing and outcomes. Overall, groups who are not non-Hispanic White have significantly better survival after a glioma diagnosis; however, AYA in these groups have poorer survival, possibly mediated by lower socioeconomic status.[95] Although rural residential location is also associated with poorer survival, traveling longer distances to receive treatment has been associated with improved outcomes in combination with non-Hispanic White race/ethnicity and higher SES—which suggests the importance of enabling AYA to travel to specialty care centers for treatment.[96]

Sex differences in primary BT have been well-defined and are measurable, especially in patients older than 14 years of age.[97,98] Numerous mechanisms have been proposed to explain potential disparities related to sex, including known differences in epigenetic regulation, chromosomal complements, and sex hormones.[92,99] Compared with the pediatric population, AYA have greater exposure to sex hormones—which may exacerbate sex-related disparities in cancer incidence and outcomes to levels comparable to those observed in older adults.

Significant variation in specific tumor types also is related to sex: Tumors like glioma are more common in males, whereas females are significantly more likely to develop pituitary tumors and meningiomas, which are mostly non-malignant.[100,101] For gliomas and several other histopathologies, AYA survival is generally worse for males than females, even after adjustment for known prognostic factors; this effect is strongest in the youngest and middle-adulthood age groups.[98,102] Sex disparity in meningioma varies substantially by age, increasing through young adulthood and peaking in middle adulthood.[103] Possible impact on fertility requires more careful clinical consideration in AYA than in older adults.

Table 12. 2024 Estimated Case Counts[a] and Age-Specific Prevalence Rates[b] for Primary Brain and Other CNS Tumors in AYA Ages 15–39 Years, Overall and by Age Group at Diagnosis and Histopathology

Histopathology	Overall (15–39 years)				15–19 years		20–24 years		25–29 years		30–34 years		35–39 years	
	Cases	Rate (95% CI)	% Cases Diagnosed In		Cases	Rate (95% CI)	Cases	Rate (95% CI)	Cases	Rate (95% CI)	Cases	Rate (95% CI)	Cases	Rate (95% CI)
			0–14 years	15–39 years										
Diffuse and anaplastic astrocytoma	15,640	14.16 (13.94-14.38)	35.9%	64.1%	1,190	5.69 (5.37-6.02)	1,840	8.50 (8.12-8.90)	2,880	12.42 (11.97-12.88)	4,370	19.15 (18.58-19.72)	5,350	24.52 (23.87-25.19)
Glioblastoma	8,010	7.25 (7.09-7.41)	26.8%	73.2%	620	2.97 (2.74-3.21)	890	4.12 (3.86-4.40)	1,300	5.62 (5.32-5.93)	2,090	9.16 (8.78-9.56)	3,100	14.20 (13.71-14.71)
Oligodendroglial tumors	4,820	4.37 (4.25-4.49)	22.8%	77.2%	140	0.69 (0.58-0.81)	320	1.48 (1.32-1.65)	610	2.64 (2.43-2.85)	1,330	5.82 (5.51-6.14)	2,420	11.08 (10.64-11.53)
Pilocytic astrocytoma	19,880	18.00 (17.75-18.25)	74.4%	25.6%	3,550	16.92 (16.36-17.48)	3,700	17.13 (16.59-17.69)	3,900	16.77 (16.25-17.30)	4,330	18.97 (18.41-19.54)	4,410	20.19 (19.60-20.79)
Unique astrocytoma variants	2,410	2.18 (2.10-2.27)	49.3%	50.7%	490	2.33 (2.13-2.55)	500	2.31 (2.11-2.52)	480	2.07 (1.89-2.26)	490	2.14 (1.95-2.33)	460	2.09 (1.90-2.29)
Ependymal tumors	8,630	7.81 (7.65-7.98)	50.9%	49.1%	1,090	5.20 (4.90-5.52)	1,320	6.10 (5.78-6.44)	1,640	7.05 (6.71-7.40)	2,040	8.92 (8.54-9.31)	2,550	11.67 (11.22-12.13)
Other gliomas	16,830	15.24 (15.01-15.47)	70.2%	29.8%	3,190	15.20 (14.68-15.74)	3,310	15.33 (14.81-15.86)	3,120	13.44 (12.97-13.92)	3,440	15.05 (14.55-15.56)	3,770	17.29 (16.74-17.85)
Neuronal and mixed neuronal-glial tumors	9,820	8.89 (8.72-9.07)	38.1%	61.9%	1,850	8.84 (8.44-9.24)	2,170	10.06 (9.64-10.49)	2,070	8.93 (8.55-9.32)	2,000	8.75 (8.37-9.14)	1,730	7.91 (7.54-8.29)
Choroid plexus tumors	1,510	1.37 (1.30-1.44)	64.1%	35.9%	420	2.02 (1.83-2.22)	310	1.44 (1.28-1.60)	260	1.12 (0.99-1.26)	270	1.19 (1.05-1.34)	250	1.13 (0.99-1.27)
Tumors of the pineal region	1,380	1.25 (1.18-1.32)	46.9%	53.1%	190	0.89 (0.76-1.02)	240	1.10 (0.97-1.25)	300	1.28 (1.14-1.43)	310	1.36 (1.21-1.52)	350	1.59 (1.42-1.76)
Embryonal tumors	13,740	12.44 (12.23-12.65)	83.1%	16.9%	2,460	11.73 (11.27-12.20)	2,600	12.04 (11.58-12.50)	2,710	11.66 (11.23-12.11)	2,930	12.83 (12.37-13.30)	3,040	13.94 (13.45-14.44)
Tumors of the cranial and spinal nerves	12,930	11.71 (11.51-11.91)	19.1%	80.9%	1,180	5.63 (5.31-5.96)	1,700	7.85 (7.48-8.23)	2,200	9.47 (9.08-9.87)	3,200	14.02 (13.54-14.52)	4,650	21.32 (20.71-21.94)
Meningiomas	16,320	14.78 (14.55-15.01)	5.7%	94.3%	520	2.49 (2.28-2.71)	1,050	4.87 (4.58-5.17)	2,140	9.22 (8.83-9.62)	4,290	18.78 (18.22-19.35)	8,320	38.12 (37.30-38.94)
Other tumors of the meninges	4,570	4.14 (4.02-4.26)	20.6%	79.4%	440	2.09 (1.90-2.30)	530	2.47 (2.26-2.68)	890	3.83 (3.58-4.09)	1,220	5.32 (5.03-5.63)	1,500	6.85 (6.51-7.20)
Germ cell tumors	4,310	3.91 (3.79-4.02)	51.3%	48.7%	660	3.13 (2.89-3.38)	870	4.01 (3.75-4.28)	930	3.99 (3.73-4.25)	940	4.13 (3.87-4.40)	920	4.22 (3.96-4.50)
Lymphoma and other hematopoietic neoplasms	1,280	1.16 (1.10-1.23)	26.0%	74.0%	110	0.52 (0.42-0.62)	140	0.63 (0.52-0.74)	200	0.84 (0.73-0.97)	320	1.41 (1.26-1.57)	520	2.41 (2.20-2.62)

Table 12. Continued

Histopathology	Overall (15–39 years)		% Cases Diagnosed In		15–19 years		20–24 years		25–29 years		30–34 years		35–39 years	
	Cases	Rate (95% CI)	0–14 years	15–39 years	Cases	Rate (95% CI)	Cases	Rate (95% CI)	Cases	Rate (95% CI)	Cases	Rate (95% CI)	Cases	Rate (95% CI)
Tumors of the sellar region	57,850	52.38 (51.95-52.81)	8.6%	91.4%	3,720	17.75 (17.19-18.33)	6,960	32.22 (31.47-32.98)	11,330	48.77 (47.88-49.67)	15,980	69.96 (68.88-71.05)	19,870	91.02 (89.76-92.29)
Unclassified tumors	8,660	7.84 (7.67-8.00)	30.6%	69.4%	1,180	5.61 (5.29-5.94)	1,420	6.59 (6.26-6.94)	1,680	7.22 (6.88-7.57)	2,090	9.15 (8.76-9.55)	2,290	10.49 (10.07-10.93)
Total	**208,620**	**10.49 (10.45-10.54)**	**34.7%**	**65.3%**	**22,990**	**6.09 (6.02-6.17)**	**29,850**	**7.68 (7.59-7.77)**	**38,640**	**9.24 (9.15-9.33)**	**51,640**	**12.56 (12.45-12.67)**	**65,490**	**16.67 (16.54-16.80)**

[a] Estimation based on CBTRUS NPCR (2000–2020) and SEER (1975–2020) data for malignant tumors and NPCR and SEER (2004–2020) data for non-malignant tumors, and SEER survival data (1975–2020 for malignant tumors and 2004–2020 data for non-malignant tumors).

[b] Rates are per 100,000 population.

Data Source: CBTRUS Adolescent and Young Adult Report: USCS - CDC's NPCR and NCI's SEER, 1975–2020 (varying).

Abbreviations: AYA, adolescents and young adults ages 15–39 years in 2024; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program. USCS, United States Cancer Statistics.

Changes in psychosocial function due to the life-long detrimental effects of cancer or cancer treatment are of increased relevance in AYA and have been well-documented in those with primary BT.[85] However, comparatively little is known about risk for neurocognitive deficits and other long-term difficulties associated with cancer diagnosis and treatment specifically among AYA. One study that examined this in individuals with adult-onset medulloblastoma (median age 33) found significant neurocognitive impairment.[104] Risk for long-term neurocognitive damage is similar among children, adolescents, and younger adults but higher than for older adults.

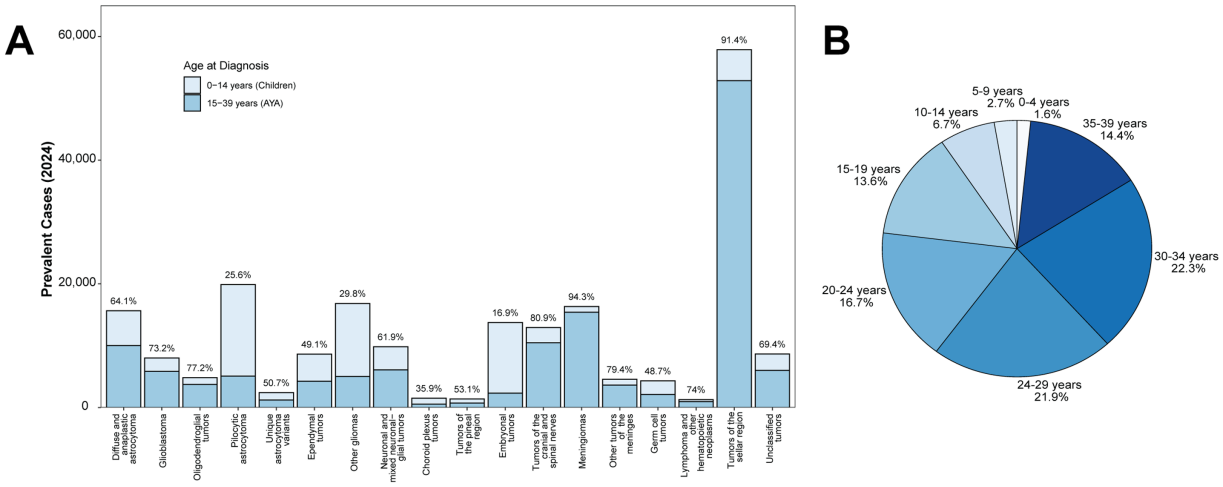
Of significant concern are pediatric brain tumor survivors who are transitioning into adolescence and young adulthood and who therefore require adult neuro-oncology care that is attentive to their needs both as a survivor of a pediatric brain tumor and as a young adult.[105] A substantial proportion (approximately 35%) of AYA currently living with a primary BT were diagnosed when they were younger than 15 years of age (**Table 12**). This varies substantially by tumor type. For example, a substantial proportion of individuals living with pilocytic astrocytoma, embryonal tumors, and other gliomas were diagnosed in childhood (**Figure 21A**). In comparison, most adult-type gliomas (diffuse and anaplastic astrocytoma, glioblastoma, oligodendrogial tumors), meningioma, tumors of the cranial and spinal nerves, and tumors of the seller region were diagnosed during the AYA years.

Mortality figures included in this report also capture a portion of the population who has undergone this transition. Approximately 11% of deaths due to primary BT included in the mortality figures presented in this report were due to tumors diagnosed in childhood (**Figure 21B**). Although not represented in the counts of newly diagnosed cases presented herein, this population represents a significant proportion of the AYA clinical population and has unique needs distinct from the needs of both other AYA and older adults.

Strengths and Limitations of Cancer Registry Data

CBTRUS, developed in collaboration with the CDC and NCI, is the largest population-based registry focused exclusively on primary BT in the United States, representing cases collected from the entire US population. The *CBTRUS Statistical Report: American Brain Tumor Association & NCI Neuro-Oncology Branch Adolescent and Young Adult Primary Brain and Other Central Nervous System Tumors Diagnosed in the United States in 2016–2020* contains population-based data on all primary BT in AYA ages 15–39 years available through the CSS in the United States.

Registration of individual cases is conducted by cancer registrars at the institution where diagnosis or treatment occurs and is then transmitted to the CCR, which then transmits this information to NPCR and/or SEER. Each CCR reports cases only for persons who are residents of that particular state, so duplicate records should not occur for persons who may have traveled across state lines for treatment. As a result, the CBTRUS dataset is a complete recording of all cases submitted to CCR for the time period examined (here, 2016–2020), with minimal duplication.



Data Source: CBTRUS Adolescent and Young Adult Report: USCS – CDC's NPCR and NCI's SEER, 1975–2020 (varying)
Abbreviations: AYA, adolescents and young adults ages 15–39 years; CBTRUS, Central Brain Tumor Registry of the United States; CDC, Centers for Disease Control and Prevention; CNS, central nervous system; NCI, National Cancer Institute; NPCR, National Program of Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics.

Fig. 21 Pediatric Brain Tumor Cases as a Proportion of (A) AYA Living with a Brain or Other CNS Tumor in 2024 and (B) AYA Deaths Due to a Primary Brain or Other CNS Tumor

The cancer registry system has no publicly available survival and outcomes data. Survival data used for this report were collected by NPCR for 39 of the 51 CCRs in the United States, primarily through linkage with death certificate and other administrative records. Data from the remaining CCRs were collected by SEER, using both active and passive methods. The feasibility of these data for use in survival studies was evaluated[106,107] and found to produce reliable and robust estimates of cancer survival. Use of passive follow-up with record linkage may result in overestimation of survival in some populations, such as those who are more likely to leave the state or country.

No mechanism currently exists within the US cancer registry system for central pathology review of cases, and histopathology code assignment at case registration is based on information contained in the patient's medical record. The *WHO Classification of Tumours of the Central Nervous System* was revised in 1993,[108] 2000,[109] 2007,[110] 2016,[27] and 2021[24]. As of 2018, the US cancer registry system uses the 2016 classification for data abstraction, but tumors included in this report may have been diagnosed using any of the available classifications before 2016, due to the variation in adoption of new standards by individual physicians and medical practices. As a result, histopathologies are reflective of the prevailing criteria for the histopathology at the time of case registration. This means that, despite possible changes to the histopathology schema over time, it is not possible, without additional variables, to go back and reclassify tumors based on new criteria. In addition to changes in histopathological criteria over time, there is significant interrater variability in histopathological diagnosis of glioma.[111,112] This also means that incomplete, incorrect, or alternatively stated diagnoses included in a pathology report or other medical record may result in an incorrect reporting of the details of an individual case.

Cancer registration in the United States requires the reporting of cases that are confirmed by using different types of diagnostic procedures, including both microscopic confirmation (where surgery was performed and the diagnosis was confirmed by a pathologist) and radiographic confirmation (where the diagnosis was based solely on imaging criteria, such as magnetic resonance imaging, computed tomography scans, or X-ray). Only microscopic confirmation allows certainty on the assignment of a specific histopathology and a CNS WHO grade. Many tumors have unique characteristics that make them identifiable on imaging, which thereby qualifies as a valid type of diagnostic procedure, but it is important to consider the lower level of certainty in specifying the correct histopathology of these tumors.

Concluding Comment

The *CBTRUS Statistical Report: American Brain Tumor Association & NCI Neuro-Oncology Branch Adolescent and Young Adult Primary Brain and Other Central Nervous System Tumors Diagnosed in the United States in 2016–2020* comprehensively describes the population-based incidence, mortality, and relative survival for primary BT in AYA ages 15–39 years, as collected and reported by CCRs covering the entire US population. This report aims to serve as a useful resource for researchers, clinicians, patients, and families. CBTRUS continually revises its reports to reflect the current collection and reporting practices of the broader surveillance community in which it works, while integrating the input it receives from the clinical and research communities, especially neuropathologists, whenever possible.

CBTRUS Mission

CBTRUS is a not-for-profit corporation committed to providing a resource for gathering and disseminating current

epidemiological data on all primary brain and other CNS tumors, both benign and malignant, for the purposes of accurately describing their incidence and survival patterns, evaluating diagnosis and treatment, facilitating etiological studies, establishing awareness of the disease, and, ultimately, for preventing all brain tumors.

Supplementary material

Supplementary material is available online at *Neuro-Oncology* (https://academic.oup.com/neuro-oncology).

Abbreviations:

AASIR, average annual age-specific incidence rate;
AASMR, average annual age-specific mortality rate;
APC, annual percentage change;
AYA, adolescents and young adults;
BMM, brain molecular marker;
BT, primary brain and other central nervous system tumors;
CBTRUS, Central Brain Tumor Registry of the United States;
CCR, Central Cancer Registry;
CDC, US Centers for Disease Control and Prevention;
CNS, central nervous system;
DCEG, Division of Cancer Epidemiology and Genetics;
ICD-O-3, *International Classification of Diseases for Oncology, Third Edition*;
IDH1/2, isocitrate dehydrogenase ½;
MGMT, O-6-methylguanine-DNA methyltransferase;
NAACCR, North American Association of Central Cancer Registries;
NCHS, National Center for Health Statistics;
NCI, National Cancer Institute of the US National Institutes of Health;
NH, Non-Hispanic;
NPCR, National Program of Cancer Registries;
NPCR-CSS, NPCR Cancer Surveillance System;
NVSS, National Vital Statistics System;
RUCC, Rural-Urban Continuum Code;
SEER, Surveillance, Epidemiology, and End Results;
SHH, Sonic Hedgehog;
TP53, tumor protein p53;
USCS, United States Cancer Statistics;
WNT, Wingless

Disclaimer

CBTRUS makes no representations or warranties, and gives no other assurances or guarantees, express or implied, with respect to the accuracy or completeness of the data presented. The information provided in this report is not intended to assist in evaluating, diagnosing, or treating individual diseases. Persons with questions regarding their individual disease should contact their own physician to obtain medical assistance. The contents in this report are solely the responsibility of the authors and do not necessarily represent the official views of the CDC or of the NCI.

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