

## Cancers Affecting Adolescents and Young Adults (AYAs)

Nearly 64,800 adolescents and young adults (AYAs) ages 15–39 were diagnosed with cancer in 2004.<sup>1</sup> The incidence of specific cancer types varies dramatically across the AYA age continuum. For example, leukemias, lymphomas, and central nervous system (CNS) tumors are prevalent in younger AYAs; in ages 20–39, these cancers decline in frequency while other cancers such as cervical, colorectal, and particularly breast cancer, comprise a growing share of AYA cancers.<sup>2</sup>

## Mortality and Survival

Cancer is the leading cause of disease-related deaths in the AYA population; it is the most common disease-related cause of death among females and is second only to heart disease among males.<sup>3</sup> In the AYA age group, only homicide, suicide, and unintentional injury claim more lives than cancer.

AYA survival varies by race and ethnicity. White, non-Hispanic AYAs have the highest cancer incidence and the highest overall 5-year survival rates. American Indian and Alaskan Native AYAs have the lowest cancer incidence rates, but they also have poor survival rates. African Americans have intermediate incidence rates and the lowest 5-year survival rates across the age range.

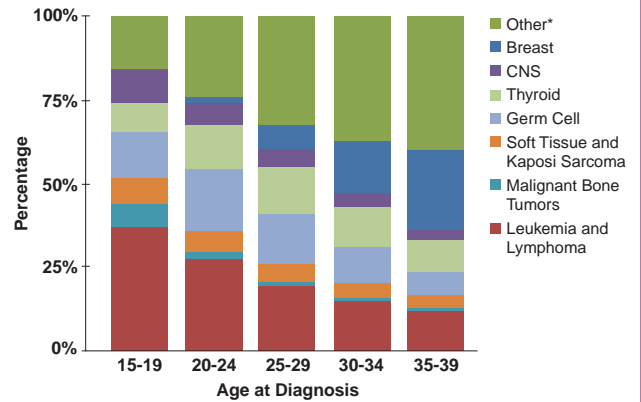
Compared with younger and older age groups, AYAs have experienced little or no improvement in cancer survival rates in more than two decades. Several factors might account for the lack of improved outcomes in AYAs with cancer, including limited access to care and insurance coverage, delayed diagnosis of primary cancers, inadequate treatment practices and settings, poor understanding of the biology and etiology distinguishing the cancers in this population, inadequate collection of patients and patient data, low number of clinical trials and poor participation, unique psychosocial and supportive care needs, inconsistent treatment and follow-up care guidelines, and limited emphasis on prevention and early detection.

<sup>1</sup> American Cancer Society.

<sup>2</sup> Data from the Surveillance, Epidemiology, and End Results (SEER) Program (<http://seer.cancer.gov>).

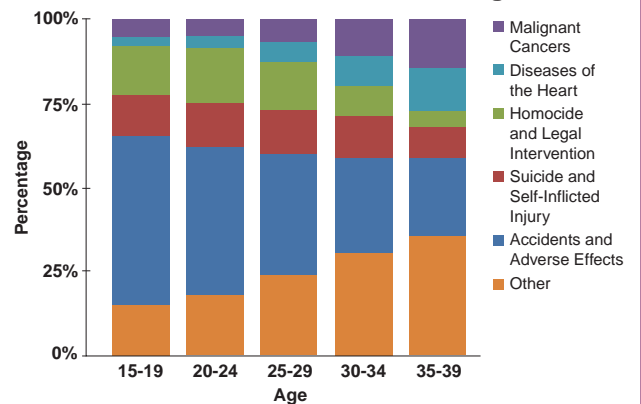
<sup>3</sup> Total U.S. deaths in 2004, ages 15–39, from the SEER Program and the National Center for Health Statistics.

Common Types of Cancer Afflicting AYAs (% cases/disease)



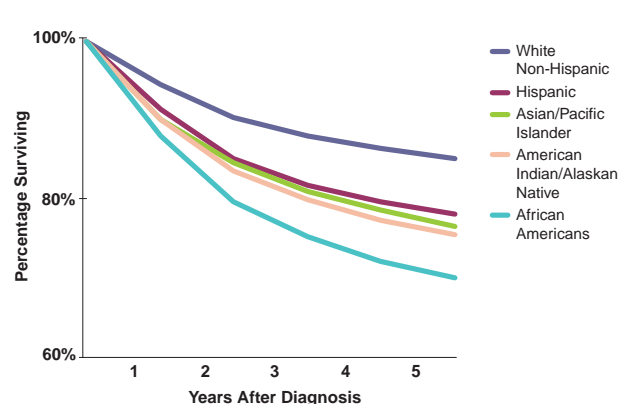
\*Includes melanoma, colorectal, cervical, and other less prevalent cancers.  
Data source: SEER 17, 2000–2004, ages 15–39.

Common Causes of Death\* Among AYAs



\*U.S. deaths, 2004. Underlying mortality data provided by the National Center for Health Statistics.

5-Year Survival of AYAs with Cancer

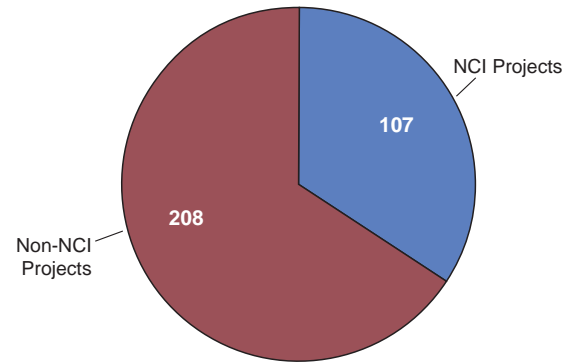


Hispanics can overlap with African Americans, Asians/Pacific Islanders, or American Indians/Alaskan Natives. Analysis was based on any death from any cancer site in both sexes and all races.

## AYA Cancer Research Support

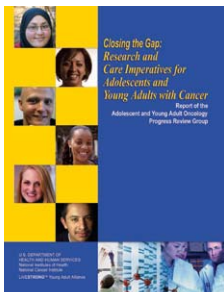
Throughout the United States and internationally, several private and public organizations (including NCI) support research projects relevant to AYA cancers. Between fiscal years (FY) 2002 and 2006, partners in the International Cancer Research Portfolio (ICRP) and the Lance Armstrong Foundation (LAF) supported 315 unique AYA cancer research projects. Of those projects, NCI funded 107 and other organizations funded 208. This research includes studies on genetic and environmental factors that contribute to cancer in AYAs, strategies to improve cancer awareness and detection, access to and quality of care for AYAs, and long-term effects and complications resulting from cancer during adolescence and young adulthood.

### Analysis of AYA Cancer Research Support, FY02–06



Data provided by partners in the ICRP (<http://www.cancerportfolio.org/index.jsp>) and LAF. The portfolio data are an estimate and not an exhaustive list of all AYA cancer research. Non-NCI organizations include LAF, American Cancer Society, California Breast Cancer Research Program, Congressionally Directed Medical Research Programs, Susan G. Komen for the Cure, Oncology Nursing Society, Prostate Cancer Foundation, National Cancer Research Institute, and Canadian Cancer Research Alliance.

## Planning for the Future



In 2005–2006, NCI partnered with LAF to address the special research and cancer care needs of AYAs and solicit recommendations for a national agenda to improve cancer prevention, early detection, diagnosis, treatment (including survivorship care), and outcomes in this population.

The group's report, *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer*, is available at: [http://planning.cancer.gov/disease/AYAO\\_PRG\\_Report\\_2006\\_FINAL.pdf](http://planning.cancer.gov/disease/AYAO_PRG_Report_2006_FINAL.pdf)

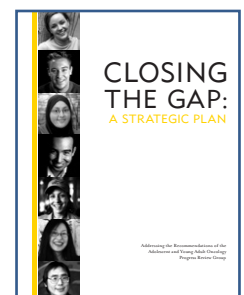
### The group developed five recommendations for improving the outcomes of AYAs with cancer:

1. Identify the characteristics that distinguish the unique cancer burden in the AYA cancer patient.
2. Provide education, training, and communication to improve awareness, prevention, access, and quality cancer care for AYAs.
3. Create tools to study the AYA cancer problem.
4. Ensure excellence in service delivery across the cancer control continuum (i.e., prevention, screening, diagnosis, treatment, survivorship, and end of life).
5. Strengthen and promote advocacy and support for the AYA cancer patient.

## Moving Forward

In November 2006, representatives from NCI and LAF's **LIVESTRONG** Young Adult Alliance met to develop strategies for transitioning the above-mentioned recommendations into reality. These strategies, detailed in the 2007 report *Closing the Gap: A Strategic Plan*, include:

- Establish a strong scientific foundation to support the biological differences in tumors found in AYAs.
- Leverage completed, ongoing, and new clinical trials to obtain knowledge about cancer in AYAs.
- Increase health care provider awareness of AYA issues by working with professional societies and advocacy organizations.
- Facilitate the development of AYA standards for, and availability of, patient navigators and health coaches.



<http://www.livestrong.org/atf/cf/%7BD0794917-422C-499C-9C48-9ED3DDC42947%7D/LAF%20YAA%20Report.pdf>