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## EXECUTIVE SUMMARY

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Relatively little is known about biologic, genetic, epidemiologic, therapeutic, psychosocial, and economic factors that affect the incidence, disease outcomes, and quality of life of adolescents and young adults (AYAs) diagnosed with cancer. However, it is known that compared with younger and older age groups, this population—defined as those **diagnosed with cancer at ages 15 through 39**—has seen little or no improvement in cancer survival rates for decades.

In 2005-2006, the National Cancer Institute (NCI) partnered with the Lance Armstrong Foundation (LAF) to conduct a Progress Review Group (PRG) to address the special research and cancer care needs of the AYA age group and solicit recommendations for a national agenda to improve cancer prevention, early detection, diagnosis, treatment (including survivorship care), and outcomes among these patients. An Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG) was convened, drawing together more than 100 experts from diverse disciplines across the research enterprise, the cancer control continuum, and the advocacy and survivor communities. Further, the PRG leadership sought the input of individuals whose work in areas not related directly to AYA cancer research and care might offer important insights for addressing AYA-specific concerns.

### **Cancers Affecting the Adolescent and Young Adult Population**

Nearly 68,000 people aged 15 to 39 years were diagnosed with cancer in 2002, approximately 8 times more than children under age 15. These cases represent about 6 percent of all new cancer diagnoses. Excluding homicide, suicide, and unintentional injury, cancer is the leading cause of death among 15 to 39 year-olds. It is the most common cause of death among females in this age group, and among males in this group only heart disease claims more lives annually than cancer.

The most common tumors in 15 to 39 year-olds (accounting for 86 percent of cancers in the age range) are **breast cancer**, **lymphoma**, **germ cell tumors** (including **testicular cancer**), **thyroid carcinoma**, **sarcoma** (bone and soft tissue), **cervical carcinoma**,

**leukemia**, **colorectal carcinoma**, and **central nervous system** tumors. However, the incidence of specific cancer types varies considerably across the AYA age continuum. For example, among younger AYAs (15 to 19 year-olds), lymphomas, germ cell tumors, and leukemias account for the largest percentages of all cancers. Between ages 20 and 39, these and other cancers decline as a percentage of all cases, while **carcinomas** (particularly breast cancer) comprise an increasing share of cancers in the AYA age cohort. Non-Hispanic whites in the AYA age group have the highest incidence of cancer, but also have the highest overall 5-year survival. American Indians/Alaska Natives have the lowest cancer incidence, but also have poor survival rates. African Americans, however, have the lowest 5-year survival rate across the age range.

### **Factors Limiting Progress Against Cancer in Adolescents and Young Adults**

Overall, progress in AYA oncology has been hampered because cancer risk and adverse cancer outcomes have been under-recognized in this population. Several closely interrelated factors may have contributed to the failure to improve the outcomes of AYAs with cancer. Access to care can be restricted or delayed, in part because AYAs have the highest uninsured rate of any age group in the country. Diagnosis can be delayed because AYAs typically see themselves as invulnerable to serious disease or injury, causing them to ignore or minimize symptoms and delay seeking medical attention. Delayed diagnosis also is common because providers tend to have a low suspicion of cancer in this population. Symptoms of cancer may be attributed to fatigue, stress, or other causes. AYAs with first symptoms of cancer may see a variety of health care providers, including pediatricians, internists, family physicians, emergency room physicians, gynecologists, dermatologists, gastroenterologists, neurologists, surgeons, orthopedists, and other specialists.

Once seen, referral patterns for AYAs with suspected or diagnosed cancers vary widely. These patients too frequently fall into a “no man’s land” between pediatric and adult oncology; they may be treated by pediatric, adult medical, radiation, surgical, or gynecologic oncologists. Most AYAs are treated in the community

rather than in cancer centers, but a robust community oncology and primary care infrastructure currently does not exist to enable patient data collection and aggregation that would support research efforts. In addition, contact with many AYA patients is lost following treatment, complicating collection of late effects and outcome data in this highly mobile population.

Research on AYAs has been further constrained by their exceedingly low participation in the relatively few clinical trials available to them, in part because diagnosing physicians seldom refer these patients to trials. Poor understanding of patient and tumor biology that distinguishes cancers in this population has contributed to minimal advances in treatment.

Inconsistency in treatment and follow-up care, coupled with insufficient research data, has prevented the development of guidelines for treating and monitoring AYAs with cancer, and few tools exist to measure the efficacy of treatment and psychosocial interventions delivered in diverse settings.

Psychosocial and support services available to AYAs with cancer (and their families/caregivers) are limited, although their needs for such services tend to be broader in scope and intensity than among younger and older patients because of the many emotional, developmental, and social changes and transitions that occur during this stage of life. Lastly, cancer prevention and early detection receive little emphasis in health care for the AYA population.

## Recommendations

The AYAO PRG identified five imperatives for improving the outcomes of adolescents and young adults with cancer.

**Recommendation 1: Identify the characteristics that distinguish the unique cancer burden in the AYAO patient.**

A significantly more robust research effort is needed to better understand tumor and human factors that contribute to AYAs' susceptibility to cancer, their response to treatment, and their disease outcomes. Among the cancers affecting AYAs, the PRG identified as particularly high priorities basic and other biologic research on aging and patient/host-related factors in non-Kaposi's sarcoma, **leukemia**, **lymphoma**,

and **breast** and **colorectal carcinomas**. Additionally, increased resources are needed for studies of AYAs' genetic susceptibility to cancer.

AYA cancer patients and survivors face developmental challenges that both exceed significantly those faced by other young people and are distinct from the challenges faced by other age groups with cancer. Research is needed to better understand patient and survivor life stage and developmental characteristics across six principal domains—intellectual, interpersonal, emotional, practical, existential/spiritual, and cultural—that singly or in combination may have profound effects on individuals' medical outcomes and quality of life.

In addition, the factors that characterize and account for disparities experienced by AYA cancer patients and survivors are understood only in the broadest terms and may include human and disease biology, pharmacogenetics, socioeconomic factors, and the appropriateness and accessibility of health services (especially clinical trials). Therefore, research is needed to elucidate in detail the factors contributing to under-service and poorer outcomes among AYAs as a whole and among racial and ethnic subgroups within the AYA population.

**Recommendation 2: Provide education, training, and communication to improve awareness, prevention, access, and quality cancer care for AYAs.**

The AYAO PRG recognized an urgent need for a variety of education, training, and communication activities to raise awareness and recognition of the AYA population at both public and professional levels as a first step toward increasing national focus and resource allocation to address the AYA cancer problem. To be effective, all education, training, and communications must be culturally appropriate and delivered by individuals who are culturally competent.

Educational and other interventions to modify the exposure of AYAs in the general population to potentially modifiable cancer risk factors (e.g., human papillomavirus, ultraviolet light, poor diet, lack of physical activity, obesity, tobacco use) offer the opportunity to reduce cancer risk during the AYA years as well as risk for cancers in older adulthood. Efforts

also are needed to promote the importance of health insurance in this population, since neither AYAs nor their families may place a high priority on maintaining coverage for young people who typically are healthy. For those diagnosed with cancer and their families, targeted education and online resources for cancer information, insurance resources, peer support, and other information needs will help empower AYAs to understand and manage their own care.

Current health care provider training programs generally do not address AYA-specific issues, resulting in poor recognition of AYAs' cancer risk and inadequate response to their medical and psychosocial needs. Core competency curricula are needed for inclusion in appropriate initial training and continuing education programs to ensure that all providers who work with adolescents and young adults have the requisite understanding of the cancers that either peak or occur more commonly in this age group, post-treatment surveillance for late effects, and the specific psychosocial, economic, educational, and communication needs of the population. Programs also are needed to train patient navigators, advocates, and other lay persons who conduct outreach to and represent AYA interests. It was the consensus of the PRG that physician involvement is the key factor in the patient's decision to participate in a clinical trial. Thus, targeted education to raise referring physicians' and medical oncologists' awareness of the potential benefit of AYAO relevant trials provides a means to improve patient outcomes.

**Recommendation 3: Create the tools to study the AYA cancer problem.**

The existing research infrastructure is inadequate to support needed AYA-focused research. Appropriate research tools to enable such studies must be developed if they do not exist, and strengthened if potentially useful infrastructure already is in place.

The most pressing needs are to: (1) create a prospective database on all AYA cancer patients; (2) increase the number of annotated AYA tumor, normal tissue, and other biospecimens; (3) create or modify assessment tools specific to AYA cancer issues; (4) improve grant coding and search term standardization; and (5) expand the number of clinical trials appropriate for and available to AYAs.

**Recommendation 4: Ensure excellence in service delivery across the cancer control continuum (i.e., prevention, screening, diagnosis, treatment, survivorship, and end of life).**

The AYAO PRG urges the implementation of two principal strategies to improve service delivery to AYAs with or at risk for cancer and ensure excellence in care across the cancer control continuum. First, standards of care for AYA cancer patients must be developed, evaluated, and disseminated. This enormous task must be undertaken with the understanding that standards are dynamic and must be updated as advances in care are achieved. Excellence in care may vary not only by cancer diagnosis but by multiple other variables (e.g., age and gender, race/ethnicity/culture, socioeconomic status, access to/source of care, insurance status) that must be addressed to meet the complete spectrum of patient needs.

Second, establishing, disseminating, and reinforcing standards of cancer care for AYAs will require the ongoing and concerted collaboration of a diverse array of stakeholders. Health care providers, research sponsors, investigators, regulators, insurers, and patient advocates should expand existing collaborations and establish a national network or coalition committed to improving the quality of life and outcomes for AYAs with cancer.

**Recommendation 5: Strengthen and promote advocacy and support of the AYA cancer patient.**

In addition to raising public and professional awareness of AYAs as a distinct understudied and underserved age group, advocacy and support services for AYA cancer patients and survivors need to be strengthened. Such effective support of AYAs with cancer must be predicated on an understanding of how cancer may affect young peoples' self-identity, self-esteem, spiritual perspectives, body image, perception of their future possible life goals, distress levels, need for information and communication, and numerous other subjective components of experiencing a life-threatening disease. Empirical research is needed to explore these aspects of the cancer experience among AYAs and inform intervention development and health care provider training.

Numerous advocacy, patient support, social service, religious, fraternal, social, and health professional organizations currently have some focus on AYA cancer patients and survivors. Training and fiscal support are needed to expand the capacity of these established entities to address the psychosocial needs of this population. In addition to building the capacity of existing resources to address the psychosocial needs of AYAs, evaluation is needed to assess the efficacy (i.e., effect on outcomes) of existing programs. These evaluations should be used to inform the development of new AYA-specific interventions.

### **Conclusion**

Cancer in adolescents and young adults is an important problem that has gone unrecognized or is only a peripheral concern among numerous research, medical, health services payor, patient support and advocacy, funding, and cancer surveillance constituencies, as

well as healthy teenagers and young adults who do not know they are at risk for cancer. This limited focus has had severe consequences—a lack of cancer survival progress spanning more than two decades and persistent diminution of young cancer survivors' quality of life.

The AYAO PRG believes that a major, ongoing AYAO-specific research initiative emphasizing AYA clinical trials and outcomes research is urgently needed. Collaboration and support from numerous governmental, academic, public health, community-based, and other private sector entities will be essential to its success. The AYAO PRG offers this report as a blueprint for a focused and structured approach to improving cancer prevention, cancer care, and the duration and quality of life for this vital segment of our society.