

Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) Study

Applied Research Program

Background

Compared to younger and older cancer populations, the adolescent and young adult (AYA) population between the ages of 15 and 39 years has seen little or no improvement in cancer survival rates for decades. In 2005, a Progress Review Group (PRG) supported by the [National Cancer Institute](#) (NCI) and the [Lance Armstrong Foundation](#) (LAF) identified important factors that might contribute to the poorer outcomes observed for many AYA cancer patients, including:

- restricted or delayed access to care;
- delays in diagnosis; and
- inconsistency in cancer treatment and follow-up care.

These patients too frequently fall into a “no man’s land” between pediatric and adult oncology. Research on AYAs has been further constrained by their exceedingly low participation in the relatively few clinical trials available to them. In addition, data on psychosocial factors specific to this population (e.g. impact of cancer on education, employment, social and family issues, fertility preservation) are lacking. Inconsistency in care, coupled with insufficient research data, have 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. The PRG determined that research in this population is a high scientific priority.

Overview and Key Objectives

To address some of the gaps noted above, a trans-NCI and extramural team planned the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) Study, a feasibility study to include approximately 530 AYA cancer patients, ages 15–39. The feasibility study was primarily designed to help

the study team understand how best to obtain consent, collect outpatient and inpatient medical records, and survey recently diagnosed AYA cancer patients in population-based community settings.

Study patients were diagnosed between July 1, 2007 and October 31, 2008 with germ cell, Hodgkin lymphoma, non-Hodgkin lymphoma, acute lymphoblastic leukemia, or sarcoma (Ewing, osteo or rhabdomyo) and were identified from population-based cancer registries. AYA HOPE is funded by the NCI, with support from the LAF, and is being conducted in seven NCI [Surveillance, Epidemiology, and End Results](#) (SEER) cancer registries: Los Angeles, Seattle-Puget Sound, Iowa, Louisiana, Detroit, Northern California, and Greater California.

The **consent component** of the study will enable the study team to identify the best ways to obtain patient or parental consent to review medical records. It will also enable the team to determine where and from what physician specialists AYAs receive care.

The **medical record component** will determine whether the study team can obtain medical records for the diagnosis and treatment of these patients. It will also determine whether these records contain sufficient detail to allow the team to examine treatment regimen, practice patterns, and the influence of insurance status, comorbidity, and other variables on therapy. The medical record abstraction collects information on type of healthcare facilities used, tumor characteristics and staging, diagnostic work-up procedures, subspecialties of physicians involved in care, details of radiation therapy and systemic therapy, comorbid conditions, and enrollment in clinical trials.

The **survey component** (a brief, 15–20 minute instrument administered via Internet or paper, with phone follow-up of non-responders) will enable the study team to

assess the receptivity of AYA patients to complete a questionnaire and report on barriers to care (e.g., financial and insurance barriers) and to assess which areas of social and physical functioning are most relevant. Survey questions address the impact of cancer, health-related quality of life, healthcare delivery practice patterns, decisions about clinical trial involvement, demographic, socioeconomic, and supportive care characteristics.

A **follow-up study** of the AYA HOPE feasibility study cohort was funded by the NCI in July, 2009, with support from the Lance Armstrong Foundation. This follow-up study concluded in July, 2010. It is the first longitudinal population-based study in the AYA oncology population in the United States.

The original study assessed patients 6 to 14 months post-diagnosis. The follow-up study provides additional survey data approximately 24 months post-diagnosis. It allows the study team to assess questions that were not possible on the original survey (e.g. follow-up care and fertility preservation decisions) and to examine certain domains over time (e.g. symptoms, job and school-related adjustment, health-related quality of life). Diagnosis of new primary cancers and vital status were assessed. The study team is also able to determine the feasibility of recontacting patients in order to collect longitudinal data in the AYA cancer population.

This study will inform the development of future studies to focus on care and outcomes in the AYA population.

Current Status

The seven SEER registries noted above (i.e., Los Angeles, Seattle-Puget Sound, Iowa, Louisiana, Detroit, Northern California, and Greater California) are responsible for collecting the medical record and survey data.

Survey data collection for the original study is complete. Medical record abstraction is ongoing. Data from the follow-up survey were collected in 2009 and 2010. Manuscripts will be forthcoming.

For More Information

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