

north carolina
cancer partnership

**Adolescent/Young Adult White Paper
Fall 2007**

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Overview

Nearly one in every 200 adolescents and young adults, ages 15-29, will develop cancer each year. It is the most common cause of death among females in this age group and is the second leading cause of death for males of this age group, next to heart disease, according to a report done by the National Cancer Institute and the Lance Armstrong Foundation.

A study performed by Surveillance Epidemiology and End Results (SEER) from the year 2000 showed that lymphomas comprised nearly 20% of cancer affecting adolescents and young adults, with the leukemia's following closely behind. Melanoma is the deadliest form of cancer that affects the adolescent and young adult population.

Relatively little is known about the genetic, epidemiologic, psychosocial, biologic and economic factors of cancer in adolescents and young adults (AYAs). Because of limited knowledge, barriers exist that usually compromise adequate care and treatment for AYAs. The survival deficit is caused by a variety of issues, including:

- Restricted access to care because of high uninsured rates
- Lack of knowledge pertaining to the biology of cancers specific to AYAs
- Falling between pediatric and adult oncology practices
- Limited number of clinical trials available
- Limited psychosocial support services for AYAs

Because there is relatively scant data to support either an environmental or an inherited predisposition to cancer in this age group, it is often hard for AYAs to know how to prevent and/or be attentive to symptoms of cancer the body might present.

Among AYAs, non-Hispanic whites have the best survival rates, with Asians shortly behind, while African Americans have the worst survival rates.

This lack of progress in survival improvements among AYAs is heavily contrasted with the survival improvements of all other age groups. Whereas the prognosis of cancer in other age groups continues to be more favorable, the current survival improvement trends for AYAs continue to lack. Improvements must be made for an increased prognosis and survival rate for the adolescent and young adult population.

Clear Definition

Each year, nearly 65,000 adolescents and young adults (AYAs), ages 15-29, are diagnosed with cancer worldwide. Empirical and observational research indicates that AYAs with cancer are distinguished by physiologic, developmental and societal characteristics, which sets them apart from the younger and older generations. This population is defined by the upper and lower age limits of 15 and 29 to facilitate clarity, consensus and data collection, in order to accommodate research and treatments for this specific age group. Although cancer occurs in only one in every 200 older adolescents and young adults, everyone is at risk (1).

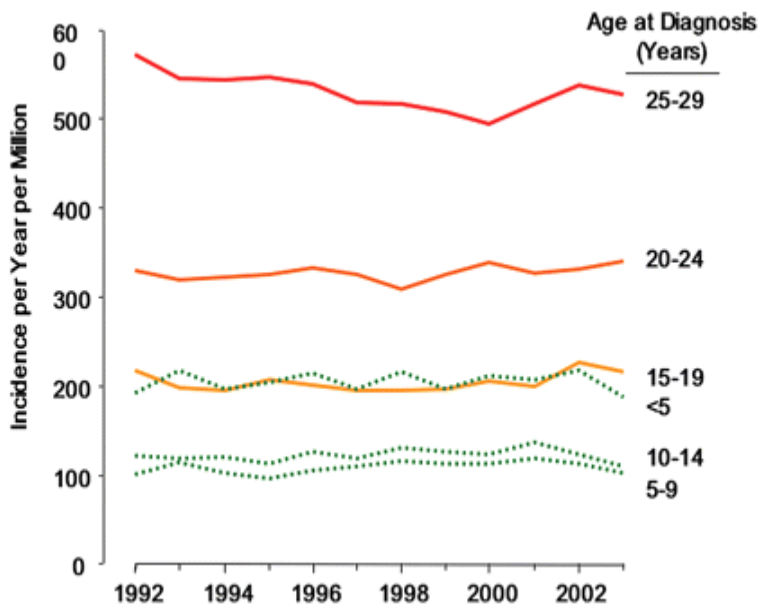


FIGURE 3 Incidence of Invasive Cancer by Calendar Year and Age at Diagnosis, Age Younger Than 30 Years, US SEER, 1993 to 2003. Data from SEER.⁵

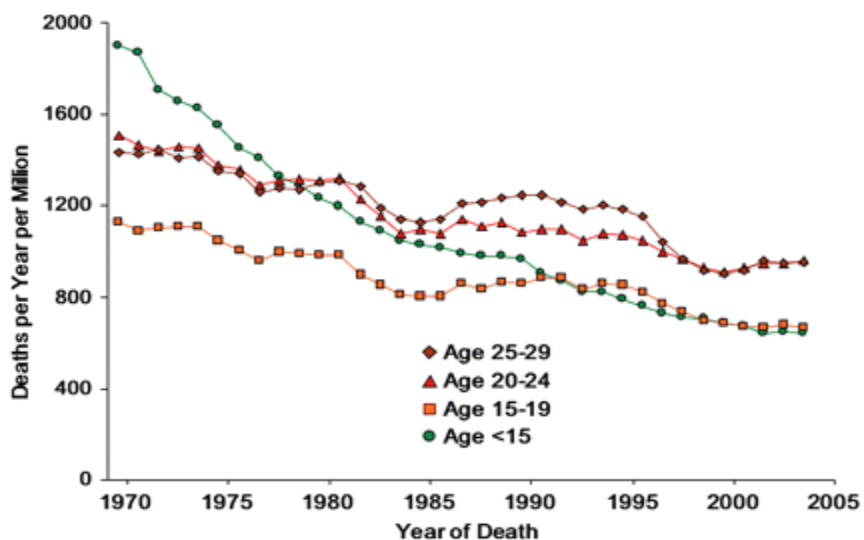


FIGURE 9 US National Annual Cancer Mortality Rate by Calendar Year for Ages Younger Than 15 Years, 15 to 19 Years, 20 to 24 Years, and 25 to 29 Years at Diagnosis. Data from SEER.⁵

There are approximately five types of cancer common among this age group:

Lymphoma, the most prominent cancer, is cancer of the lymph nodes; the tiny, bean-shaped organs that help fight diseases

Leukemia, cancer of the blood and bone marrow or germ cell tumors, which are special cells in a developing embryo that eventually become the testes in males and the ovaries in females are the second most prominent

Melanoma, cancer of the skin and deadliest form of cancer

Thyroid cancer, cancer that begins in the thyroid gland, which is located in the front of the neck

Soft tissue sarcomas, a cancer that develops in supportive and connective tissue such as fat, muscle, nerves, tendons, joints, blood vessels, and lymph nodes (2).

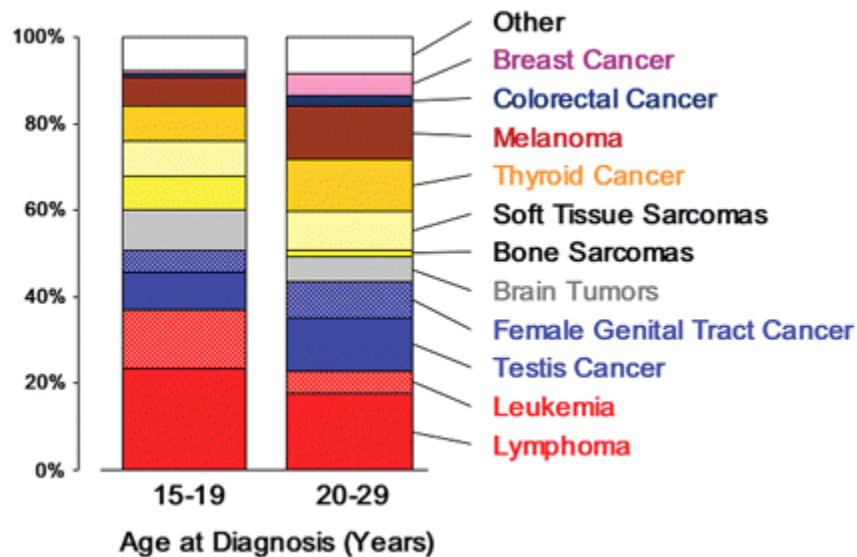


FIGURE 4 Relative Incidence of the Most Frequent Types of Invasive Cancer in 15- to 29-year-olds, US SEER, 1992 to 2000. Data from SEER.⁵

Adolescents and Young Adults with cancer face a different set of challenges than older and younger people with cancer. The AYA population faces different types of cancers that are rarely related to environmental carcinogens, a recognizable inherited predisposition, or a family cancer syndrome (1).

This population's age, life-position, and unique set of issues puts them in a very fragile position compared to children under age 15 and the older adult populations. These issues stem from struggles with becoming independent to the location of family and peer support, to a lack of experience in making major medical decisions and managing medical treatment. The AYA population may also encounter issues with health insurance, life insurance, job security and career planning, fertility, intimacy and the long term physical and emotional ramifications that accompany a cancer diagnosis (3). In addition, many AYA survivors have a full life expectancy, which puts them at higher risk for developing late-term side-effects from the treatment. The overall progress of treatment and prevention of cancer in AYAs has been hampered because this age gap has been under-recognized in the overall population (4).

At the beginning of the last quarter century, the diagnosis of cancer in adolescents and young adults carried a more favorable prognosis, on average, compared to other age groups. Since then, there has been a lack of progress in survival rates amongst older adolescents and young adults relative to their age (5). A large challenge in this area is the deficit in translational research. Solutions to the deficit need to take place in order to increase the survival rates for AYA patients.

TABLE 2 Potential Explanations for the Survival Deficit in Older Adolescents and Young Adults Compared with Younger and Older Patients* (5)

General Category	Primary Factors
<i>Personal/patient</i>	<i>Independence/autonomy</i> <i>Feelings of invincibility</i> <i>Underutilization of health care services</i> <i>Awareness</i> <i>Delay in diagnosis</i> <i>Health insurance</i> <i>Financial limitations</i> <i>Participation in clinical trials</i> <i>Translational research</i>
<i>Family/community</i>	<i>Awareness</i> <i>Lack of education</i> <i>Lack of guidance</i> <i>Inadequate community resources</i>
<i>Health professionals</i>	<i>Awareness</i> <i>Delay in diagnosis</i> <i>Education/training</i> <i>Reimbursement</i> <i>Health insurance</i> <i>Tumor specimens</i> <i>Lack of clinical trials</i>
<i>Societal/cultural</i>	<i>Awareness (by employers, school personnel, neighbors)</i> <i>Health insurance</i> <i>Delays in diagnosis</i>

Issues that affect AYA's include:

- Understanding the complex psychosocial environment, in relation to the patients mental and emotional health
- Managing chronic and delayed adverse effects of treatment.
- Overcoming a lack of progress in increasing survival rates.
- Improving the quality of life needs of AYA survivors with a particular emphasis on the economical and psychosocial costs associated with diagnosis, treatment and long-term follow-up (5).
- Healthcare access, which includes a lack of insurance within the AYA population
- Lack of understanding behind the biology of cancers specific to AYAs.

Males in this age group have a higher risk of developing cancer, with the risk directly proportional to age, as well as having a worse prognosis than females.

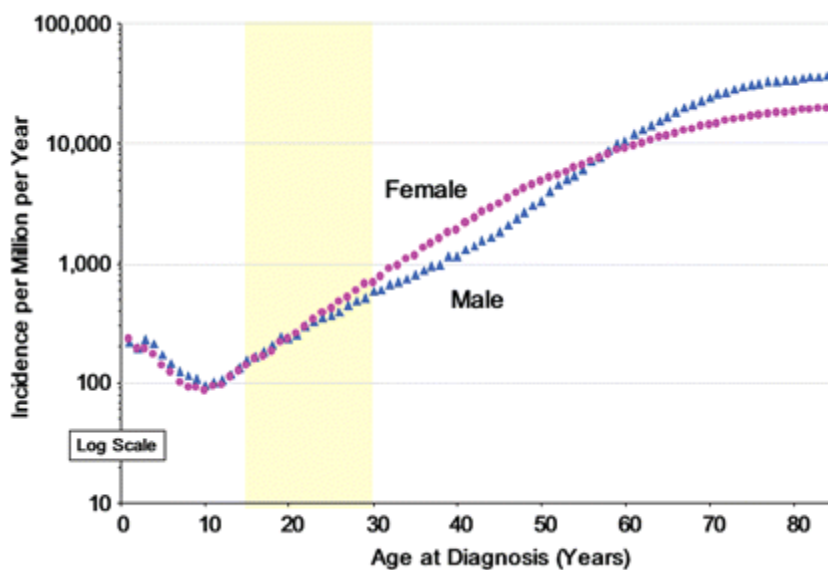


FIGURE 1 Incidence of Invasive Cancer by Individual Year of Patient Age at Diagnosis and by Gender, US SEER, 1973 to 2003. The ordinate is a log scale, and the yellow background zone designates 15- to 29-year-olds. Data from SEER.⁵

African Americans, American Indian/Alaska Natives have a worse prognosis than white non-Hispanics and Asians (5), although Non-Hispanic Whites have the highest incidence of cancer amongst AYAs with the lowest incidence cited among American Indians (1).

Recently, the allied health community has started to recognize and address the needs of the AYA population. Both national organizations, such as the Lance Armstrong Foundation, and self-start up groups, such as PlanetCancer.org, are leading the way in research and initiatives. However, the formal

development of national and international organizations is essential to addressing these deficits and ultimately creating a formal discipline of adolescent and young adult oncology (5). Specifically, resources should be devoted to educating the public, health professionals, insurers, and legislators about cancers during this unique phase of life and about the special needs of the AYA patients.

Burden – Including Disparities

National

Cancer is the leading cause of death among adolescents and young adults, excluding homicide, suicide and unintentional injury. In addition, it is the most common cause of death among females in this particular age group, and is the second most common cause of death among males.

In the year 2000, nearly 21,400 AYAs in the United States were diagnosed with cancer, showing a 3.6% increase from 1975-2000 (5). Lymphomas accounted for 20% of all cancers among AYA cancer patients. Based on recent trends, an estimated 20,260 new cases of AYA cancer can be expected to be diagnosed during the year 2007 (1). Over 600,000 of the 9 million cancer survivors in the United States are AYA survivors (6). When the definition of survivor is expanded to include spouses, family and close friends of AYA survivors, between 1.2 million and three million people in the United States are affected by cancer (7).

While the overall survivorship rates may seem promising, one must acknowledge the increase in mortality rates within the AYA population in order to comprehend the magnitude of the national burden.

State

North Carolina State Center for Health Statistics, NC Department of Health and Human Services Resources indicates that there is not sufficient information being collected about the AYA population in the state of North Carolina. This lack in research proves that there is a much greater problem at hand, in which standardization for data collection of the AYA population must be addressed.

2000-2004 Age Specific Cancer Rates per 100,000 Populations

15-29	2000-2004			2004	
	Total			Total	
	CASES	RATE		CASES	RATE
ORAL CAVITY	53	0.6		17	0.9
ESOPHAGUS	*	*		*	*
STOMACH	8	0.1		*	*
COLON/RECTUM	84	1.0		20	1.1
LIVER	10	0.1		*	*
GALLBLADDER	*	*		*	*
PANCREAS	7	0.1		*	*
LARYNX	8	0.1		5	0.3
LUNG/BRONCHUS	20	0.2		6	0.3
BONE	88	1.0		19	1.1
SOFT TISSUE	91	1.0		22	1.2
MELANOMA (SKIN)	376	4.3		65	3.6
FEMALE BREAST	123	2.9		20	2.3
CERVIX UTERI	83	2.0		19	2.2
CORPUS UTERI	25	0.6		7	0.8
OVARY	81	1.9		9	1.0
PROSTATE	*	*		*	*
TESTES	296	6.6		69	7.4
BLADDER	24	0.3		*	*
KIDNEY	45	0.5		7	0.4
ENDOCRINE	270	3.1		83	4.6
MULTIPLE MYELOMA	*	*		*	*
LEUKEMIA	192	2.2		35	1.9
BRAIN/OTHER CNS	190	2.2		38	2.1
HODGKINS DISEASE	327	3.8		66	3.7
NON-HODGKINS LYMPHOMA	161	1.8		33	1.8
OTHER CANCERS	168	1.9		40	2.2
ALL CANCERS	2,741	31.5		594	33.0

NC Central Cancer Registry (11/2007)
Numbers are subject to change

*Counts less than 5 are suppressed
Rates based on counts of less than 10 are unstable

Regional

There is not sufficient data regionally for the AYA population of North Carolina.

County

There is not sufficient data for the counties of North Carolina for the AYA population.

Dimensions (including optimal standards)

Prevention

Very little prevention research has been done for the AYA population. Of the research that has been conducted, it has been largely ineffective (5). Overall, the vast majority of cases of cancer diagnosed in the AYA population appear to be spontaneous and unrelated to either carcinogens in the environment or family cancer syndromes (1).

Risk Factors

Risk factors are those that increase an individual's chance of getting any illness, such as cancer. Risk factors affect every individual throughout their lifetime, but vary depending on life variables either within or outside of the individual's control.

Germline mutations (cancer family syndromes) represent less than 5% of the overall cancer incidences among AYAs (4).

Possible Protective Factors

Although prevention seems to be largely ineffective at this age, there are a few important preventative methods that would help in decreasing one's chance of developing cancer both as AYAs and throughout their lifetime. Decreasing tobacco usage, encouraging the use of sun protectants, and administration of vaccines to prevent several sexually transmitted diseases are the most relevant prevention techniques available to the AYA population (4,8).

Eating a variety of colorful fruits and vegetables are essential because they are packed with vitamins, minerals, and antioxidants that help in the prevention of cancer (9). For example, a plant-based diet provides phytonutrients that have been shown to stop the growth of cancer cells and activate certain enzymes that can kill cancer-causing toxins.

Other guidelines that physicians recommend include, a diet of high-fiber foods such as whole grain breads, rice, pasta and cereals, limiting refined carbohydrates, including pastries, sweetened cereals and soft drinks, as well as decreasing the amount of fat in meals by baking, broiling or boiling foods. Limiting intake of red meats and substituting fish, poultry or beans as well as avoiding salt-cured, smoked, charbroiled, and pickled foods are important (10).

Evidence suggests that being overweight raises the risk for recurrence of cancer and reduces the odds of survival for many cancers. Increased body weight has been linked with higher death rates for all cancers combined (4,8). Exercise is important because any excess weight causes the body to produce and circulate more of the hormones (estrogen and insulin) which can stimulate cancer growth (9). Exercise helps promote the healing of tissues and organs damaged by cancer and its treatments, which builds strength and endurance, and reduces the risk of certain types of adult cancers and decreases stress (10).

Rare exceptions of environmentally induced malignancies at this age include: melanoma, cervical carcinoma, non-Hodgkin lymphoma, Hodgkin and Burkitt lymphomas respectively from ultraviolet light, human papillomavirus, human immunodeficiency virus, and Epstein-Barr virus (5). In addition, Clear cell adenocarcinoma of the vagina or cervix in adolescent females has been caused by diethylstilbestrol taken parentally by the mother in attempts to prevent spontaneous abortion. Radiation-induced cancer may occur in AYA's after exposure as a child. In fact, many AYA survivors have reported a second malignant neoplasm as a result of prior treatment with chemotherapy and/or radiotherapy (5).

All of these prevention and healthy lifestyle methods are also important in the prevention of secondary cancers, as the likelihood of developing a secondary cancer significantly increases after one diagnosis of cancer. And being aware of these factors as an AYA survivor is important because lifestyles are often established during these critical years. Cancer control efforts in adolescents and young adults will help decrease their incidence rates as older adults overall as well as decrease the risk of secondary malignancies amongst AYA survivors.

Screening & Early Detection

A lack of standardized screening and primary care issues increases the disparities in proper cancer care among young adult cancer patients when compared to other populations of cancer patients. Common symptoms of cancer in AYA's include: masses in the testis, breast, abdomen, neck or elsewhere; persistent fatigue; abnormal discharge from an orifice; lymph gland swelling, knee/shoulder pain or swelling or increased intracranial pressure (1). Although there are various symptoms, some cancers don't present any symptoms, or are so minimal that the patient ignores the signs. Consequently many cancers are left untreated for some time allowing the cancer to spread and multiply, and further limiting the patient from the optimal care.

Barriers in screening & early detection:

- Restricted or delayed access to care, because the AYA population is typically under or uninsured (4)
- Sense of invincibility, which causes patients to ignore or minimize obvious symptoms
- Physicians poorly trained or unwilling to care for AYAs
- Under-recognition by medical professionals of cancer or its symptoms and signs in the age group.
- Greater lag time, interval between onset of first symptoms to the day of cancer diagnosis (5).
- "No man's land"- AYAs fall between the pediatric and adult oncology clinics, therefore receiving inconsistent treatment protocols, of which, many were not meant to treat AYAs.

In addition, early detection isn't typically discussed in school health education programs in part because of the controversy between physicians about the efficacy of AYAs performing accurate breast or testicular self-examinations, and because many physicians are unaware of the specific cancer risks among AYAs. Surveillance in this age group is usually limited to pap smears among females (4).

In turn, cancer awareness must increase nationally and resources must be expanded throughout schools to address the cancer problems in the AYA population, which might help to increase enrollment in health insurance plans and reduce delays in diagnosis (4). Encouraging periodic health exams and physical Adolescent/Young Adult White Paper, Fall 2007

activity proves to be useful (8). Further, clinical trials must be encouraged by family physicians in order to increase treatment choices and accelerate treatment advances for screening and early detection (4).

Care & Treatment

Trying to find an oncologist and treatment center can be very overwhelming. It is important to find a doctor who has treated other AYA patients with varying types of cancer and who can provide the best available treatment options. AYAs must talk with their current physician/ nurse to find a cancer center or local hospital that would best meet their needs. Advantages of treatment at a cancer center include: specifically trained doctors in the AYA population; more clinical trials offered generally; greater availability of support services including nutritional assistance and/or counseling (2).

Age is a large indicator of available treatment options, although some adult treatments are better for AYAs and vice versa. For example, several studies of older adolescents with Acute Lymphoblastic Leukemia have shown that being treated with pediatric drug regimes tended to live longer, than those treated through adult regimes. Data from the US National Cancer Data Base also revealed that adolescent’s ages 15-19 with non-Hodgkin lymphoma, leukemia, liver cancer and bone tumors had a survival advantage if treated at a National Cancer Institute pediatric group institution (11). On the other hand, young adults with malignant melanoma, colorectal carcinoma, breast cancer, or epithelial ovarian cancer tend to be better served by adult medical oncologists, gynecologic oncologists, and surgical oncologists (1).

Treatment Facility	Contact Information
Lineberger Bone Marrow and Stem Cell Transplantation Program	http://cancer.med.unc.edu/patient/programs/bone-marrow.asp (888) 263-5293
Lineberger Comprehensive Cancer Center	http://cancer.med.unc.edu (886) 828-0270
Pediatric Cancer (Duke University Health System)	http://www.dukehealth.org/Services/PediatricCancer (888) 275-3853
Brenner Children’s Hospital	http://www.brennerchildrens.org (800) 446-2255
Children’s Hospital (University Health Systems of Eastern Carolina)	http://www.uhseast.com/childrens_home.cfm?id=8&oTopID=8 (252) 847-4980

Once a treatment facility is found, options for treatment are discussed depending on type, stage of the cancer, age and overall health of the patient (2).

Common treatment methods:

- Surgery, an operation to find and remove the tumor, is readily performed on AYAs as opposed to younger or older patients who have more coexisting morbidities and have a harder time dealing with anesthesia.

- Chemotherapy, the use of drugs to kill cancer cells, particularly oral chemotherapy, is often more problematic in AYA patients either because of the lack of parental oversight, feelings of invincibility, or impediments to compliance because of financial limitations, and/or conflicts with school or transportation (12,13).
- Radiation therapy, the use of high-energy x-rays or other radiation particles to kill cancer cells
- Immunotherapy, a treatment that stimulates or restores immune function
- Targeted therapy, a treatment designed to specifically interfere with cancer cell growth and spread are used.
- Stem cell transplantation, the replacement of one's stem cells in the bone marrow with a donors healthy stem cells.
- Clinical trials, the carefully conducted tests in patients of new treatments or of potentially better ways to use current treatments (2).

Physical Challenges

Psychosocial Challenges

Weight gain/loss	Dependence from parents/caregivers
Mucositis	Peer group approval
Dermatitis	Negative self-image
Bleeding/infection	Impaired feelings of intimacy
Alopecia	Loss of school/work time

(1)

Coping Strategies

Prayer
Exercise (if possible)
Support groups
Optimum nutrition
Professional counseling
Journaling
Visiting with friends/family
Painting/drawing

(1)

Clinical Trials

Clinical trials are research studies that compare standard treatments with newer treatments that may be more effective. These treatments can include new medications and procedures, new combinations of existing therapies, new methods of treatment, or better ways to improve the patients overall quality of life. Clinical trials help study whether a new therapy is safe and effective in hopes to create new and better therapies (2). Prevention, screening, diagnosis and/or treatment are the scientific approaches used as methods in clinical trials.

Despite the importance of these clinical trials, only 1-2% of young adult oncology patients participate in clinical trials (4), which is the lowest proportion of patients in any other age group. In contrast, over 90% of children younger than age 15 enter into clinical trials (14).

Possible barriers for lack of participation:

- Lack of clinical trials for AYAs
- Lack of awareness
- Inadequate trial availability (because few NCI Cancer therapy programs are available)
- Feeling of being treated as a “guinea pig”
- Concern of added time commitment
- Lack of desire among physicians’ to work with AYAs

(4)

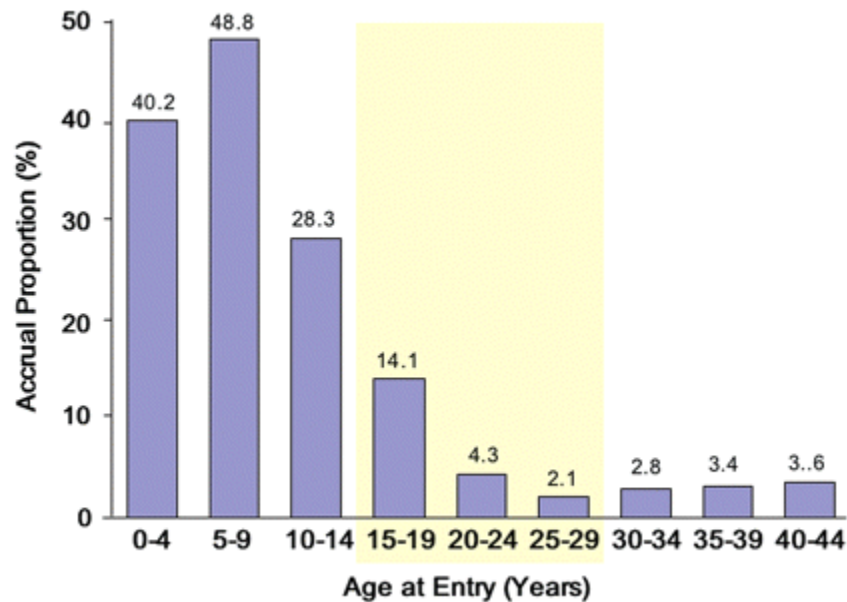


FIGURE 5 Estimated Proportion of Newly Diagnosed Cancer Patients Accrued to National Treatment Trials by Patient Age at Study Entry, 1997 to 2003. Clinical trial data courtesy of Montello M, Budd T, Cancer Treatment Evaluation Program, US National Cancer Institute. Population data from the US Bureau of Census.⁷ The yellow background zone designates the 15- to 29-year-old age range. Data from SEER.⁵

Available Clinical Trials for AYAs:

Facility	Contact
American Cancer Society (free, confidential matching service to national clinical trials)	http://www.cancer.org/docroot/home/index.asp
Specialized Programs of Research Excellence (UNC Lineberger Comprehensive Cancer Center)	http://cancer.med.unc.edu/ct/
Coalition of Cancer Cooperative Groups	www.cancertrials-help.org
Duke University Medical Center	http://www.cancer.duke.edu/CTrials/
Wake Forest University Medical Center	http://www1.wfubmc.edu/cancer/Clinical+Trials/
Center Watch	http://www.centerwatch.com/
Clinical Trials.Gov	http://clinicaltrials.gov/

Ways to combat Low Clinical Trial Participation:

- Improve access to care through understanding barriers to participation
- Develop a cancer resource network that provides information about clinical trials to patients, families, providers and the public
- Enhance compliance of protocol-prescribed therapy
- Establish and promote participation in trials specifically designed for this age group (14).

Beyond Treatment

An estimated 600,000 cancer survivors alive today were diagnosed between the ages of 15 and 29 (15). This percentage is low compared to the rapidly increasing percentage rates of children and adults with cancer. Low insurance rates, feelings of invincibility, lack of age relevant clinical trials and unwilling physicians, all attribute in part to the survival rate decline (16) among AYAs; as well as a lack of relevant studies to examine the immediate and long-term emotional and psychosocial affects of treatment (4).

Beyond treatment is often referred to as survivorship, which includes a variety of elements for each patient. The most common elements that encompass survivorship include: late-term effects, long-term effects, psychosocial disorders, daily living, pain and palliative care and end of life.

1. Late-Term Effects

Late-term effects are those effects that are delayed and can surface months to years after treatment ends and can be permanent. For AYAs these are important to recognize early on, as these patients have the majority of life ahead of them. Because late effects are a result of treatment, nearly any treatment may cause late effects.

Examples:

Infertility risks
Injury to the lungs
Inflammation of the lungs
Decrease in hormone levels (resulting in early menopause)
Osteoporosis
Hearing loss
Gum disease
Scar tissue build up in the pelvis
Loss of memory

Screening for late effects is important to help minimize their prevalence. Yearly thyroid examinations, testing function of lungs, regular echocardiograms, imaging tests and routine blood tests should be performed on AYA patients throughout survival (2).

2. Long-Term Effects

Long-term effects develop during treatment, are lingering or chronic and continue after treatments are over. Many long-term effects improve or resolve with time, such as anemia, fatigue and anxiety. Some long-term effects are permanent, such as limb loss, some types of limb weakness or nerve damage (7).

Examples:

Long-Term Effects
Fatigue
Changes in heart
Reduced lung capacity with difficulty breathing
Kidney and urinary problems
Neuropathy (numbness, tingling and other sensations in certain areas of the body)
Muscle weakness
Inability to focus
Secondary cancers

After cancer treatment has been completed, it is essential that AYA patients seek long-term follow-up care. Having access to support is a vital part of regaining as normal a lifestyle as possible. Survivors may choose to stay with their oncologists or may return to their primary care doctor. Basic follow-up care can be with the oncologist or primary care, but patients should consult an oncologist on an annual basis until this is no longer deemed necessary. A detailed summary of all the previous treatments and medical

records should be on hand. Several items of importance include: keeping a chronological chart which lists all the doctor visits, test, biopsies, CT scans, treatments, MRI's, X-rays and blood work, so that medical practitioners can become quickly familiar with the patients case by reading their charts (3). The patient should also obtain and keep a file of all medical records for themselves in the event of change in hospital and/or physician care. These records can be attained through the primary oncologist.

Available Long-Term Follow-Up Clinics in NC:

Duke University Medical Center

Durham, NC 27710

(919) 684-3401

www.mc.duke.edu

University of North Carolina

Chapel Hill, NC 27599

(919) 966-1609

<http://cancer.med.unc.edu/patient/clinical-care.asp>

Wake Forest University Medical Center

Medical Center Boulevard

Winston-Salem, NC 27157

<http://www1.wfubmc.edu/cancer/>

3. Psychosocial Problems

AYA survivors often experience a variety of emotions, including anxiety, depression, fear of recurrence, anger and isolation. Usually, the most difficult issues include coping with interpersonal relationships, changes to body image and stress about prolonged disability. Issues such as amputations, fatigue, organ trauma, and increased likelihood of secondary cancers are all possible outcomes (17, 18) that tend to cause an “unsettled state of mind,” thus creating anxieties about physical, social and future plans (19).

Many survivors develop Post Traumatic Stress Disorder, which may cause nightmares and flashbacks, difficulty sleeping, and feelings of being detached from society (20). Higher risk factors for Post Traumatic Stress Disorder includes being female, persons with mental health or learning problems that were pre-existing, and recipients of Hematopoietic Cell Transplants (bone marrow or stem cell transplant) (10). Research also shows that AYA and childhood survivors report low Quality of Life, both physically and psychosocially, which is a large reason for psychosocial treatment (1).

Persistent anxieties over relapse, death, or late effects tend to be higher in AYA cancer patients. Because of this, discussing topics such as cancer education, interpersonal relationships, social support and management of depressive symptoms have helped to decrease the negative affect of cancer treatment (21). Health care providers should discuss the need for a referral to a mental health professional for a patient dealing with these symptoms. Treatment options vary from counseling in group or individual settings to medication.

Additionally, the American Cancer Society conducted a study revealing that young adolescent cancer patients feel most socially connected with other cancer-afflicted peers of the same age range. Survivors like to address common concerns between each other. For example, coping with uncertainty about one's Adolescent/Young Adult White Paper, Fall 2007

health and future, feelings of being alone and isolated, body changes, sexuality and intimacy, dating and relationships, and employment issues. They also feel it's necessary for young adults to have age-appropriate educational material written in a way that makes sense to them in order to provide more effective emotional support (8).

Exercising can reduce the symptoms of fatigue and improve other symptoms. It can also improve physical functioning and many aspects of quality of life. Moderate exercise has been shown to improve anxiety, and self-esteem, as well as heart and blood vessel fitness, muscle strength, and body composition.

Through discussing issues such as social support, interpersonal relationships, cancer education and management of depressive symptoms, survivors reported decrease in the negative effects of cancer, stress and fatigue.

4. Daily Living

Insurance

AYA survivors also realize the importance of insurance and on-going surveillance and assessment of long-term effects of treatment (8). Being at such a fragile age with health insurance, AYAs and their parents must explore all resources for paying for healthcare. Those who are uninsured should seek assistance from social service organizations or social workers to identify possible programs to help obtain low cost insurance and/or State or Federal public assistance programs that the patient may qualify for. Some health care providers can arrange payment plans for paying for primary care services as well as having lab work done for a reduced rate at the patient's county or city health department (10).

School/Academic Life

Returning to school after treatment can greatly impact AYAs. Certain therapies can affect memory and learning abilities, specifically patients treated with brain tumors, tumors involving the eye or ear, acute lymphoblastic leukemia and Non-Hodgkin's lymphoma. Any student with previous cancer treatments, who is having difficulty in school, should undergo a specialized evaluation by a psychologist at the time of recognition by the patient, teacher or parent. This evaluation is important simply because many problems don't become apparent until years after treatment is completed. Common problem areas are: spelling, reading, concentration, memory, processing (ability to complete assignments that require multiple steps) and planning (10).

Once a problem is identified, special accommodations can be requested to help maximize the student's learning potential. For example, the use of tape-recorded textbooks and lectures, modification of test requirements (extra time, oral instead of written exams) and duplicate sets of textbooks to keep at home are all helpful strategies.

In long-term follow up, the goal is to stay as healthy as possible and to succeed in school, and or work. A summary of the patients' cancer treatment should be administered to the school by the attending physician and should include: name of the disease(s), date and description of any relapses, name, address and phone number of the hospital where care was received, and the names of all the chemotherapy and or other treatment methods that were given (10).

Workforce

The same rules and regulations apply to the AYA who is returning to work. The state mandated cancer plan states that discrimination against AYA survivors is unlawful and considerations must be made according to the patients personal needs.

Accommodations include:

- Providing extended leave or flexible work hours to accommodate treatment schedules.
- Relocating an employee from a physical area that may compromise his or her health.
- Providing a fatigued cancer survivor sufficient time to rest.
- Allowing a survivor to work from home when practical.

(22)

Policy

In addition to these accommodations, there are laws that protect AYA students and those who return to work with health issues.

Rehabilitation Act of 1973-Section 504: modifications in the curriculum (such as allowing the use of a calculator and extra time for assignments or test-taking) and the environment (such as seating near the front of the classroom or allowing extra time between classes).

Individuals with Disabilities Education Act: requires that public schools provide “free and appropriate education in the least restrictive environment” for students treated for cancer, traumatic brain injury, or other health related impairment.

Americans with Disabilities Act: protects against discrimination in employment, transportation, communication, government and public accommodations for people with disabilities.

Fertility

Fertility is a major concern among AYA cancer patients in regards to late-term effects. There are various causes of infertility in cancer patients. The endocrine glands (ovaries, testis, thyroid, and adrenal glands) release hormones that regulate fertility and pregnancy. The body’s endocrine system is vulnerable to the effects of cancer treatments, thus damaging or altering a gland, later resulting in infertility (2). Chemotherapy therapy and radiation therapy can also damage the endocrine glands.

Recent advances in reproductive endocrinology and oncology have made it possible for many people to preserve their fertility. A lot depends on the gender, type and stage of cancer, and the relationship status of survivor, etc. as to whether the survivor is fertile.

Fertility preserving options (Men):

- Sperm banking
- Testicular tissue preservation
- Testicular sperm extraction
- Testicular sperm preservation

(Women)

- Embryo (fertilized egg) cryopreservation
- Oocyte (unfertilized egg) cryopreservation

- Ovarian-tissue preservation
- Abdominal radical trachelectomy
- Oral contraception

(2)

Unfortunately, fertility preservation isn't always successful and may not always be available or appropriate for everyone. Patients must seek advice from their attending physicians. In the event that the patient is no longer fertile, adoption is always available.

5. Pain and Palliative Care

Palliative care is a form of care that helps the patient have the best possible quality of life as their cancer progresses. Palliative care helps to relieve pain, improve emotional and mental well-being of all patients at all stages of survivorship, which is critical to AYA patients.

A study was conducted consisting of interviews with 66 children and their families to investigate how the experience of pain varied during cancer treatment. At diagnosis, 49% experienced cancer-related pain. Procedure- and treatment-related pain was the major problems initially. Procedural pain gradually decreased, but treatment-related pain was constant and dominating. Pain intensity measurement was seldom performed, and parents increasingly considered themselves better judges of their child's pain than professionals (23).

Oncologists reported a lack of formal courses in pediatric palliative care, a strikingly high reliance on trial and error in learning to care for dying children, and a need for strong role models in this area. Pediatric oncologists are working to integrate symptom control, psychosocial support, and palliative care into the routine care of the seriously ill child and AYA.

6. End of life

Everyone wants to live life to the fullest, but when cancer becomes a reality, it's important to explore all medical options. When a cure is no longer in sight, the end of life becomes a reality. Hospice is a medical, emotional, spiritual and social support system for patients and provides help to create a peace of mind.

The deficit of survival in young adult cancer patients tends to be caused because of a lack of awareness and a lack of translational research as well as a lack of tumor specimens for research. This lack of awareness is found within groups such as, legislators, health policy administrators, insurance company directors, national medical organization leaders, and leaders of institutions of higher learning, who should be particularly informed and educated about such issues.

As a result to this problem, major cancer organizations such as the American Society of Clinical Oncology, the American Cancer Society, the National Cancer Institute, the National Comprehensive Cancer Network, C-Change, and the national cancer cooperative groups should heavily advocate for the AYA population (5).

Hospice & Palliative CareCenter:

<http://www.hospicecarecenter.org/>

336-768-3972

Association for Home and Hospice Care of NC:

<http://www.homeandhospicecare.org/>

1-800-999-2357

Hospice of the Carolina Foothills:

<http://hocf.net/home/>

828.894.7000

Carolina Center for Hospice and End of Life Care:

<http://www.carolinasendoflifecare.org/>

(919) 617-4100

Genomics

Sequencing of the human genome and new technologies for global molecular analysis are helping to create special opportunities to study the molecular differences among young adult cancer patients. Emerging data, mainly from Acute Lymphoblastic Leukemia (ALL) indicates the differences in host vs. patient and tumor biology in young adults as opposed to any other age range (4).

Young adults with the ALL subtype TEL-AML fusion transcript have a better prognosis, then patients with BCR-ABL mutations. Knowing these variations helps doctors to choose the correct treatment methods. The role of epigenetics, including methylation of cancer-causing genes, show age-related differences in cancer outcomes. Age-related changes in these epigenetic regulations may cause the expression of genes to exaggerate their drug toxicity. Some of these key cancer-causing genes include LATS-1, CDH1, p57,p14 and p15 (4).

Some hormonal differences in the young adult age group tend to cause higher induction death rates (due in part to the toxic effects of the chemotherapy given), pancreatitis, treatment-related neuropathy (functional disturbance or pathologic changes in the peripheral nervous system) and glucose intolerance (4).

Barriers for studying the genomics related to young adult cancer patients are plentiful. For example, the study of sarcomas is limited because of the limited funding, while the number, size and quality of sarcoma's biological samples are limited. Also, the understanding of leukemia's, lymphomas, breast and colorectal carcinomas are limited because of the few normal tissue samples that are available to perform research (4).

Complementary Medicine

Some AYAs cope during and after treatment by using complementary medicine (24). Complementary and alternative medicine generally refers to practices that aren't integral parts of conventional medicine. Complementary medicines that AYAs are more apt to join include yoga, massage therapy, music and dance, and the use of natural herbs for nourishment.

What's On the Horizon

New methods of screening

Special Populations/Other Considerations

Ethnic/ Racial Minorities

Among AYAs, non-Hispanic whites have the highest risks of developing cancer, while Asians, American Indians, and Native Alaskans have the lowest risk (4). Although, African Americans and American Indian/Alaska Natives have the worst outcomes compared with non-Hispanic whites and Asians. This phenomenon may result in inequalities in access to health care, in receipt of quality health care, and/or differences in co-morbidities. Other factors may include: differences in exposure, access to high-quality regular screening (for breast, cervical, and colorectal cancers) and timely treatment. A lack in representation of minorities in clinical trials also proves to be a crucial component for decreasing survival rates. Barriers to healthy lifestyles, early detection services and good medical care are contributing to higher cancer incidence and mortality rates for underserved minorities in this country when compared with white U.S. citizens (25).

Eliminating cancer health disparities will require multifaceted approaches and an understanding of biological and non-biological factors. Disease biology, pharmacogenetic differences, social, economic factors and participation in clinical trials are key factors in incidence and survival disparities among racial and ethnic groups.

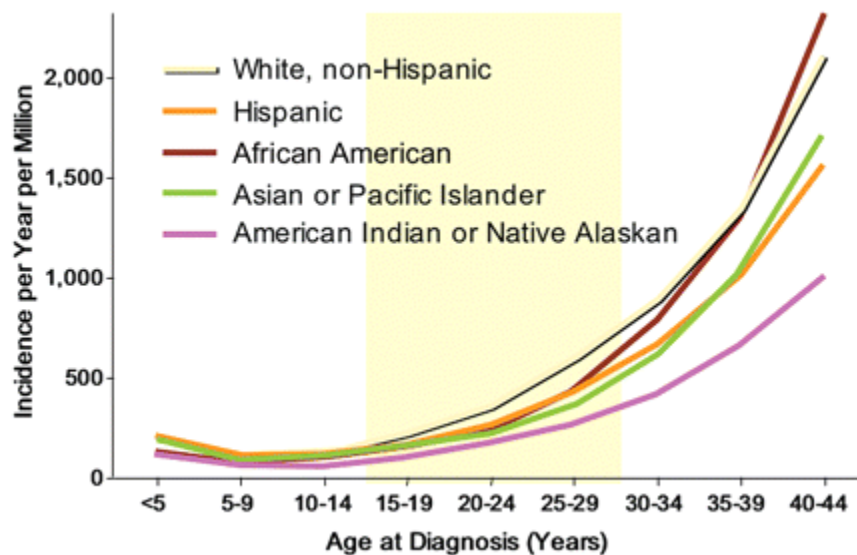


FIGURE 2 Incidence of All Invasive Cancer by Race/Ethnicity and Age at Diagnosis, Age Younger Than 45 Years, US SEER, 1990 to 2003. The yellow background zone designates the 15- to 29-year-old age range. Data from SEER.⁵

African-American

Death rates for all cancers combined for both men and women are highest among blacks (26). African Americans face a higher likelihood of developing and dying from each of the four most common cancers in the US (lung, colon, breast, and prostate) and have shown the worst outcomes in pediatric leukemia and lymphoma (27). From a survey detailing the annual five-year relative survival rates between white and black Adolescent/Young Adult White Paper, Fall 2007

leukemia and lymphoma survivors aging in range from 20-29, black patients were progressively worse than those for whites (27).

Overall, African American AYAs reported receiving less aggressive initial therapy compared to what was offered to the white AYAs. In addition, surgery and radiation treatments were offered less to the African American females compared to the White females. In treating ALL, the most common childhood malignancy, African Americans had the poorest outcome (4).

For breast cancer in AYAs, black females are twice as likely to be diagnosed and have three times higher mortality rates as a result. Both African American and Hispanic women presented having higher disease stage and a higher prevalence of adverse prognostic indicators in comparison with white women (28), yet the White females received more prompt and efficient care. Blacks and Hispanics were significantly less likely to report having had preventive services offered as screening for breast cancer (29).

AJCC Stages

Race	Total Cases	AJCC Stages	
		Phase II	Phase IV
Both Races	302,763	Cases/ 5-Year RSR (%)	Cases/ 5-Year RSR (%)
White	254,919	91,981/ 86.2	11,222/ 19.9
Black	25,467	76,296/87.1	8,970/ 21.2
		8,564/ 78.5	1,532/ 12.6

Table 13.3: Cancer of the Female Breast: Number of Cases and 5-Year Relative Survival Rates (RSR) (%) by Race and AJCC Stage (3rd edition), Ages 20+, 12 SEER Areas, 1988-2001

Native Americans

Native Americans have the poorest survival from “all cancers combined” than any other racial group (30). Researchers from the American Cancer Society reported in 2000, that Native Americans with cancer have a significantly lower survival rate than other American cancer patients (31), due to the lack of health insurance. The researchers found the five-year cancer survival rate for Native Americans was 36 percent compared with a survival rate of 47 percent among other Americans; although, some lifestyle factors may be causes of these rates. In general, Native Americans have a higher risk of dying from non-cancer related causes (31).

Asian American

The language barrier presents difficulty in medical advances in this population, although, incidence and mortality rates seem very low for the Asian American population. Compared to Hispanic and African American women, Asians have the lowest mortality rates for cervical carcinoma (32). In treating ALL, the most common childhood malignancy, African Americans had the poorest outcome and Asian Americans had the best (4).

Hispanic/Latino

In the United States, there is a lack of progressive care for the Hispanic/Latino population simply because of language barriers. Hospitals have recently realized this problem and realize the need for translators. Other reasons for the gap in care are apparent. Hispanic AYAs reported receiving less aggressive initial therapy Adolescent/Young Adult White Paper, Fall 2007

compared to what was offered to the white AYAs. In addition, surgery and radiation treatments were offered less to the Hispanic females compared to the White females. Hispanic youth make approximately 2.4 doctor visits per year (in comparison to white youth who make 3.6) due to lack of health insurance (33), which causes a hindrance to the preventative care for Hispanic AYAs.

Even though Hispanic women have lower rates of breast cancer compared to non-Hispanic White women, breast cancer is the leading cause of cancer deaths among Hispanics (34). Both African American and Hispanic women presented having higher disease stage of breast cancer and a higher prevalence of adverse prognostic indicators in comparison with white women (28).

Hispanics were significantly less likely to report having had preventive services offered as screening for breast cancer (29).

Traditionally Underserved

For many of the traditionally underserved population, incidence of cancer is similar to that of the rest of the population. Disabilities and handicaps, however, may increase the likelihood of late-term diagnoses. For some populations, such as adolescents with Down’s syndrome, the risk of cancer in general is increased. Adolescents with Down’s syndrome have a 10 to 30-fold increased incidence of leukemia, but the reasons are unknown (35). Several considerations have been presented including: immune deficiency leading to decreased immune surveillance, abnormal cell kinetics, developmental error with disruption of hemostasis and susceptibility to viral transformation.

- Blind
- Deaf
- Physically Disabled
- Mentally Handicapped
- Uninsured/ Indigent Men: **See Above**
- Illiterate

I. *Inventory of North Carolina Resources (Counties)*

a. *Prevention: groups and organizations that provide services intended to protect against disease by preventing it from occurring, reducing the risk of its occurrence aka “primary prevention.”*

Name of Organization	County	Contact Name	Address	City, State Zip	Phone & Fax	E-mail Address
American Cancer Society			8300 Health Park, Suite 10	Raleigh, NC 27615	Phone: (919) 334-5218 Fax: (919) 841-1422	www.cancer.org
NC Dept. of Human Services			10 Sunnybrook Rd.	Raleigh, NC	(919) 250-4553	http://www.ncdhhs.gov/

Moses Cone Health System Regional Cancer Center			501 N. Elam Ave.	Greensboro, NC 27403	(336) 832-8000	http://www.mosescone.com/body.cfm?id=49
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b. Awareness & Education: Groups and organization that provide lay health advisory information about early detection of cancer.

Name of Organization	County	Contact Name	Address	City, State Zip	Phone & Fax	Email/ website
Kidscan!		Jill Shipman	4420 Lake Boone Trail	Raleigh, NC 27607	(919) 784-6455	kidscan@rexhealth.com
Leukemia and Lymphoma Society		Holly D'Addurno	401 Harrison Oaks Blvd.	Cary, NC 27513	(919) 677-3993	www.lls.org
Wake Forest University Health Systems			Medical Center Blvd.	Winston Salem, NC 27157	(336) 716-7980	http://www1.wfubmc.edu/
AstraZeneca Cancer Support Network			PO Box 221644	Charlotte, NC 28222	(866) 992-9276	http://www.webmd.com/content/Article/120/113796.htm

c. Screening & Early Detection: Organizations that offer community screenings intended to promote the early detection of cancer.

Name of Organization	County	Contact Name	Address	City, State Zip	Phone & Fax	Email
Moses Cone Health System Regional Health Center			501 N. Elam Ave.	Greensboro, NC 27403	(336) 832-8000	http://www.mosescone.com/11479.cfm
Mission Hospital, Inc.			445 Biltmore Ave.	Asheville, NC 28801	(828) 213-4656	http://www.missionhospitals.org/cancer.htm
Duke University Health Systems			2301 Erwin Rd.	Durham, NC 27710	(919) 684-8111	www.dukehealth.org
UNC Hospital			101 Manning Dr.	Chapel Hill, NC 27514		http://cancer.med.unc.edu/

d. Diagnosis: Organizations that provide diagnostic services

Name of Organization	County	Contact Name	Address	City, State Zip	Phone & Fax	E-mail Address
Forsyth Medical			3333 Silas	Winston Salem,	(336) 718-5000	www.novanthhealth.org

Center			Creek Parkway	NC 27103		
Duke University Health Systems			2301 Erwin Rd.	Durham, NC 27710	(919) 684-8111	www.dukehealth.org
Caldwell Memorial Hospital			321 Mulbery St., SW P.O. Box 1890	Lenoir, NC 28645	(828) 759-4960	www.caldwell-mem.org
CMC-Northeast			George Batte Cancer Center 100 Medical Park Drive	Concord NC, 28025-2983	704-783-3000	www.northeastmedical.org

e. *Care & Treatment*

Need to specify services / equipment and other resources specific to treatment type.

i. *Standards of Care*

ii. *Clinical Trials*

Name of Organization	County	Contact Name	Address	City, State Zip	Phone & Fax	E-mail Address
Pitt County Memorial Hospital			2100 Stantonsburg Road	Greenville NC, 27834-2818	(252) 847-4100	www.uhseast.com
Mission Hospital			428 Biltmore Avenue	Asheville NC, 28801-4690	(828) 213-1111	www.missionhospitals.org
Rex Healthcare			4420 Lake Boone Trail	Raleigh NC, 27607-6599	919-784-3105	www.rexhealth.com
Wake Forest University Medical Center (Brenner's Children's Hospital)			Medical Center Blvd.	Winston Salem, NC 27157	336-716-2255	http://www.brennerchildrens.org/
Duke University Health Systems			2301 Erwin Rd.	Durham, NC 27710	(919) 684-8111	www.dukehealth.org
UNC Healthcare					919-966-4432	http://www.unclineberger.org/patient/clinical-trials.asp

f. *Survivorship & Support*

Name of Organization	County	Contact Name	Address	City, State Zip	Phone	E-mail Address/ Website
Cancer Services, Inc.		Sara Patterson	3175 Maplewood Ave.	Winston Salem, NC 27103	336-760-9983	www.Cancerservicesonline.org
Comprehensive Cancer Center of WFUBMC-			Medical Center Boulevard	Winston-Salem NC, 27157-	336-713-6954	http://www.psycho-oncology.net/community.shtml

Cancer Patient Support Program				1001		
Lance Armstrong Foundation						http://www.livestrong.org/site/c.khLXK1PxHmF/b.2661019/k.8FE9/Cancer_Support.htm
Look Good...Feel Better		Jami Myers			336-463-2346	http://www1.wfubmc.edu/cancer/Additional+Resources/Support+Programs/
Cancer Services of Gaston County			246 East Garrison Blvd.	Gastonia, NC 28054	704-864-1271	http://www.gastoncancerservices.org/
Alamance Regional Medical Center			1240 Huffman Mill Rd.	Burlington, NC 27215	336-538-7000	http://www.armc.com/pediatric%2Drehab%2Dcenter/
Duke Comprehensive Cancer Center			DUMC Box 2714	Durham, NC 27710	919-684-3377	www.cancer.duke.edu

g. Advocacy Groups/Organizations

Name of Organization	County	Contact Name	Address	City, State Zip	Phone & Fax	E-mail Address
Cornucopia House			111 Cloister Court Overlook Building Suite 220	Chapel Hill, NC 27514	919-401-9333	http://cornucopiahouse.org/
Watauga Medical Center (Watauga Wellness Cancer Program)			336 Deerfield Road	Boone NC, 28607-2600	828-262-4332	www.wataugamc.org
Duke University Medical Center (Cancer Patient Support Program)		Cheyenne Corbett	DUMC, Box 3139	Durham, NC 27710	919-684-4497	http://www.cancer.duke.edu/support/
CMC-Northeast, Inc.			100 Medical Center Drive	Concord, NC 28025	704-403-1275	http://www.cmc-northeast.org/centers/BCC/support_services.html
Mission Hospitals			428 Biltmore Ave.	Asheville, NC 28801	828-213-4656	http://www.missionhospitals.org/body.cfm?id=61&oTopID=11

h. Individuals

Name of Individual	Why A Good Asset?	Address	City, State Zip	Phone & Fax	E-mail Address

II. Recommendations

a. What Needs to Be Done

- Identify characteristics that distinguish the unique cancer burden of the AYA population
- Better education, training and communication to improve awareness, prevention, access and quality cancer care to AYAs
- Create more efficient tools to study the AYA population
- Educate and promote participation in clinical trials
- Excellence in service delivery in areas of prevention, screening, diagnosis, treatment, survivorship and end of life
- Promote advocacy and support of the AYA population
- Establish a working group of representatives from public agencies and private organizations should convene to determine what additional data collection and funding is required to better capture treatment and survival data of AYAs.
- Studies of biologic differences in cancer types, host factors, late effects and cancer treatments in this population should be emphasized to improve knowledge to better inform the design of treatment, prevention, and QOL.

a. Where Does It Need to Be Done

b. Who Needs to Do It

c. How Does It Get Done, Including Policies

d. Target Populations, Special Considerations, Different Approaches

e. What Are Our Measurements

f. How Long Will It Take

g. How Much Will It Cost

h. Other

a. Reference Materials

Literature	Resources
Too Young to be Ill, Patient Advocate Foundation	www.livestrong.org
When your Brother or Sister has Cancer, National Cancer Institute	www.lls.org
It Can't Be!, Doug Ulman Foundation	http://www.fertilehope.org/
	www.patientadvocate.org
	www.supersibs.org
	www.caringbridge.org
	www.planetcancer.org
	www.teenslivingwithcancer.org
	www.thesamfund.org
	www.ulmanfund.org
	http://cancercontrolplanet.cancer.gov/

Scholarships for AYAs:

The SAMFund: Surviving And Moving Forward

The SAMFund provides grants and scholarships for young adult survivors of cancer between the ages of 17 and 30. For more information, send email to info@thesamfund.org.

National Collegiate Cancer Foundation (United States)

The National Collegiate Cancer Foundation sponsors an annual nonrenewable \$1,000 scholarship for college students whose lives have been impacted by cancer and who are seeking to continue their higher education while still undergoing treatment. Applicants must be college students between the ages of 17 and 27. Recipients are selected on the basis of financial need, an essay, recommendations, cancer story, and demonstrating a "Will Win" attitude. The deadline is September 15. For more information, call 1-717-215-0943, write to National Collegiate Cancer Foundation, Scholarship Committee, PO Box 14521, Silver Spring, MD 20911, or send email to info@collegiatecancer.org.

The Ryan Mullaly Second Chance Fund (United States)

The Ryan Mullaly Second Chance Fund offers a \$1,000 scholarship for cancer survivors. Candidates must be US citizens or permanent residents, have been diagnosed with cancer between the ages of 13 and 20, and currently be age 25 or younger. Priority is given to student's still undergoing treatment, students with a significant treatment history, students with substantial post-treatment side effects, and students just beginning their college education. For more information, write to Ryan Mullaly Second Chance Fund, 26 Meadow Lane, Pennington, NJ 08534, call 1-609-737-1800, or send email to The2ndChanceFund@aol.com.

Patient Advocate Foundation (United States)

The Patient Advocate Foundation awards eight Scholarships for Survivors of \$5,000 per year for cancer

survivors to initiate or complete a course of study that has been interrupted or delayed by a diagnosis of cancer or other life-threatening, chronic or debilitating disease. Recipients must maintain a GPA of at least 3.0 on a 4.0 scale. Recipients are required to complete 20 hours of community service during the school year. The application deadline is May 1. For more information, write to Patient Advocate Foundation, 700 Thimble Shoals Blvd., Suite 200, Newport News, VA 23606, call 1-800-532-5274, or fax 1-757-873-8999.

b. National Organizations

c. What's Being Done in Other States

d. Potential External Resources

e. Relationship to Other Cancers/Issues

References:

1. American Cancer Society (2007). With *CA- A Cancer Journal for Clinicians*. Young Adult Oncology: *The Patients and Their Survival Challenges*. 2007; 57:242-255. Retrieved from <http://caonline.amcancersoc.org/cgi/content/full/57/4/242>.
2. American Society of Clinical Oncology (ASCO). (2006). Retrieved from: <http://www.plwc.org/portal/site/PLWC/menuitem.724de8b96edd64acfd748f68ee37a01d/?vgnextoid=57a1ea97a56d9010VgnVCM100000f2730ad1RCRD&vgnnextfmt=default>
3. Ulman D. (2006). No Way, It Can't Be! *A Guidebook for Young Adults Facing Cancer*. The Ulman Cancer Fund for Young Adults.
4. Albritton K., Anderson B., Caligiuri M., Nichols C. & Ulman D. (2006). Closing the Gap: *Research and Care Imperatives for Adolescents and Young Adults with Cancer*. US Department of Health and Human Services.
5. Barr R, Bleyer A. and Viny A. (2000). Cancer in 15-29 Year Olds, U.S. SEER, 1975-2000. pp 2-13, 174-187.
6. President's Cancer Panel (2003). *Living Beyond Cancer: Challenges for Adolescent and Young Adult Cancer Survivors*. TX. pp 1-2.
7. Lance Armstrong Foundation. *Livestrong Young Adult Alliance 2007*. Austin: Lance Armstrong Foundation; 2007.
8. American Cancer Society (2006). Peer and Family Support Tops Needs of Young Adult Cancer Survivors. Retrieved from http://www.cancer.org/docroot/MED/content/MED_2_1x_Peer_and_Family_Support_Tops_Needs_of_Young_Adult_Cancer_Survivors.asp
9. Andreoli A, de Lorenzo A (2005). Nutrition and Fitness: *Obesity, the Metabolic Syndrome, Cardiovascular Disease, and Cancer; Physical Activity and Body Composition*. World Rev Nutr Diet. vol 94, pp 60-67.
10. Landier W. (2006). Healthlink: Healthy Living after Treatment of Childhood Cancer. Children's Oncology Group. Retrieved from <http://www.survivorshipguidelines.org/pdf/EducationalIssues.pdf>
11. Rauck AM, Fremgen AM, Menck HR, et al. Adolescent Cancers in the United States: a National Cancer Data Base report. *J Pediatr Hematol Concol* 1999; 21:310.
12. Festa RS, Tamaroff MH, Chasalow F, Lanzkowsky P. Therapeutic adherence to oral medication regimens by adolescents with cancer. I. Laboratory assessment. *J Pediatr* 1992;120:807-811.[Medline].
13. Kyngas HA, Kroll T, Duffy ME. Compliance in adolescents with chronic diseases: a review. *J Adolesc Med* 2000;26:379-388.

14. Bleyer WA, Tejada H, Murphy SB, et al. National cancer clinical trials: children have equal access; adolescents do not. *J Adolesc Health* 1997;21:366–373.[Medline].
15. Bleyer WA. Presentation, “Survivorship Challenges among Cancer Patients Diagnosed at Age 15–29,” Austin, TX, September 22, 2003.
16. Albritton, K. (2005). Age Matters: The problems with Teen Cancer Care. *The Quarterly Journal of the National Candlelighters Childhood Cancer Foundation Office*, Spring 2005, 1-5.
17. Oeffinger, K. (2000). Childhood Cancer Survivors and Primary Care Physicians. *The Journal of Family Practice*, 49(8).
18. Schwartz, C.L. (2003). Health Status of Childhood Cancer Survivors. *JAMA: Journal of the American Medical Association*, 290(12).
19. Yeh, C.-H. (2002). Life Experience of Taiwanese Adolescents with Cancer. *Scandinavian Journal of Caring Sciences*, 16(3).
20. National Cancer Institute. (2007). Assessment of Post-traumatic Stress Disorder in the Cancer Setting. Retrieved from <http://www.cancer.gov/cancertopics/pdq/supportivecare/post-traumatic-stress/HealthProfessional/page5>
21. Badger, T., Segrin, C., Meek, P., Lopez, A.M., Bonham, E., & Sieger, A. (2005). Telephone Interpersonal Counseling with Women with Breast Cancer: Symptom Management and Quality of Life. *Oncology Nursing Forum*, 32(2).
22. Hoffman B. Between a disability and a hard place: the cancer survivors’ catch-22 of proving disability status under the Americans with Disabilities Act. *59 Maryland Law Review* 352–439 (2000).
23. Ljungman G, Gordh T, Sorensen S, Kreuger A. Pain variations during cancer treatment in children: a descriptive survey. *Ped Hem Oncol* 2000;17(3):211-221.
24. Carlsson, M., Arman, M., Backman, M., et al. (2005). Coping in women with breast cancer in complementary and conventional care over 5 years measured by the mental adjustment to cancer scale. *Journal of Alternative and Complementary Medicine*, 11.
25. Brigham and Women’s Hospital. (2003). Underserved U.S. Minorities Face Unequal Burden of Cancer. Retrieved from: http://www.hms.harvard.edu/news/pressreleases/bwh/0303minorities_cancer.html
26. U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2002 Incidence and Mortality Web-based Report*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2005.
27. American Society of Hematology (2007). Childhood, Youth Cancer Survival Factors Vary by Race, Follow-up Care. Retrieved from: <http://www.prnewswire.com/cgi-bin/stories.pl?ACCT=104&STORY=/www/story/12-11-2006/0004489037&EDATE=>
28. Shavers VL, Harian LC, Stevens JL. Racial/ethnic variation in Adolescent/Young Adult White Paper, Fall 2007

clinical presentation, treatment, and survival among breast cancer patients under age 35. *Cancer* 2003;97:134-137.

29. Lees KA, Wortely PM, Coughlin SS. Comparison of racial/ethnic disparities in adult immunizations and cancer screening.

American Journal of Preventive Medicine 2005;29:404-411.

30. Institute of Medicine. The unequal burden of cancer. An assessment of NIH research and programs for ethnic minorities and the medically underserved. Washington, D.C.: National Academy Press; 1999

31. American Cancer Society (2000). Lower Survival Rates Found in Native Americans with Cancer. Retrieved from

http://www.cancer.org/docroot/NWS/content/NWS_1_1x_Lower_Survival_Rates_Found_in_Native_Americans_with_Cancer.asp

32. National Cancer Institute. (2006). *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975-2000*. NIH Pub. No. 06-5767. Bethesda, MD 2006.

33. Coiro, M., Zill, N., and Bloom, B. Health of Our Nation's Children. National Center for Health Statistics. *Vital and Health Statistics*, 10(191): 1-67, 1994.

34. National Cancer Institute. (1998). Cancer facts: breast cancer and mammography facts.

35. Robison LL, Nesbit ME, Sather HN *et al*. Down syndrome and acute leukemia in children: a 10-year retrospective survey from Children's Cancer Study Group. *J Pediatr* 105, 235-42, 1984.