



CLOSING THE GAP: A STRATEGIC PLAN

Addressing the Recommendations of the
Adolescent and Young Adult Oncology
Progress Review Group

It has been estimated that nearly 70,000 young adults will be diagnosed with cancer every year.

That number is staggering. Even more shocking is the fact that despite the advances in prevention, early detection and treatment, we have not seen improvements in survival rates for this age group.

While we are seeing improvements in survival rates for younger and older patients, the survival rates for young adults have improved far less – and the gap is worsening.

In fact, due to this lack of progress in survival improvement since 1975, young adults diagnosed with cancer today have a worse prognosis than those diagnosed 25 years ago. That is simply unacceptable. It is time to give attention to this long ignored population. It is

time to bring a concentrated focus to improving outcomes for young adults with cancer.

My Foundation, through the LIVESTRONG Young Adult Alliance, has had the opportunity to work with the National Cancer Institute to create the reports of the Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG). The recommendations of the AYAO PRG outlined the priority areas for change, and this report provides a plan for bringing about those changes.

I hope that the efforts of everyone involved in the AYAO PRG will serve as a catalyst for change and that these innovative solutions will combat the disparities in cancer care faced by young adults.

As someone diagnosed at the age of 25, I am all too familiar with the unique challenges faced by young adults with cancer, and I am personally committed to effecting positive change for young adults. I commend the work of all of the participants in the PRG process and look forward to congratulating them on the future successes that result from their efforts.

LIVESTRONG.



Lance Armstrong

THIS REPORT

is a culmination of several years' hard work by many passionate, dedicated people, all of whom believe two things: first, that young adults diagnosed with cancer between the ages of 15 and 40 have fallen through the cracks on every front, including clinical, research, financial and psychosocial. Second, that we have a responsibility to change this.

The participants at the inaugural meeting of the LIVESTRONG Young Adult Alliance were a diverse group of advocates, researchers, and clinicians, all unified by the desire to improve survival rates and quality of life for young adults with cancer.

When we left the meeting, however, we were unified by another emotion — hope. Our hope is that this report will serve as a catalyst to a national movement on behalf of young adults with cancer. And that, one day, we will look back on the publication of this document as a turning point in the diagnosis, treatment and care of young adults with cancer.

Best regards,

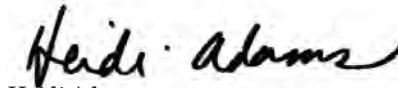
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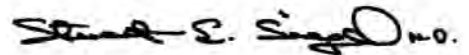
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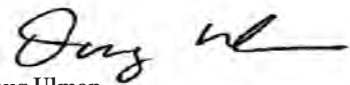
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In Austin, Texas in November 2006, a landmark event occurred when participants met in the first public-private partnership of its kind. The LIVESTRONG Young Adult Alliance (LSYAA) and the National Cancer Institute's Adolescent and Young Adult Oncology (AYAO) Progress Review Group (PRG) came together with a joint purpose: the commencement of the inaugural meeting of the LSYAA and the collective creation of an action plan to address AYAO PRG recommendations for improving the outcomes and quality of life for adolescents and young adults with cancer.

This remarkable, collaborative effort would not have been successful without the integral contributions of the following:

- The Steering Committee of the LIVESTRONG Young Adult Alliance, led by committee chairs Brandon Hayes-Lattin and Randi Rosenberg, as well as Heidi Adams, Archie Bleyer, Craig Lustig, Selma Schimmel, Stuart Siegel, Doug Ulman, Brock Yetso and Brad Zebrack. Their commitment of time,

energy, and expertise was invaluable in making this meeting and report possible.

- The PRG Leadership—Cherie Nichols, Barry Anderson, Michael Caligiuri, and Karen Albritton—who generously provided guidance and technical support throughout the process.
- The staff at the National Cancer Institute's Office of Science Planning and Assessment, under the leadership of Cherie Nichols, and in particular, Jamelle Banks, who provided continued support of the PRG process, oversaw the development of the research portfolio, and provided important advice throughout the meeting planning and report development.
- The Breakout Group co-chairs for facilitating their meeting sessions and ensuring that their groups identified actionable strategies that will truly make a difference: Ronald Barr, Barbara Jones, David Lyon, Craig Nichols, Muneesh Tewari, Beth Virnig, and Karla Wilson.
- The staff at the Lance Armstrong Foundation, under the superb leadership of Tina Hamilton and Devon McGoldrick, who made sure that

the entire process ran smoothly. Christina Chien and Kendra Schroeder provided exemplary meeting planning support. Jennifer Long, Diana Guentzel, Melissa Sileo, and Barbara Neyens provided excellent assistance in formatting and finalizing this report.

- The staff of SAIC for their management, logistical and technical support. Beth Mathews-Bradshaw and Debby Berlyne of SAIC worked tirelessly and showed meticulous attention to detail, leadership, and expertise in helping to plan the meeting and write this report. Karen Rulli demonstrated expertise and skill in carrying out the portfolio analysis. Adam Book, Greg Cole, Julia Huiberts, and Adey Smith provided excellent writing support.
- Janis Mullaney at the Foundation for the National Institutes of Health for her important work in overseeing the partnership between the Lance Armstrong Foundation and the National Cancer Institute.

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for Addressing the Recommendations of the
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TABLE OF CONTENTS

8	Introduction
8	Why Focus on Cancer in Adolescents and Young Adults?
8	Incidence
8	Survival
10	Biology of AYA Cancers
10	Lack of Effective Treatments
11	Health Services Issues
12	AYAO Progress Review Group
13	Research Portfolio
15	LIVESTRONG Young Adult Alliance
16	Purpose of this Report
17	CHAPTER 1: Implementation Strategies for Progress Review Group (PRG) Recommendation 1 — Identify the Characteristics that Distinguish the Unique Cancer Burden in the Adolescent and Young Adult (AYA) Oncology Patient
18	Related Research
	Implementation Strategies
19	Strategy 1
21	Strategy 2
22	Strategy 3
23	Strategy 4
25	CHAPTER 2: Implementation Strategies for Progress Review Group (PRG) Recommendation 2—Provide Education, Training, and Communication to Improve Awareness, Prevention, Access, and Quality Cancer Care for Adolescents and Young Adults (AYAs)
26	Related Research
	Implementation Strategies
27	Strategy 1
29	Strategy 2
31	Strategy 3
32	Strategy 4
35	CHAPTER 3: Implementation Strategies for Progress Review Group (PRG) Recommendation 3—Create the Tools to Study the Adolescent and Young Adult (AYA) Cancer Problem
36	Related Research
	Implementation Strategies
37	Strategy 1

39	CHAPTER 4: Implementation Strategies for Progress Review Group (PRG) Recommendation 4—Ensure Excellence in Service Delivery Across the Cancer Control Continuum (i.e., Prevention, Screening, Diagnosis, Treatment, Survivorship, and End of Life)
40	Related Research
	Implementation Strategies
41	Strategy 1
43	Strategy 2
44	Strategy 3
45	Strategy 4
46	Strategy 5
47	CHAPTER 5: Implementation Strategies for Progress Review Group (PRG) Recommendation 5— Strengthen and Promote Advocacy and Support of the Adolescent and Young Adult (AYA) Cancer Patient
48	Related Research
	Implementation Strategies
49	Strategy 1
50	Strategy 2
51	Strategy 3
52	Strategy 4
53	Strategy 5
54	CHAPTER 6: Action Plan
55	Topic 1: Science
56	Topic 2: Standards
57	Topic 3: Awareness
58	Next Steps
58	Conclusion
	Figures
9	Figure 1: 5-Year Survival of Patients with Cancer by Era, SEER, 1975-1998
9	Figure 2: Cancers Whose Survival Rates Decline During AYA Age Range: SEER 17 Relative Survival
13	Figure 3: Analysis of AYAO Research by Funding Organization
13	Figure 4: Trends in AYAO Research, FY 2002-2005
14	Figure 5: Analysis of NCI Funded Research by Common Scientific Outline
14	Figure 6: Analysis of Non-NCI-Funded Research by Common Scientific Outline
15	Figure 7: Analysis of AYAO Research by AYAO PRG Recommendation Category
18	Figure 8: AYAO Research Projects Relevant to Recommendation 1, FY2002–FY2005
26	Figure 9: AYAO Research Projects Relevant to Recommendation 2, FY2002–FY2005
36	Figure 10: AYAO Research Projects Relevant to Recommendation 3 FY2002–FY2005
40	Figure 11: AYAO Research Projects Relevant to Recommendation 4, FY2002–FY2005
48	Figure 12: AYAO Research Projects Relevant to Recommendation 5, FY2002–FY2005
	Appendices
59	Appendix A: LIVESTRONG Young Adult Alliance (LSYAA) Inaugural Meeting and Adolescent and Young Adult Oncology Progress Review Group Implementation Meeting Agenda
61	Appendix B: LSYAA Inaugural Meeting and AYAO PRG Implementation Meeting Participant List
66	Appendix C: An Analysis of the Adolescent and Young Adult Oncology Research Portfolio (November 2006)
104	Appendix D: Glossary

LIVESTRONG™ Young Adult Alliance (YAA) Adolescent and Young Adult Oncology (AYAO) Progress Review Group (PRG) Implementation Report and Action Plan

Introduction

Cancer is a leading cause of death in adolescents and young adults¹ (AYAs). However, the medical community has not focused as much attention on this group as it has on other age groups with cancer. This report provides an overview of the challenges faced by AYAs with cancer and offers implementation strategies to improve survival rates and quality of life for AYAs with cancer.

Why Focus on Cancer in Adolescents and Young Adults?

Why focus on cancer in adolescents and young adults (AYAs)? Aren't they too young to develop cancer?

The reality is that cancer is a leading cause of death for young adults, but this fact has not catalyzed the medical community to focus on the AYA population the way it has rallied to treat older adults and children with cancer. In 2002, almost 68,000 people aged 15 to 39 years were diagnosed with cancer, approximately eight times more than children under age 15. Yet AYA susceptibility to cancer and the adverse outcomes in this age group have been under-recognized.

Many of the cancers that occur in AYAs have different biological characteristics than the same cancers in children or older adults. Because of the relative lack of attention to and biological research on cancers in this age group, it is difficult to identify the most appropriate treatments for AYAs with many of these cancers. Improved knowledge of tumor biology could lead to improved prevention, detection, and treatment strategies that would optimize outcomes for these patients.

Appropriate treatments for AYAs, once they

are developed, will only work if an appropriate system is available for delivering them to AYAs. Unfortunately, AYAs face unique challenges to obtaining care that are not experienced by younger and older cancer patients. Treatment schedules are difficult to balance with careers, school, dating, and young families. Many young adults have inadequate health insurance coverage or no coverage at all. Delays in diagnosis can occur due to the fact that many young adults do not have a primary care provider. The providers they eventually see might not consider cancer as a potential diagnosis and referrals might be delayed or inappropriate. Many clinical trials are not open to AYAs, or doctors may not refer AYAs to trials for which they could be eligible. As a result, fewer tissue samples are collected from this age group; as a result, fewer diagnostic and treatment data are available and, consequently, less is known about AYA cancers. This has an adverse effect on cancer outcomes in this population.

So the answer to the question—why focus on cancer in adolescents and young adults (AYAs)?—is that their numbers are significant, their cancers are unusual, their medical care is often inadequate, and their outcomes for many cancers have not improved in the last three decades.

Incidence

After homicide, suicide, and unintentional injury, cancer is the most common cause of death among those aged 15–39 years. It is the most common cause of death due to disease among females in this age group, and only heart disease claims more lives annually than cancer among male AYAs.²

The most common tumors in AYAs aged 15–39 years are breast cancer, lymphoma, germ

cell tumors (including testicular cancer), melanoma, thyroid carcinoma, sarcoma, cervical carcinoma, leukemia, colorectal carcinoma, and central nervous system tumors.³

Among AYAs, non-Hispanic whites have the highest incidence of cancer and the highest overall 5-year-survival rates. American Indians/Alaska Natives have the lowest cancer incidence and poor survival rates. African Americans have intermediate incidence rates and the lowest 5-year survival rate across the age range.

Survival

In general, cancer in AYAs has a relatively good prognosis. High survival rates for several AYA diseases (e.g. melanoma, thyroid, and testicular) have historically raised the average survival rates for this age group. In 1975–1980, patients aged 15–39 years with cancer had a distinct 5-year survival advantage compared to younger and older patients (see Figure 1, lower line). However, over the past 20 years, cancer survival rates have improved significantly for children and for adults aged 40 and older but survival for AYA cancers has not improved significantly. This lack of improvement flattens the 1993–1998 survival curve by age (see Figure 1, upper line) and removes the survival advantage that the AYA population had 25 years ago.

Based on recent Surveillance Epidemiology and End Results (SEER) data, survival for several individual cancers (e.g., leukemia, Hodgkin, ovarian cancer, and Ewing sarcoma) declines with age, beginning in the second decade. This means that AYAs have lower survival rates than younger patients with the same diseases (see Figure 2).

¹ In this report, AYAs are defined as individuals aged 15 through 39 years at cancer diagnosis. The justification for this definition is provided on page 7 of this introductory chapter.

² Total U.S. Deaths 2003, ages 15–39, data from SEER and the National Center for Health Statistics.

³ SEER 17, 2000–2003.

Figure 1

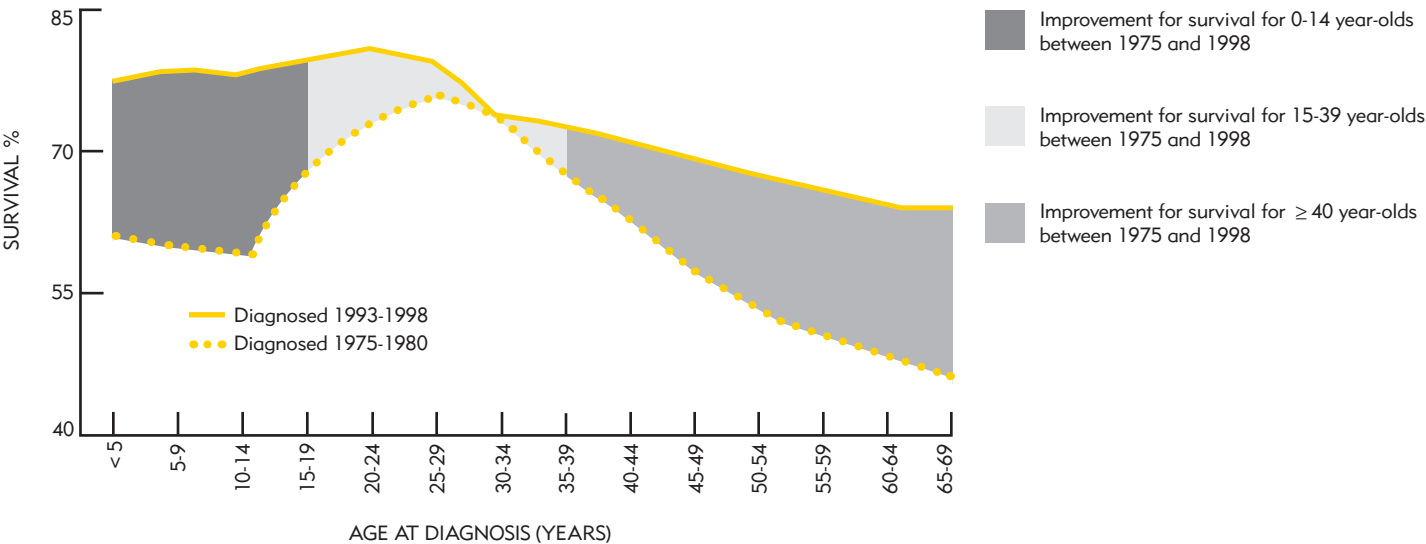
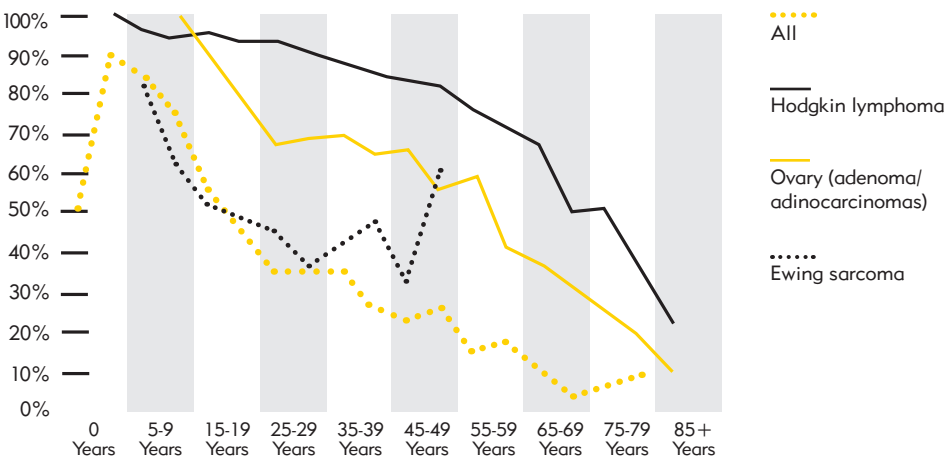


Figure 2

Cancers whose survival rates decline during AYA age ranch:
SEER 17 relative survival



AGES OF SURVIVAL RATE DECLINE:
All: 5-10 yrs
Hodgkin Lymphoma: 5-10 yrs
Ovarian Adinocarcinomas: 10+ yrs
Ewing Sarcoma: 10+ yrs

It is not known if the age-specific survival differences observed for these diseases are due to biologic differences in the same disease by age or differences in treatment and health services. Clinical and biological research on AYA oncology (AYAO) is critically needed to address these stagnant outcomes.

Biology of AYA Cancers

For certain types of cancer, important biologic differences exist between AYAs and other age groups. For example:

- Gastrointestinal stromal tumor (GIST)—Mutations in certain genes (c-KIT and PDGFRA) are common in older adults but rare in young adults with GIST.,⁴⁻⁵
- Colon cancer—The biological features of colorectal cancer in young adults are different from those in older patients with this disease. For example, differences have been identified in p53 gene expression levels and the number of repetitive DNA segments (microsatellites), which are highly susceptible to becoming malignant.,^{6,7,8}
- Breast cancer—Breast cancer in women under 40 years of age is more likely than in older patients to be poorly differentiated, negative for estrogen receptor expression, and have alterations in certain genes, such as p53 and erbB2.,^{9,10,11,12}
- Renal cell carcinoma—Renal cell carcinoma in young adults is more likely than in older

adults to metastasize to the lymph nodes and to exhibit molecular features associated with poor outcomes.,^{13,14}

• Acute lymphoblastic leukemia (ALL)—The profile of chromosomal abnormalities in ALL differs among infants, children, and adults. Research has shown that young adults have much better outcomes when they are treated according to pediatric rather than adult ALL treatment regimens.,^{15,16}

Other cancers that AYAs develop—such as acute myelogenous leukemia, Ewing sarcoma, diffuse large B-cell lymphoma, osteosarcoma, and brain tumors—could be biologically different from the same cancers in older and younger patients. These biologic differences could contribute to the different outcomes experienced by AYA patients compared to younger and older patients. Additional research is needed to make this determination.

The relative dearth of information about AYA tumor biology could be related to the fact that few annotated tumor samples have been collected from this population, especially when compared to research efforts focused on cancers in children or older adults. Developing such tumor bank resources and studying AYA tumor samples could have a significant impact on the study of AYAO biology.

In addition, the physiologic and hormonal changes that occur in AYAs, such as puberty

and the pre- to post-menopause transition, could influence their susceptibility to cancer and response to treatment. The temporary hormonal changes that occur during and after pregnancy could also change a woman's susceptibility to cancer and influence her response to treatment.¹⁷

Age-specific differences in treatment response are an area of research that deserves additional focus. Although some investigations focus on drug metabolism in children or older adults, none are known to focus on drug metabolism in adolescents or young adults.

Thus, it is clear that additional scientific research is needed to understand the relationship between cancer and cancer treatment with respect to the biological transitions that naturally occur in AYAs.

Lack of Effective Treatments

Advances in treatment for cancers in AYAs have been limited. This is partly because little research has focused specifically on treatments in this population. Unlike pediatric cancer patients, few AYAs participate in treatment clinical trials. Only 20 to 35 percent of older adolescents (15 to 19 years old) are treated at institutions that participate in National Cancer Institute (NCI)-sponsored treatment clinical trials, and only 10 percent of these teens are enrolled in trials.^{18,19} Participation rates are

- ⁴ Prakash, S., Sarraan, L., Socci, N., DeMatteo, R.P., Eisenstat, J., Greco, A.M., Maki, R.G., Wexler, L.H., LaQuaglia, M.P., Besmer, P., et al. (2005). Gastrointestinal stromal tumors in children and young adults: A clinicopathologic, molecular, and genomic study of 15 cases and review of the literature. *J. Pediatr. Hematol. Oncol.* 27, 179-187.
- ⁵ Miettinen, M., Lasota, J., and Sobin, L.H. (2005). Gastrointestinal stromal tumors of the stomach in children and young adults: A clinicopathologic, immunohistochemical, and molecular genetic study of 44 cases with long-term follow-up and review of the literature. *Am. J. Surg. Pathol.* 29, 1373-1381.
- ⁶ Chiang, J.M., Chen, M.C., Changchien, C.R., Chen, J.S., Tang, R., Wang, J.Y., Yeh, C.Y., Fan, C.W., and Tsai, W.S. (2003). Favorable influence of age on tumor characteristics of sporadic colorectal adenocarcinoma: Patients 30 years of age or younger may be a distinct patient group. *Dis. Colon Rectum* 46, 904-910.
- ⁷ Liang, J.T., Huang, K.C., Cheng, A.L., Jeng, Y.M., Wu, M.S., and Wang, S.M. (2003). Clinicopathological and molecular biological features of colorectal cancer in patients less than 40 years of age. *Br. J. Surg.* 90, 205-214.
- ⁸ Chiang, J.M., Wu Chou, Y.H., Ma, S.C., and Chen, J.R. (2004). Influence of age on adenomatous polyposis coli and p53 mutation frequency in sporadic colorectal cancer-rarity of co-occurrence of mutations in APC, K-ras, and p53 genes. *Virchows. Arch.* 445, 465-471.
- ⁹ Sidoni, A., Cavaliere, A., Bellezza, G., Scheibel, M., and Bucciarelli, E. (2003). Breast cancer in young women: Clinicopathological features and biological specificity. *Breast* 12, 247-250.
- ¹⁰ Querzoli, P., Albonico, G., di Iasio, M.G., Ferretti, S., Rinaldi, R., Cariello, A., Pedriali, M., Matteuzzi, M., Maestri, I., and Nenci, I. (2001). Biophenotypes and survival of BRCA1 and TP53 deleted breast cancer in young women. *Breast Cancer Res. Treat.* 66, 135-142.
- ¹¹ Johnson, S.M., Shaw, J.A., and Walker, R.A. (2002). Sporadic breast cancer in young women: Prevalence of loss of heterozygosity at p53, BRCA1, and BRCA2. *Int J Cancer* 98, 205-209.
- ¹² Walker, R.A., Lees, E., Webb, M.B., and Dearing, S.J. (1996). Breast carcinomas occurring in young women (< 35 years) are different. *Br. J. Cancer* 74, 1796-1800.
- ¹³ Sanchez-Ortiz, R.F., Rosser, C.J., Madsen, L.T., Swanson, D.A., and Wood, C.G. (2004). Young age is an independent prognostic factor for survival of sporadic renal cell carcinoma. *J. Urol.* 171, 2160-2165.
- ¹⁴ Siemer, S., Hack, M., Lehmann, J., Becker, F., and Stockle, M. (2006). Outcome of renal tumors in young adults. *J. Urol.* 175, 1240-1243; discussion 1243-1244.
- ¹⁵ Pui, C.H., and Evans, W.E. (1998). Acute lymphoblastic leukemia. *N. Engl. J. Med.* 339, 605-615.
- ¹⁶ Nachman, J. (2005). Clinical characteristics, biologic features and outcome for young adult patients with acute lymphoblastic leukaemia. *Br. J. Haematol.* 130, 166-173.

even lower in older AYAs; only 1 to 2 percent of 20 to 39 year-olds are enrolled in clinical trials sponsored by pediatric or adult NCI Cooperative Groups.²⁰

AYA participation rates in clinical trials might be low because few clinical trials are available for AYA patients or because physicians do not enroll AYA patients in trials for which they are eligible. Those between 15 and 18, in particular, have access to a limited number of trials.

Although the tumor biology and physiology of patients aged 15 to 18 years is generally similar to those of patients over age 18, these patients usually are excluded from first-line adult drug development studies. Although nearly all pediatric cancer treatment trials are technically open at least to 18-year-old patients, older teens are not always included in pediatric trials and are not always eligible for adult trials. Some of the cancers diagnosed in young adults are not studied in adult trials, so adolescents treated in centers without pediatric cooperative group trials do not have access to clinical trials for their cancer. Similarly, adolescents with a disease that is uncommon in childhood and not studied by the Pediatric Oncology Group are excluded from adult cooperative trials because they are younger than 18.

Furthermore, most AYAs are treated in the community rather than in cancer centers, where most cancer clinical trials are conducted. No community oncology and primary care system currently exists to ensure that data on these patients are collected and studied. It is difficult to collect data on late effects and outcomes on this very mobile population because their contact information changes frequently, making it challenging to keep in touch with them after

they finish treatment. Furthermore, some AYAs do not want to communicate regularly with their treatment providers and the health care system in general because they want to move on with their lives after their treatment.

Health Services Issues

Other issues that have contributed to the lack of progress in improving AYA cancer survival include:

- Delayed diagnosis—Cancer symptoms are often missed in AYAs. It can take months or even years to obtain a correct diagnosis and begin appropriate treatment. Many healthcare providers do not consider cancer when faced with ambiguous symptoms in AYA patients. In addition, AYAs sometimes see themselves as invulnerable to serious illness and might not think that cancer could be the cause of their symptoms. As a result, they often ignore symptoms and put off consulting a doctor. Furthermore, many AYAs have no primary care provider and do not have regular check-ups; they therefore do not know where to go for help.
- Inconsistent referrals to specialists—The types of specialists to which AYAs are referred for diagnosis and treatment vary greatly and often depend on the referring physician. AYAs with cancer are seen by internists, family physicians, gynecologists, emergency room physicians, dermatologists, gastroenterologists, neurologists, and other specialists who could have very different referral patterns.²¹ Referrals might be made to pediatric or adult medical, radiation, surgical, or gynecologic oncologists. Few research data are available to indicate which

providers are most suitable for AYAs with cancer because this depends on the disease and patient's age at diagnosis. Patients referred to inappropriate providers are less likely to enroll in clinical trials, less likely to benefit from advances in available therapies, and, consequently, more likely to have adverse outcomes.

- Lack of psychosocial support—Because of the many emotional, developmental, and social changes during this stage of life, AYAs with cancer tend to have very diverse and intense needs for psychosocial and supportive care. AYAs typically need to stay in school or keep working during their treatment, and some must care for their children. Schools and employers might not understand or accommodate cancer treatment effects on AYA physical and cognitive health. The psychosocial and supportive care services available in pediatric and older adult-oriented settings rarely target the needs of AYAs with cancer. AYAs who lack appropriate psychosocial support during and after cancer treatment might be less likely to adhere to their treatment and follow-up care regimens.
- Lack of health insurance—AYAs are less likely to have health insurance than children or older adults. Nearly one-third of all 18- to 24-year-olds in the United States are uninsured, and more than twice as many 18- to 24-year-olds are uninsured or underinsured as 45- to 55-year-olds.²² Young adults are rarely covered by their parents' health insurance policies after age 23, and Medicaid and the State Child Health Insurance Program stop covering young people at age 19. Many of the jobs that AYAs hold offer limited or no health insurance benefits, and AYAs with

¹⁷ Sakoda L.C., Horn-Ross P.L. (2002). Reproductive and menstrual history and papillary thyroid cancer risk: the San Francisco Bay Area thyroid cancer study. *Cancer Epidemiol Biomarkers Prev.* 11(1), 51-7.

¹⁸ Bleyer W.A., Tejeda H., Murphy S.B., Robison L.L., Ross J.A., Pollock B.H., Severson R.K., Brawley O.W., Smith M.A., Ungerleider R.S. (1997). National cancer clinical trials: children have equal access; adolescents do not. *J Adolesc Health* 21(6), 366-73.

¹⁹ Albritton K., Bleyer W.A. (2003). The management of cancer in the older adolescent. *Eur J Cancer* 39(18), 2584-99.

²⁰ Bleyer W.A., Barr R. Highlights and challenges. In: Bleyer W.A., O'Leary M., Barr R., Reis L.A.G. (eds). *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, including SEER Incidence and Survival 1975-2000*. National Cancer Institute, NIH Pub. No. 06-5767, Bethesda, MD, June 2006; at: www.seer.cancer.gov/publications/aya.

²¹ Goldman S., Stafford C., Weinthal J., et al. (2000). Older adolescents vary greatly from children in their route of referral to the pediatric oncologist and national trials. *Proc. Am. Soc. Clin. Oncol.* 18:abstract #1766.

²² Bleyer W.A., Barr R. Highlights and challenges. In: Bleyer W.A., O'Leary M., Barr R., Reis L.A.G. (eds). *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, including SEER Incidence and Survival 1975-2000*. National Cancer Institute, NIH Pub. No. 06-5767, Bethesda, MD, June 2006; at: www.seer.cancer.gov/publications/aya.

such benefits often decline them or choose plans with high deductibles and limited benefits due to cost. Even those with relatively comprehensive insurance might choose not to undergo treatment and follow-up care when they have to pay substantial out-of-pocket fees. In addition, a cancer diagnosis can make it difficult for AYAs to obtain insurance at reasonable rates for the rest of their lives.

AYAO Progress Review Group

The NCI, in collaboration with the LIVESTRONG Young Adult Alliance, established the Adolescent and Young Adult Oncology (AYAO) Progress Review Group (PRG) to develop a national agenda for AYAO issues.

The PRG includes prominent members of the scientific, medical, and advocacy communities whose charge is to:

- Assess the state of research in adolescent and young adult oncology, including:
 - Comprehensively defining and describing issues facing adolescents and young adults with cancer
 - Identifying areas of strength, gaps, and opportunities
- Define and prioritize investment areas; compare and contrast these priorities with the NCI research portfolio
- Prepare a written report that describes findings and recommendations for meeting unmet opportunities and needs within the construct of discovery, development and delivery
- Discuss a plan of action with NCI leaders, key stakeholders, and funders to ensure that the priority areas are well addressed
- Identify and act on collaborative strategic implementation initiatives.

The AYAO PRG defined the AYA population as comprising individuals aged 15 through 39 years at cancer diagnosis. The lower age limit of 15 was chosen for several reasons, including that younger AYA cancer patients are undergoing some of the life transitions associated with adolescence and feel out of place in a pediatric setting. Others do not start these transitions until after the teenage years and find themselves in adult-oriented settings that do not recognize their psychosocial immaturity. Our health care system is split in a binary fashion between pediatric and adult medicine, particularly

among the subspecialties and certainly in oncology. But the point of transition between the two is blurry—no rules dictate where AYA patients should receive care. Pediatric hospitals increasingly have upper age limits of 21 and beyond and non-pediatric hospitals often accept patients as young as 15. Patterns-of-care studies show that 15-year-old cancer patients are less likely to be treated in pediatric hospitals than younger patients, and 50% of patients aged 16-17 receive their care in adult facilities.

The AYAO PRG selected the upper age limit of 39 for its definition of AYAs because the biologic and physiologic issues that begin around the time of puberty and achievement of full adult stature remain relatively distinct during the 20s and 30s. Between ages 15 and 39, patients have passed puberty but have not yet experienced the effects of hormonal decline (menopause for females) or immune response decline. Few have developed the chronic medical conditions (e.g., atherosclerosis, hypertension, type II diabetes, alcoholism) that cause organ dysfunction and the need for concomitant medications that can influence oncologic decision-making and the care of older patients. The AYAO PRG concluded that, based on input from AYA survivors and advocates, the majority of patients up to age 40 are more likely to feel they have more in common with younger patients than with middle-aged and older patients.

The AYAO PRG held a roundtable meeting on April 24-26, 2006, in Denver, Colorado, to discuss the current state of knowledge, identify gaps in research efforts, and develop and prioritize research recommendations that will advance progress in the field. At this meeting, AYAO PRG members and approximately 75 additional participants divided into breakout sessions for detailed discussions of the following topics:

- Awareness
- Prevention/Cancer Control/Epidemiology/Risk
- Biology
- Access
- Insurance
- Clinical Care Models
- Clinical Trials/Research
- Special Populations
- Psychosocial Behavioral Factors

- Health-Related Quality of Life
- Long-Term Effects

Each breakout group developed a set of recommendations that their co-chairs presented to all roundtable participants. At the end of the meeting, the AYAO PRG prioritized the breakout recommendations and selected the final list of five recommendations to highlight in the AYAO PRG report.

The AYAO PRG report, which was published in August 2006, provides a detailed overview of the characteristics of AYAs with cancer and possible reasons for the lack of progress in improving cancer survival rates in this population. The report also describes the five consensus recommendations developed during the roundtable meeting:

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

- Elucidate unique biologic characteristics of AYA cancers and AYA patients that affect disease outcome in this population.
- Elucidate life stage/developmental characteristics that influence care seeking, adherence to treatment, and medical and psychosocial outcomes.
- Identify and ameliorate health disparities experienced by AYA cancer patients and survivors.

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

- Raise awareness of AYA cancer issues as a first step toward increasing national focus and resource allocation to address the AYA cancer problem.
- Provide targeted education to patients, families/caregivers, and the public about AYA cancer issues.
- Educate multidisciplinary providers who work with AYAs to improve referrals and services to this population.

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

- Create large prospective database of AYA cancer patients to facilitate research on this age group.
- Increase the number of annotated specimens to support research progress.

- Create/modify assessment tools specific to AYA cancer issues.
- Improve grant coding and search term standardization to enable evaluation of research efforts and progress.
- Expand clinical trials for AYAs to increase treatment choices and accelerate treatment advances.

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

- Develop, evaluate, and disseminate standards of care for AYA cancer patients and survivors to improve outcomes.
- Establish a national network or coalition of providers and advocates seeking to achieve a standard of excellence in AYA cancer care

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

- Address the subjective experience of AYA patients
- Build the capacity of existing resources to address AYA psychosocial needs.
- Evaluate existing programs and develop new interventions.

Research Portfolio

In 2006, NCI sponsored a research portfolio analysis to identify recent projects that address AYAO issues.

Initially, the analysis focused only on research funded by NCI. Keyword searches were performed on an NCI project database to identify projects that were active between FY2002 and FY2005 and whose abstract contained the terms “young,” “teen,” or “adolescent.” Approximately 500 projects included these search terms. A closer examination by scientists found that the majority of these projects did not focus on AYA cancers; 300 projects were therefore eliminated from the portfolio. Examples of research that were excluded at this point were projects addressing interventions for adolescents to prevent cancer later in life (e.g., smoking-cessation campaigns or projects to improve adolescent diets to prevent post-menopausal breast cancer); other studies addressed the long-term side effects of treatment for a childhood cancer. The remaining 200 NCI-funded projects

Figure 3: Analysis of AYAO Research by Funding Organization

AYAO RESEARCH PROJECTS FY 2002-2005

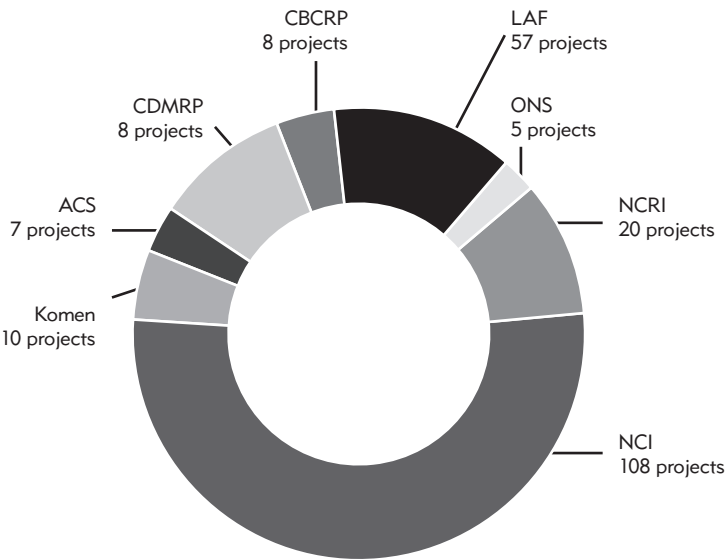
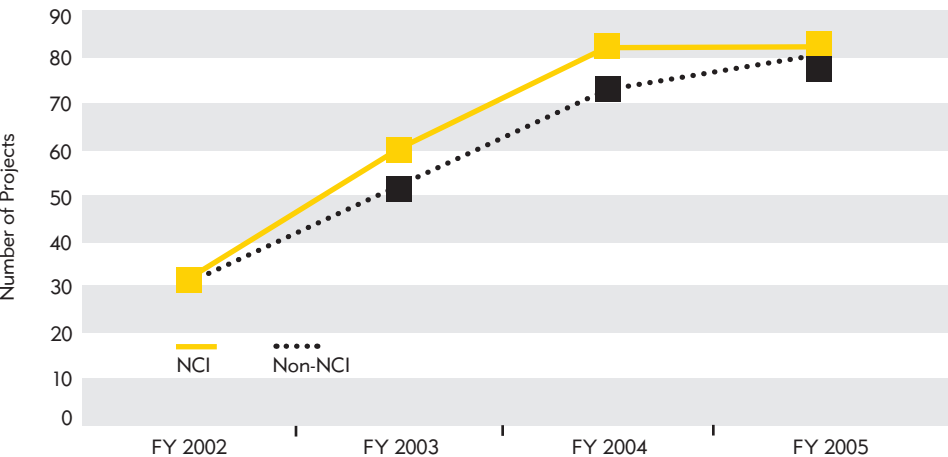


Figure 4: Trends in AYAO Research, FY 2002-2005

AYAO PROJECTS FY 2002-2005



were evaluated for relevance to AYAO on the basis of whether or not they specifically addressed the etiology, biology, prevention, detection, treatment, survivorship, or outcomes associated with cancers occurring in 15-39 year olds. After this filter was used, 108 NCI-funded projects were determined to be relevant.

This search strategy has many limitations. First, the strategy might inadvertently exclude projects that address a cancer that is pre-dominant or important in AYAO because these projects' abstracts do not mention individuals in this age range. Specifically, a keyword-based search could miss projects conducting basic biology research on cancers affecting young adults (such as testicular cancer), projects describing familial cancer syndromes that predispose individuals to cancer at an early age, and projects on "early-onset" cancers

typically found in older adults. In addition, although many projects found to be relevant do address AYAO biology, these are not necessarily investigating the differences between AYAs and other age groups. Very few projects in the portfolio actually include this type of comparative analysis.

After NCI-funded projects were analyzed, the AYAO research portfolio analysis was expanded to projects supported by other funding organizations, including the American Cancer Society (ACS), California Breast Cancer Research Program (CBCRP), Congressionally Directed Medical Research Program (CDMRP), Susan G. Komen for the Cure (Komen), Lance Armstrong Foundation (LAF), National Cancer Research Institute (United Kingdom, NCR), and Oncology Nursing Society (ONS). These projects were either identified by keyword searches

of the International Cancer Research Portfolio (ICRP), or their abstracts were supplied directly by the funding organization. All projects were evaluated for relevance to AYAO.

In all, the analysis identified 235 distinct projects that are directly relevant to AYAO research. Of these, 108 were funded by NCI and 127 were funded by other organizations (Figure 3).

The number of AYAO research projects increased between FY 2002 and FY 2005 for all funding organizations (Figure 4).

The projects are relevant to nearly 50 different disease sites. The cancer site with the highest number of AYA oncology projects is breast cancer. Forty-seven NCI projects and 43 projects funded by other organizations addressed breast cancer in AYAs. Other disease sites with high

Figure 5: Analysis of NCI Funded Research by Common Scientific Outline

PROJECTS FUNDED BY NCI

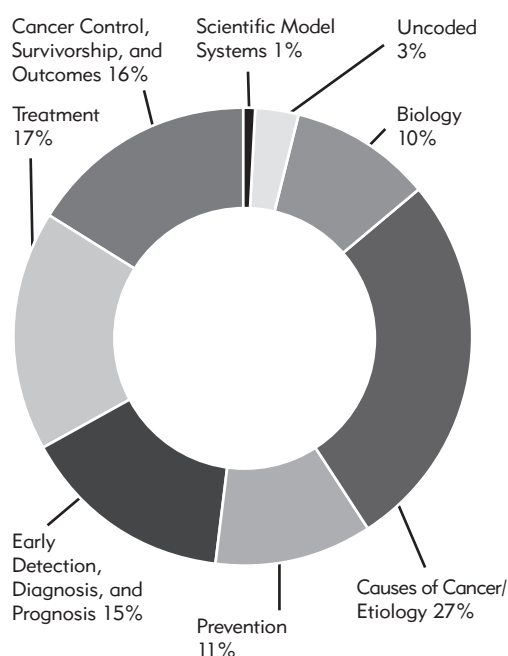


Figure 6: Analysis of Non-NCI-Funded Research by Common Scientific Outline

PROJECTS FUNDED BY NON-NCI ORGANIZATIONS

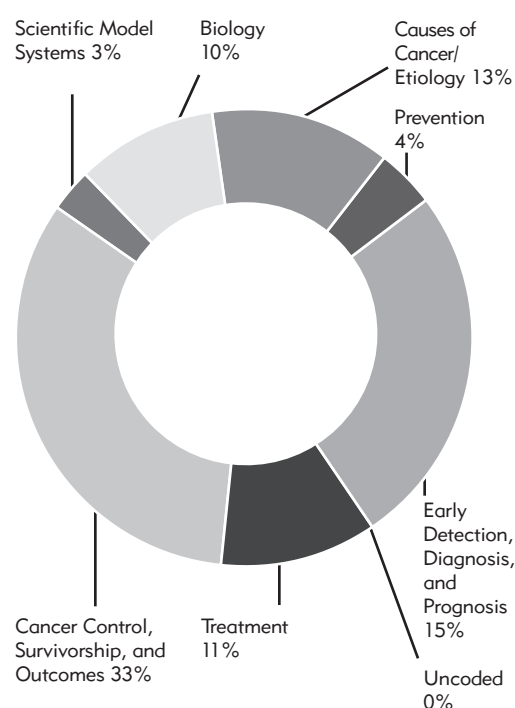
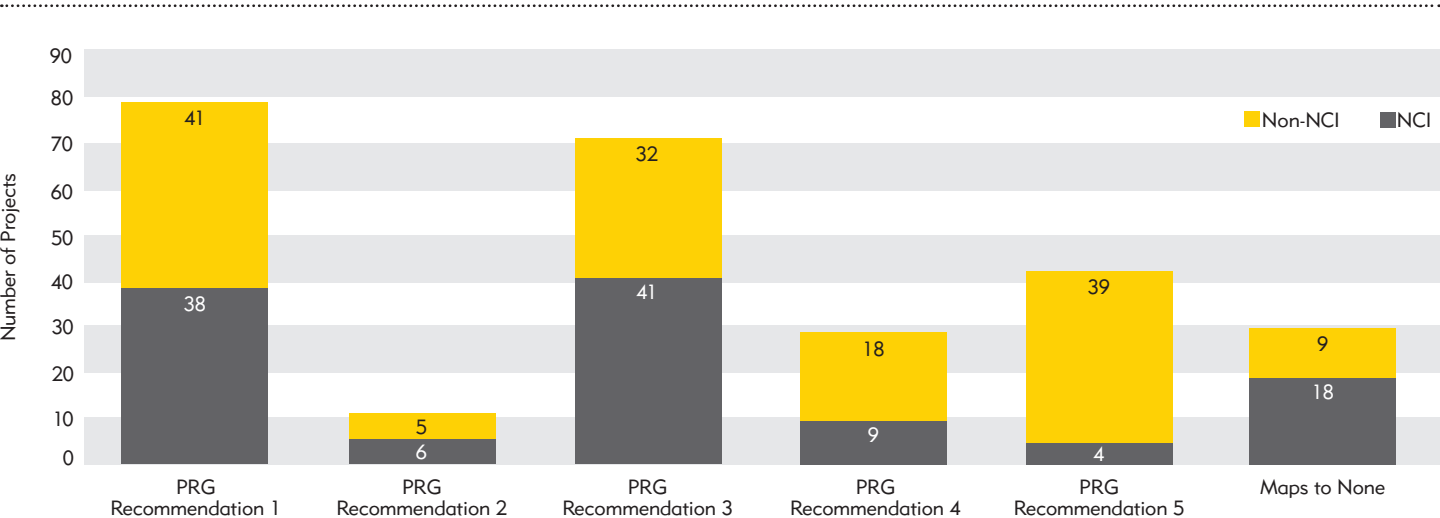


Figure 7: Analysis of AYAO Research by AYAO PRG Recommendation



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

numbers of projects in the research portfolio were nervous system cancers, sarcomas, blood cancers, and genital system cancers. When the projects were analyzed according to NCI’s Common Scientific Outline categories, the category with the greatest proportion of projects funded by NCI was causes of cancer/etiology (Figure 5). For projects funded by other organizations, the highest proportion of projects was in the cancer control, survivorship, and outcomes category (Figure 6).

The 235 AYAO-related research projects were categorized according to the recommendations identified in the AYAO PRG report, Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer. Projects were subjectively organized based on the “best fit” with each abstract, when possible, to one of the 16 available sub-recommendations. The absoluteness and reproducibility of this approach has limitations because relevance

to PRG recommendations was not an initial criterion for including projects in the original analysis of NCI’s portfolio. In fact, 29 projects (18 NCI, 9 non-NCI) did not match any PRG recommendation. In other cases, the fit was only approximate; caveats about these are provided in the relevant chapters of this report.

Among NCI-funded research projects, the PRG recommendations with the largest number of related projects were Recommendation 1 (unique characteristics) and Recommendation 3 (tools for studying AYA cancers). Among projects funded by other organizations, the PRG recommendations with the largest number of related projects were Recommendation 3 (tools for studying AYA cancers) and Recommendation 5 (advocacy) (Figure 7).

The projects associated with each PRG recommendation are summarized in Chapters 1–5 of this report. These chapters also provide analyses of the relevance of the AYAO research

portfolio to PRG sub-recommendations.

LIVESTRONG Young Adult Alliance

The LIVESTRONG Young Adult Alliance, launched in 2006, is a coalition of organizations that have joined together to improve survival rates and quality of life for AYAs with cancer. The Alliance promotes relevant research and community-based programs and services. It also generates awareness in the medical and political arena of the needs and issues of AYAs with cancer.

Member organizations include nonprofit organizations and medical institutions. These organizations provide expertise for the implementation of the strategies and mission of the LIVESTRONG Young Adult Alliance and bring a broad base of knowledge related to the many issues facing the young adult cancer community. The Alliance intends to be a clearinghouse of information, a leader in coordinated efforts, and a venue for sharing best practices.

Purpose of this Report

The LIVESTRONG Young Adult Alliance and NCI cosponsored a meeting on November 10-12, 2006, in Austin, Texas. This meeting brought together members of the AYAO PRG, the Alliance, and other scientists, providers, and advocates. The meeting served the dual purpose of being the inaugural meeting of the Alliance and the implementation meeting for the AYAO PRG recommendations.

During the meeting, Alliance leaders explained the purpose and structure of the Alliance. Participants then divided into breakout groups. Each group was assigned to address one of the following issues:

- AYAO professional track/professional development
- Psychosocial advocacy and support
- Biologic research and tissue sample/collection
- AYA public relations campaign
- Standards of excellence/standards of care
- Patient navigation/health coaches
- Clinical trials

Each breakout group was asked to focus on one or two of the AYAO PRG report recommendations and develop implementation strategies for these recommendations. At the end of the meeting, representatives of each breakout group presented the implementation strategies developed by their group. These strategies are presented in the chapters 1-5 of this report.

This report presents the implementation strategies developed at the November 2006 LIVESTRONG Young Adult Alliance/AYAO PRG meeting according to the AYAO PRG report recommendations that they were intended to address. Each of Chapters 1-5 focuses on a single AYAO PRG report recommendation and the implementation strategies designed to address that recommendation. Each chapter also includes a review of recent scientific research relevant to that AYAO PRG recommendation. For each implementation strategy, the report lists potential partners, potential resources, and a timeline.

CHAPTER

1

Implementation Strategies for Progress Review Group (PRG) Recommendation 1 — Identify the Characteristics that Distinguish the Unique Cancer Burden in the Adolescent and Young Adult (AYA) Oncology Patient

I learned, as a 32-year-old breast cancer patient, that there were too many questions no one could answer: Where can I find information relevant to my age group? If mammograms aren't really effective in young women's dense breasts, what else can be used to properly screen and diagnose us? Will standard chemotherapy work, even though no women my age were in the clinical trials? Will cancer derail my career aspirations? How can I find other patients to talk to who aren't my grandparents' age? Why is cancer more aggressive in younger women? Survival rates are quoted at five years after diagnosis—what are my chances to live another 30, 40 or 50 years? And while it wasn't on my radar screen, would I ever be able to have children if some day I wanted to?

—Randi Rosenberg (diagnosed with breast cancer at age 32)

The Adolescent and Young Adult Oncology (AYAO) Progress Review Group (PRG) recognizes the importance of studying the unique characteristics of adolescents and young adults (AYAs) diagnosed with cancer, including biology, life stage and developmental characteristics, and disparities experienced by AYAs relative to other age groups. Although research on this topic has been limited, several studies suggest that important differences do exist between AYAs and older or younger patient populations with similar diseases.

To address the need for more research in these areas, the AYAO PRG's first recommendation is: **Recommendation 1:** Identify the characteristics that distinguish the unique cancer burden in the AYAO patient.

- Elucidate unique biologic characteristics of AYA cancers and AYA patients that affect disease outcome in this population.
- Elucidate AYA life stage/developmental characteristics that influence care seeking, adherence to treatment, and medical and psychosocial outcomes.
- Identify and ameliorate health disparities experienced by AYA cancer patients and survivors.

Research Related to this AYAO PRG Recommendation

Recent research efforts that address AYA biology (AYAO PRG Recommendation 1) are summarized in Figure 8.

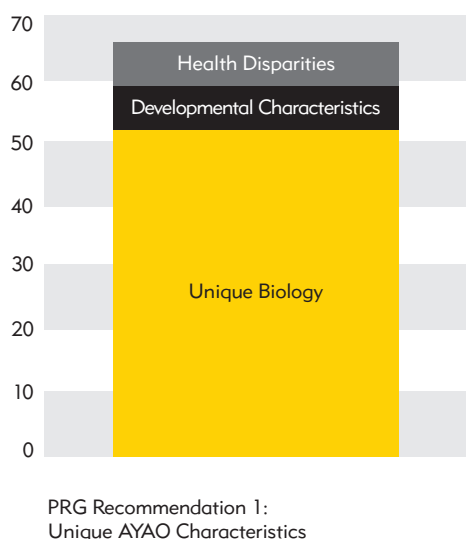


Figure 8: AYAO Research Projects Relevant to Recommendation 1, FY2002–FY2005

The AYAO research portfolio analysis identified 79 projects funded between FY2002 and FY2005 that were related to unique AYA characteristics. Approximately half (38) of these projects were funded by NCI, one-quarter (22) by the Lance Armstrong Foundation (LAF), and the remainder by the American Cancer Society (ACS), Congressionally Directed Medical Research Programs, Susan G. Komen for the Cure, National Cancer Research Institute (United Kingdom), and Oncology Nursing Society. The projects can be categorized by relevance to the following PRG sub-recommendations:

AYAO Biology

Sixty-six projects address the unique biologic characteristics of AYA cancers that affect disease outcome. Two are clinical studies focused on novel, molecular targeting agents

for the treatment of Ewing sarcoma and neurofibromatosis. Several projects address biological risk factors for developing AYA cancers, including levels of circulating hormones, obesity, viral infection, and polymorphisms in steroid biosynthesis or metabolism genes. The remaining projects are basic research studies focused on molecular characteristics of cancers that occur in AYAs, such as alterations in expression or function of tumor suppressor genes, oncogenes, transcription factors, and DNA repair systems.

Developmental Characteristics

Eight projects focus on elucidating the developmental or life-stage characteristics that influence care seeking, adherence to treatment, and medical and psychosocial outcomes. Four projects are studying quality of life after treatment for cancer, two projects focus on reducing the risk of secondary cancers after treatment for an AYA cancer, and two projects address communication and information seeking among adolescents with cancer or at risk of developing cancer.

Health Disparities

Six projects are studying disparities experienced by AYA cancer patients and survivors. Four projects address the genetic factors that increase cancer susceptibility for certain racial groups, and two projects focus on socioeconomic status with respect to cancer prevention and survival.

Implementation Strategies

To address AYAO PRG Recommendation 1, participants in the LIVESTRONG Young Adult Alliance/AYAO PRG meeting proposed the implementation strategies described below.

STRATEGY 1

Biological Research and Tissue Sample/Collection Breakout Group

Establish a strong scientific foundation for the biology of AYA cancers using retrospective analyses of existing biology or epidemiology studies that might not have focused on the AYA age group but that include the relevant (age-appropriate) tumor specimens. Use results from the retrospective studies to generate focus areas and hypotheses to be tested prospectively using existing tissue and data resources.

Phase 1

Using data from existing tissue and cohort studies will result in high-yield, low-cost research results on AYAO biology that will be critical for generating the next set of questions or hypotheses that can be pursued in a prospective manner. The results of this preliminary research could provide support for the perception that AYA cancers are biologically distinct and warrant dedicated resources for research.

In a typical grant solicitation, a government agency (such as NCI) cannot request that certain scientists perform specific retrospective analyses on previously published papers using identified sets of tumor samples. Rather, they must overcome many hurdles to obtain approval for an initiative idea on a certain topic, release that initiative, and perform lengthy reviews of the many applications they receive. Even then, they do not have a direct say in exactly which studies are performed or by whom. The approach outlined in Strategy 1 is much more direct because LAF/AYAO PRG leadership will contact the tumor bank directors and coordinate funding efforts by determining which scientists will perform the study and what exactly will be studied, bypassing the many steps associated with reviewing grants from unqualified scientists. Thus, this approach is much more direct than most government-funded research projects.

This approach directly identifies the resources and the scientists who have the relevant expertise needed to accomplish these goals quickly. This new knowledge will help make the case for additional studies (i.e., it will provide evidence that biologic differences exist between tumors in AYAs and in older or younger individuals) and could help convince NCI, the Department of Defense, and other government agencies to fund additional research on this topic.

The scientific foundation for the biology of AYA cancers will be established by:

- Reviewing current tissue, tumor, and data bank inventories to identify existing AYA specimens.
- Asking the directors of the tissue and data banks to identify thought leaders who are already using these resources successfully.
- Targeting the suggested thought leaders and soliciting proposals from them for short-term (1-year) studies examining existing data from earlier studies for AYA-specific analysis.
- Mining epidemiologic data from prior cohort studies.
- Including the military in epidemiologic studies of AYA cancers because
 - A large part of the current military population falls into the AYA age range. These individuals can (and do) develop cancer, and it is in the government's interest to protect their health.
 - This population is unique in that all members have the same insurance and access to healthcare, and removal of these variables allows for better analysis of the biology of cancer in this population without confounding factors.
- Ensuring that the studies are large enough to provide statistical significance when the AYA data are examined.

Phase 2

Invite a small number of selected investigators (including some involved in the Phase 1 studies)

who have a proven track record in this area of research to pursue the hypotheses identified in Phase 1 and to submit applications for Phase 2 studies. Knowing that money might be available for Phase 2 could motivate researchers to perform well in Phase 1. LAF will review the applications with support from the AYAO PRG leadership

The resulting effort will more closely resemble a contract than a grant in that specific milestones must be met by the investigators for funding to continue. Principal investigators will need a prior commitment from a tumor bank and will be required to focus on non-Kaposi's sarcomas, leukemias, lymphomas, breast cancer, colorectal cancer, or germ cell tumors. Investigators will also be required to share data and make their data accessible to the broader research community. All awardees will meet annually to review the data and discuss collaboration opportunities. At that time, LAF and the AYAO PRG leadership will determine whether funding should be continued for each investigator.

This strategy will use existing tissue and data resources and principal investigators with proven track records to answer the most important questions resulting from Phase 1 in a relatively rapid and cost-effective fashion. This strategy offers a quick, targeted approach for increasing knowledge of AYAO biology without pursuing more traditional channels for obtaining funds from the government. Because no Program Announcement (PA) or request for applications (RFA) will be issued and reviewed by the government, the timeframe will be relatively short.

Each Phase 2 project will last 5 years, contingent upon successful annual review of progress. The high cost of Implementation Strategy 1 is directly related to the microarray studies to be performed on the tumor specimens, not the actual retrieval of samples from the tumor banks.

23 This implementation strategy is also relevant to Recommendation 3: Identify the characteristics that distinguish the unique cancer burden in the AYAO patient.

STRATEGY 1
Timeline
By 6 months: Issue targeted solicitation and review data bank mining proposals.
By 18 months: Complete and publish studies.
At the end of Month 18: Convene a retreat to review the results of these studies and determine research directions for Phase 2.
Years 2–6: Complete Phase 2 of Strategy 1.
Cost ²⁴
Phase 1: Six proposals at \$100,000 per proposal = \$600,000 total (maximum).
Phase 2: Three projects at \$300,000 per year for each of six diseases = \$6M total per year (including direct costs plus 10% for indirect costs)
Resources
NCI supplements to P30, P50, and P01 grants.
Potential Partners
NCI's Cancer Diagnosis Program will provide a current list of existing tissue banks and their directors.
Tissue and data bank principal investigators.
NCI's Office of Cancer Survivorship will provide lists of existing cohorts of AYA patients for epidemiologic studies.
Department of Defense, particularly for epidemiologic studies of AYA cancers.
US Oncology, which owns and coordinates 70% of community oncology practices and might have a central repository of existing data.
LAF and cooperating public and private organizations (both disease specific and non-specific).
National Institutes of Health (NIH) Clinical and Translational Science Award supplements.
Congress for set-aside funds for Department of Defense budget (could convince Congress of the importance of studying this topic because of large AYA population in the military).
ACS.
Companies that give technology-based gifts.
Local companies that could offer matching funds.

²⁴ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

STRATEGY 2

*Biological Research and Tissue Sample/Collection
Breakout Group*

Publish a summary of this meeting in the journal *Clinical Cancer Research*.

A published summary of this meeting would make the case for the importance of AYAO research and stimulate more interest in this area. This summary would include the implementation strategies for all breakout groups, with a possible focus on race differences.

STRATEGY 2
Timeline
Year 1: This summary should be published within the first year after the implementation meeting.
Cost ²⁵
None identified.
Resources
None identified.
Potential Partners
<i>Clinical Cancer Research.</i>
Other journals if Clinical Cancer Research does not agree to publish the summary, such as <i>Blood</i> , <i>Journal of the National Cancer Institute</i> , <i>The Oncologist</i> , and <i>New England Journal of Medicine</i> .

²⁵ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

STRATEGY 3

*Biological Research and Tissue Sample/Collection
Breakout Group*

Encourage NCI to develop and solicit a program announcement (PA) and, when funds are available, a request for applications (RFA) for projects based on data gleaned from Implementation Strategy I (Phases I and 2). These initiatives should focus on the role of biology in AYA cancers.

The goal of this implementation strategy is to develop a long-term strategic plan for continued scientific and clinical advancement in the field of AYAO.

If preliminary data can be developed from Implementation Strategy I that make the case for studying the biological characteristics of these cancers, NCI might be willing to solicit research from the broader scientific community on this topic. By releasing a PA or RFA, NCI would be showing that it considers AYAO to be an important area of research and this could convince other agencies to fund AYA cancer research in the future. Also, an official solicitation reflects to some degree NCI strategic priorities.

The PA/RFA process is a longer term strategy to ensure that funding for AYAO continues after Implementation Strategy I is complete.

STRATEGY 3
Timeline
Start 2 years after preliminary results are available from Phase 1 of Implementation Strategy 1. These initiatives should be continuous solicitations.
Cost ²⁶
None identified.
Resources
None identified.
Potential Partners
NCI and other National Institutes of Health (NIH) Institutes (such as the National Institute on Aging)

²⁶ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

STRATEGY 4

Clinical Trials Breakout Group

Encourage completed, ongoing, and new clinical trials to obtain new knowledge about cancer in AYAs.

Preliminary data indicate that AYAs with cancer have an outcomes deficit and a distinctive biology. Additional supportive or refutive data are needed to focus future efforts. The efforts described above would be designed to compile existing data, initiate a universal registration effort to characterize and track the AYA population, and implement incremental changes (at a relatively low cost) to existing clinical trial structures to facilitate extraction of age-specific data.

Phase 1

- **Publish white paper²⁷ on known biologic and outcomes differences.** Establishing credibility for the existence of biological and health care disparities in AYAs is an important goal. An immediate step toward achieving this goal is to collect existing evidence and generate a white paper. This will raise awareness and establish a starting point for further efforts.
- **Develop and execute a systematic approach to analyze retrospective AYA data in published trials and trial databases (including SEER data).** Some published reports of clinical trials are stratified by age. A retrospective meta-analysis of this published work could yield insights into distinctive biological and clinical characteristics of AYA cancers.

Furthermore, even when published reports do not stratify results by age, the raw data underlying the study almost always contain subject age information. A retrospective analysis should include an effort to obtain and analyze such data from databases developed by clinical trials groups and centers, health care networks, the Food and Drug Administration, and the pharmaceutical industry.

Before the collection effort begins, data collection templates must be developed to drive the systematic compilation of data. Three experts should draft the general precepts for the analysis and review them with a panel that includes representatives from the breakout groups at the LIVESTRONG Young Adult Alliance/AYAO PRG meeting.

The three experts should include a biostatistician with cooperative group experience, a representative from the NCI Cancer Therapy Evaluation Program (CTEP), and an AYA investigator with experience as a cooperative group chair.

Reviewers should include an NCI CTEP statistician with meta-analysis experience, a medical oncologist with cooperative group experience, a Clinical Trials Breakout Group member, and a Biology Breakout Group member.

Phase 2

- **Require the inclusion of age data in annual reports from Cancer Centers, Cooperative Groups, and Community Clinical Oncology Programs.** The enrollment of subjects in clinical trials almost always involves collection of data on patient age; however, these data are frequently ignored in analysis and reporting unless the research has age-specific features. These age data (which are almost certainly available) should be used in analyzing and reporting results. This can be a requirement in government programs and can be requested of private programs. This is expected to add little to the cost of data collection and analysis.
- **Request age data from private oncology care networks (e.g. US Oncology, Kaiser).** See previous item.
- **Require that all new NCI-sponsored clinical trials specify age target ranges.** Such a requirement would make it easier to identify trials relevant to AYAs and would facilitate identification of ongoing AYAO-relevant trials for patients and care providers.

- **Require health-related quality-of-life assessments in all Phase III and randomized Phase II clinical trials when doing so is appropriate and informative.** This would enhance the value of clinical trials across the board but could also identify distinct features of AYAs.
- **Use the Childhood Cancer Survivor Study model to create a universal “registration trial” to identify AYAs, obtain prospective consent, and generate enthusiasm among AYAs for participation in clinical trials (use branding, status symbolism, etc.).** Public relations tactics, including the use of popular icons, unique promotional gifts, and other high-profile symbols, would make enrollment attractive to AYAs.

This “trial” would be an effort to gather data for hypothesis development. It would entail registering AYA patients and collecting data related to disease, treatments, and trials; outcomes; and demographic and psychosocial characteristics. Registrants would agree to future contact for follow-up and would receive materials promoting participation in medical clinical trials and/or surveys regarding the psychosocial aspects of the AYA cancer health-care experience and life after cancer treatment. Enrollment should be available through the Internet portal described in Implementation Strategy I in Chapter 3.

- **Use results of retrospective data analysis (Year 1) in conjunction with known disease impact factors to prioritize clinical trial development.** The results of the Year 1 retrospective data collection and analysis effort described above would be used to clarify the features of diseases, treatment pharmacology, outcome disparities, and other effects that are unique to AYAs. This information would be combined with the top eight cancer “impact factors” identified in the NCI AYAO PRG report (http://planning.cancer.gov/disease/AYAO_PRG_Report_2006_FINAL.pdf) to prioritize the development of new clinical trials targeting the AYAO population.

27 In this report, “white paper” is defined as an authoritative report on a major issue written by a team of experts.

STRATEGY 4	
Timeline	
Year 1:	<ul style="list-style-type: none"> Develop white paper. Conduct retrospective literature/database analysis.
Years 2–5:	<ul style="list-style-type: none"> Standardize reporting of age data in clinical trials. Require health-related quality-of-life assessments. Create “registration trial.” Prioritize trial development.
Cost ²⁸	
Year 1:	\$0.3 million.
Years 2-5:	\$8.4 million.
Resources	
American Society of Clinical Oncologists.	
American Association for Cancer Research.	
Department of Defense.	
ACS.	
Leukemia and Lymphoma Society.	
Potential Partners	
Cooperative groups.	
Pharmaceutical industry.	
Food and Drug Administration.	
Cancer Centers.	
Community Clinical Oncology Programs.	
US Oncology.	
Kaiser.	

²⁸ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

CHAPTER

2

Implementation Strategies for Progress Review Group (PRG) Recommendation 2—Provide Education, Training, and Communication to Improve Awareness, Prevention, Access, and Quality Cancer Care for Adolescents and Young Adults (AYAs)

I saw several doctors about the lump on my head, but no one thought anything of it. The only reason I found out I had cancer was chance. When I visited my dermatologist for another reason, as I was literally walking out of the clinic, he flagged me down to examine the lump. Even when the dermatologist was alarmed, it never occurred to me, my parents, or several doctors that it could be cancer. Had I not gone back to my dermatologist for a completely unrelated reason, I probably would not be alive today.

—Anne Willis (diagnosed with Ewing sarcoma at age 15)

The Adolescent and Young Adult Oncology (AYAO) Progress Review Group (PRG) stressed the urgent need for a variety of education, training, and communication activities to raise public and professional awareness and recognition of adolescents and young adults (AYAs) with cancer. This education, training, and communication must be culturally appropriate and delivered by culturally competent people.

To address the need for more activity in these areas, the AYAO PRG's second recommendation is:

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

- Raise awareness of AYA cancer issues as a first step toward increasing national focus and resource allocation to address the AYA cancer problem.
- Provide targeted education to patients, families/caregivers, and the public about AYA cancer issues.
- Educate multidisciplinary providers who work with AYAs to improve referrals and services to this population.

Related Research

Recent research efforts that address education, training, and communication (AYAO PRG Recommendation 2) are summarized in Figure 9.

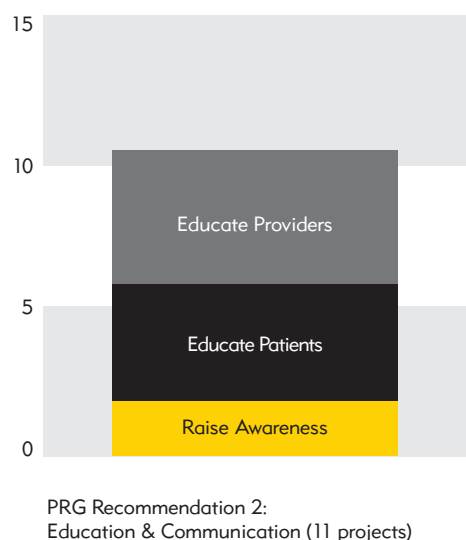


Figure 9: AYAO Research Projects Relevant to Recommendation 2, FY2002–FY2005

The AYAO research portfolio analysis identified 11 projects funded between FY2002 and FY2005 that were related to Recommendation 2. Most (6) of these projects were funded by NCI; the remainder were funded by the Lance Armstrong Foundation (LAF), American Cancer Society, Susan G. Komen for the Cure, and National Cancer Research Institute (United Kingdom). The projects can be categorized by relevance to the following PRG sub-recommendations:

Raising Awareness

Four projects focus on raising awareness of AYA cancer risk and prevention strategies among susceptible populations, including teens who use tanning booths or daughters of women who have had breast cancer. One of these projects is also aimed at understanding how adolescents perceive cancer risk, including their perceptions of gene-behavior

interactions and how behavior modifications may reduce the risk of developing cancer.

Educating Patients

Five projects are studying targeted education for patients, families and caregivers, and the public about AYA cancer issues. Two projects address fertility after treatment for cancer, two focus on educating AYAs about genetic testing for inherited predisposition to cancer, and one addresses teaching young men about testicular self-examination.

Educating Providers

Only two projects focus on educating multidisciplinary providers who work with AYAs to improve referrals and services to this population. One of these projects funds a medical oncology fellowship program to train physicians in AYAO issues. The other project is investigating fertility issues and pregnancy-related complications in cancer survivors to improve the likelihood of post-treatment parenthood for AYAs with cancer by increasing oncologists' understanding and awareness of post-treatment fertility issues and related treatment modifications.

Implementation Strategies

To address Recommendation 2, participants in the LIVESTRONG Young Adult Alliance/AYAO PRG meeting proposed the implementation strategies described below.

STRATEGY 1

Professional Development Breakout Group

Bring together experts with experience in AYA programs to prepare a white paper²⁹ that lays out a blueprint for the professional development of AYA cancer providers.

Based on the white paper, prepare a position statement that lays the foundation for creating nationally accepted criteria and standards of care for practice, ultimately leading to the development of formal, certified training programs for AYAO healthcare practitioners.

A credible forum is needed to develop curricula and establish standards of care with appropriate dissemination vehicles. A credible, authoritative source, such as a white paper, is likely to increase organization buy-in and serve as a critical first step in creating AYA professional development curricula, guidelines for standardizing patient care, and certification programs for AYAO professional development. Including professional societies in the observer group will ensure organizational buy-in. It will also ensure the involvement of representatives who are receptive to new ideas and change and who are actively engaged in the re-examination, evolution, and improvement of the professions they represent.

Outcome measures for this strategy include the white paper, position statements for publica-

tion, endorsements, and dissemination.

Preparing and disseminating the white paper will involve the following steps:

- Host the meeting to prepare the white paper at an institution (such as the National Institutes of Health [NIH]) whose reputation and position lends credibility and creates buy-in.
- Create a “core group” to write the paper with representatives from the dozen or so AYA programs in the United States and, if necessary to develop a well-rounded group, a few additional participants, such as members of professional societies; survivors of AYA cancers; and professionals with expertise in social work, psychology, and relevant, non-oncological healthcare professions. The core group should not exceed a “critical mass” and should be designed for compactness, efficiency, and focused success.
- To give additional avenues for input into the process, create a larger “observer group” of professional society representatives to meet at the same time as the core group, discuss professional development in AYAO, contribute their ideas to the core group, and help disseminate the white paper.
- Disseminate the white paper and position statement by publishing related materials in professional journals and reaching out to professional societies and societies for medical and nursing students.

²⁹ In this report, “white paper” is defined as an authoritative report on a major issue written by a team of experts.

STRATEGY 1	
Timeline	
0-6 months: Secure funding and plan kick-off meeting.	
6-12 months: Hold the meeting (to be co-chaired by representatives of the LIVESTRONG Young Adult Alliance and AYAO PRG).	
Cost ³⁰	
\$20,000	
Resources	
Consider alternative meeting funding sources, such as public and private grants from: <ul style="list-style-type: none"> • Aflac. • Aetna. • NIH (R13 grant mechanism). • Alliance for Self Care Research. • American Society of Clinical Oncology. 	
Potential Partners	
Centers with established AYAO programs (core group).	
Professional and ancillary organizations (larger observer group).	
American Academy of Family Medicine.	
American Academy of Family Physicians.	
American Academy of Nurse Practitioners.	
American Brain Tumor Association.	
American College of Obstetricians and Gynecologists.	
American Psychological Association.	
American Society of Clinical Oncology.	
American Society of Pediatric Hematology/Oncology.	
Association of Hematology/Pediatric Oncology Nurses.	
Association of Pediatric Oncology Social Workers.	
Cooperative Groups.	
LAF.	
Leukemia and Lymphoma Society.	
National Association of Social Workers.	
Oncology Nursing Society.	
Public health organizations.	

³⁰ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

STRATEGY 2

Psychosocial Advocacy and Support Breakout Group

Evaluate and help improve existing sources of information and support for AYAs with cancer. Develop a Web portal to connect information seekers to existing information and service providers.

AYAs with cancer should be encouraged to seek information about their disease, treatment, and potential late effects. Many nonprofit organizations, government agencies, healthcare providers, and others provide AYA-related cancer information on the Internet. However, this information is not coordinated or overseen by anyone, so its accuracy and appropriateness are not known. Furthermore, no central source of such information is available. Some of the information is not available in an age-appropriate and relevant way for AYAs. As a result, AYAs and their loved ones often have trouble locating relevant information and assessing the accuracy of the information they do find. A centralized resource would improve access to appropriate information and services for AYAs, assist member organizations by driving traffic to their websites, and streamline professional collaboration by connecting information and service providers with one another.

To improve existing sources of information and support and develop a new Web portal, the break-

out group recommended the following activities:

- Use NCI's Health Information National Trends Survey (HINTS), which collects nationally representative data on the American public's use of cancer-related information, to identify the major information sources that AYAs use to learn about cancer.
- Develop a set of criteria to assess the availability, accuracy, relevance, and appropriateness (with respect to age, culture, comprehensiveness, accuracy, and timeliness) of information sources available to AYAs.
- Use the criteria to evaluate the information provided by these sources and share the assessment results with the information providers so that they can enhance their offerings for AYAs.
- "Certify" the information providers that meet the AYA cancer information criteria. The group that certifies the providers could seek out and assess known information sources. Information providers could also apply for certification. Certified organizations could help others improve their offerings to qualify for certification. Certification would be for a designated period of time—organizations would need to reapply for certification periodically to ensure that they are maintaining their sites. Certification could be coordinated or developed under auspices of the LIVESTRONG Young Adult Alliance.
- Develop a searchable and well-organized Web-based portal (perhaps based in LAF's

website, which is well known) that takes those seeking information on AYA-related cancer information to certified websites.

- All participating organizations would offer links to the portal on their sites.
- The portal would have little content but would link users to websites with the information they need.
- The portal would categorize the sites by age, geographic region, type of cancer, and other criteria.
- An AYA advisory board would ensure that the portal has a youth-oriented design and uses appropriate terminology for its audience.
- The portal would provide searchable links to personal stories.
- The portal should take advantage of new technologies such as interactive gaming and artificial intelligence, which can customize web pages for users.
- Create an 800-number (or work with existing telephone information services to expand their offerings) that links those without Internet access to information on cancer in AYAs. Additional non-electronic options include an AYA information kit or resource guidebook with descriptions of AYA-specific programs distributed through doctor's offices.
- Publicize the portal through media that are popular with AYAs, such as MTV, YouTube, Facebook, and MySpace.

STRATEGY 2
Timeline
Years 1–2: Create the Web portal (the portal will require ongoing maintenance).
Cost ³¹
\$75,000 to assess current offerings and create a template for certification.
\$50,000-100,000 to design, create, and pilot test the portal.
\$10,000 per year to maintain and update the portal.
Resources
Graduate student to assess existing services and create a template for certification.
Young Adult Alliance members to provide “seal of approval.”
NCI’s usability lab to test the portal.
Potential Partners
NCI’s Cancer Information Service.
ACS.
LAF.
Academic researchers who study information seeking and AYA cancers.
AYA advisory board.
Teen and generation X/Y advertising and Web-development companies.
Existing phone-based information services.
International resources.

³¹ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

STRATEGY 3

Psychosocial Advocacy and Support Breakout Group

Increase healthcare providers’ early recognition of AYA cancers and referrals to appropriate specialists.

Advocacy is needed to ensure that healthy AYAs and primary care providers are aware that cancer is a possibility if patients present with certain types of symptoms. The healthcare providers (including primary care providers, emergency room personnel, and school-based clinic staff) that AYAs typically turn to when their cancer symptoms appear do not always consider cancer as a potential diagnosis. Many rarely see AYAs with cancer and do not realize that although cancers are not typical in this population, AYAs can and do develop cancer. As a result,

diagnoses of cancer in AYAs are often delayed and these cancers are not treated early, when treatments are most effective. In addition, these providers are not necessarily aware of developmentally appropriate resources, services, and referral resources for AYAs.

Because these providers see cancer in AYAs so rarely, it is not practical to provide them with state-of-the-art training on cancers in this population. Instead, they need simple messages (e.g., “Persistent symptoms? Think cancer.”) to remind them that certain symptoms in AYAs could be signs of cancer.

It is unlikely that healthy AYAs will acknowledge their risk of developing cancer. For this reason, it is critical for providers to keep cancer in mind

as a possible diagnosis when treating AYAs.

Healthcare providers’ recognition of AYA cancers and appropriate referrals should be increased by:

- Working with professional societies and advocacy organizations to develop continuing education programs for “frontline” providers and oncologists.
- Developing a simple message (e.g., “consider cancer”) that can be widely disseminated to frontline providers and oncology professionals who treat AYAs.
- Customizing the information for different audiences—for example, some providers might prefer continuing education credits, while others would respond best to short written materials.

STRATEGY 3
Timeline
Within 6 months, identify potential partners, establish contact and develop a tactical plan.
Within 2 years, begin dissemination program through annual meetings of professional societies.
Cost ³²
Not identified.
Resources
Staff to develop relationships with organizations and encourage them to provide resources pro bono.
Potential Partners
NCI’s Cancer Information Service.
American College Health Association.
Advocacy organizations (e.g., LAF, ACS).
Children’s Oncology Group.
Professional Societies (e.g., Society for Adolescent Medicine, Oncology Nursing Society, Association of Pediatric Oncology Nurses, Association of Oncology Social Work, Association of Pediatric Oncology Social Workers).
For-profit medical education companies.

32 All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

STRATEGY 4

Public Relations Breakout Group

Penetrate the consciousness of the public and frontline providers with the AYA message: “Consider Cancer.”

Young adults believe that they are invincible, so they rarely believe that they could have cancer, even when symptoms develop. This sense of being immune to disease and death makes many AYAs put off obtaining a diagnosis of their symptoms. Moreover, most AYAs defer readily to an authority figure, such as a doctor, who tells them their symptoms cannot be due to cancer. Even if they are diagnosed, many AYAs cannot adhere to their treatment schedules due to the unique challenges of balancing career, school, and young families.

Parents do not want to believe that their AYA children could develop cancer. As a result, they are likely to dismiss symptoms reported by their children and rarely think of cancer as a possibility.

Providers often fail to suspect that their AYA patients have cancer. As some of the personal stories in this report show, they do not always recommend appropriate diagnostic steps or referrals for patients with symptoms that could be caused by cancer. They also fail to refer AYA patients with potential cancer symptoms to appropriate specialists for diagnosis and treatment. AYA-specific content in continuing medical education (CME) and professional conferences should create incentives for changing behavior in the medical community by creating a willingness to consider cancer as a possibility in AYAs.

It is therefore critical to spread the word to the public, particularly AYAs and their families, and to providers who treat AYAs that young people can and do develop cancer. But this must be done strategically, by partnering with appropriate industry representatives and using techniques and communications vehicles that appeal to AYAs and that they use as information sources (including coffee shops, games, and music). Surveying best practices used previously

for similar public health initiatives and partnering with groups that have implemented these practices successfully should also help ensure that this strategy will succeed.

Five steps are required to implement this strategy:

Phase 1—Gather important baseline information

- Identify baseline levels of awareness by surveying the target populations (the public and frontline providers) to better understand their perceptions of the AYA population's cancer risk.
- Evaluate best practices (other public health or social initiatives) for disseminating health-related messages and changing behavior.
- Identify and understand the incentives that could encourage the target audiences to change their behavior.

Phase 2—Develop a unique identity and message for the AYA cancer issue

- Enlist a professional marketing firm to develop a brand identity and campaign, such as the campaign to associate the color pink with breast cancer or Bono's (RED) campaign to raise money to fight AIDS in Africa.
- Consider using celebrities and/or lay people to disseminate the message.

Phase 3—Bring together all key touchpoints (points of contact) in the AYA world to create a coordinated affinity campaign

- Bring together key stakeholders (including representatives of coffee shops; schools/parent-teacher associations; and the Web, publishing, sports, music, gaming, fashion/retail, and telecommunications industries) to change public awareness and make a statement that cancer affects the AYA population too.
- Identify strategies that are appropriate for each of the different age groups within the AYA population. For example, a marketing campaign should recognize that the younger members of this population tend to focus on short-term goals and are group oriented; these individuals probably have emerging, but not complete, independence from parents or primary caregivers. The campaign should disrupt traditional attitudes about

invincibility while raising awareness about cancer and the AYA population. The campaign should send a message to encourage trusting one's instincts regarding health and not to ignore potential symptoms.

Phase 4—Mobilize survivors and families by leveraging existing Young Adult Alliance member networks

- Consider the following strategies:
 - Grassroots campaigns.
 - Visits by education teams to schools to discuss awareness.
 - Outreach by family members to other families affected by a cancer diagnosis in an AYA.
- Create materials and programs.
- Develop consistent messaging.
- Provide current and accurate data.

Phase 5—Develop AYA content for use in CME and professional conferences for frontline providers

- Work with organizations that offer CME to teach the medical professional community about cancer in AYAs.
- Incorporate AYA information into other units to reach as many providers as possible because providers might not choose units focused on AYA cancers.
- Develop incentives to change the medical community's behavior so that, for example, providers are more likely to consider cancer as a possibility in AYAs.

STRATEGY 4	
Timeline	
Months 1–6: Phase 1 (Gather important baseline information)	
Months 6–12: Phase 2 (Develop a unique identity and message for the AYA cancer issue)	
Year 2: Phase 3 (Bring together all key touchpoints [points of contact] in the AYA world to create a coordinated affinity campaign)	
Year 3: Phase 4 (Mobilize survivors and families by leveraging existing Young Adult Alliance member networks)	
Year 4: Phase 5 (Develop AYA content for use in CME and professional conferences for frontline providers)	
Cost ³³	
Year 1: Approximately \$500,000	
Resources	
Dedicated staff of two people	
In-kind exchanges, such as using existing connections to celebrities and sports figures and leveraging points of contact at professional marketing firms.	
Potential Partners	
Nielsen Media Research (Phase 1 data-gathering partner).	
Roper Center for Public Opinion Research (Phase 1 data-gathering partner).	
Datamonitor (Phase 1 data-gathering partner).	
Annenberg Public Policy Center, University of Pennsylvania (Phase 1 data-gathering partner).	
Robert Wood Johnson Foundation (Phase 1 data-gathering partner).	
Annie E. Casey Foundation (Phase 1 data-gathering partner).	
Kaiser Family Foundation (Phase 1 data-gathering partner).	
Research America (Phase 1 data-gathering partner).	
Market research companies (Phase 1 data-gathering partner).	

³³ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

STRATEGY 4

Potential Partners (continued)

University students (Phase 1 data-gathering partner).
Professional organizations (Phase 1 data-gathering partner).
Ad Council (Phase 1 best practice model and partner).
HIV/AIDS awareness campaigns (Phase 1 best practice model and partner).
Mothers Against Drunk Driving (Phase 1 best practice model and partner).
American Legacy Foundation's truth® tobacco campaign (Phase 1 best practice model and partner).
AARP (Phase 1 best practice model and partner).
Partnership for a Drug-Free America (Phase 1 best practice model and partner).
Planned Parenthood (Phase 1 best practice model and partners).
Rock the Vote (Phase 1 best practice model and partner).
Susan G. Komen for the Cure (Phase 1 best practice model and partner).
Nike (Phase 2 partner).
Ad Council (Phase 2 partner).
American Association of Advertising Agencies (Phase 2 partner).
Google (Phase 3 partner).
MySpace (Phase 3 partner).
Craig's List. (Phase 3 partner).
Starbucks (Phase 3 partner).
Health in Hollywood (Phase 3 partner).
iTunes (Phase 3 partner).
MTV (Phase 3 partner).
For-profit medical education companies (Phase 5 partner).
Professional societies (Phase 5 partner).

CHAPTER

3

Implementation Strategies for Progress Review Group (PRG) Recommendation 3— Create the Tools to Study the Adolescent and Young Adult (AYA) Cancer Problem

In May 2005, I was training for a marathon, studying for my finals, and hanging out with my friends, like any normal 22-year-old. In the midst of taking my final exams, however, a persistent cough developed that eventually made me short of breath. I checked myself into the hospital after my last exam. Once admitted to the emergency room, physicians discovered that 1.5 liters of fluid had accumulated around my heart. Immediately, surgery to remove the fluid was performed but doctors still could not figure out why this occurred. Internists, cardiologists, and infectious disease specialists were all mystified. Finally, a few days later, I was diagnosed with cancer of unknown primary, stage IV, and I was shocked. After 10 months, my diagnosis was changed to non-small cell lung cancer. Having never smoked a day in my life, it was incredibly surprising. Although I experienced strong results from my intravenous chemotherapy, Tarceva, which was effective for some patients with non-small-cell lung cancer in a clinical trial, was unsuccessful in stabilizing the cancer. I then received a combination of radiation and chemotherapy. In March 2006, I started on more chemotherapy (Alimpta) every 3 weeks. So far, the cancer has been reduced by 25%. I still get sick, nauseous, and everything else that accompanies chemo. My attitude remains positive as I believe life is 10% what happens to you and 90% how you react to it.

Dan Waeger (diagnosed with non-small-cell cancer at age 22)

The existing research infrastructure is inadequate to support needed adolescent and young adult (AYA)-focused research. The AYA Oncology (AYAO) Progress Review Group (PRG) therefore recommended that new research tools be developed to enable AYA-specific studies and that existing tools be strengthened where potentially useful infrastructures are already in place.

To address the need for more research in these areas, the AYAO PRG's third recommendation is: Recommendation 3: Create the tools to study the AYA cancer problem

- Create a large prospective database of AYA cancer patients to facilitate research on this age group.

- Increase the number of annotated specimens to support research progress.
- Create/modify needed assessment tools specific to AYA cancer issues.
- Improve grant coding and search term standardization to enable evaluation of research efforts and progress.
- Expand clinical trials for AYAs to increase treatment choices and accelerate treatment advances.

Related Research

Recent research efforts that address tools to study AYA cancer (AYAO PRG Recommendation 3) are summarized in Figure 10.

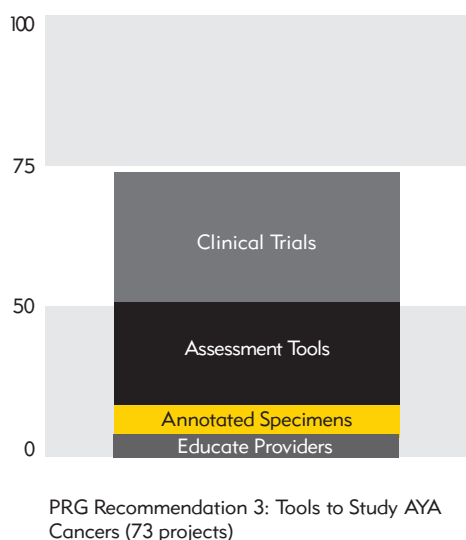


Figure 10: AYAO Research Projects Relevant to Recommendation 3 FY2002–FY2005

The AYA research portfolio analysis identified 73 projects funded between FY2002 and FY2005 that were related to Recommendation 3. More than half of these projects were funded by NCI; the remainder were funded by the Lance Armstrong Foundation, Congressionally Directed Medical Research Program, California Breast Cancer Research Program, National Cancer Research Institute (United Kingdom) Susan G. Komen for the Cure, and Oncology Nursing Society. Forty-two of the 73 research projects/clinical trials in this category focus on premenopausal breast cancer. Four projects focus on sarcoma, and seven projects are not specific to any single cancer type. The remaining projects address cancers of the brain/CNS, cervix, colon/rectum, testes, or hematologic system. The projects can be categorized by relevance to the following PRG sub-recommendations:

Prospective Databases

Three projects are creating or using databases of AYA cancer patients. One project is establishing a registry of tumors from patients with Von Hippel-Lindau (VHL) disease, which is most common in the AYA age group. Another project is collecting breast tissues from premenopausal women to ascertain the relationship between dietary intake of isoflavones and subsequent DNA methylation in the breast. A third project is analyzing the association between breast cancer and levels of steroid hormones, IGF-I, or insulin. No projects are creating a “large prospective database of AYA cancer patients” as recommended by the PRG.

Annotated Specimens

Eleven projects are collecting annotated specimens from patients in the AYA age range. These tissues include premenopausal breast cancer, early-onset colorectal cancer, cervical cancer, and VHL. One project is using this information to identify the characteristics that distinguish inflammatory from other types of breast cancer; another project is using tissue samples from patients with Ewing sarcoma to create novel therapies targeted to specific genotypes. Four projects are examining biomarkers of cancer risk, prognosis, or etiology, including one study of the association between HPV viral subtypes and types of cervical cancer. Two studies focus on the association between endocrine factors and mammographic breast density.

Assessment Tools

Twenty-eight projects are using assessment tools that are specific to AYA cancer issues. Fourteen of these focus on imaging technologies or proteomics tools that can be used for the early detection of breast cancer in young women, for whom mammography is less effective due to increased breast density. Five projects are examining risk assessment models for women with a family history of breast cancer. The remaining projects focus on health-related quality of life tools, including psychological and physiologic assessments, to monitor AYAs following treatment for testicular cancer, Hodgkin lymphoma, breast cancer, and colorectal cancer.

Grant Coding

No projects in the AYAO portfolio focus on improving grant coding and search term standardization to enable evaluation of research efforts and progress.

Clinical Trials

Thirty-six projects involve clinical studies that include patients in the AYA age range. Twelve of these trials are identifying and ameliorating side effects of cancer treatment, including menopausal symptoms, infertility, and cognitive dysfunction among AYAs. Fourteen trials are testing novel therapies for AYA cancers. Three projects involve oncology groups, programs, centers, or collaborations with drug companies focused on treating specific AYA cancers. One project is minimizing barriers to AYA enrollment in early-stage clinical trials. The remaining trials address prevention or detection strategies for young adult cancers.

Implementation Strategies

To address Recommendation 3, participants in the LIVESTRONG Young Adult Alliance/AYAO PRG meeting proposed the implementation strategy described below. Implementation Strategies 1–3³⁴ in Chapter 2 of this report are also relevant to AYAO PRG Recommendation 3.

34 Strategy 1: Phase 1—establish a strong scientific foundation for the biology of AYA cancers using retrospective analyses of existing biology or epidemiology studies—and Phase 2—use results from the retrospective Phase 1 studies to generate focus areas and hypotheses to be tested prospectively using existing tissue and data resources; Strategy 2: Publish a summary of this meeting in the journal *Clinical Cancer Research*; and Strategy 3: Encourage NCI to develop and solicit a program announcement and request for applications for projects based on data gleaned from Strategy 1.

STRATEGY 1

Clinical Trials Breakout Group

Create tools to enhance clinical trial activity in AYA cancer patients.

Better tools are needed to facilitate AYA clinical trial development, design studies and conduct analyses, and encourage AYA participation in clinical trials. Disproportionately low enrollment of AYAs in clinical trials for which AYAs are eligible suggests a shortfall in current tools used to recruit and retain AYAs. In addition, existing assessment and design tools do not account for AYAs' distinctive characteristics, address statistical problems associated with small sample sizes, or facilitate incorporation of minors in clinical trials.

The proposed strategy involves creating tools to promote enrollment among AYA consumers coupled with tools to create incentives for clinical researchers to recruit AYAs into trials. Equally important are novel tools for designing trials, increasing trial value, meeting human research subject protection requirements, and improving trial protocol adherence.

The steps (listed below) involved in creating tools to enhance clinical trials activity will take 5 years to complete.

Phase 1

- **Establish a “one-stop shop” on the internet for information and guidance that stimulates participation in clinical trials.** This strategy parallels other implementation strategies in this report but has several unique features. For example, prior to providing links to sites dedicated to specific diseases and special interests, the portal should present the viewer with generic lists of “Things You Should Do” and “Questions to Ask Your Physician” for both AYA patients and family members. Messages promoting participation in clinical trials should be embedded in these materials. The portal should also promote and facilitate enrollment in the “registration trial” described in Implementation Strategy 4 in Chapter 1 of this report (encourage completed, ongoing, and new clinical trials to obtain new knowledge about cancer in AYAs). The group

recommended that LAF Web developers and managers undertake this effort. They suggested that representatives of groups that provide clinical trials information on their Web sites work with clinical trial experts at cancer.gov (or PDQ), clinicaltrials.org, and the Coalition of Cancer Cooperative Groups.

- **Develop a legal/administrative toolkit to facilitate accrual of minor patients and institutional review board (IRB) approval of protocols that mix minor and adult patients, especially in community-based IRBs.** Too often, legal and administrative complications discourage researchers and institutions from proposing or conducting trials involving minors or a mix of minor and adult subjects (the AYA age range, specifically). A legal and administrative toolkit should be developed to provide key guidelines and boilerplate documents and forms that would help investigators and institutions generate the documentation and patient materials required to meet internal and external human protection requirements for such trials. One or two representatives from both pediatric and adult central IRBs should be charged by central IRB directors/managers to address this need.
- **Apply new strategies to study design (e.g., adaptive statistics) and outcomes measures (e.g. quality of life, surrogate markers, tumor response), which are especially needed for AYAs due to the limited patient population and their distinctive features.** The paucity of AYAO enrollees in clinical trials makes it difficult, using standard statistical designs, to achieve generally accepted levels of significance or power while preserving benefit to the patient.

New design and analysis strategies, derived in part from Bayesian methods and known collectively as “adaptive” designs, have been advocated by prominent researchers and are being explored by the Food and Drug Administration (FDA). The FDA and NCI should agree to novel statistical designs and the changes in outcome measures that they entail. This will come about when investigators begin to submit clinical study proposals that actually

use these novel statistical designs and measures. Upcoming meetings highlighting this topic should be surveyed to identify new methodologies and surrogate measures that could be applied to AYA clinical trials.

AYAO clinical trial researchers should adopt and promote the use of such designs to benefit the patient and speed up results. A representative from the FDA could formally represent the AYA community at an upcoming FDA meeting to highlight adaptive designs.

Phase 2

- **Modify existing quality-of-life assessment tools (FACT, Feeny/Barr, etc.) to address unique needs and circumstances of AYA patients.** AYA quality of life involves peer acceptance, physical activity, fertility, career building, and other factors that are different from those in older and younger groups. Standard tools for assessing quality of life should be modified to take into account concerns unique to the AYA age group.
- **Apply the health disparities support grant funding model used by Cancer Centers to AYA populations.** (Support this decision with data garnered through Implementation Strategy 2 in Chapter 1: Leverage completed, ongoing, and new clinical trials to obtain new knowledge about cancer in AYAs.) Cancer Center support grants incorporate a health disparities funding model that requires proportional representation of populations experiencing health care disparities in clinical trials. Such a model could be applied to AYAs.

This change should be required for all clinical research performed by NCI-funded investigators, institutions, and cooperative clinical trial groups. NCI would need to determine that such a change in guidelines is appropriate and important. In addition, the NCI Center to Reduce Cancer Health Disparities would need to determine that the AYA population fits the cancer health disparity criteria.

Efforts to obtain recognition that AYAs experience health disparities have had limited

success so far; however, it is hoped that results obtained in the analyses recommended in Implementation Strategy 2 in Chapter 2 can be used to reveal disparities and unique biological features that would support such actions.

- Leverage known behavioral interventions and models (e.g. HIV, diabetes) for AYAs to improve participant adherence in clinical trials. Adherence to clinical trial protocols has been poor among AYAs. HIV and diabetes investigators and practitioners have developed strategies that appear to produce good adherence in their clinical trials as well as in protracted standard therapies. The AYA clinical trial community should explore and adopt methods that have proven useful in those groups.
- Use educational and communication tactics employed by the American Society for Clinical Oncology (ASCO) and NCI for enhancing clinical trial participation by AYA patients. ASCO and NCI have invested considerably in developing effective educational materials and other tools to promote trial participation by cancer patients and oncologists, especially with regard to children's cancer; however, no AYA-focused material is currently available.

Existing efforts can be leveraged by creating AYA-focused, Web-based information and educational programming for the public and oncology health care team members. Little financial investment would be required to accomplish this; however, NCI would need to determine that such information was needed and that the effort would have a major positive effect.

- Evaluate performance-based incentives in the U.K. National Health Service for clinical trial participation (National Institute for Clinical Excellence [NICE]). Programs in the United Kingdom have dramatically increased AYA clinical trial participation through a pay-for-performance system in which care providers receive incentives for compliance with standards of clinical excellence, including enrollment of patients in clinical trials. Standards are developed by evaluating cost versus outcome. Although a pay-for-performance scheme is unlikely to be implemented in the United States, evaluating the performance metrics used in the U.K. program could help inform U.S. efforts.

STRATEGY 1	
Timeline	
Year 1:	<ul style="list-style-type: none"> · Develop AYA website/portal that promotes trial participation. · Develop legal/administrative IRB toolkit. · Implement adaptive design strategies.
Years 2-5:	<ul style="list-style-type: none"> · Modify quality-of-life tools. · Apply health disparities funding model. · Leverage HIV behavioral interventions for adherence. · Exploit NCI and ASCO communication tactics for trial enrollment. · Evaluate U.K. NICE performance-based methods and measures.
Cost ³⁵	
Not identified.	
Resources	
Insurance companies.	
Search engines and other Web service providers (e.g. Google, Yahoo, AOL).	
Legal profession organizations.	
International Society for Quality of Life Research.	
American Society of Clinical Oncologists.	
American Association for Cancer Research.	
American Cancer Society.	
Potential Partners	
FDA.	
IRB administrator professional groups (e.g. Public Responsibility in Medicine and Research).	
Insurance industry.	
Advocacy organization websites.	
International Society for Quality of Life Research.	
HIV cooperative groups.	
American Association of Diabetes Educators.	
National Institute for Health and Clinical Excellence (NICE) (United Kingdom).	

³⁵ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

CHAPTER

4

Implementation Strategies for Progress Review Group (PRG) Recommendation 4— Ensure Excellence in Service Delivery Across the Cancer Control Continuum (i.e., Prevention, Screening, Diagnosis, Treatment, Survivorship, and End of Life)

While on a routine jog with my brother in Columbia, Maryland, I became severely short of breath. I had asthma and was familiar with the panic of not being able to fill my lungs, but something told me this was different. As a precaution, I made an appointment to have some tests conducted the next day. When I got a CT scan, it showed a growth the size of two golf balls lodged between my spine, ribs, and lungs. I had surgery the next week but the doctors still didn't know it was cancer so I had to go and get a bunch of second opinions. After my diagnosis and treatment, no one gave me a follow-up plan. When I went out to find information about the disease and advice to help me with what I was going through, I couldn't find anything. I also couldn't find other people my age to talk to. Plus, when you are my age, you're not sure how much you should tell your friends and how much they would understand. I lived in four cities in just a few short years following my diagnosis. In every city, it was up to me to seek care and then to try to coordinate the care and exchange of information between physicians...not something someone in their 20s is usually prepared to do. I felt like I was in uncharted territory—not being able to get a timely diagnosis, then being diagnosed and finding myself in a system that was unprepared to help a young adult medically and socially.

—Doug Ulman (diagnosed with chondrosarcoma and twice with melanoma at age 19)

In its fourth recommendation, the Adolescent and Young Adult Oncology (AYAO) Progress Review Group (PRG) proposed two principal strategies for improving the delivery of services to adolescents and young adults (AYAs) with or at risk for cancer and ensuring that they receive excellent care across the cancer control continuum:

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

- Develop, evaluate, and disseminate standards of care for AYA cancer patients and survivors to improve outcomes.
- Establish a national network or coalition of providers and advocates seeking to achieve a standard of excellence in AYA cancer care.

Related Research

Recent research efforts that address screening, diagnosis, treatment, survivorship, and end of life in AYAs (AYAO PRG Recommendation 4) are summarized in Figure 11.

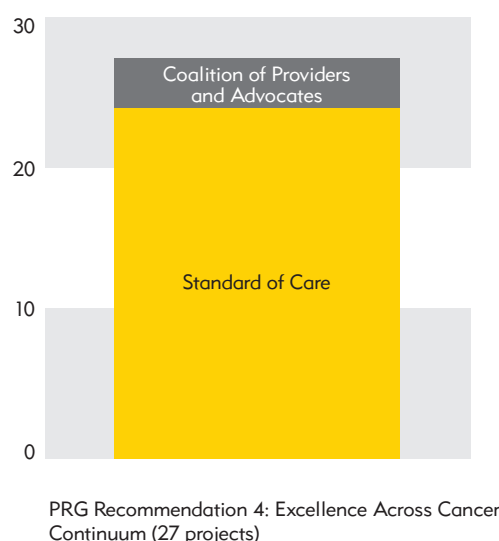


Figure 11: AYAO Research Projects Relevant to Recommendation 4, FY2002–FY2005

The AYAO research portfolio analysis identified 27 projects funded between FY2002 and FY2005 that were related to Recommendation 4. Approximately one-third of these projects were funded by NCI; the remainder were funded by the Congressionally Directed Medical Research Program, American Cancer Society, Lance Armstrong Foundation (LAF), National Cancer Research Institute (United Kingdom), Susan G. Komen for the Cure, Oncology Nursing Society, and California Breast Cancer Research Program. Approximately half of the projects focus on breast cancer. Small numbers of projects focus on brain or hematologic cancers, and 10 focus on several cancer sites or are relevant to all cancers. The projects can be categorized by relevance to the following PRG sub-recommendations:

Standards of Care

Twenty-four projects are relevant to standards of care for AYAs. These projects are evaluating prevention, screening, and treatment strategies

that may influence standards of care and improve outcomes for AYAs with cancer. A few of the studies are assessing the impact of cancer treatment on quality of life, mental health, and related outcomes. Although these projects are not developing standards of care directly, they are conducting research that will provide evidence, in conjunction with expert opinion and best practices, that could contribute to the development of clinical care guidelines by clinical oncology groups and other clinical guideline networks.

Coalition of Providers and Advocates

Four projects are related to the establishment of a network or coalition of providers or advocates seeking to achieve a standard of excellence in cancer care. One project involves the merger of four large pediatric oncology groups to form the Children's Oncology Group, which will improve treatment, prevention, and cancer care for young patients (including AYAs). Another project is a collaborative fellowship program offered jointly by two federal agencies, including NCI and the National Naval Medical Center, which treats military personnel (many of whom are AYAs) that have cancer. Another project is bringing together individuals from cancer centers across the United Kingdom to discuss AYA cancer care practices and research priorities. The final project supported a multidisciplinary international symposium on adolescent non-Hodgkin lymphoma.

Implementation Strategies

To address Recommendation 4, participants in the LIVESTRONG Young Adult Alliance/AYAO PRG meeting proposed the implementation strategies described below.

STRATEGY 1

Standards of Excellence/Standards of Care Breakout Group

Develop standards-of-care (SOC) guidelines for AYAO programs and patients, and disseminate these guidelines to the community.

AYA cancer survivors are an underserved population. No consistent standards or protocols of care are available for this population, and the evidence base needed to establish standards across the continuum of care is weak. AYAs are often treated disparately, have poor access to clinical trials, and have limited peer and psychosocial support. Knowledge about AYA clinical care is limited, and service development in the United States for this population is embryonic. Research funding in this area can be improved. The implementation of consistent SOC could lead to changes in outcomes for AYAO patients.

Although between 9 and 12 AYAO programs are in some form of conceptual or practical

development, the United States has no national group for young adult cancer care. It is important to take advantage of this opportunity to design these efforts carefully from the beginning so that they achieve their goals.

Moreover, patients need to know that they are receiving the best care possible, and SOC guidelines will help ensure increased consumer acceptance and satisfaction with treatment.

Developing SOC guidelines will involve the following activities:

- Form an “AYAO Standards Panel” of scientists and advocates to help facilitate this effort. Existing AYAO programs should be used as references for developing the SOC.
 - Develop a white paper³⁶ of proposed SOC guidelines using existing documents and programs as a starting point. References should include existing guidelines, such as those developed by

the National Cancer Comprehensive Network (Clinical Practice Guidelines in OncologyD, available at http://www.nccn.org/professionals/physician_gls/default.asp). The AYAO Standards Panel should first review and add to general medical and oncology guidelines and then generate AYAO-specific SOC guidelines.

- Convene a national meeting of stakeholders to validate the proposed SOC guidelines. The American Society of Clinical Oncology, NCI, or one or more of the cooperative oncology groups could subsequently validate the guidelines.
- Seek assistance from LAF, along with partner organizations, for disseminating the newly developed guidelines.

³⁶ In this report, “white paper” is defined as an authoritative report on a major issue written by a team of experts.

STRATEGY 1	
Timeline	
Months 6-9: Establish the AYAO Standards Panel and begin deliberations.	
Months 12-18: Develop and validate the SOC guidelines.	
Months 19-24: Disseminate results.	
Cost ³⁷	
\$100,000 to establish the AYAO Standards Panel	
\$75,000 for the national stakeholders meeting	
\$100,000 for dissemination.	
Resources	
Funding from LAF, American Academy of Pediatrics (AAP), American Society of Clinical Oncology (ASCO), American College of Surgeons (ACoS), and, potentially, corporate partners.	
Institute of Medicine (IOM) cost model.	
Insurance companies.	
Existing AYAO programs as references for developing the SOC.	
Potential Partners	
Government/policy organizations (e.g., National Comprehensive Cancer Network, IOM, Department of Defense, U.S. Preventive Services Task Force).	
Advocacy organizations (e.g., ACS, LAF).	
Professional societies (e.g., American Academy of Nurse Practitioners, AAP, American Board of Internal Medicine, ACoS, American Medical Association, ASCO, Leukemia and Lymphoma Society).	
Cooperative groups (e.g., Children's Oncology Group).	
Existing and evolving AYA programs (both national and international).	
Payers (e.g., insurance companies, Medicare, Medicaid).	

³⁷ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

STRATEGY 2

Standards of Excellence/Standards of Care Breakout Group

Develop tools for capturing and measuring quality-of-care data and for disseminating these data to the community.

Standards and quality of care cannot be improved without established measures of care. Therefore, metrics for performance-based care need to be developed. These metrics will enable the standardization and validation of the SOC guidelines and facilitate the ongoing assessment and modification of the SOC guidelines.

The tools for capturing, measuring, and disseminating quality-of-care data should be developed by:

- Convening a working group on benchmarking and metrics. The group should include some representatives from the AYAO Standards Panel.
- Defining desired outcomes for AYAO patients.
- Developing appropriate metrics and technology to assess the tools based on standards and desired outcomes.

STRATEGY 2

Timeline

This strategy can be pursued in parallel with Implementation Strategy 1 above, but it cannot be completed until the first strategy is done. This strategy should begin after the initial meeting of the AYA Standards Panel; it will take approximately 2 years to complete.

Cost³⁸

\$200,000 to establish the metrics development working group.

\$100,000 for ongoing maintenance of metrics/tools.

\$50,000 per year for dissemination by LIVESTRONG Young Adult Alliance.

Resources

Funding from various government organizations (e.g., National Institutes of Health [NIH], AHRQ, Medicare, Medicaid), LAF, LIVESTRONG Young Adult Alliance, and insurance companies (e.g., Aflac)

Professional societies (e.g., ACoS, ASCO, American Psychological Oncology Society, American Society of Hematology).

Advocacy organizations (e.g., ACS, LIVESTRONG Survivorship Center network).

Government/policy organizations (e.g., NCI [including the Cancer Advisory Board], Department of Veterans Affairs).

Agency for Healthcare Research and Quality (AHRQ).

Insurance companies (e.g., Kaiser Center for Health Research).

Cooperative groups.

Select members of AYA Standards Panel.

Expert consultants.

Rand.

Quality Oncology Practice Initiative.

³⁸ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

STRATEGY 3

Standards of Excellence/Standards of Care Breakout Group

Analyze existing models of care and provide a “knowledge garden” information resource.

The lack of information on existing models makes it difficult for practitioners to assess how the needs of the AYAO community are being met. A comprehensive source of updated information on models being explored is needed for groups that are either testing existing models of care or initiating AYAO programs. In addition, this informational database would facilitate the sharing of best practices and the identification of potential improvement strategies. An important goal for this informational database is to support advances in the field.

To implement this strategy, the breakout group recommended:

- Creating an informational database that includes all available information on existing models of care and updating the database regularly.
- Establishing an advisory group to identify the format for collecting and monitoring data.

STRATEGY 3
Timeline
6-9 months: Establish this information resource (which will need to be maintained with regular updates and additions).
Cost ³⁹
\$200,000 per year to develop and maintain this information resource.
Resources
Funding from LAF, NCI, ACS, and AHRQ.
Potential Partners
Professional societies.
Advocacy organizations.
Government/policy organizations.
Existing and future AYAO centers, both national and international.
Comprehensive cancer centers.
Community cancer centers (e.g., Association of Community Cancer Centers).
International AYAO organizations in the United Kingdom and Australia.

³⁹ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

STRATEGY 4

Professional Development Breakout Group

Develop and disseminate evidence- or consensus-based treatment and follow-up guidelines for AYA cancers.

Although the National Cancer Comprehensive Network and Children's Oncology Group have developed SOC guidelines for some aspects of cancer care, they have not developed evidence- or consensus-based treatment and follow-up guidelines for young adults. The development of best treatment guidelines is a transformational area that needs to be addressed.

These guidelines are likely to have a positive impact on outcomes and the normal transition to adulthood. Once these guidelines are in place, improvements in outcomes for AYAs should resemble those experienced by other age groups. In addition, measurable improvements should occur in both patient and physician satisfaction.

The evidence- or consensus-based treatment and follow-up guidelines will be developed and disseminated by:

- Establishing LAF/LIVESTRONG Young Adult Alliance treatment review groups.
- Evaluating published treatment results (meta-analysis).
- Disseminating best treatment regimens through LIVESTRONG Young Adult Alliance and partners.
- Continuing to update published data and treatment recommendations regularly.

STRATEGY 4
Timeline
6 months: Establish disease review groups.
12-18 months: Produce the first reports; thereafter, produce yearly reports.
Cost ⁴⁰
\$500,000 per year.
Resources
Assistance from the ACS, Leukemia and Lymphoma Society, and other disease-related societies or organizations.
Potential Partners
Advocacy organizations (e.g., ACS).
Professional societies (e.g., ASCO).
Government/policy organizations (e.g., NCI, National Comprehensive Cancer Network).
Cooperative groups.

⁴⁰ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

STRATEGY 5

Professional Development Breakout Group

Educate current and future health care professionals on the diagnosis and treatment of cancer in AYA patients through certified curricula and professional training opportunities.

This longer term goal will be built on the proposed white paper and position statement (Implementation Strategy I in Chapter 3).

It is important to reach both neophyte and experienced practitioners. Integrating AYAO interests into medical school curriculums is considered the “gold” standard; however, the basic medical school curriculum is already tightly packed and is unlikely to accommodate additional components on AYAO issues. Although this goal should be pursued, it is likely to take several years to achieve. A more immediately attainable alternative is to prepare stock chapters on AYAO issues that could be disseminated to publishers for inclusion in textbooks. Even if the material is not covered in the medical school curriculum, it could at least be available to students.

For healthcare workers who have completed their undergraduate education, fellowship opportunities should be offered to those who wish to study AYAO issues in greater depth. Fellowships contribute to scholarly development and competence early in the practitioner’s career; these practitioners can then spend their entire careers disseminating the message and training new practitioners. A long-term educational strategy is to offer formal AYAO postgraduate training programs that are certified by accreditation organizations (such as the Accreditation Council for Graduate Medical Education and Oncology Nursing Certification Corporation).

Developing continuing education units (CEUs) targeting AYAO issues is an efficient way to disseminate information to seasoned practitioners because many are required by their disciplines to complete a specific number of CEUs to maintain their licenses or certifications. Training systems that use a train-the-trainer approach (such as the

End-of-Life Nursing Education Consortium) are the best way to disseminate knowledge to both trainees and instructors.

Outcome measures for this implementation strategy include streamlined access for AYAs with cancer to knowledgeable healthcare providers, greater patient satisfaction, and improved survival and quality of life.

This implementation strategy can be achieved by the following steps:

- Achieve national credibility for professional AYAO training programs.
- Harness relevant professional society support for the curricula and training opportunities.
- Develop interdisciplinary education and training programs for all providers, including physicians, nurses, and social workers.
- Encourage third-party payers to cover AYA cancer care through transdisciplinary support for professional development and the creation of care standards.
- Target a broad array of caregivers, including non-oncology specialists who are often the first to treat AYAs with cancer.
- Develop courses on AYA cancer topics that offer continuing education units (CEUs).
- Create stock textbook chapters on AYAO issues for distribution to publishers.
- Encourage professional development at AYAO programs through fellowship opportunities.
- Obtain accreditation for AYAO training programs from such accrediting organizations as the Accreditation Council for Graduate Medical Education and Oncology Nursing Certification Corporation.

STRATEGY 5
Timeline
Years 1–3 years: Develop continuing medical education programs for current practitioners.
Years 3–5: Increase prevalence of AYAO issues in healthcare educational resources and implement certification processes.
Cost ⁴¹
Not identified.
Resources
Not identified.
Potential Partners
Professional societies (e.g., Association of Pediatric Oncology Nurses, American Academy of Family Physicians, American Society of Clinical Oncology, Leukemia and Lymphoma Society, Oncology Nursing Society, and American Brain Tumor Association).
Advocacy organizations.
Congressional support.
Aflac.
LAF.
ACS.

⁴¹ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

CHAPTER

5

Implementation Strategies for Progress Review Group (PRG) Recommendation 5— Strengthen and Promote Advocacy and Support of the Adolescent and Young Adult (AYA) Cancer Patient

I wish there was some type of guidebook to tell you how to keep your relationships going while you're potentially dying. I also wish there was something to tell you how to keep your best friends included in your cancer world, while you bond with your cancer friends. It's so easy to lose sight of your friends because your "new" cancer family really understands you and you don't have to explain everything. You get so consumed with cancer and sometimes it feels like there is nothing else. While my friends were enjoying their 20s, I was getting zapped by radiation.

—Tamika Felder (diagnosed with cervical cancer at age 25)

The Adolescent and Young Adult Oncology (AYAO) Progress Review Group (PRG) stressed the urgent need for a variety of education, training, and communication activities to raise public and professional awareness and recognition of adolescents and young adults (AYAs) with cancer. Such education, training, and communications must be culturally appropriate and delivered by culturally competent people.

To address the need for more research in these areas, the AYAO PRG's final recommendation is: Recommendation 5: Strengthen and promote advocacy and support of the AYA cancer patient

- Address the subjective experience of AYA patients
- Build the capacity of existing resources to address AYA psychosocial needs
- Evaluate existing programs and develop new interventions

Related Research

Recent research efforts that address advocacy and support of the AYA cancer patient (AYAO PRG Recommendation 5) are summarized in Figure 12.



PRG Recommendation 5: Strengthen and Promote Advocacy (43 projects)

Figure 12: AYAO Research Projects Relevant to Recommendation 5, FY2002–FY2005

The AYA research portfolio analysis identified 43 projects funded between FY2002 and FY2005 that were related to Recommendation 5. Approximately three-quarters of these projects were funded by the Lance Armstrong Foundation (LAF); small numbers of projects were funded by the Oncology Nursing Society, Susan G. Komen for the Cure, Congressionally Directed Medical Research Program, American Cancer Society (ACS), and California Breast Cancer Research Program. Only two projects in this category were funded by NCI. Approximately three-quarters of these projects do not target a specific cancer site. Five of the projects focus on breast cancer, and a smaller number of projects focus on brain or colorectal cancer, or Hodgkin lymphoma. The projects can be categorized by relevance to the following PRG sub-recommendations:

Subjective Experiences of AYAs

Nine projects address the subjective experiences of AYAs with cancer. These projects focus on

cognitive function, psychosexual development, fertility issues, overall quality of life, physical symptoms, and social well-being during or after treatment.

Psychosocial Resources

Twenty-five projects focus on AYA psychosocial needs during or after treatment for cancer. Twenty-one of these projects are funded by LAF and are enhancing existing community-based resources for cancer survivors and their families. These projects include several retreats and conferences, a patient navigator program, a peer support program, and several camps for adolescent survivors and sometimes their siblings. The remaining projects are identifying the psychological and social impact of cancer on AYAs or developing interventions to provide information to AYAs with cancer on a broad range of topics, including fertility options after cancer.

Programs and Interventions

Eight projects are evaluating and refining interventions to increase psychosocial well-being for AYA survivors. These projects focus on such issues as physical and social activity, psychosexual health, post-traumatic stress disorder, and health behaviors.

Implementation Strategies

To address Recommendation 5, participants in the LIVESTRONG Young Adult Alliance/AYAO PRG meeting proposed the implementation strategies described below.

STRATEGY 1

Patient Navigation/Health Coaches Breakout Group

Evaluate and catalog existing peer-to-peer support programs and patient navigator programs that serve the AYA community.

Patient navigator programs can be difficult to define because they provide access to multiple and diverse resources. Two equally important models currently exist: peer-to-peer support programs and patient navigator programs. Both provide important, but different, resources. Peer-to-peer programs are designed to connect the newly diagnosed patient with others who have been through a similar experience. Patient navigator programs provide newly diagnosed patients with access to accurate, timely information on issues related to their cancer diagnosis and care. These programs can be Web based, telephone based, or face to face. AYAs need access to both professional navigators and AYA peers because the two models provide complementary resources.

However, too little is known about the volume and capacity of these programs and obtaining access to either kind of program is difficult because no credible, central portal gives reliable information on available resources. A comprehensive review of existing programs will allow the identification of the “gems” of each program, and this will contribute to implementation strategies 2 and 3 below.

STRATEGY 1
Timeline
Year 1: Complete evaluation and catalog.
Cost ⁴²
Not identified.
Resources
NCI or LAF in-kind, such as an intern to analyze existing programs.
LIVESTRONG Young Adult Alliance Working Group.
Potential Partners
All existing patient navigation and peer-to-peer programs.
NCI.
ACS.
LAF.

⁴² All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

STRATEGY 2

Patient Navigation/Health Coaches Breakout Group

Facilitate the development of peer-to-peer networks and access to these networks through a central portal, and explore the potential for evaluation.

The number of AYA survivors who can serve as peer advocates is small and the programs that provide peer advocates differ in size, focus, and means of access. AYAs with cancer need access to peers who “match” them (with respect to type of cancer, cancer stage, treatment received, life phase, geographic location, education, and religion). A central portal would provide the most efficient access to existing programs. The portal should leverage existing social networks, such as MySpace and Facebook, and use popular AYA communication media, such as e-mail and cell phones.

When crisis situations arise in peer-to-peer programs, such as when a peer is working with a depressed or suicidal patient, the patient or peer might need protection. It might therefore be helpful to create a training manual and organize workshops to help peers recognize warning signs and identify strategies to manage unpleasant, unhealthy, or unsafe situations. These protections should ultimately help strengthen the programs and this should, in turn, facilitate the recruitment of peers.

STRATEGY 2
Timeline
5 years to fully implement and evaluate
Cost ⁴³
Not identified.
Resources
Not identified.
Potential Partners
NCI.
ACS.
Prepare to Live “Buddy Search.”
MySpace.
Wellness Community.
Gilda’s Club.
Retreats and camps, i.e., Camp Mak-A-Dream.
CancerCare.
Planet Cancer.
HopeLab.
LAF.
Tamika and Friends.
Ulman Cancer Fund for Young Adults.
Young Survival Coalition
Y-ME
LIVESTRONG Young Adult Alliance.

⁴³ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

STRATEGY 3

Patient Navigation/Health Coaches Breakout Group

Facilitate development of AYA standards for patient navigation or health coaching programs, including training of navigators and coaches, and provide centralized information on these resources.

It is not clear that standardized AYA-specific navigators exist; consequently, the level and type of services available to this population varies greatly. Some existing patient navigator programs, such as the ACS Navigator Program, serve some AYAs, and for a few programs, including the LIVESTRONG SurvivorCare Patient Navigator program, AYAs comprise the majority of the population served.⁴⁴ Staff in these programs have learned that AYAs need access to a more diverse array of services than younger and older patients. The development of standards for AYA-specific patient navigator programs would help ensure that all AYAs who use these programs have equal access to the wide variety of services needed by AYAs diagnosed with cancer.

To a great extent, the “gems” identified in Implementation Strategy 1 (evaluate and catalog existing peer-to-peer support programs and patient navigator programs that serve the AYA community) should be used as models. Due to this population’s diversity, no single “right” model might exist. However, all models should provide equal access to available services and trained, competent navigators with expertise in issues that arise from diagnosis through long-term effects and survivorship. The central portal for navigators (Implementation Strategy 2) would provide a way to store and disseminate information on these programs and resources.

STRATEGY 3

Timeline
Years 3–6: Develop and disseminate standards for patient navigators or health coaches; collect and disseminate centralized information on these resources
Cost ⁴⁵
Not identified.
Resources
Ralph Lauren Center for Cancer Care and Prevention.
Foundation for Informed Medical Decision Making.
Pfizer (patientnavigation.com).
Funding
Potential Partners
NCI.
ACS.
LAF.
Comprehensive cancer centers.
US Oncology.
American Association of Oncology Social Work.
American Society for Clinical Oncology.

⁴⁴ Additional patient navigator and peer-to-peer programs include the News Channel 9 program in Washington, DC; the Avon Breast Cancer Crusade Program; the Ulman Cancer Fund’s WHAT’S NEXT! Young Adult Patient Navigator Program at Johns Hopkins Sidney Kimmel Comprehensive Cancer Center; Y-ME’s programs; the Young Survival Coalition’s ResourceLink™; and the Prepare to Live Buddy Search program.

⁴⁵ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

STRATEGY 4

Psychosocial Advocacy and Support Breakout Group

Identify indicators of success—such as increasing AYA knowledge of their own diagnosis and treatment, decreasing isolation and fear, reducing distress, and increasing survival and quality of life—for programs that offer supportive services to AYAs.

Advocacy organizations need simple evaluation tools to show that their programs are effective and reflect the needs and experiences of AYAs. These organizations can use information on program effectiveness to

- Improve their programs.
- Convince providers to refer AYAs to their programs.
- Show boards of directors and funders that their programs are worthy of support.
- Develop measurable objectives for grant applications.

Building an evidence base for AYA programs and interventions will enhance the likelihood of their dissemination, application, and use. LIVESTRONG Young Adult Alliance member organizations have varying degrees of skills and resources to evaluate programs and program impacts using systematic and organized procedures.

Indicators of success will be identified by:

- Developing simple, standardized instruments that can be used to assess program outcomes.
- Identifying existing instruments that are relevant to AYA cancer programs.
- Developing a clearinghouse of new and existing evaluation tools for service providers.
- Developing an intranet that providers can use to share best practices.
- Encouraging organizations that serve AYAs to use these instruments, as well as personal stories, to assess the effectiveness of their programs.

STRATEGY 4
Timeline
Years 1–3: Identify indicators of success and disseminate these indicators.
Cost ⁴⁶
\$500,000, to be made available on a competitive basis, for identifying, developing, testing, and disseminating evaluative instruments.
Resources
Not identified.
Potential Partners
LIVESTRONG Young Adult Alliance members.
Consultants to create the intranet.
Academic institutions with expertise in evaluation.

⁴⁶ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

STRATEGY 5

Psychosocial Advocacy and Support Breakout Group

Provide opportunities for peer-to-peer support and awareness.

Developmental theory suggests that adolescents and young adults learn well from same-aged peers. In addition, social relationships play a key role in enhancing quality of life and well-being. Peers are inherently credible sources of information of support, and every organization that serves AYAs with cancer has ties to AYAs who can share their stories.

Opportunities for peer-to-peer support and awareness include:

- Online portal (see Implementation Strategy 2 in Chapter 2—evaluate and help improve existing sources of information and support for AYAs with cancer.).
- A touring AYA fair (“Cancer-palooza”) to visit different parts of the country or a national AYA summit. Such events would offer inspiring speakers, posters from organizations offering services in the area, and opportunities for networking with peers. The fair could also build awareness and help raise funds for community programs. The health fair could be linked to local events, such as Ride for the Roses or local cancer survivorship celebrations.
- A cohort of AYAs to share their personal stories in different ways, such as through blogs, YouTube, MySpace, and other youth-oriented media.

STRATEGY 5

Timeline

Years 1–3: Develop opportunities for peer-to-peer support and awareness. These activities should begin immediately.

Cost⁴⁷

\$100,000 seed money for planning.

\$500,000 to \$1 million for implementation.

Resources

Event space.

Insurance.

Staffing.

Public relations/marketing.

Potential Partners

Community organizations.

Health centers.

Corporate sponsors.

Universities.

Foundations.

Media.

Corporate sponsors.

⁴⁷ All cost figures are general estimates. Detailed in-depth cost analysis will be necessary to implement this strategy.

CHAPTER

Action Plan



To address the five Adolescent and Young Adult Oncology (AYAO) Progress Review Group (PRG) recommendations, the LIVESTRONG Young Adult Alliance (YAA)/AYAO PRG meeting breakout groups identified and described 18 implementation strategies. Based on common themes within these strategies, the YAA, National Cancer Institute (NCI), and AYAO PRG have developed the following action plan to implement the AYAO PRG recommendations.

The plan lists proposed actions in sequential order that have been categorized into three themes: science, standards, and awareness. Related actions for each theme are listed in approximate order of increasing complexity. Many of the actions associated with each theme can be implemented concurrently. However, successful implementation of some of the last actions under each theme will be contingent on the results of the earlier actions.

Topic 1: Science

Demonstrate the need to focus attention and resources on AYA cancers by establishing a strong scientific foundation showing that AYA cancers are biologically distinct and warrant dedicated resources for research.

ACTION	PARTNERS AND RESOURCES
1. Publish a summary of the LIVESTRONG YAA/AYAO PRG meeting in a peer-reviewed journal. (<i>Biological Research and Tissue Sample/Collection Breakout Group, Chapter 1, Strategy 2</i>)	<i>Clinical Cancer Research, Blood, Journal of the National Cancer Institute, The Oncologist, New England Journal of Medicine</i>
2. Publish a white paper on known biologic and outcomes differences in AYAs with cancer. (<i>Clinical Trials Breakout Group, Chapter 1, Strategy 4, Phase 1</i>)	American Society of Clinical Oncologists (ASCO), American Association for Cancer Research (AACR), Department of Defense (DoD), American Cancer Society (ACS), Leukemia and Lymphoma Society, cooperative groups, US Oncology, cancer centers, Food and Drug Administration (FDA)
3. Analyze retrospective AYA data related to treatment and prevention strategies in published trials and trial databases. (<i>Clinical Trials Breakout Group, Chapter 1, Strategy 4, Phase 1</i>)	ASCO, AACR, DoD, ACS, Leukemia and Lymphoma Society, cooperative groups, US Oncology, cancer centers, FDA
4. Use creative (more rapid and targeted) funding strategies to support retrospective analysis of AYA-relevant information from existing biological and epidemiological data. (<i>Biological Research and Tissue Sample/Collection Breakout Group, Chapter 1, Strategy 1, Phase 1</i>)	Tissue/data bank principal investigators and directors, DoD, NCI, US Oncology
5. Use creative funding strategies to support leaders in AYAO to conduct prospective research on AYA cancer biology, including microarray studies. (<i>Biological Research and Tissue Sample/Collection Breakout Group, Chapter 1, Strategy 1, Phase 2</i>)	Lance Armstrong Foundation (LAF), Susan G. Komen for the Cure, ACS, congressional funds, companies
6. Encourage NCI to develop and solicit a program announcement (PA) and, when funds are available, a request for applications (RFA) for projects based on data gleaned from Actions 4 and 5 above. These initiatives should focus on the role of biology in AYA cancers. (<i>Biological Research and Tissue Sample/Collection Breakout Group, Chapter 1, Strategy 3</i>)	National Institutes of Health (NIH) Institutes, NCI
7. Require the collection of data on age and quality of life and the inclusion of AYAs in clinical trials. (<i>Clinical Trials Breakout Group, Chapter 1, Strategy 4, Phase 2</i>)	ASCO, AACR, DoD, ACS, Leukemia and Lymphoma Society, cooperative groups, US Oncology, cancer centers, FDA
8. Increase AYA participation in clinical trials by: <ul style="list-style-type: none"> Using proven strategies to recruit patients to clinical trials and encourage them to adhere to the trial protocols. Creating a Web-based portal with information on clinical trials. Distributing a legal/administrative toolkit to facilitate accrual of minor patients and institutional review board (IRB) approval of clinical studies that include minors and adults. (<i>Clinical Trials Breakout Group, Chapter 3, Strategy 1, Phases 1 and 2</i>)	Insurance companies, Web service providers, legal professional associations, International Society for Quality of Life Research, ASCO, AACR, ACS, IRB administrator professional groups, Leukemia and Lymphoma Society, advocacy organizations, cooperative groups, US Oncology, cancer centers, National Institute for Health and Clinical Excellence, FDA
9. Develop new clinical trials that use innovative study designs and outcome measures (including quality of life and tumor response) so that trials with small numbers of AYAs can yield meaningful, relevant, and useful results. (<i>Clinical Trials Breakout Group, Chapter 3, Strategy 1, Phase 1</i>)	ASCO, AACR, DoD, ACS, Leukemia and Lymphoma Society, cooperative groups, US Oncology, cancer centers, FDA

Topic 2: Standards

Identify and evaluate existing information, resources, and tools relevant to standards of care, patient navigator/health coach programs, psychosocial resources, models of care, and evaluation tools for AYA cancers.

Build on the scientific foundation and existing information, resources, and tools to improve cancer treatment and supportive services among AYAs.

ACTION	PARTNERS AND RESOURCES
1. Identify desired care outcomes for AYAs with cancer and indicators of success. (<i>Standards of Excellence/Standards of Care Breakout Group, Chapter 4, Strategy 2</i>)	NIH, Agency for Healthcare Research and Quality (AHRQ), Medicare/Medicaid, LAF/YAA, insurance companies, professional societies, government organizations, advocacy organizations, cooperative groups, consultants, and academic institutions
2. Prepare and publish a white paper and position statement to support the creation of formal, certified training programs for AYAO healthcare practitioners. (<i>Professional Development Breakout Group, Chapter 2, Strategy 1</i>)	Aflac, Aetna, ASCO, Alliance for Self-Care Research, AACR, Oncology Nursing Society, ACS, Leukemia and Lymphoma Society, cooperative groups, Children's Oncology Group
3. Analyze existing models of care and provide a "knowledge garden" information resource. (<i>Standards of Excellence/Standards of Care Breakout Group, Chapter 4, Strategy 3</i>)	LAF/YAA, NCI, ACS, AHRQ, professional societies, advocacy organizations, government policy organizations, comprehensive cancer centers, AYAO centers, Association of Community Cancer Centers, International AYAO organizations in United Kingdom and Australia.
4. Create and maintain a database of information on existing models of care ("knowledge garden") to support the assessment of existing models, the establishment of new programs for AYAs, and the sharing of best practices and potential improvement strategies. (<i>Standards of Excellence/Standards of Care Breakout Group, Chapter 4, Strategy 3</i>)	LAF/YAA, NCI, ACS, AHRQ, professional societies, advocacy organizations, government policy organizations, comprehensive cancer centers, AYAO centers, Association of Community Cancer Centers, International AYAO organizations in United Kingdom and Australia
5. Measure quality of care and effectiveness of supportive services for AYAs. (<i>Standards of Excellence/Standards of Care Breakout Group, Chapter 4, Strategy 2</i>)	Graduate student, LAF, NCI's Cancer Information Service, ACS, academic researchers, AYA advisory board, teen and generation X/Y advertising and Web-development companies
6. Evaluate and catalog existing peer-to-peer support and patient navigator programs that serve the AYA community to identify best practices and support the development of new peer-to-peer networks and standards for patient navigators/health coaches. (<i>Patient Navigation/Health Coaches Breakout Group, Chapter 5, Strategy 1</i>)	NCI or LAF in-kind, YAA task force, existing patient navigator and peer-to-peer programs, ACS, LAF, NCI
7. Create a certification program to assess the availability, accuracy, relevance, and appropriateness of information and services that might be useful to AYAs with cancer. (<i>Psychosocial Advocacy and Support Breakout Group, Chapter 2, Strategy 2</i>)	YAA members, consultants, and academic institutions
8. Facilitate development of AYA standards for patient navigator programs. (<i>Patient Navigation/Health Coaches Breakout Group, Chapter 5, Strategy 3</i>)	Harlem Hospital Ralph Lauren Cancer Center, Foundation for Informed Medical Decision Making, Pfizer through patientnavigation.com, NCI, ACS, LAF, comprehensive cancer centers, US Oncology, ASCO, Association of Oncology Social Work
9. Develop and disseminate standards of care guidelines for AYA cancer programs, including evidence-based treatment and follow-up guidelines, and organize a national meeting of stakeholders to validate the proposed guidelines. (<i>Standards of Excellence/Standards of Care Breakout Group, Chapter 4, Strategy 1 and 4</i>)	LAF/YAA, AAP, ASCO, American College of Surgeons, Institute of Medicine cost model, insurance companies, existing AYAO programs, professional societies, advocacy organizations, government policy organizations, cooperative groups, comprehensive cancer centers, AYAO centers

Topic 3: Awareness.

Increase public and provider awareness that AYAs develop cancer and enhance providers' capability to provide appropriate services and referrals to AYAs.

ACTION	PARTNERS AND RESOURCES
<p>1. Initiate a public relations campaign to raise public awareness of cancer in AYAs and communicate the "Consider Cancer" message using strategies that are appropriate for different age groups. (<i>Public Relations Breakout Group, Chapter 2, Strategy 4</i>)</p>	<p>In-kind exchanges; data-gathering partners such as Nielson Media Research, Datamonitor, and Kaiser Family Foundation; best practices models such as those of MADD, AARP, and Rock the Vote; Nike, American Advertising Association, and Ad Council; touchpoints such as Google, MySpace, and Health in Hollywood; and continuing medical education (CME) companies, and professional societies</p>
<p>2. Disseminate simple messages (e.g., "Persistent symptoms? Consider cancer") as reminders that can be widely disseminated to frontline providers and oncology professionals who treat AYAs. (<i>Psychosocial Advocacy and Support Breakout Group, Chapter 2, Strategy 3; Public Relations Breakout Group, Chapter 2, Strategy 4</i>)</p>	<p>NCI's Cancer Information Service, advocacy organizations, professional societies, CME companies</p>
<p>3. Distribute an AYA information kit or resource guidebook to the public through doctors' offices. (<i>Psychosocial Advocacy and Support Breakout Group, Chapter 2, Strategy 2</i>)</p>	<p>Graduate student, LAF, NCI's Cancer Information Service, ACS, academic researchers, AYA advisory board, teen and generation X/Y advertising and Web-development companies</p>
<p>4. Develop a Web-based portal that provides AYAs and service providers with access to certified sources of information and support services, including peer-to-peer and patient navigator programs. (<i>Psychosocial Advocacy and Support Breakout Group, Chapter 2, Strategy 2; Patient Navigation/Health Coaches Breakout Group, Chapter 5, Strategy 2</i>)</p>	<p>Graduate student, LAF, NCI's Cancer Information Service, ACS, academic researchers, AYA advisory board, teen and generation X/Y advertising and Web-development companies</p>
<p>5. Offer an 800-number that links those without Internet access to information and services for AYAs with cancer. (<i>Psychosocial Advocacy and Support Breakout Group, Chapter 2, Strategy 2</i>)</p>	<p>Graduate student, LAF, NCI's Cancer Information Service, ACS, academic researchers, AYA advisory board, teen and generation X/Y advertising and Web-development companies</p>
<p>6. Educate future healthcare professionals about the diagnosis and treatment of cancer in AYAs through certified curricula. (<i>Professional Development Breakout Group, Chapter 4, Strategy 5</i>)</p>	<p>Advocacy organizations, professional societies, congressional support, Aflac, LAF, ACS</p>
<p>7. Develop fellowship opportunities at AYAO centers. (<i>Professional Development Breakout Group, Chapter 4, Strategy 5</i>)</p>	<p>Advocacy organizations, professional societies, congressional support, Aflac, LAF, ACS</p>
<p>8. Offer accredited continuing education for frontline providers that AYAs initially consult about their cancer symptoms. (<i>Psychosocial Advocacy and Support Breakout Group, Chapter 2, Strategy 3; Professional Development Breakout Group, Chapter 4, Strategy 5; Public Relations Breakout Group, Chapter 2, Strategy 4</i>)</p>	<p>Advocacy organizations, professional societies, congressional support, Aflac, LAF, ACS</p>

NEXT STEPS

The LIVESTRONG YAA will work with NCI, AYAO PRG members, advocates, and other stakeholders to coordinate the implementation effort. The Alliance will establish implementation task forces to identify actions within each theme that can be linked together to prevent duplication of effort and use resources efficiently. The task forces will also develop multiple-step strategies for actions that are contingent on one another to ensure a longer term commitment of funds for successful implementation of the entire project.

The LIVESTRONG YAA, AYAO PRG, NCI, and other stakeholders will collaborate to secure the necessary resources such as people—advocates, scientists, providers, patients, family members, and others—as well as funding and data. Potential sources of these resources are NCI and other federal funders, LAF and other advocacy organizations, medical professional societies, pharmaceutical companies, and insurance companies.

Once planning is completed and resources are mobilized, the Alliance will oversee the implementation of the recommendations. The Alliance anticipates that implementation will begin by the end of 2007.

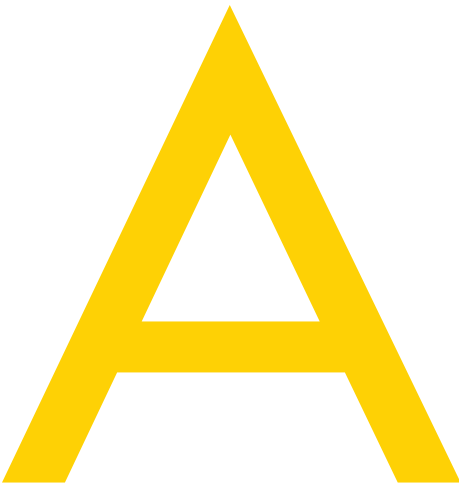
CONCLUSION

The November 2006 LIVESTRONG YAA/AYAO PRG meeting was an innovative public-private collaboration that created an action plan for improving the outcomes and quality of life for AYAs with cancer. The plan's success will depend on buy-in and participation from government agencies, advocacy groups, healthcare providers, private sector participants such as pharmaceutical companies, and AYAs with cancer.

The Alliance, AYAO PRG members, and NCI believe that this can be achieved if we keep the following in mind:

- **Unity is strength**—By working together, we have the opportunity to change the status quo.
- **Knowledge is power**—Understanding that the AYA population experiences a cancer health disparity is the first step; spreading the word to the public, providers, and AYAs will set the stage for supporting the research necessary to improve outcomes for AYAO patients.
- **Attitude is everything**—Alliance members, NCI, and the AYAO PRG members are committed to meeting the challenge of changing the system and creating a new future for the AYAO population.

APPENDIX



LIVESTRONG Young Adult Alliance/Adolescent and Young Adult Oncology Progress Review Group Implementation Meeting

November 10-12, 2006

Agenda
November 10-12, 2006

FRIDAY, NOVEMBER 10

11:00am - 1:00pm Registration

1:30pm - 2:45pm Welcome
Phoenix North

- o Welcome- Doug Ulman
- o Opening Remarks and Introductions –
Brandon Hayes-Lattin, Randi Rosenberg
 - YAA Organizational Update
 - History
 - Relationship with the Lance Armstrong Foundation
 - How we have arrived at this point
 - Mission and Vision
 - Organization of the Alliance
 - o Membership
 - o Leadership
 - o Organizational Guidelines
 - Strategies and Objectives of the YAA
 - o Committee Introduction & Preview

2:45pm- 3:15pm Q & A

3:15pm - 4:00pm PRG: Overview, Major Recommendations, & Goals for Break-out Groups
– Barry Anderson, Michael Caligiuri, Cherie Nichols, Randi Rosenberg

6:00pm - 8:00pm Keynote Address with Dinner
Phoenix North

SATURDAY, NOVEMBER 11

7:30am - 8:00am **Breakfast**
Phoenix Central

TIME	Breakout Group Topic <i>Robertson</i>	Breakout Group Topic <i>DeZavala</i>	Breakout Group Topic <i>DeWitt</i>	Breakout Group Topic <i>Phoenix North</i>
8:00- 9:30	AYAO Professional Track/ Professional Development	Psychosocial Advocacy & Support	Biologic Research & Tissue Sample/Collection	AYA Public Relations Campaign
9:30- 9:45	MORNING BREAK	MORNING BREAK	MORNING BREAK	MORNING BREAK
10:00- 11:30	AYAO Professional Track/ Professional Development	Psychosocial Advocacy & Support	Biologic Research & Tissue Sample/Collection	AYA Public Relations Campaign
11:30- 12:45	LUNCH	LUNCH	LUNCH	LUNCH
12:45- 2:15	Standards of Excellence/ Standards of Care	Patient Navigation/ Health Coaches	Clinical Trials	
2:15- 2:30	AFTERNOON BREAK	AFTERNOON BREAK	AFTERNOON BREAK	AFTERNOON BREAK
2:30- 4:00	Standards of Excellence/ Standards of Care	Patient Navigation/ Health Coaches	Clinical Trials	

7:00pm - 9:00pm **Dinner**
Phoenix Central
An Evening of Entertainment
Phoenix North
Jonna Tamases' One Woman Show: *Jonna's Body, Please Hold*

SUNDAY, NOVEMBER 12

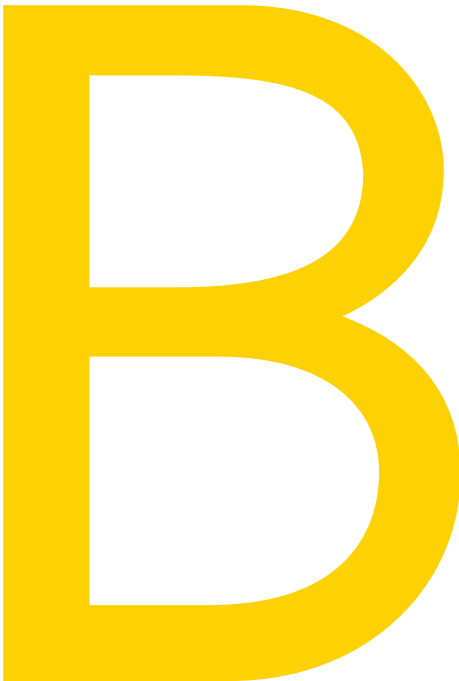
8:00am - 8:30am **Breakfast**
Phoenix Central

8:30am - 10:30am **Alliance Actions**
Phoenix North

- o Breakout Session Report Out – Brandon Hayes-Lattin,
Randi Rosenberg
Ronnie Barr, Karla Wilson
Brad Zebrack, Barbara Jones
Michael Caligiuri, Muneesh Tewari
Heidi Adams, David Lyon
Craig Nichols, Stuart Siegel
Beth Virnig, Brock Yetso
Barry Anderson, Archie Bleyer
- o my.livestrong – Jennifer Long
 - overview of communications tools and usage
- o Take Home Messages and Closing Comments
- o Sign- up for Committees

10:30am **Adjournment**

APPENDIX



LIVESTRONG™ Young Adult Alliance Inaugural Meeting and Adolescent and Young Adult Oncology Progress Review Group Implementation Meeting

Austin, Texas
November 10-12, 2006

MEETING ROSTER

Heidi Adams,
Breakout Group Co-Chair
Planet Cancer

Barry Anderson, MD, PhD,
Breakout Group Co-Chair
National Cancer Institute,
Cancer Therapy Evaluation Program,
Pediatric Section

Doug Bank
Testicular Cancer Resource Center

Jamelle Banks, MPH
National Cancer Institute, Office of Science Planning and Assessment

Ronald Barr, MD,
Breakout Group Co-Chair
McMaster University

Christine Baze
Popsmeat.org

Carolyn Bell, MSW
Lymphoma Research Foundation

Joyce Bichler, MSW
Gilda's Club Worldwide

Kristin Bingen, PhD
Medical College of Wisconsin

Elana Bizer
Association of Pediatric Oncology Social Workers

Archie Bleyer, MD,
Breakout Group Co-Chair
Children's Oncology Group

Laura Brown
Planet Cancer

Michael Caligiuri, MD,
Breakout Group Co-Chair
The Ohio State University Comprehensive Cancer Center

Stephen Carey
The Sean Kimerling Testicular Cancer Foundation

Pat Christen
Hope Lab

Anderson (Andy) B Collier III, MD
Vanderbilt-Ingram Cancer Center
at Vanderbilt University Medical Center

Elizabeth Daniels

Waiting Room Magazine,
Cancer Unsensored

Samantha Eisenstein

Surviving And Moving Forward: The SAMFund
for Young Adult Survivors of Cancer

Chad A Ellis, PhD

National Cancer Institute,
Cancer Centers Branch

Angelina Esparza, RN

American Cancer Society

Joseph Flynn, MD

Landstuhl Regional Medical Center

Allan Goldberg, MPA

First Descents

Stephanie Guastella

Children's Hospital of Orange County

Brooke Hamilton

National Cancer Institute,
Office of Liaison Activities

Brandon Hayes-Lattin, MD

Oregon Health and Science University

Roger Herdman, MD

Institute of Medicine

Jessica Jacobs, MPH

Fertile Hope

Barbara Jones, PhD, MSW

Association of Pediatric Oncology Social Workers

Stuart Kaplan, MD

Children's Oncology Camp Foundation

Ernest Katz, PhD

The Wellness Community

Suzanne Kho, MSEd

Lance Armstrong Foundation

Rebecca A Kirch, JD

American Cancer Society

Kendra Kirsch

Y-ME National Breast Cancer Organization

Bill Kubicek

Next Step

Aura Kuperberg, PhD

Teen Impact

Ellen LaPointe

Hope Lab

Julie Larson, LMSW

CancerCare

Craig Lustig, MPA

The Children's Cause for Cancer Advocacy

David Lyon,

Breakout Group Co-Chair
Lance Armstrong Foundation

Jenny McClendon

The Susan G Komen Breast
Cancer Foundation

Andy Miller, MHSE, CHES

Lance Armstrong Foundation

Jennifer Mills, LMSW, MPH, CHES

Lymphoma Research Foundation

Claire Neal, MPH, CHES

Lance Armstrong Foundation

Cherie Nichols, MBA

National Cancer Institute,
Office of Science Planning and Assessment

Craig Nichols, MD,

Breakout Group Co-Chair
Oregon Health and Science University

Emily Peterson

National Marrow Donor Program

Leila Polintan

The Children's Cause for Cancer Advocacy

Michelle Pollak

The Wellness Community

Michele Przepyszny

Young Survival Coalition

Randi Rosenberg

Young Survival Coalition

Julia Rowland, PhD

National Cancer Institute,
Office of Cancer Survivorship

Jodi Sax, JD

The LifeLab

Elizabeth Saylor

The Ulman Cancer Fund for Young Adults

Selma Schimmel

Vital Options International ,The Group Room®
Cancer Talk Radio Show

Heather Shappell, MS, CGC

FORCE (Facing Our Risk of Cancer Empowered)

Rochelle Shoretz, JD

Sharsheret

Lydia Shrier, MD, MPH

Children's Hospital Boston

Stuart E Siegel, MD,

Breakout Group Co-Chair
Childrens Hospital of Los Angeles

Carol Sienche

National Cancer Institute
Office of Education and Special Initiatives

Mary Jo Sims, APRN-BC, CS

Froedtert Hospital Cancer Care

Lauren Spiker

Melissa's Living Legacy Foundation

Sanya Springfield, PhD

National Cancer Institute,
Center to Reduce Cancer Health Disparities

Kristin Stegenga, RN, MSN

Association of Pediatric
Hematology/Oncology Nurses

Muneesh Tewari, MD, PhD,

Breakout Group Co-Chair
Fred Hutchinson Cancer Research Center

Eran Thomson

Prepare to Live

Doug Ulman

Lance Armstrong Foundation

Carmina Valle, MPH

National Cancer Institute,
Office of Cancer Survivorship

Staci Vernick Goldberg

American Association for Cancer Research

Beth Virnig, PhD, MPH,

Breakout Group Co-Chair
University of Minnesota, School of Public Health

Hannah K Vogler

The Colon Club

Dan Waeger

National Collegiate Cancer Foundation

Stacia Wagner, LSW

Children's Brain Tumor Foundation

Karen Weiss, MD

Food and Drug Administration,
Office of Oncology Drug Product

Kate West

Teenage Cancer Trust

Kimberly D Williams

Tamika and Friends, Inc

Bruce Williams

Enzon Pharmaceuticals

Anne Willis

National Coalition for Cancer Survivorship

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Breakout Group Co-Chair
Oncology Nursing Society

Brock Yetso,

Breakout Group Co-Chair
The Ulman Cancer Fund for Young Adults

Matthew Zachary

Steps For Living, Inc

Andrew Young

CanTeen

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Breakout Group Co-Chair
University of Southern California,
School of Social Work

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Lead Science Writer
Science Applications International
Corporation (SAIC)

Adam Book, PhD

SAIC

Greg Cole, PhD

SAIC

Julia Huiberts, MS

SAIC

Karen Rulli, PhD

SAIC

Adey Smith, MS

SAIC

LANCE ARMSTRONG
FOUNDATION AND ADDITIONAL
STAFF ATTENDEES

Kim Cooper

Lance Armstrong Foundation

Tina Hamilton

Lance Armstrong Foundation

Beth Mathews-Bradshaw

SAIC

Devon McGoldrick, MPH

Lance Armstrong Foundation

Betty Otter-Nickerson

Lance Armstrong Foundation

Mitch Stoller

Lance Armstrong Foundation

LIVESTRONG™ Young Adult Alliance Inaugural Meeting and Adolescent and Young Adult Oncology Progress Review Group Implementation Meeting

Austin, Texas
November 10-12, 2006

Breakout Groups

MORNING SESSIONS

AYAO Professional Track/ Professional Development

Ronald Barr, MD, *Co-Chair*
Karla Wilson, RN, MSN, FNP, CPON, *Co-Chair*
Kristin Bingen, PhD
Anderson Collier III, MD
Angelina Esparza, RN
Allan Goldberg, MPA
Stephanie Guastella
Jessica Jacobs, MPH
Kendra Kirsch
Bill Kubicek
Aura Kuperberg, PhD
Julie Larson, LMSW
Jenny McClendon
Craig Nichols, MD
Emily Peterson
Kristin Stegenga, RN, MSN
Stacia Wagner, LSW
Julia Huiberts, MS, *Science Writer*

Psychosocial Advocacy & Support

Brad Zebrack, PhD, MSW, MPH, *Chair*
Doug Bank
Christine Baze
Joyce Bichler, MSW
Laura Brown
Elizabeth Daniels
Barbara Jones, PhD, MSW

Stuart Kaplan, MD
Ernest Katz, PhD
Ellen LaPointe
Craig Lustig, MPA
Andy Miller, MHSE, CHES
Julia Rowland, PhD
Jodi Sax, JD
Elizabeth Saylor
Rochelle Shoretz, JD
Lydia Shrier, MD, MPH
Carol Sienche
Mary Jo Sims, APRN-BC, CS
Dan Waeger
Kimberly Williams
Debby Berlyne, PhD, *Science Writer*

Biologic Research & Tissue Sample/Collection

Michael Caligiuri, MD, *Co-Chair*
Muneesh Tewari, MD, PhD, *Co-Chair*
Janelle Banks, MPH
Archie Bleyer, MD
Pat Christen
Chad Ellis, PhD
Joseph Flynn, MD
Roger Herdman, MD
Suzanne Kho, MSED
Michele Przypyszny
Selma Schimmel
Stuart Siegel, MD
Sanya Springfield, PhD
Carmina Valle, MPH
Beth Virnig, PhD, MPH
Karen Weiss, MD
Karen Rulli, PhD, *Science Writer*

AYA Public Relations Campaign

Heidi Adams, *Co-Chair*
 David Lyon, *Co-Chair*
 Elana Bizer
 Stephen Carey
 Samantha Eisenstein
 Brooke Hamilton
 Rebecca Kirch, JD
 Claire Neal, MPH, CHES
 Leila Polintan
 Michelle Pollack
 Heather Shappell, MS, CGC
 Lauren Spiker
 Eran Thomson
 Staci Vernick Goldberg
 Hannah Vogler
 Kate West
 Bruce Williams
 Anne Willis
 Brock Yetso
 Andrew Young
 Matthew Zachary
 Adey Smith, MS, *Science Writer*

Kate West
 Anne Willis
 Karla Wilson, RN, MSN, FNP, CPON
 Andrew Young
 Brad Zebrack, PhD, MSW, MPH
 Adam Book, PhD, *Science Writer*

Patient Navigation/Health Coaches

Beth Virning, PhD, MPH, *Co-Chair*
 Brock Yetso, *Co-Chair*
 Doug Bank
 Christine Baze
 Elana Bizer
 Laura Brown
 Stephen Carey
 Elizabeth Daniels
 Samantha Eisenstein
 Angelina Esparza, RN
 Stuart Kaplan, MD
 Ernest Katz, PhD
 Kendra Kirsch
 Bill Kubicek
 Ellen LaPointe
 David Lyon

Andy Miller, MHSE, CHES

Emily Peterson

Jodi Sax, JD

Elizabeth Saylor

Heather Shappell, MS, CGC

Rochelle Shoretz, JD

Mary Jo Sims, APRN-BC, CS

Kristin Stegenga, RN, MSN

Eran Thomson

Stacia Wagner, LSW

Kimberly Williams

Matthew Zachary

Beth Mathews-Bradshaw, *Science Writer*

Claire Neal, MPH, CHES
 Michelle Pollack
 Lydia Shrier, MD, MPH
 Carol Sienche
 Sanya Springfield, PhD
 Muneesh Tewari, MD, PhD
 Staci Vernick Goldberg
 Hannah Vogler
 Karen Weiss, MD
 Bruce Williams
 Greg Cole, PhD, *Science Writer*

AFTERNOON SESSIONS

Standards of Excellence/Standards of Care

Craig Nichols, MD, *Co-Chair*
 Stuart Siegel, MD, *Co-Chair*
 Jamelle Banks, MPH
 Joyce Bichler, MSW
 Kristin Bingin, PhD
 Pat Christen
 Joseph Flynn, MD
 Allan Goldberg, MPA
 Brooke Hamilton
 Jessica Jacobs, MPH
 Barbara Jones, PhD, MSW
 Suzanne Kho, MSED
 Aura Kuperberg, PhD
 Julie Larson, LMSW
 Craig Lustig, MPA
 Leila Polintan
 Michele Przyppyszny
 Julia Rowland, PhD
 Selma Schimmel
 Lauren Spiker
 Carmina Valle, MPH
 Dan Waeger

Clinical Trials

Barry Anderson, MD, PhD, *Co-Chair*
 Archie Bleyer, MD, *Co-Chair*
 Heidi Adams
 Ronald Barr, MD
 Michael Caligiuri, MD
 Anderson Collier III, MD
 Chad Ellis, PhD
 Stephanie Guastella
 Roger Herdman, MD
 Rebecca Kirch, JD
 Jenny McClendon

APPENDIX

Portfolio Review:
An Analysis of the Adolescent and
Young Adult Oncology Research Portfolio
November 2006

U.S. Department of
Health and Human Services
National Institute of Health
National Cancer Institute

LIVESTRONG™ Young Adult Alliance

Table of Contents

Introduction.....	1
AYAO Research Portfolio	2
Analysis of the AYAO Portfolio by Disease Site.....	4
Analysis of the AYAO Portfolio by Common Scientific Outline	6
Analysis of the AYAO Portfolio by PRG Recommendation	8
AYAO Research Projects	15

List of Tables

Table 1.	AYAO PRG Recommendations and Sub-recommendations	1
Table 2.	Cancer Site Relevance in the AYAO Portfolio, FY 2002-FY 2005.....	4
Table 3.	AYAO Research Portfolio FY 2002–FY 2005	15
Table 4.	AYAO Clinical Trials Retrieved by Keyword Searches	35

List of Figures

Figure 1.	Analysis of AYAO Research by Funding Organization	2
Figure 2.	Trends in AYAO Research, FY 2002–FY 2005	3
Figure 3.	Analysis of NCI-funded Research by CSO	6
Figure 4.	Analysis of Non-NCI-funded Research by CSO.....	7
Figure 5.	Trends in AYAO Research by CSO.....	7
Figure 6.	Analysis AYAO Research by PRG Recommendation Category	8
Figure 7.	Proportion of NCI or non-NCI Research with Relevance to Each of the PRG Categories.....	9
Figure 8.	Trends in AYAO Research by PRG Category	9
Figure 9.	Projects Addressing PRG Recommendation 1	10
Figure 10.	Projects Addressing PRG Recommendation 2	11
Figure 11.	Projects Addressing PRG Recommendation 3	12
Figure 12.	Projects Addressing PRG Recommendation 4	13
Figure 13.	Projects Addressing PRG Recommendation 5	14

INTRODUCTION

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 care needs of Adolescents and Young Adults with Cancer. Members of the Adolescent and Young Adult Oncology (AYAO) PRG identified five priorities for research that would accelerate progress in Adolescent and Young Adult Oncology. These priority recommendations (and sub-recommendations) are listed in **Table 1**.

Table 1. AYAO PRG Recommendations and Sub-recommendations

PRG Recommendations	Sub-recommendations
Recommendation 1: Identify the characteristics that distinguish the unique cancer burden in the AYAO patient.	<ul style="list-style-type: none"> – Elucidate unique biologic characteristics of AYA cancers and AYA patients that affect disease outcome in this population. – Elucidate AYA life-stage/developmental characteristics that influence care seeking, adherence to treatment, and medical and psychosocial outcomes. – Identify and ameliorate health disparities experienced by AYA cancer patients and survivors.
Recommendation 2: Provide education, training, and communication to improve awareness, prevention, access, and quality cancer care for AYAs.	<ul style="list-style-type: none"> – Raise awareness of AYA cancer issues as a first step toward increasing national focus and resource allocation to address the AYA cancer problem. – Provide targeted education to patients, families/caregivers, and the public about AYA cancer issues. – Educate multidisciplinary providers who work with AYAs to improve referrals and services to this population.
Recommendation 3: Create the tools to study the AYA cancer problem.	<ul style="list-style-type: none"> – Create a large prospective database of AYA cancer patients to facilitate research on this age group. – Increase the number of annotated specimens to support research progress. – Create/modify needed assessment tools specific to AYA cancer issues. – Improve grant coding and search term standardization to enable evaluation of research efforts and progress. – Expand clinical trials for AYAs to increase treatment choices and accelerate treatment advances.
Recommendation 4: Ensure excellence in service delivery across the cancer control continuum (i.e., prevention, screening, diagnosis, treatment, survivorship, and end of life).	<ul style="list-style-type: none"> – Develop, evaluate, and disseminate standards of care for AYA cancer patients and survivors to improve outcomes. – Establish a national network or coalition of providers and advocates seeking to achieve a standard of excellence in AYA cancer care.
Recommendation 5: Strengthen and promote advocacy and support of the AYA cancer patient.	<ul style="list-style-type: none"> – Address the subjective experience of AYA patients. – Build the capacity of existing resources to address AYA psychosocial needs. – Evaluate existing programs and develop new interventions.

AYAO RESEARCH PORTFOLIO

A portfolio analysis was performed to identify recent¹ research projects that address issues in AYAO. Research projects included in this study were funded by the American Cancer Society (ACS), the California Breast Cancer Research Program (CBCRP), the Congressionally Directed Medical Research Program (CDMRP), the Komen Breast Cancer Foundation (KOMEN), the NCI, the National Cancer Research Institute (NCRI, UK), or the Oncology Nursing Society (ONS). Projects were identified by searching the International Cancer Research Portfolio (ICRP) using the keywords: *teen, adolescen**, *young adult**, *young men, young man, young women, young woman, young people, or premenopaus**. In addition, 57 projects funded by the LAF were also included in the analysis.

The resulting research portfolio contains 235 distinct projects that are directly relevant to AYAO research (i.e., they specifically mentioned adolescents or young adults). Of these, 108 were funded by NCI and 127 were funded by other organizations (**Figure 1**). The number of AYAO research projects increased between FY 2002 and FY 2005 for all funding organizations (**Figure 2**).

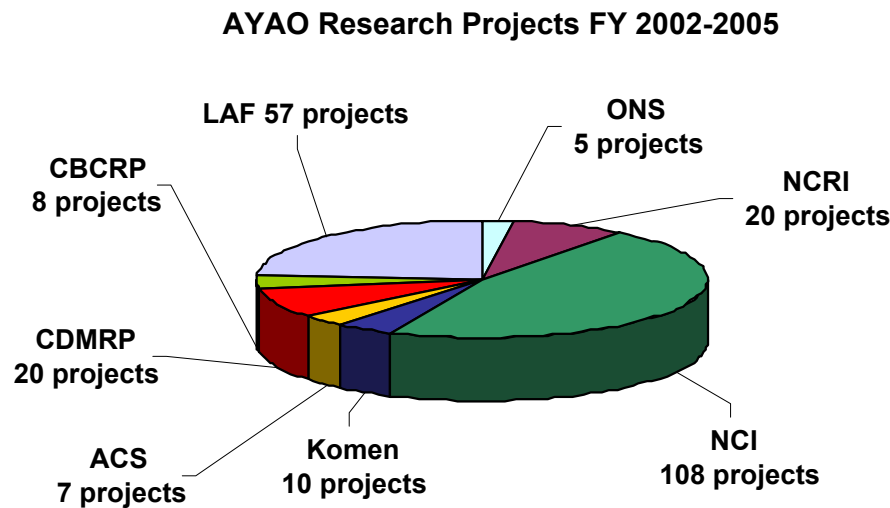


Figure 1. Analysis of AYAO Research by Funding Organization

¹ Projects were included if they were active between October 1, 2001 and September 30, 2005 (NCI fiscal years 2002 through 2005).

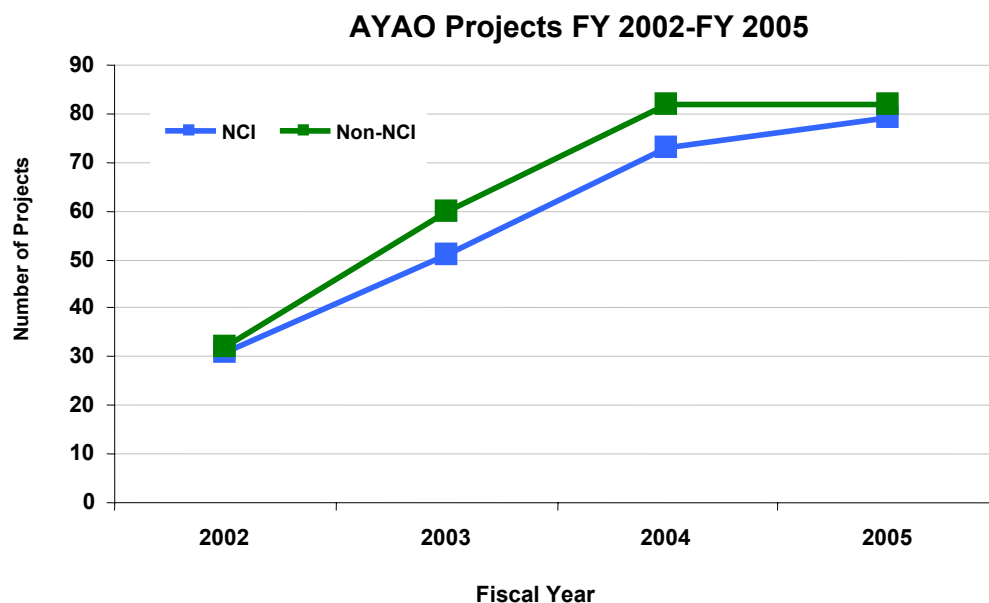


Figure 2. Trends in AYAO Research, FY 2002–FY 2005

This report summarizes the portfolio of AYAO research projects according to various parameters, including Disease Site, Common Scientific Outline (CSO), and PRG Recommendation/Sub-recommendation. The full list of AYAO projects and their corresponding PRG assignments is also included in this report.

ANALYSIS OF THE AYAO PORTFOLIO BY DISEASE SITE

An analysis of the AYAO research portfolio by disease site reveals that this list of projects is relevant to nearly 50 different disease sites. **Table 2** lists the number of projects addressing AYA cancers that were funded by either NCI or one of the non-NCI funding organizations.²

For research funded by NCI as well as other funding organizations, the cancer site with the highest number of AYAO projects is breast cancer (early onset). There were 47 NCI-funded projects and 43 projects funded by other organizations that addressed breast cancer in AYAs between FY 2002 and FY 2005.

Other disease sites with high numbers of projects in this research portfolio were nervous system cancers, sarcomas, blood cancers, and genital system cancers.

Table 2. Cancer Site Relevance in the AYAO Portfolio, FY 2002-FY 2005

Disease Site	Number of NCI-Funded Projects	Number of Projects Funded by Other Groups	Total Number of Projects
Adrenocortical Cancer	1	0	1
Bladder Cancer	2	0	2
Blood Cancer	17	6	23
Bone Cancer, Osteosarcoma/Malignant Fibrous Histiocytoma	11	5	16
Bone Marrow Transplantation	2	0	2
Brain Tumor	12	2	14
Breast Cancer	47	43	90
Cervical Cancer	7	2	9
Colon and Rectal Cancer	6	5	11
Ear Cancer	0	1	1
Endometrial Cancer	4	0	4
Esophageal Cancer	4	1	5
Eye Cancer	1	0	1
Gastrointestinal Tract	8	5	13
Genital System, Female	11	3	14
Genital System, Male	9	9	18
Head and Neck Cancer	7	2	9
Hodgkin's Disease	8	4	12
Kidney Cancer	6	1	7
Leukemia	4	2	6
Liver Cancer	6	3	9
Lung Cancer	8	4	12
Melanoma	4	4	8
Myeloma	5	0	5
Nasal Cavity and Paranasal Sinus Cancer	2	1	3
Nervous System	17	3	20
Neuroblastoma	4	0	4
Non-Hodgkin's Lymphoma	9	4	13
Not Site-Specific Cancer	20	6	26
Oral Cavity and Lip Cancer	1	0	1
Ovarian Cancer	6	1	7
Pancreatic Cancer	4	0	4
Pharyngeal Cancer	0	2	2

² Projects funded by the Lance Armstrong Foundation were not coded to disease sites and are not represented in Table 2.

Table 2. Cancer Site Relevance in the AYAO Portfolio, FY 2002-FY 2005 (cont.)

Disease Site	Number of NCI-Funded Projects	Number of Projects Funded by Other Groups	Total Number of Projects
Prostate Cancer	4	4	8
Respiratory System	9	5	14
Retinoblastoma	0	1	1
Salivary Gland Cancer	2	0	2
Sarcoma	15	3	18
Rhabdomyosarcoma, Childhood	4	0	4
Sarcoma, Soft Tissue	7	0	7
Skin Cancer	3	1	4
Stomach Cancer	4	1	5
Testicular Cancer	6	5	11
Thymoma, Malignant	1	0	1
Thyroid Cancer	2	0	2
Uncoded	3	1	4
Urinary System	6	1	7
Vaginal Cancer	1	0	1
Vascular System	3	0	3

ANALYSIS OF THE AYAO PORTFOLIO BY COMMON SCIENTIFIC OUTLINE

Research projects relevant to Adolescent and Young Adult Oncology were analyzed according to NCI's CSO categories. CSO is a classification system used by NCI and other funding organizations to categorize research into broad areas of scientific interest. These categories include:

1. Biology
2. Causes of Cancer/Etiology
3. Prevention
4. Early Detection, Diagnosis, and Prognosis
5. Treatment
6. Cancer Control, Survivorship, and Outcomes
7. Scientific Model Systems.

The following figures summarize the CSO breakdown for the group of AYAO projects funded by NCI and those funded by other organizations.³

The CSO category with the greatest proportion of projects in the NCI portfolio is Causes of Cancer/Etiology. In contrast, the CSO category called Cancer Control, Survivorship, and Outcomes contains the greatest proportion of projects in the portfolio of research funded by other organizations.

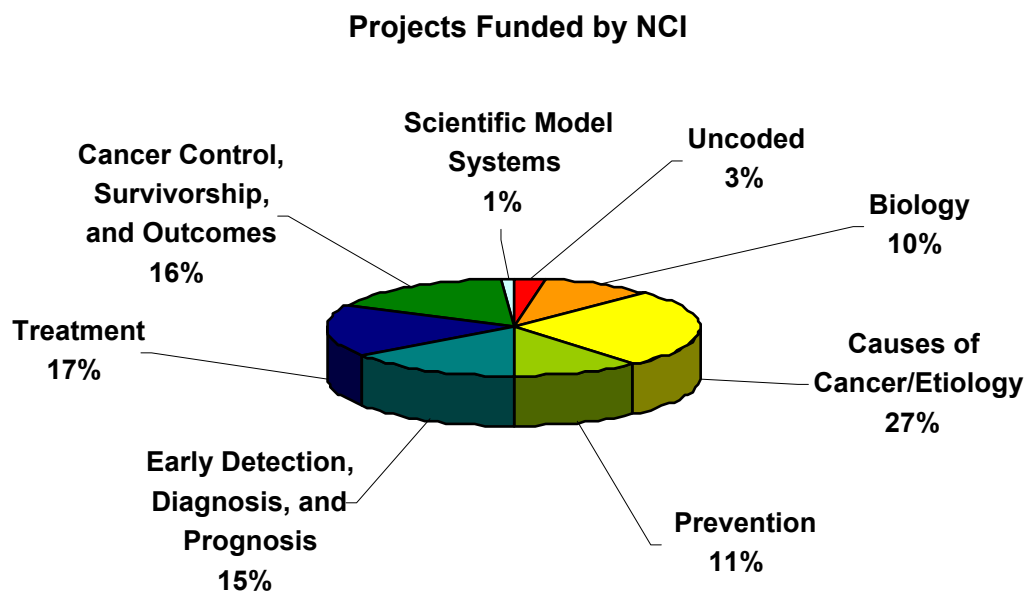


Figure 3. Analysis of NCI-funded Research by CSO

³ Projects funded by the Lance Armstrong Foundation were not coded to CSO and are not included in Figures 3–5.

Projects Funded by Non-NCI Organizations

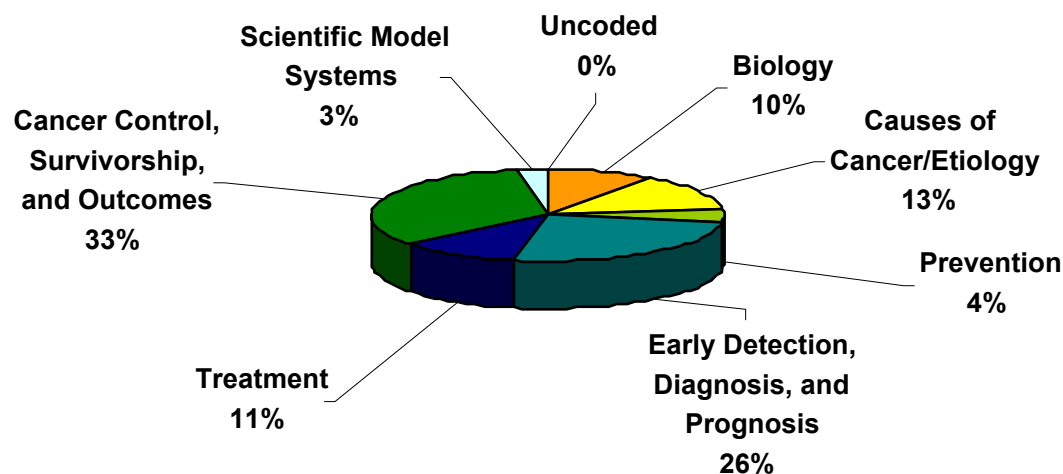


Figure 4. Analysis of Non-NCI-funded Research by CSO

The number of AYAO-related research projects relevant to each of the CSO categories increased between FY 2002 and FY 2005.

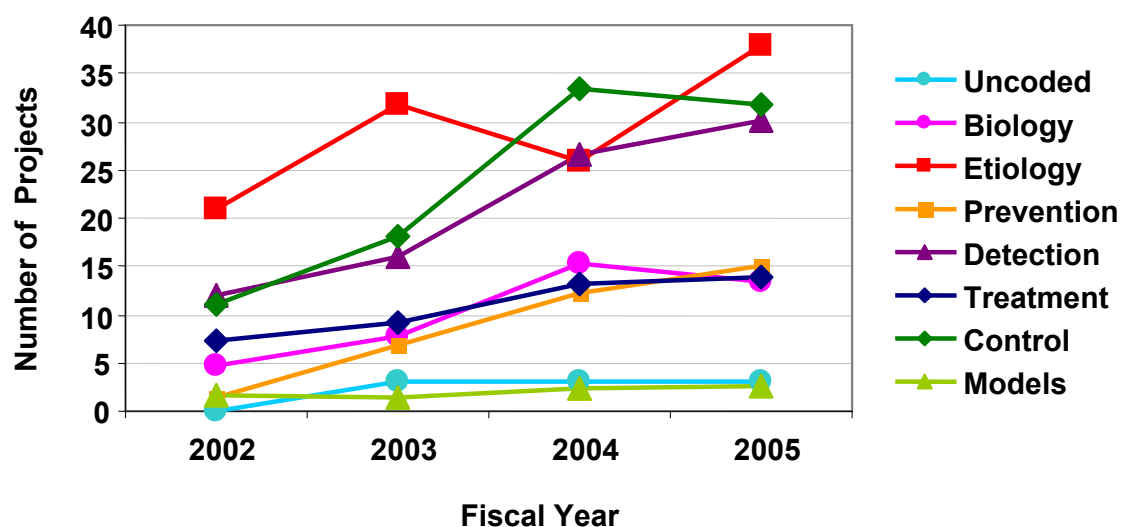


Figure 5. Trends in AYAO Research by CSO

ANALYSIS OF THE AYAO PORTFOLIO BY PRG RECOMMENDATION

The 235 AYAO-related research projects were analyzed according to their relevance to each of the AYAO PRG recommendations. Among NCI-funded research projects, the PRG recommendations with the largest number of related projects are PRG 1 (Unique Characteristics) and PRG 3 (Tools for Studying AYA Cancers). For projects funded by non-NCI organizations, the PRG recommendations with the largest number of related projects are PRG 3 (Tools for Studying AYA Cancers) and PRG 5 (Advocacy) (Figures 6 and 7).

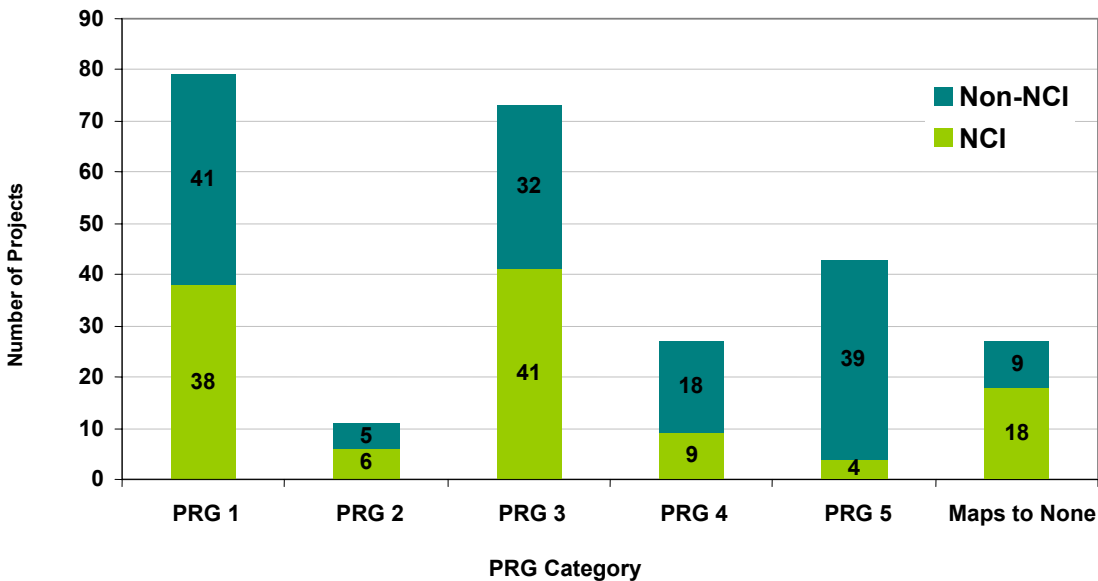


Figure 6. Analysis of AYAO Research by PRG Recommendation Category

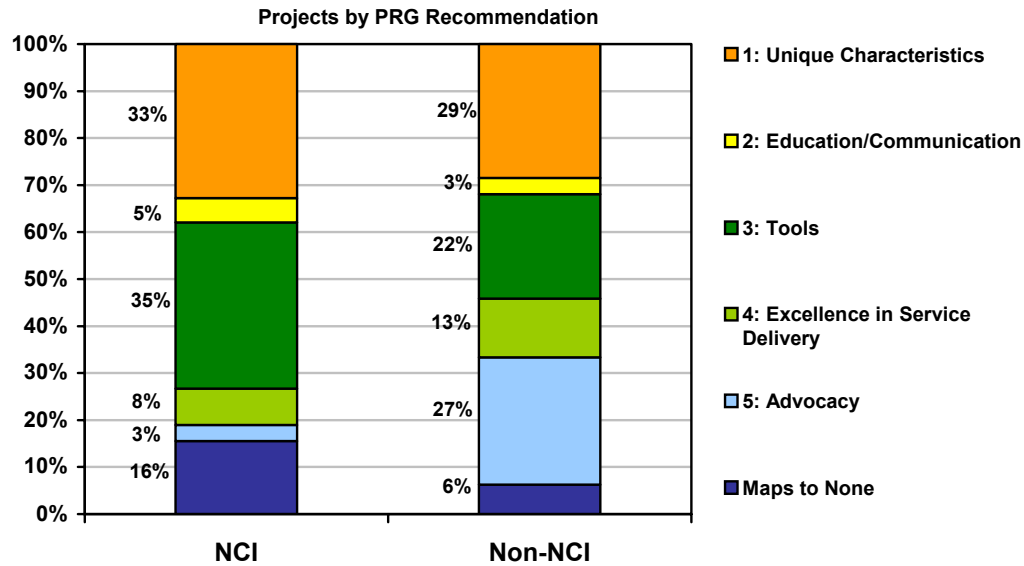


Figure 7. Proportion of NCI or non-NCI Research with Relevance to Each of the PRG Categories

The number of projects addressing each of the PRG recommendations increased between FY 2002 and FY 2005 (**Figure 8**).

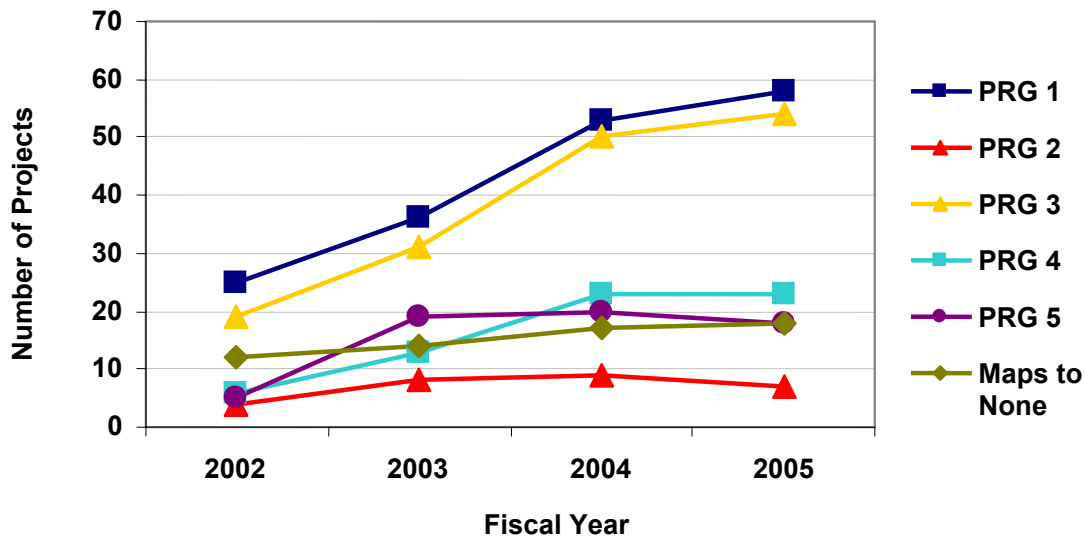


Figure 8. Trends in AYAO Research by PRG Category

ANALYSIS OF THE AYAO PORTFOLIO BY PRG SUB-RECOMMENDATION

The projects that had relevance to each of the main AYAO PRG recommendations were further categorized according to the sub-recommendations listed in Table 1. The results of this analysis are summarized in **Figures 9–13**.

PRG Recommendation 1: Unique AYAO Characteristics

Projects addressing PRG 1 focused on: the unique biologic characteristics of AYA cancers and AYA patients that affect disease outcome; the life stage or developmental characteristics that influence care seeking, treatment adherence, and outcomes; and ameliorating health disparities experienced by AYAs. The majority of projects funded by NCI or other organizations addressed the unique biology of AYA cancers and AYA patients.

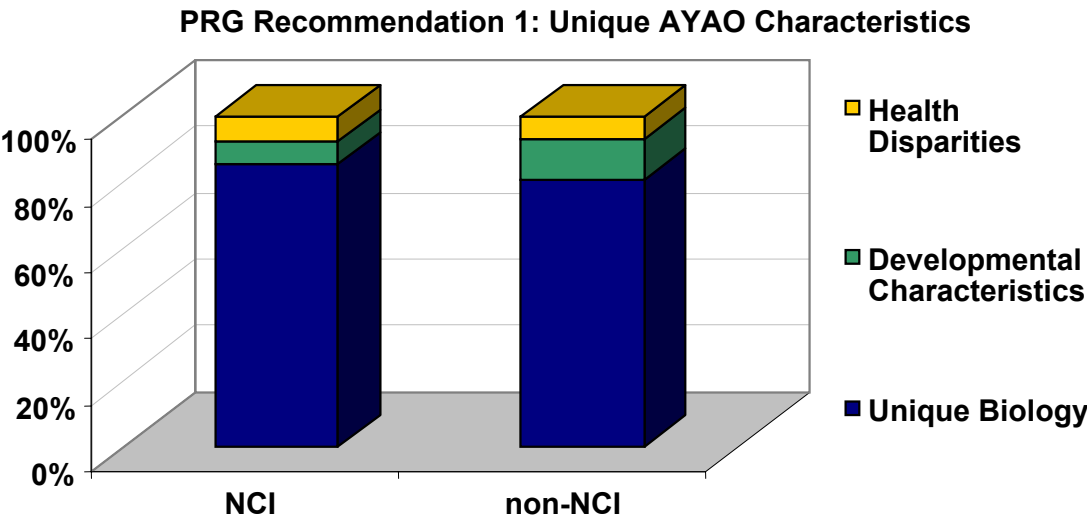


Figure 9. Projects Addressing PRG Recommendation 1

PRG Recommendation 2: Education & Communication

Projects addressing PRG recommendation 2 focused on: education, training, and communication for providers and patients to improve awareness, prevention, access, and quality care for AYAs. The majority of NCI-funded research relevant to this PRG recommendation addressed awareness while most of the projects funded by non-NCI organizations addressed patient education.

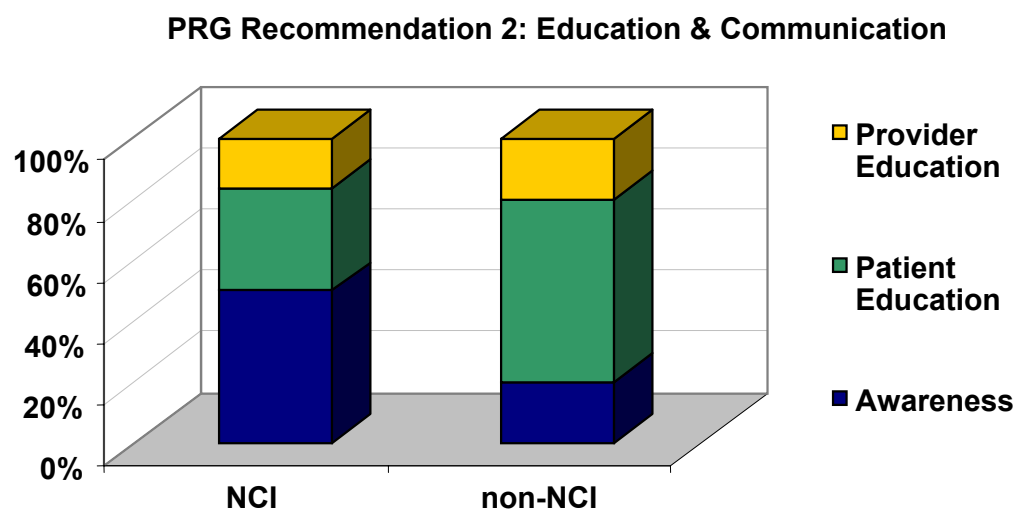


Figure 10. Projects Addressing PRG Recommendation 2

PRG Recommendation 3: Tools to Study AYA Cancers

NCI-funded projects addressing PRG recommendation 3 focused on: expanding clinical trials to include AYAs, increasing the number of annotated specimens, creating assessment tools to study AYA cancers (including risk assessment models, and novel methods of detecting cancer in young patients), and the creation of a prospective database of AYA cancer patients. The majority of research funded by all funding organizations focused on clinical trials and assessment tools.

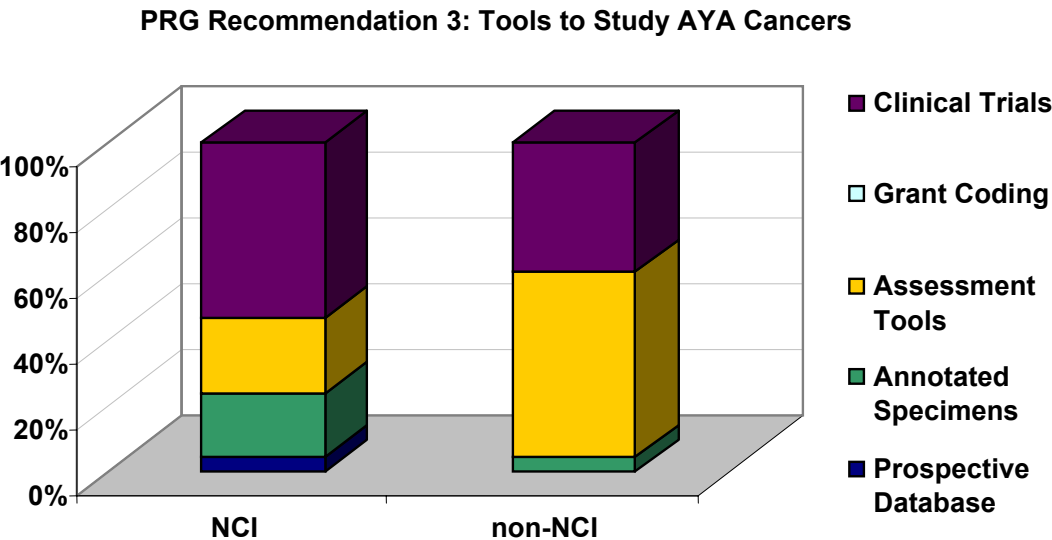


Figure 11. Projects Addressing PRG Recommendation 3

PRG Recommendation 4: Excellence across the Cancer Continuum

Research projects addressing PRG recommendation 4 focused on: developing and improving standards of care for AYA patients and establishing a national network of providers and advocates seeking to achieve excellence in AYA care.

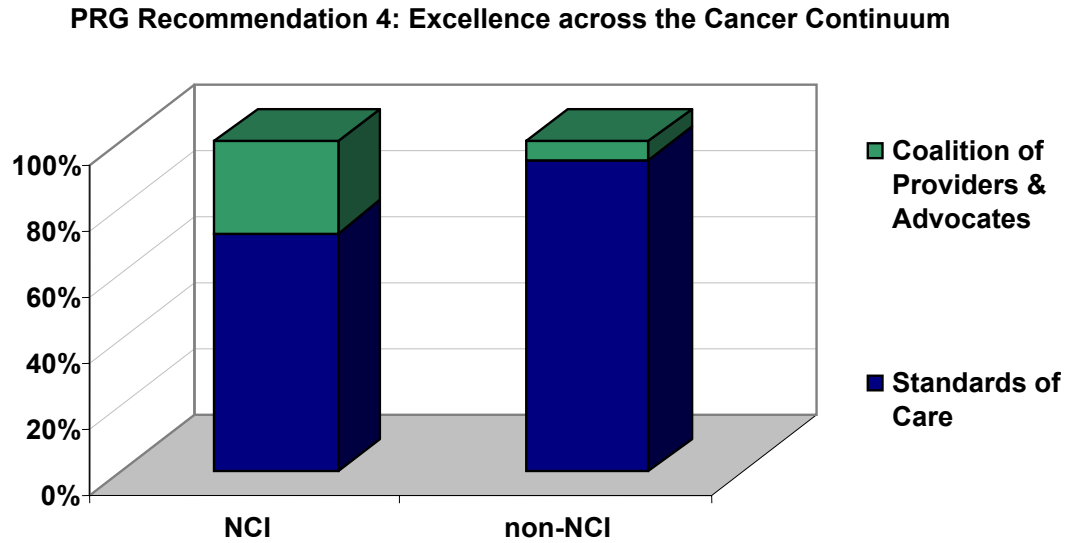


Figure 12. Projects Addressing PRG Recommendation 4

PRG Recommendation 5: Strengthen and Promote Advocacy

NCI-funded research addressing PRG recommendation 5 focused on: the subjective experience of AYAs, resources for addressing psychosocial needs, and the development and evaluation of programs and interventions.

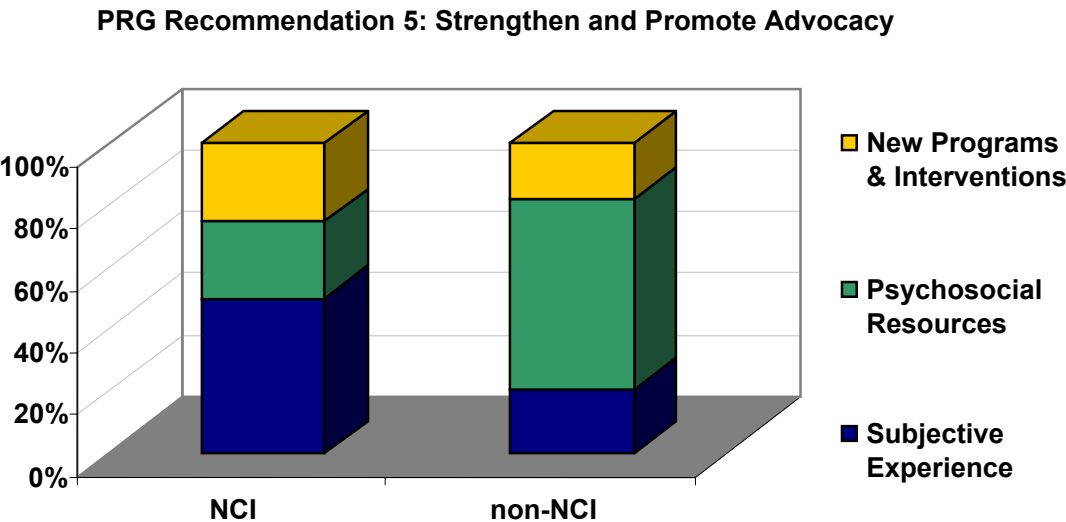


Figure 13. Projects Addressing PRG Recommendation 5

AYAO RESEARCH PROJECTS

The following table lists the 235 research projects funded between FY 2002 and FY 2005 that were considered to be directly relevant to Adolescent and Young Adult Oncology. These projects were identified by searching the ICRP using the keywords: *teen, adolescen**, *young adult**, *young men, young man, young women, young woman, young people*, or *premenopaus**. Projects were included if they were active between October 1, 2001 and September 30, 2005. Projects funded by LAF are also included on this list.

Research listed in this table was funded by the ACS, the CBCRP, the CDMRP, the KOMEN, the LAF, the NCI, the NCRI (UK), or the ONS.

Projects in this table are grouped alphabetically by funding organization. Abstracts for each of these projects can be read by clicking on the blue hyperlinked title.

Table 3. AYAO Research Portfolio FY 2002–FY 2005

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
ACS		√	√	√	Indiana University, Indianapolis	Decker, Carol L.	Resilience and Quality of Life in Adolescents with Cancer					√	
ACS			√	√	University of Utah	Erickson, Jeanne M.	Fatigue in Adolescents with Cancer				√		
ACS	√	√	√	√	Van Andel Research Institute	Giambernardi, Troy A.	Analysis of MMP-8 in Melanoma and Development	√					
ACS		√	√	√	Dana-Farber Cancer Institute	Li, Frederick P.	Cancer Etiology, Prevention, Detection in High Risk Individuals/Families	√	√				
ACS	√	√	√	√	Dana-Farber Cancer Institute	Parsons, Susan K.	Trajectories of Health and Adaptation after Pediatric Stem Cell Transplant				√		
ACS		√	√	√	Indiana University, Indianapolis	Phillips, Celeste R.	Master's Degree Scholarship in Cancer Nursing				√		
ACS			√	√	American Cancer Society	Ward, Elizabeth	Surveillance Research of the American Cancer Society		√				

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
CBCRP	√	√	√		University of California, San Francisco	Berlin, Lucy	Chemotherapy-Induced Ovarian Damage: Prevention and Impact			√			
CBCRP			√	√	University of California, Berkeley	Bloom, Joan	Young Breast Cancer Survivors: Ten Years Later					√	
CBCRP				√	University of California, San Francisco	Kushner, Peter	Estrogen Receptor Beta Agonists to Prevent Breast Cancer				√		
CBCRP				√	University of California, San Diego	Nelson, Thomas	Early Breast Cancer Detection Using 3D Ultrasound Tomography			√			
CBCRP			√	√	Environmental Health Investigations Branch	Reynolds, Peggy	Birth Characteristics and Breast Cancer in Young Women						√
CBCRP	√	√	√		University of California, San Francisco	Rugo, Hope	Chemotherapy-Induced Ovarian Damage: Prevention and Impact			√			
CBCRP		√	√	√	University of California, Irvine	Su, Min-Ying (Lydia)	Angiogenesis in Hyperplasia to In-Situ Breast Cancers			√			
CBCRP	√	√	√		Stanford University	Westphal, Lynn	Chemotherapy-Induced Ovarian Damage: Prevention and Impact			√			
CDMRP	√	√	√	√	Washington University	Achilefu, Samuel	Optical Imaging of Mammaglobin Expression in Breast Cancer			√			
CDMRP			√	√	New York, State University of, Buffalo	Boehmke, Marcia	The Development of a Comprehensive Instrument to Measure Symptoms and Symptom Distress in Women After Treatment for Breast Cancer					√	
CDMRP			√	√	SUNY at Stony Brook	Botchkina, Galina	Validation of Quantitative Multimodality Analysis of Telomerase Activity in Urine Cells as a Noninvasive Diagnostic and Prognostic Tool for Prostate Cancer			√			

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
CDMRP			√	√	Georgetown University School of Medicine	Clarke, Robert	Endocrine Therapy of Breast Cancer	√					
CDMRP		√	√	√	Mayo Clinic and Foundation, Rochester	Frost, Marlene	Changes in Ovarian Stromal Function in Premenopausal Women Undergoing Chemotherapy for Breast Cancer						
CDMRP		√	√	√	Dana-Farber Cancer Institute	Garber, Judy	A Randomized Study of the Effects of Tibolone on Bone Density, Menopausal Symptoms and Breast Density in High-Risk Women After Prophylactic Oophorectomy			√	√		
CDMRP			√	√	New York University	Hiremath, Minoti	Beta-Catenin in Hormone Receptor Negative Breast Cancer	√					
CDMRP			√	√	Dorn VAMC/Dorn Research Institute	Hrushesky, William	Sage Gene Expression Profiles Characterizing Cure				√		
CDMRP			√	√	The University of Texas Medical Branch	Huang, Yafei	Early Markers for Breast Cancer Risk in Nipple Aspirate Fluid			√			
CDMRP			√	√	Roswell Park Cancer Institute	Ip, Margot	Conjugated Linoleic Acid (CLA) and the Estrogen Receptor in Prevention of Breast Cancer				√		
CDMRP		√	√	√	University of Kansas Medical Center	Klemp, Jennifer	The use of a cognitive protectant to help maintain quality of life and cognition in premenopausal women with breast cancer undergoing adjuvant chemotherapy				√		
CDMRP				√	Pittsburgh, University of	Latimer, Jean	A New Paradigm for African American Breast Cancer Involving Stem Cell Differentiation in a Novel Cell Culture System	√					
CDMRP				√	Fred Hutchinson Cancer Research Center	Li, Christopher	Use of Depo-Medroxyprogesterone Acetate and Risk of Premenopausal Breast Cancer						√
CDMRP			√	√	IFO - Italian National Cancer Institute Regina Elena	Muti, Paola	Endogenous 6-Hydroxymelatonin Excretion and Subsequent Risk of Breast Cancer: A Prospective Study						√

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
CDMRP	√	√	√	√	Wake Forest University School of Medicine	Naughton, Michelle	Quality of Life and Functional Status Across the Life Course						√
CDMRP			√	√	Boston University	Oberai, Assad	Towards the Early Detection of Breast Cancer in Young Women			√			
CDMRP	√	√	√	√	Washington University	Pandita, Tej	Chromatin Structure and Breast Cancer Radiosensitivity	√					
CDMRP				√	Duke University	Ramanujam, Nirmala	Miniature and Molecularly Specific Optical Screening Technologies for Breast Cancer			√			
CDMRP	√	√	√	√	Missouri, University of, Columbia	Sauter, Edward	Proteome Analysis in Nipple Aspirate Fluid			√			
CDMRP	√	√	√	√	Columbia University	Terry, Mary Beth	Early Life Factors and Breast Cancer Risk	√					
KOMEN			√	√	Fundacao Medica do Rio Grande do Sul	Ashton-Prolla, Patricia	Identification and Characterization of Patients at Risk for Hereditary Breast Cancer in Southern Brazil.	√					
KOMEN			√	√	New York University School of Medicine	Cowin, Pamela	Role of Beta-Catenin in Hormone Receptor Negative Breast Cancer	√					
KOMEN		√	√	√	University of Central Florida	Dow, Karen	Fertility After Breast Cancer: A web-based Program		√			√	
KOMEN			√	√	University of North Carolina at Chapel Hill	Gammon, Marilie	Reproduction, oral contraceptives & Breast Cancer Survival in Young Women	√					
KOMEN			√	√	Wayne State University	Hu, Jiani	Improving Specificity of Breast Cancer Diagnosis with Proton MRSI			√			
KOMEN		√	√	√	Department of Pathology, Johns Hopkins University	Li, Jinong	Capture breast cancer early: Detecting ductal carcinoma in situ by serum proteomic analysis using ProteinChip®174; arrays and SELDI-mass spectrometry			√			

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
KOMEN			√	√	Children's Hospital Boston	Orkin, Stuart	Mouse Models of Secretory Breast Carcinoma (SBC)	√					
KOMEN			√	√	The University of Western Australia	Saunders, Christobel	The Relationship Between Breast Cancer and Pregnancy: A Study of the Diagnosis, Management and Outcomes in Young Breast Cancer Patients and Their Families				√	√	
KOMEN			√	√	The Research Foundation of SUNY on behalf of SUNY	Schmitz, Christoph	Lesion Discrimination in Young Women by Functional Optical Tomography			√			
KOMEN		√	√	√	Wake Forest University School of Medicine	Tallant, Elisabeth	Prevention of Breast Cancer Cell Growth by Angiotensin-(1-7)				√		
LAF				√	Lankenau Institute for Medical Research	Alexander Muller, PhD	Primordial Germ Cell Tumor Susceptibility at the Pgct1 Locus	√					
LAF	√				The University of Texas, MD Anderson Cancer Center	Andrea Canada, PhD	A Pilot Intervention to Enhance Psychosexual Development in Adolescents and Young Adults with Cancer					√	
LAF				√	Dana-Farber Cancer Institute	Andrea K. Ng, MD MPH	Breast MRI Screening in Female Survivors of Hodgkin's Disease				√		
LAF			√	√	Dana-Farber Cancer Institute	Ann Partridge, MD MPH	Ovarian Reserve in Young Women after Chemotherapy for Early Breast Cancer				√		
LAF		√			Children's Hospital of Los Angeles	Aura Kuperberg	Team Building and Leadership Training Sailing Retreat					√	
LAF		√	√	√	The Miriam Hospital	Bernardine Pinto, PhD	Translating Research-based Physical Activity Promotion Among Young Cancer Survivors: A Pilot Study					√	
LAF		√			The Ulman Cancer Fund for Young Adults	Brock Yetso	Bearing Witness to Cancer					√	
LAF		√			The Ulman Cancer Fund for Young Adults	Brock Yetso	No Way! It Can't Be: A Guidebook for Young Adults Facing Cancer					√	

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
LAF			√		The Ulman Cancer Fund for Young Adults	Brock Yetso	CancerCore, A Young Adult Patient Navigator Program					√	
LAF		√			Gilda's Club Quad Cities	Claudia Robinson	Ambassadors Club					√	
LAF		√	√		University of Connecticut	Crystal Park, PhD	Predicting and Understanding Positive Life Changes in Young Adult Cancer Survivors	√				√	
LAF		√			Special Love, Inc.	David Smith	Fantastic Friends Weekened					√	
LAF			√		Tomorrow's Children's Fund	Dayna Cavanaugh	Cure and Beyond					√	
LAF	√				Columbia University	Debra J. Wolgemuth, PhD	Role of the A-type Cyclins in the Distinct Classes of Testicular Tumors	√					
LAF		√			The University of Texas Southwestern Medical Center at Dallas	Diego Castrillon, MD, PhD	Genetic Models of Testicular Cancer	√					
LAF	√				The University of Texas, MD Anderson Cancer Center	Ellen Gritz, PhD	Neurocognitive Function and Quality of Life after Testicular Cancer Treatment			√			
LAF	√				Planet Cancer	Heidi Adams	Planet Cancer					√	
LAF		√			Columbia University	Howard Lieberman, PhD	Genetic Control of Testicular Cancer	√					
LAF				√	The University of Texas Southwestern Medical Center at Dallas	James Amatruda, MD, PhD	A Novel Zebrafish Genetic Model of Testicular Cancer	√					
LAF	√	√			Stanford University	James Brooks, MD	Gene Expression Profiles of Testicular Tumors	√					

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
LAF				√	Sloan-Kettering Institute for Cancer Research	James Korkola, PhD	Genomic Change in Germ Cell Tumors: Target Genes and Clinical Relevance	√					
LAF	√				The Institute of Cancer Research Royal Cancer Hospital	Janet Shipley, PhD	Identificaion of Genes Involved with Testicular Cancer	√					
LAF				√	Sloan-Kettering Institute for Cancer Research	Jeanne Carter, PH.D	Cross Sectional Study of Psychosexual Impact of Cancer-Related Infertility			√		√	
LAF		√			James Whitcomb Riley Hospital for Children	Jennifer Harley	Riley Children's Cancer Center Teen Retreat					√	
LAF		√			Dana- Farber Cancer Institute	Julianne Pistorino	Transitions to Independence					√	
LAF				√	Stanford University Medical Center	Julien Sage, PhD	Mechanisms of Cancer Initiation in Testicular Germ Cell Tumors	√					
LAF				√	Dana-Farber Cancer Institute	K. Viswanath, PhD	Disparities in Information Seeking Among Cancer Survivors	√				√	
LAF	√	√			University of Pennsylvania, School of Medicine	Katherine L. Nathanson, MD	Variants in Androgen Metabolism Genes and Testicular Cancer Susceptibility	√					
LAF	√	√			The University of Texas Southwestern Medical Center at Dallas	Kevin C. Oeffinger, MD; Laura Snell, MPH	Feasibility Study for Project VISION: A Virtual Center for Survivors					√	
LAF		√			School of Architecture, University of Arkansas-Fayetteville	Laura Terry	Camp Aldersgate Design/Build Program					√	
LAF			√		Thomas Jefferson University	Lora Rhodes, LSW	Navigating the New Normal					√	

Table 3. AYA0 Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
LAF			√		University of Michigan	Marcia Leonard, RN, NP	The Fertility Counseling and Gamete Cryopreservation Program					√	
LAF	√				University of Dayton	Marie-Claude Hofmann, PhD	Gene Expression Profile of Experimental Seminoma Compared to its Normal Cellular Counterpart	√					
LAF	√				Children's Hospital of Philadelphia	Mary Rourke, Ph.D	Promoting the Successful Adaptation of Young Adult Cancer Survivors: An Intervention Study				√	√	
LAF			√		Creative Healing Project	Matthew Brenner	Listen Up!					√	
LAF		√			Super Sibs!	Melanie Goldish	SuperSibs! Journals					√	
LAF		√	√		Centre Regional Francois Baclesse, Service de Recherche Clinique	Michel Henry-Amar, MD, PhD; John Raemaekers, MD, PhD	Long-Term Survivorship of Hodgkin's Lymphoma Patients Enrolled in Successive Prospective EORTC Lymphoma Group Trials			√			
LAF	√				The Periwinkle Foundation	Pat Prior Sorrells	Camp Periwinkle					√	
LAF	√				University of California, San Francisco	Paul Turek, MD	Genetic Comparison of the Normal, Infertile, and Cancerous Human Testis	√					
LAF		√			Memorial Sloan-Kettering Cancer Center	Penny Damaskos	Post-Treatment Resource Program					√	
LAF			√	√	Dartmouth College	Raine Riggs, PhD	Sleep and Cognitive Functioning in Breast Cancer Survivors			√			
LAF		√	√	√	Brigham & Women's Hospital	Robert Blelloch, MD, PhD	Reprogramming the Embryonic Cancer Cell	√					

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
LAF		√			Camp Sunshine	Sally Hale	Outdoor Challenge course					√	
LAF		√	√	√	Dana-Farber Cancer Institute	Sharon Bober, PhD	Breast Cancer Risk After Hodgkin's Disease: Development of an Educational Intervention for Young Female Survivors	√				√	
LAF				√	Beckman Research Institute of the City of Hope	Smita Bhatia, MD, MPH	Key Adverse Events after Childhood Cancer	√					
LAF	√	√	√		The Norwegian Radium Hospital	Sophie D. Fossa, Prof.DR.Med	Post-Treatment Fertility in Young Adult Former Cancer Patients		√				
LAF				√	University of California, San Francisco	Stacey Hart, PhD	Colorectal Cancer: Distress, Couple Dynamics and Psychological Adjustment			√		√	
LAF			√	√	University of Washington	Stephen Schwartz, PhD	Pluripotency Genes and TCGG Risk: SNP Discovery and Association Testing	√					
LAF		√			Children's Oncology Camp Foundation	Stu Kaplan, MD	Young Adult Survivors Conference					√	
LAF			√	√	University of Southern California, Keck School of Medicine	Sue Ellen Martin, MD, PhD	Creation of The Germ Cell Tumor and Tissue Bank Resource			√			
LAF			√		The Minnie Pearl Cancer Foundation	Susan Gregory, MSW	Young Adults with Cancer Retreat					√	
LAF				√	Baylor College of Medicine	Thomas Zwaka, MD, PhD	Embryonic Stem Cells as a Novel Model for Germ Cell Tumor Development	√					
LAF		√			American Cancer Society, Hawaii Pacific Inc.	Tina Clothier	Grow With Strength					√	
LAF					University of Maryland School of Medicine	Toni Antalis, PhD	The Role of Testisin, a Putative Type II Tumor Suppressor Gene, in the Testis	√					

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
LAF			√	√	The Scripps Research Institute	Vasco Liberal, PhD	The Involvement of Cyclin E in Testicular Cancer Development and Progression	√					
LAF			√	√	Beckman Research Institute of the City of Hope	Virginia Sun, RN, MSN	Symptom Clusters and Quality of Life in Chemotherapy-induced Peripheral Neuropathy			√			
LAF			√	√	University of California, San Diego	Wayne Bardwell, PhD, MBA	Trajectory of Depression, Quality of Life and Diet Adherence in Breast Cancer	√		√			
NCI	√	√	√	√	National Childhood Cancer Foundation	Adamson, Peter C	Children's Oncology Group Phase 1/Pilot Consortium			√			
NCI			√	√	Mount Sinai School of Medicine of NYU	Ambrosone, Christine B.	Race & Risk Factors for Early/Aggressive Breast Cancer	√					
NCI	√				National Cancer Institute	Ambs, Stefan	Identification of Allele Variant Genes That Are Risk Factors for Human Breast and Prostate Cancer	√		√			
NCI			√		National Cancer Institute	Ambs, Stefan	The Molecular Profile of Inflammatory Breast Cancer			√			
NCI			√	√	University of Texas Hlth Sci Ctr San Ant	Baillargeon, Jacques G	Obesity in Hispanic Children with Leukemia	√					
NCI	√	√	√	√	Mount Sinai School of Medicine of NYU	Bernstein, Jonine L	Interaction of Radiation, BRCA1/2, and Breast Cancer	√					
NCI				√	Sloan-Kettering Institute for Cancer Res	Bernstein, Jonine Lisa	Breast Cancer, Radiation and the Atm-CHEK2 Pathway	√					
NCI	√	√	√	√	Mayo Clinic Coll of Medicine, Rochester	Boardman, Lisa A	Molecular Basis of Young Onset Colorectal Cancer			√			
NCI				√	Vanderbilt University	Boice, John Dunning	Genetic Consequences of Therapies for Cancer						√

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
NCI	√	√	√		National Cancer Institute	Brinton, Louise	Hormone-Related Cancers						√
NCI		√	√		Columbia University Health Sciences	Cairo, Mitchell S.	First INT'l Symposium on Childhood and Adolescent NHL				√		
NCI		√	√	√	Sloan-Kettering Institute for Cancer Res	Cheung, Irene Y	Molecular Detection of Occult Neuroblastoma			√			
NCI			√	√	University of Southern California	Cortessis, Victoria K	A Genetic Linkage Study of Testicular Cancer	√					
NCI			√	√	University of Southern California	Cozen, Wendy	Risk Factors for Young Adult Hodgkin'S Disease in Twins						√
NCI			√	√	Virginia Commonwealth University	Danish, Steven J	A Bridge to Better Health: Developing Adolescent Health		√				
NCI			√	√	Dana-Farber Cancer Institute	Davis, Ian J	Mit Transcription Factor Family in Pediatric Solid Tumor	√					
NCI		√	√	√	University of Iowa	Dennis, Leslie K	Tanning Bed Use Among Ui Students		√				
NCI	√				National Cancer Institute	Devesa, Susan S	Descriptive Studies						√
NCI				√	St. Jude Children's Research Hospital	Dome, Jeffrey S	Telomere Maintenance Mechanisms in Human Osteosarcoma	√					
NCI				√	Fox Chase Cancer Center	Dorgan, Joanne F	Adolescent Diet, Hormones & Breast Cancer Susceptibility	√					
NCI		√	√	√	University of Colorado Hlth Sciences Ctr	Eckhardt, S Gail	Overcoming Age-Dependent Barriers to Early Phase Trials			√			

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
NCI			√	√	Vanderbilt University	Eid, Josiane E	B-Catenin Regulation by the Proto-Oncoprotein Syt	√					
NCI		√	√	√	Vanderbilt University	Eid, Josiane E	Cell Adhesion Control by the Proto-Oncoprotein Syt	√					
NCI			√	√	Scott and White Memorial Hospital	Elkins, Gary R	Hypnosis for Hot Flashes in Breast Cancer Survivors				√		
NCI				√	University of Kansas Medical Center	Fabian, Carol J	Flaxseed Lignan for Breast Cancer Chemoprevention			√			
NCI		√	√		National Cancer Institute	Fine, Howard	Developmental Therapeutics for Improved Treatment of Tumors of the Central Nervous System in Children and Adults			√			
NCI	√	√	√	√	Brigham and Women's Hospital	French, Christopher A	T(15;19) in Aggressive Pediatric Carcinoma	√					
NCI				√	Fred Hutchinson Cancer Research Center	Friedman, Debra L	Social & Physical Activity of Childhood Cancer Survivors					√	
NCI		√			National Cancer Institute	Gail, Mitchell	Epidemiologic Field Studies			√			
NCI	√				National Cancer Institute	Gail, Mitchell	Risk Assessment			√			
NCI	√		√		National Cancer Institute	Gause, Barry L.	Medical Oncology Fellowship Office		√		√		
NCI		√	√	√	University of Chicago	Gehlert, Sarah	Center for Interdisciplinary Health Disparities Research	√					
NCI	√	√	√		University of Arizona	Giuliano, Anna R	HPV Methylation: A Biomarker of Cervical Lesion Progress						√

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
NCI			√	√	Northern California Cancer Center	Glaser, Sally L	Body Size, Physical Activity, and Hodgkin'S Disease Risk			√			
NCI	√	√	√	√	Roswell Park Cancer Institute Corp	Green, Daniel M	Long-Term Complications of Children/Adolescents & Cancer						√
NCI	√	√			National Cancer Institute	Greene, Mark	Pharmacogenetic Determinants of Outcomes Following Treatment for Cancer	√					
NCI	√	√			University of Vermont & St Agric College	Grossman, Cynthia	Mother-Daughter Communication About Breast Cancer Risk	√	√				
NCI		√	√	√	University of North Carolina Chapel Hill	Gulley, Margaret L	Development of Assays to Detect EBV in Breast Cancers	√					
NCI	√	√	√	√	Massachusetts General Hospital	Haber, Daniel A.	Targets of Ewing Sarcoma-Wilms Tumor 1 Oncoprotein	√					
NCI			√	√	World Hlth Org Intl Agcy Res on Cancer	Hashibe, Mia	International Head and Neck Cancer Consortium						√
NCI		√	√	√	State University of New York at Buffalo	Hastrup, Janice L	Beliefs About Gene-Behavior Interactions in Disease		√				
NCI		√	√		National Cancer Institute	Helman, Lee J.	Solid Tumors			√			
NCI	√	√	√	√	Columbia University Health Sciences	Hershman, Dawn	Osteoporosis Prevention in Early Stage Breast Cancer				√		
NCI	√	√	√	√	University of Florida	Jiang, Huabei	Optical Imaging of Breast Cancer			√			
NCI	√	√	√		National Cancer Institute	Kaye, Frederic J.	Mechanisms of Oncogene Action in Tumorigenesis	√					

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
NCI			√	√	Children's Hospital of Philadelphia	Kazak, Anne E	Psychological Outcome in Childhood Cancer Survivors					√	
NCI			√	√	Children's Hospital of Philadelphia	Kazak, Anne E	Psychological Outcome in Childhood Cancer Survivors					√	
NCI				√	Northern California Cancer Center	Keegan, Theresa H M	Socioeconomic Disparities in Survival After Hodgkin Lym*	√					
NCI			√		National Cancer Institute	Khan, Javed	Gene Expression Profiling of Normal Tissues			√			
NCI			√	√	Sloan-Kettering Institute for Cancer Res	Koutcher, Jason A	Dynamic Magnetic Resonance Imaging of Bone Tumors	√					
NCI	√	√	√		University of Washington	Koutsky, Laura	HPV Testing--Self-Collected Samples for Cervical Cancer	√					
NCI			√	√	University of Washington	Koutsky, Laura A	RNA Analysis of HPV Viral Loads	√					
NCI		√	√	√	Fred Hutchinson Cancer Research Center	Lampe, Johanna W	Breast and Bone Density: Impact of Colonic Environment	√					
NCI	√	√			National Cancer Institute	Land, Land	Studies of Atomic Bomb Survivors						√
NCI			√	√	Baylor College of Medicine	Lau, Ching	Genomic Profile-Based Prognostic Markers for Ependymoma	√					
NCI	√	√	√		Baylor College of Medicine	Lau, Ching C	Genomic Profile-Based Prognostic Markers for Ependymoma	√					
NCI		√	√	√	Fred Hutchinson Cancer Research Center	Li, Christopher I	C-ERBB-2 and Risk of Contralateral Breast Cancer	√					

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
NCI	√	√			National Cancer Institute	Linnet, Martha	Studies of Medical Radiation and Other Therapeutic Agents						√
NCI	√	√			National Cancer Institute	Linnet, Martha	Studies of Non-Ionizing Radiation-Related Cancer						√
NCI			√	√	Ohio State University	Love, Richard R	Luteal Adjuvant Oophorectomy in Vietnamese Breast Cancer			√	√		
NCI		√	√	√	University of Texas Medical Br Galveston	Lu, Lee-Jane W	Mammographic Density and Soy Isoflavones				√		
NCI	√				National Cancer Institute	Lubin, Jay H	Studies of Environmental and Occupational Exposures						√
NCI			√	√	University of Alabama at Birmingham	Madan-Swain, Avi	Problemsolving with Parents of Pediatric Cancer Survivor					√	
NCI	√	√	√		Fred Hutchinson Cancer Research Center	Madeleine, Margaret	Chlamydia Trachomatis and Cervical Cancer	√		√			
NCI			√	√	Mayo Clinic Coll of Medicine, Rochester	Maran, Avudaiappan	Estrogen Metabolites in the Control of Osteosarcoma	√					
NCI		√	√	√	University of Hawaii at Manoa	Maskarinec, Gertraud	Breast Density, IGF-I, & Prolactin, in Four Populations			√			
NCI		√	√	√	University of Texas MD Anderson Can Ctr	Matin, Angabin	Testicular Cancer Susceptibility Genes on Mouse Chr 19.	√					
NCI			√	√	Italian National Cancer Institute	Muti, Paola C	Endogenous Hormones and Premenopausal Breast Cancer Risk			√			
NCI			√	√	University of Iowa	O'Dorisio, M Sue	Academic Public Private Partnership Program			√			

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
NCI			√	√	Sloan-Kettering Institute for Cancer Res	Oeffinger, Kevin Charles	Mammography and High-Risk Survivors of Pediatric Cancer			√			
NCI	√	√	√		Brigham and Women's Hospital	Ogunyemi, Omolola I	Breast Cancer Risk Assessment with Bayesian Networks			√			
NCI				√	Johns Hopkins University	Olivi, Alessandro	Enhancement of Brain Tumor Immunotherapy by FAS-L Rnai						√
NCI	√	√	√	√	University of Chicago	Olopade, Olufunmilayo I	Genetics of Breast Cancer in Blacks	√					
NCI				√	Sloan-Kettering Institute for Cancer Res	O'Reilly, Richard J	Molecular Targeting of Developmental Cancers in Children	√					
NCI		√	√	√	Boston University Medical Campus	Palmer, Julie R	Gene Polymorphisms in Relation to Cancer in Black Women	√					
NCI	√	√	√	√	National Childhood Cancer Foundation	Pollock, Brad H.	Community Clinical Oncology Program			√	√		
NCI	√	√	√	√	University of Missouri-Columbia	Sauter, Edward R	Protein Profiling in Nipple Aspirate Fluid			√			
NCI			√	√	University of Missouri Columbia	Sauter, Edward R	Altered Breast Methylation After Low/Hi Dose Isoflavones						
NCI		√	√	√	University of Texas MD Anderson Can Ctr	Schover, Leslie R	Spirit:Reproductive Peer Counseling for Breast Cancer		√				
NCI			√	√	University of Washington	Sharar, Sam R	Virtual Reality Analgesia for Procedural Cancer Pain						√
NCI				√	University of Washington	Silber, John R	AP Endo as a Predictor of Response to Glioma Therapy						√

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
NCI		√	√	√	Medical University of South Carolina	Sutkowski, Natalie A	Role of Herv-K18 Superantigen in EBV Lymphomagenesis						√
NCI			√		National Cancer Institute	Swain, Sandra M.	Adjuvant Therapy of Breast Cancer			√			
NCI		√			National Cancer Institute	Swain, Sandra M.	Developmental Therapeutics			√			
NCI				√	Thomas Jefferson University	Thakur, Mathew L	PET Imaging of Breast Cancer Using Oncogene Expression			√			
NCI		√	√	√	University of Toronto	Thompson, Lilian U	Interactive Effects of Flaxseed and Tamoxifen in Breast*				√		
NCI			√	√	University of Texas SW MED Ctr/Dallas	Tomlinson, Gail E	Serum Markers /Angiogenesis in Von Hippel-Lindau Disease			√			
NCI				√	Children'S Hospital Los Angeles	Triche, Timothy J	Diagnostic and Prognostic Sarcoma Signatures	√					
NCI	√	√			University of South Florida	Trotti, Andrew	The Late Effects of Normal Tissue (LENT) IV Conference			√	√		
NCI			√		National Cancer Institute	Tsokos, Maria	Regulation of apoptosis in Ewing's sarcoma and neuroblastoma	√					
NCI		√	√	√	New York University School of Medicine	Turnbull, Daniel H	Functional and Molecular MRI of Mouse Brain Tumors	√					
NCI		√	√	√	Stanford University	Whittemore, Alice S	Breast Cancer Risk Modifiers in BRCA Mutation Carriers			√			
NCI			√		National Cancer Institute	Widemann, Brigitte Charlotte	Clinical development of novel drugs for children with cancer and neurofibromatosis type I	√		√			

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
NCI		√	√	√	Medical University of South Carolina	Sutkowski, Natalie A	Role of Herv-K18 Superantigen in EBV Lymphomagenesis						√
NCI			√		National Cancer Institute	Swain, Sandra M.	Adjuvant Therapy of Breast Cancer			√			
NCI		√			National Cancer Institute	Swain, Sandra M.	Developmental Therapeutics			√			
NCI				√	Thomas Jefferson University	Thakur, Mathew L	PET Imaging of Breast Cancer Using Oncogene Expression			√			
NCI		√	√	√	University of Toronto	Thompson, Lilian U	Interactive Effects of Flaxseed and Tamoxifen in Breast*				√		
NCI			√	√	University of Texas SW MED Ctr/Dallas	Tomlinson, Gail E	Serum Markers /Angiogenesis in Von Hippel-Lindau Disease			√			
NCI				√	Children'S Hospital Los Angeles	Triche, Timothy J	Diagnostic and Prognostic Sarcoma Signatures	√					
NCI	√	√			University of South Florida	Trotti, Andrew	The Late Effects of Normal Tissue (LENT) IV Conference			√	√		
NCI			√		National Cancer Institute	Tsokos, Maria	Regulation of apoptosis in Ewing's sarcoma and neuroblastoma	√					
NCI		√	√	√	New York University School of Medicine	Turnbull, Daniel H	Functional and Molecular MRI of Mouse Brain Tumors	√					
NCI		√	√	√	Stanford University	Whittemore, Alice S	Breast Cancer Risk Modifiers in BRCA Mutation Carriers			√			
NCI			√		National Cancer Institute	Widemann, Brigitte Charlotte	Clinical development of novel drugs for children with cancer and neurofibromatosis type I	√		√			

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
NCI		√	√	√	Northwestern University	Wilson, Regina	Role of the E1^E4 Proteins in the Life Cycle of Hpv's						√
NCI	√	√	√	√	University of Texas MD Anderson Can Ctr	Worth, Laura L	IL-12 Gene Therapy for Metastatic Osteosarcoma						√
NCI				√	Panorama Research, Inc.	Wright, Susan C	Antibody Therapy Targeting a Novel Neuroblastoma Antigen						√
NCI	√	√	√		Johns Hopkins University	Yager, James	Mitochondrial Sod & Breast Cancer Risk-Mechanism	√					
NCI		√	√	√	University of Southern California	Zebrack, Bradley J	Quality of Life Assessment in Childhood Cancer Survivors	√					
NCRI		√	√	√	Centre for Reproductive Biology	Anderson, R A	Protection of male germ cell integrity from chemo and radiotherapy						√
NCRI			√	√	University of Bradford	Bibby, Michael	Feasibility of utilizing the hollow fibre assay to investigate and predict therapeutic response in tumours of the Ewing's sarcoma family (ESFT's)	√					
NCRI	√	√	√	√	University College London	Boshoff, Chris	Molecular signatures of sarcoma	√					
NCRI	√	√	√	√	University of Leicester	Chairman, UKCCSG	Euro Ewing 99 (Biological Studies)	√		√			
NCRI	√	√	√	√	University of Leicester	Chairman, UKCCSG	Ewing tumour studies 1999			√			
NCRI		√	√	√	University of Leicester	Chairman, UKCCSG	PNET 4: Perspective Randomised Control Trial of Hyperfractionated vs Conventionally Fractionated Radiotherapy in Standard Risk Medulloblastoma			√			

Table 3. AYA0 Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
NCRI			√	√	International Agency for Research on Cancer (IARC)	Corbex, M	Multicentre study of genetic and environmental determinants of Nasopharyngeal Carcinoma in the endemic region of North Africa						√
NCRI		√	√	√	University of Southampton	Corner, Jessica	The Macmillan Listening Study	√			√		
NCRI			√	√	Queen Mary, University of London	Cuzick, Jack	Epidemiology Mathematics & Statistics Group				√		
NCRI	√	√	√		The University of Birmingham	Delecluse, Henri-Jacques	A study of the mechanisms governing Epstein-Barr virus (EBV) entry and infection of non-B cells using tagged viral recombinants: Consequences for the pathogenesis of EBV-associated tumorigenesis						√
NCRI	√	√	√		London School of Hygiene and Tropical Medicine	dos Santos Silva, Isabel	Insulin-like growth factors (IGFs), oestrogens, mammographic density and breast cancer risk in premenopausal women			√			
NCRI		√	√	√	Queen Mary, University of London	Duffy, Stephen	Cancer Screening and Aetiology Group				√		
NCRI	√	√	√	√	Institute of Cancer Research	Houlston, Richard	CORGI study for identifying new, colorectal tumour genes using linkage analysis	√					
NCRI	√	√	√		University of Oxford	Macaulay, Val	The Type - 1 insulin-like growth factor receptor as target for anticancer therapy						√
NCRI			√	√	University of Edinburgh	Melton, D	The importance of cell cycle control and DNA repair gene polymorphisms in genetic predisposition to melanoma	√					
NCRI	√	√	√		Western General Hospital	Melton, D W	The importance of nucleotide excision repair gene polymorphisms in genetic predisposition to melanoma	√					
NCRI		√	√	√	MRC Clinical Trials Unit	Parmar, M K	Clinical trials in osteosarcoma and soft tissue sarcoma			√			

Table 3. AYAO Research Portfolio FY 2002–FY 2005 (cont.)

Funder	FY 02	FY 03	FY 04	FY 05	Institution	PI	Title (Click to View Abstract)	P R G 1	P R G 2	P R G 3	P R G 4	P R G 5	N o n e
NCRI		√	√	√	Centre for Reproductive Biology	Sharpe, R M	Androgen-oestrogen interactions in regulation of germ cell maturation						√
NCRI		√	√	√	MRC Clinical Trials Unit	Stenning, S P	Clinical trials in lymphoma			√			
NCRI	√	√			St George's Hospital	Wilson, J	Promoting testicular self-examination and awareness amongst young men with learning disabilities		√				
ONS			√	√	Regis University	Cullen, Patricia	Functional Status and Quality of Life in Children with Medulloblastoma			√	√	√	
ONS			√	√	Baylor College of Medicine	Hockenberry, Marilyn	Symptom Clusters in Children/Teens on Cisplatin or Ifosfamide			√		√	
ONS				√	Yale University	Knobf, M. Tish	Cognitive Function in Women with Drug or Surgery Induced Menopause			√		√	
ONS			√	√	Dana Farber Cancer Institute	Roper, Kristin	Quality of Life After Treatment for Hodgkins Disease	√				√	
ONS			√	√	Baylor College of Medicine	Simon, Cara	Pediatric Oncology Nursing Research Mentorship				√		

The following clinical trials, funded by NCI, were also identified in the keyword searches. While these trials are relevant to AYAO, they are by no means the only clinical trials that address cancers in this population. There are approximately 700 additional clinical trials that recruit patients in the 15–39 year age range. Those trials are listed in a separate document.

Table 4. AYAO Clinical Trials Retrieved by Keyword Searches

Funder	Title (Click to View Abstract)	PRG 1	PRG 2	PRG 3	PRG 4	PRG 5	None
NCI	Phase I Study of Pemetrexed Disodium in Children and Adolescents With Recurrent Solid Tumors			√			
NCI	Phase I Study of the Effect of Tamoxifen on Breast Density in Premenopausal Women With Breast Cancer or at High Risk for Breast Cancer			√			
NCI	Phase II Pilot Chemoprevention Study of Deslorelin in Combination With Low-Dose Add-Back Estradiol and Testosterone in Premenopausal Women With or Without a BRCA Gene Mutation Who Are at High Risk for Breast Cancer			√			
NCI	Phase II Randomized Study of Triptorelin for Preserving Ovarian Function in Premenopausal Women With Early-Stage Operable Breast Cancer Undergoing Adjuvant or Neoadjuvant Systemic Chemotherapy			√			
NCI	Phase III Randomized Study of Four Chemotherapy Regimens in Children or Adolescents With Newly Diagnosed Disseminated Lymphoblastic Lymphoma or Localized Lymphoblastic Lymphoma			√			
NCI	Phase III Randomized Study of Ovarian Function Suppression in Combination With Tamoxifen Versus Ovarian Function Suppression in Combination With Exemestane Versus Tamoxifen Alone in Premenopausal Women With Endocrine-Responsive Breast Cancer			√			
NCI	Phase III Randomized Study of Ovarian-Function Suppression and Tamoxifen or Exemestane With Versus Without Adjuvant Chemotherapy in Premenopausal Women With Endocrine-Responsive Resected Breast Cancer			√			
NCI	Phase III Randomized Study of Risedronate For Prevention of Bone Loss in Premenopausal Women Undergoing Chemotherapy For Primary Breast Cancer			√			
NCI	Phase III Randomized Study of Triptorelin and Exemestane Versus Triptorelin and Tamoxifen in Premenopausal Women With Endocrine-Responsive Breast Cancer			√			
NCI	Phase III Randomized Study of Zoledronate for the Prevention of Bone Loss in Premenopausal Women Receiving Adjuvant Chemotherapy For Early Stage Breast Cancer			√			

APPENDIX

Glossary



AAP	American Academy of Pediatrics
ACoS	American College of Surgeons
ACS	American Cancer Society
AHRQ	Agency for Healthcare Research and Quality
ALL	Acute lymphoblastic leukemia
ASCO	American Society of Clinical Oncology
AYA	Adolescent and young adult
AYAO	Adolescent and young adult oncology
CBCRP	California Breast Cancer Research Program
CDMRP	Congressionally Directed Medical Research Programs
CEU	Continuing Education Unit
CME	Continuing Medical Education
CTEP	Cancer Therapy Evaluation Program
FDA	Food and Drug Administration
GIST	Gastrointestinal stromal tumor
HINTS	Health Information National Trends Survey
IOM	Institute of Medicine
IRB	Institutional review board
LAF	Lance Armstrong Foundation
NCI	National Cancer Institute
NCR	National Cancer Research Institute (United Kingdom)
NICE	National Institute for Health and Clinical Excellence
NIH	National Institute of Health
ONS	Oncology Nursing Society
PA	Program announcement
PRG	Progress Review Group
RFA	Request for applications
SEER	Surveillance Epidemiology and End Results
SOC	Standards of care

