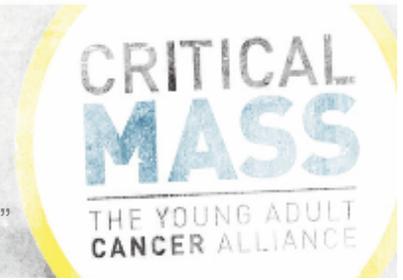


# PUBLIC POLICY FACT SHEET

November 2016

“Eliminating barriers adolescent & young adult cancer patients face to survive & thrive”



**Critical Mass: The Young Adult Cancer Alliance** brings together a diverse group of stakeholders – patients, advocates, clinicians, researchers, and representatives from government organizations and professional societies – who have all seen first-hand the devastation cancer can cause in the life of a young person.

Through collaboration, knowledge-sharing, and raising our voices together, **Critical Mass breaks down barriers and promotes collaboration** on initiatives that can change the way adolescent and young adult cancer patients and survivors receive care.

**Critical Mass is the sole unifying voice** representing the 70,000 adolescent and young adult cancer patients diagnosed each year in the United States; clarify and quantify the barriers facing 15-39 year olds with cancer and working with policy makers to develop strategies to overcome them.

Critical Mass is a 501(c)3 organization. Donations are tax deductible to the fullest extent allowed by law.

For more information, contact:

Kate Yglesias Houghton  
President & CEO  
kate.houghton@criticalmass.org  
@heycriticalmass

## OUR CANCER IS DIFFERENT.<sup>1</sup>

In 2006, the LIVESTRONG Young Adult Alliance (which would become Critical Mass: The Young Adult Cancer Alliance in 2012) was formed to serve as the catalyst to a national movement on behalf of young adults with cancer.

At the time, research showed that nearly **70,000 people aged 15 to 39 were diagnosed with cancer each year**, which was approximately **eight times more than children under 15**. It was the most common cause of disease-related death in this age group.

With the help of LIVESTRONG, the National Institutes of Health (NIH), and National Cancer Institute (NCI), the Adolescent and Young Adult Oncology Progress Review Group was formed and their work led to a series of reports that focused not only on the adolescent and young adult cancer problem but also steps for addressing their needs.

The progress review group identified two basic problems with adolescent and young adult care:

1. **Age was not taken into account** and,
2. **Cancer care and delivery did not meet the 15-39-year-old patient's needs.**

## WHY AGE MATTERS

**Biology.** Between 15 and 39, patients have passed puberty but have not yet experienced significant health care issues such as diabetes, heart disease, or menopause. In addition, **adolescents and young adults are more susceptible to certain types of cancers and more likely to be diagnosed with different subtypes than other groups**. This can impact treatment effectiveness and care decisions. Genetic factors are also important to understand when treating and caring for adolescents and young adult cancer patients. Increase research in this area as well as the availability of appropriate genetic counseling and testing in this population is critical.

**Location.** This same age group - 15 to 39 year olds - is also a highly mobile demographic with patients moving for school or career opportunities. This can lead to **inconsistent medical care and an irregular follow-up schedule** once the patient leaves home. For college-aged patients, there is little to no continuity of care. It is not uncommon for a student to see a number of different health care providers at a college or community health



clinic. In addition, most adolescents and young adults are treated in community-based hospitals rather than in cancer centers where most cancer clinical trials are conducted. Dr. Archie Bleyer, a founder of the adolescent and young adult cancer movement wrote in the April 2016 edition of the Journal of Oncology Practice that clinical trial enrollments for 15-39 year old patients in the US are “disappointing... The adolescent and young adult age group has the lowest portion of patients with cancer entered into clinical trials, in part because this age group has the lowest proportion of patients referred to academic medical centers.” This can mean **less access to cutting-edge research and care.**<sup>ii</sup>

**Chronic Conditions.** Few 15 to 39 year olds have developed comorbidities which may influence oncology-related decisions.

**Identity.** Older adolescent cancer patients are undergoing life transitions associated with late adolescence and feel out of place in a pediatric setting. At a time when the average 16 or 17-year-old is making the decision about where to go to college, many of their fellow patients may not have even started elementary school. The same is true for adolescents and young adults treated in adult settings where they have more in common with their nursing staff than fellow patients. In addition, adolescent and young adult compliance with **medications and procedures can become a battleground as the young patient asserts his or her independence**; in any other circumstances, this would be considered a perfectly normal developmental response, but in this case is potentially very problematic as it can interfere with treatment adherence and self-care

**Caregivers.** This is all further complicated by who is included in the process of making medical decisions: patient or parent, parent or spouse, next of kin or life partner, etc. Unlike older patients with cancer, **most caregivers for adolescent and young adult cancer patients are parents.** The LIVESTRONG online survey found that 82 percent of respondents reported that their parents were their primary caregivers; by contrast, 36 percent of patients between 40 and 59 and 3 percent older than 60 reported that their parents were their primary caregivers. About half of all adolescents and young adults surveyed reported that their **primary caregiver had to make accommodations (including taking time off work) for a period of at least two months.** The inclusion of parents and other family members or caregivers in the communication channels is paramount.

## WHY SERVICES MATTER

**Diagnosis.** Cancer symptoms are often missed in an adolescent or young adult’s original diagnosis. Many **providers do not initially consider cancer as the cause of presenting symptoms.** Older adolescents and young adults with pediatric diagnoses may often be seen by doctors in adult cancer centers with little to no experience in their more rare diseases (e.g. sarcoma, which is a rare cancer more common in children).

**Treatment.** Pediatric and adult **protocols are often different** and it is not always clear for adolescent and young adult patients which treatment plan should be used. In addition, some published research show that adolescents and young adults have better outcomes using pediatric protocols such as lymphomas and ALL leukemia. However, their use is not mandatory.



**Referrals.** Adolescents and young adults with cancer may have at first gone to their internist, family physician, gynecologist, an emergency room specialist, dermatologist, gastroenterologist, neurologist, or another specialist who all have very different referral patterns and relationships within the general medical community. An adolescent or young adult patient may be referred to a local hospital that may have little experience treating their specific disease or may admit them to a pediatric unit where they do have experience. Bottom line: **referrals are inconsistent**, which is a challenge when collecting information about adolescent and young adult cancers and treatment plans.

**Psychosocial Support.** Young adults are also at a unique stage in their emotional, cognitive, and social development, which cancer disrupts. This population faces many short- and long-term health and psychosocial issues, such as difficulty re-entering school or the workforce; developing mental health disorders; and approaching intimate or personal relationships. Survivors of adolescent and young adult cancers are also at **increased risk for psychiatric conditions such as anxiety, depression, substance abuse, and suicide**. For many, their diagnosis is often the first time have confronted mortality. The Adolescent and Young Adult HOPE Survey found that 12 months after their cancer diagnosis, 41 percent of adolescent and young adult cancer survivors reported an unmet need for counseling and other forms of psychological support.

**Insurance.** Cancer care, no matter the age, is expensive and recent research shows a direct correlation between a diagnosis and filing for bankruptcy. However, 15-39-year-old patients are **more likely than any other age group to be uninsured** which carries an even larger financial burden. The Samfund found that “[young adults] are more likely than elderly survivors to report financial barriers to medical care, and are also 56–67% more likely than age-matched peers to forego medical care due to its cost.”<sup>iii</sup>

**Palliative & End of Life Care.** Palliative and end of life care options are generally **geared to younger or older people**. Hospital staff are often not experienced in the unique needs of the adolescent and young adult patient and there is nothing designed specifically to address their needs.

**Care Transitions.** And last, but definitely not least, adolescent and young adult cancer survivors need extensive follow-up and cancer surveillance by a physician who is aware of chronic conditions and other possible late effects. Surveys suggest that survivors of adolescent and young adult cancers were **less likely to get necessary medical care** (or the care would be delayed) than similar individuals without a cancer history.

## A DECADE OF ADVANCES

Critical Mass was founded to address the issues detailed above and since 2006 has achieved many notable advances for the adolescent and young adult community.

**Adolescent and Young adult Focus.** There has been a rapid increase in the number of adolescent and young adult -focused educational resources, scientific publications, and meetings.

**Research & Clinical Trials.** Retrospective analyses have provided evidence for the biological distinctiveness of some adolescent and young adult cancers. The Alliance for Clinical Trials in



Oncology and the NCI-supported National Clinical Trials Network have each created Subcommittees specific to adolescent and young adult patient care and needs.

**Guidelines.** There are now established guidelines for adolescent and young adult cancer care, including recommended components of an adolescent and young adult program and training for professionals. The National Comprehensive Cancer Network published guidelines for care of adolescent and young adult and there have also been efforts to recognize and support excellence in service delivery.

**Collaboration.** Finally, Critical Mass is no longer the single annual meeting that brings together the adolescent and young adult oncology community to collaborate and share research. Now there is a professional society, several global journals and one US-based one, and a host of regional meetings exclusively addressing adolescent and young adult topics.

## REMAINING GAPS

But the work is far from over. More research and focus on cancer care including treatment and services specific to adolescents and young adults with cancer is urgently needed:

**Understanding Trends.** Incidences of certain cancers such as acute lymphoblastic leukemia, acute myeloid leukemia, Hodgkin lymphoma, and brain tumors have declined among adolescents and young adults during the past 10 years. Other cancers have seen improvements possibly due to prevention efforts. However, many others have actually increased such as thyroid cancer, melanoma, and colon cancer. **More research is needed to understand what is driving these increases and decreases,** and to better address the consequences.

**Data.** Researchers lack annotated tumor samples, psychosocial data, and information about the adolescent and young adult patient experience from this age group. **It is not uncommon for patients diagnosed with cancer between 15 and 39 years of age to be told that no information is available to answer questions** about, for example their chances of survival or risk for infertility. A large prospective database of adolescent and young adult cancer patients, to facilitate research and care, treatment, and post-treatment issues is also needed for this age group.

**Access to Clinical Trials.** Adolescents and young adults still have the **lowest rate of enrollment in clinical trials** of all age groups. Outreach, access, and even just having trials available in adolescent and young adult cancers are all factors that need to be examined.

**Research Coordination.** The NCI and Centers for Disease Control (CDC) have no formal way to coordinate either internal efforts to study adolescents and young adults with cancer or improvements in their care. In fact, the NCI has consolidated their clinical trial into five programs - four that focus on adult cancers and one that focuses on childhood cancer called the Children's Oncology Group. There is **no program through NCI dedicated to trials for 15-39 year-olds diagnosed with cancer.**<sup>iv</sup>



**Psychosocial Support.** Available research has shown that the psychosocial needs of young cancer survivors – from the high school student to the mother of two – vary and that it is impossible to develop a support plan based solely on age assumptions.

**Life After Cancer.** Most unique to the adolescent and young adult experience is their life long after treatment. As noted above, young adults are more likely to take on a **heavy financial burden** directly related to their cancer diagnosis and care. Many more young people are surviving their cancers and living long past their treatment. While this is a positive aspect, **cancer treatment can also affect fertility and the possibilities for fertility preservation.** Reasons for adolescents and young adults not using fertility preservation range from not knowing that their fertility was at risk, to not being presented with fertility preservation options, to not having enough time to pursue preservation, or the significant financial burden.<sup>v vi</sup>

**Disease Risk.** The CDC compared adolescent and young adult cancer survivors to people in their age group who have never had cancer and found that adolescent and young adult cancer survivors have approximately **double the prevalence of cardiovascular disease** and are also at **increased risk for diabetes, asthma, and hypertension.** Furthermore, adolescent and young adult cancer survivors are **twice as likely to be disabled after treatment** than their cancer-free peers.

**Secondary Cancers.** It is crucial to also review what long-term survivorship means for adolescents and young adults compared to an elderly cancer survivor. Adolescent and young adult cancer survivors are not only **at risk for a recurrence of their original cancer, but they are also at higher risk for developing a new type of cancer.** Sixteen percent of new cancers are diagnosed in people who have had cancer previously. Adolescent and young adult cancer survivors are also at greater risk for developing secondary cancers because of the cancer treatments and screenings they received as a patient. Radiation treatment and imaging is one of the most important risk factors for secondary cancers and these cancers often do not arise until 10 to 20 years after initial exposure.

## HOW PUBLIC POLICY CAN HELP

Federal agencies don't recognize 15-39 year olds as their own population which means funding, research, and outreach is divided into two camps – pediatrics and adult – with no clear line and a huge gap in care.

Our goals are simple and require little to no federal funding:

1. **Help adolescents and young adults achieve recognition as an underserved population that requires government action eliminate barriers to care and treatment;**
2. **Create a structural change to the field of oncology that recognizes adolescent and young adult cancer care and treatment as a specialized field, and reframe the conversation; and**
3. **Reframe survivorship for 15 to 39 years olds from short-term survival to long-term barriers that adolescents and young adults patients face when returning to a life that allows them to be contributing members of society.**

---

*Transforming the care and treatment of adolescents and young adults with cancer.*

CRITICAL MASS: THE YOUNG ADULT CANCER ALLIANCE | CRITICALMASS.ORG



## ADDITIONAL REFERENCES

1. Wu XC, Prasad PK, Landry I, Harlan LC, Parsons HM, Lynch CF, Smith AW, Hamilton AS, Keegan TH, AYA HOPE Study Collaborative Group. Impact of the AYA HOPE Comorbidity Index on Assessing Health Care Service Needs and Health Status among Adolescents and Young Adults with Cancer. *Cancer Epidemiol Biomarkers Prev* 2015 Dec;24(12):1844-9.
2. Shnorhavorian M, Harlan LC, Smith AW, Keegan TH, Lynch CF, Prasad PK, Cress RD, Wu XC, Hamilton AS, Parsons HM, Keel G, Charlesworth SE, Schwartz SM, AYA HOPE Study Collaborative Group. Fertility preservation knowledge, counseling, and actions among adolescent and young adult patients with cancer: A population-based study. *Cancer* 2015 Oct 01;121(19):3499-506.
3. DeRouen MC, Smith AW, Tao L, Bellizzi KM, Lynch CF, Parsons HM, Kent EE, Keegan TH, AYA HOPE Study Collaborative Group. Cancer-related information needs and cancer's impact on control over life influence health-related quality of life among adolescents and young adults with cancer. *Psychooncology* 2015 Sep;24(9):1104-15.
4. Parsons HM, Harlan LC, Schmidt S, Keegan TH, Lynch CF, Kent EE, Wu XC, Schwartz SM, Chu RL, Keel G, Smith AW, AYA HOPE Collaborative Group. Who Treats Adolescents and Young Adults with Cancer? A Report from the AYA HOPE Study. *J Adolesc Young Adult Oncol* 2015 Sep;4(3):141-50.
5. de Moor JS, Alfano CM, Breen N, Kent EE, Rowland J. Applying evidence from economic evaluations to translate cancer survivorship research into care. *J Cancer Surviv* 2015 Sep;9(3):560-6.
6. Kent EE, Breen N, Lewis DR, de Moor JS, Smith AW, Seibel NL. US trends in survival disparities among adolescents and young adults with non-Hodgkin lymphoma. *Cancer Causes Control* 2015 Aug;26(8):1153-62.
7. Potosky AL, Harlan LC, Albritton K, Cress RD, Friedman DL, Hamilton AS, Kato I, Keegan TH, Keel G, Schwartz SM, Seibel NL, Shnorhavorian M, West MM, Wu XC, AYA HOPE Study Collaborative Group. Use of appropriate initial treatment among adolescents and young adults with cancer. *J Natl Cancer Inst* 2014 Nov;106(11).
8. Parsons HM, Schmidt S, Harlan LC, Kent EE, Lynch CF, Smith AW, Keegan TH, AYA HOPE Collaborative. Young and uninsured: Insurance patterns of recently diagnosed adolescent and young adult cancer survivors in the AYA HOPE study. *Cancer* 2014 Aug 01;120(15):2352-60.
9. Keegan TH, Tao L, DeRouen MC, Wu XC, Prasad P, Lynch CF, Shnorhavorian M, Zebrack BJ, Chu R, Harlan LC, Smith AW, Parsons HM, AYA HOPE Study Collaborative Group. Medical care in adolescents and young adult cancer survivors: what are the biggest access-related barriers? *J Cancer Surviv* 2014 Jun;8(2):282-92.
10. Zebrack B, Kent EE, Keegan TH, Kato I, Smith AW, AYA HOPE Study Collaborative Group. "Cancer sucks," and other ponderings by adolescent and young adult cancer survivors. *J Psychosoc Oncol* 2014;32(1):1-15.



11. Smith AW, Bellizzi KM, Keegan TH, Zebrack B, Chen VW, Neale AV, Hamilton AS, Shnorhavorian M, Lynch CF. Health-related quality of life of adolescent and young adult patients with cancer in the United States: the Adolescent and Young Adult Health Outcomes and Patient Experience study. *J Clin Oncol* 2013 Jun 10;31(17):2136-45.
12. Kent EE, Smith AW, Keegan TH, Lynch CF, Wu XC, Hamilton AS, Kato I, Schwartz SM, Harlan LC. Talking About Cancer and Meeting Peer Survivors: Social Information Needs of Adolescents and Young Adults Diagnosed with Cancer. *J Adolesc Young Adult Oncol* 2013 Jun;2(2):44-52.
13. Smith AW, Parsons HM, Kent EE, Bellizzi K, Zebrack BJ, Keel G, Lynch CF, Rubenstein MB, Keegan TH, AYA HOPE Study Collaborative Group. Unmet Support Service Needs and Health-Related Quality of Life among Adolescents and Young Adults with Cancer: The AYA HOPE Study. *Front Oncol* 2013;3:75.
14. Bellizzi KM, Smith A, Schmidt S, Keegan TH, Zebrack B, Lynch CF, Deapen D, Shnorhavorian M, Tompkins BJ, Simon M, Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) Study Collaborative Group. Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. *Cancer* 2012 Oct 15;118(20):5155-62.
15. Keegan TH, Lichtensztajn DY, Kato I, Kent EE, Wu XC, West MM, Hamilton AS, Zebrack B, Bellizzi KM, Smith AW, AYA HOPE Study Collaborative Group. Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. *J Cancer Surviv* 2012 Sep;6(3):239-50.
16. Parsons HM, Harlan LC, Lynch CF, Hamilton AS, Wu XC, Kato I, Schwartz SM, Smith AW, Keel G, Keegan TH. Impact of cancer on work and education among adolescent and young adult cancer survivors. *J Clin Oncol* 2012 Jul 01;30(19):2393-400.
17. Kent EE, Parry C, Montoya MJ, Sender LS, Morris RA, Anton-Culver H. "You're too young for this": adolescent and young adults' perspectives on cancer survivorship. *J Psychosoc Oncol* 2012;30(2):260-79.
18. Harlan LC, Lynch CF, Keegan TH, Hamilton AS, Wu XC, Kato I, West MM, Cress RD, Schwartz SM, Smith AW, Deapen D, Stringer SM, Potosky AL, AYA HOPE Study Collaborative Group. Recruitment and follow-up of adolescent and young adult cancer survivors: the AYA HOPE Study. *J Cancer Surviv* 2011 Sep;5(3):305-14.

---

<sup>i</sup> [Journal of Adolescent and Young Adult Oncology: The History and Accomplishments of the LIVESTRONG Young Adult Alliance \(2011\)](#)

<sup>i</sup> [Research and Care Imperative for Adolescents and Young Adults with Cancer \(2006\)](#)

<sup>i</sup> [Strategic Plan for Addressing the Recommendations of the Adolescent and Young Adult Oncology Progress Report \(2007\)](#)

<sup>i</sup> [Summary Report of the LIVESTRONG Young Adult Alliance Implementation Plan \(2012\)](#)

<sup>ii</sup> [Journal of Oncology Medicine: Adolescent and Young Adult Cancer Participation \(2016\)](#)

<sup>iii</sup> [Cancer Medicine Journal: The cost of cancer: a retrospective analysis of the financial impact of cancer on young adults \(February 2016\)](#)

<sup>iv</sup> [An Overview of NCI's National Clinical Trials Network \(2015\)](#)



---

<sup>v</sup> [LIVESTRONG, Cancer Legal Resource Center, & Fertile Hope Position Statement: Health Insurance Coverage for Iatrogenic Infertility \(2011\)](#)

<sup>vi</sup> [Fertile Hope & LIVESTRONG Iatrogenic Infertility Due to Cancer Treatments: A Case for Fertility Preservation Coverage \(2011\)](#)

