Adolescent and Young Adult Cancer Survivors Social Media Toolkit

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Tip: Viewing this PDF in Google Chrome? Use “Ctrl+Click” on links to open them in a new tab.

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ABOUT THIS TOOLKIT

This toolkit is designed to help stakeholders implement evidence-based practices when communicating about adolescent and young adult cancer. It can also help you plan, implement and evaluate your social media strategy and make the case for why it’s important. It can be used throughout the year or for specific health observances like National Young Adult Cancer Awareness Week in April, back-to-school in the fall or National Cancer Survivors Day in June.

WHO SHOULD USE THIS TOOLKIT?

Public health professionals, cancer control professionals, cancer centers, coalitions, community-based organizations and other stakeholders can use this toolkit and adapt its messaging for their unique audiences and areas of expertise.

ABOUT ADOLESCENT AND YOUNG ADULT CANCER

Over 70,000 adolescents and young adults (AYA) are diagnosed with cancer every year in the United States (National Cancer Institute, 2015). AYA typically refers to patients 15 to 39 years old (Perales, Drake Pemmaraju & Wood, 2016). The National Cancer Institute (NCI) reports that cancer is the leading cause of disease-related death for this age group (NCI, 2015). In addition, the economic burden of cancer survivorship is particularly significant for AYA survivors. Guy et al. (2013) estimated that the average excess economic burden placed on a cancer survivor is over $16,000 per year. While insurance protections in the Patient Protection and Affordable Care Act (ACA) increased insurance coverage rates among young adults diagnosed with cancer between the ages of 18-25, uncertainties in the future of the ACA may contribute to financial distress for AYAs diagnosed with cancer (Parsons et al., 2017).

Until recently, AYA cancer patients and survivors were not considered a distinct demographic group, and were often lumped together with childhood or older adult cancer patients and survivors. Despite improvements in outcomes for childhood and older adult cancers, the same gains have not been realized for AYA cancer patients (Lewis, Seibel, Smith & Stedman, 2014). With over 90% of adults ages 18-29 using social networking sites, social media can be an effective way to reach AYA patients, survivors and their families (Perales, Drake, Pemmaraju & Wood, 2016). Diverse channels of communication, like videos or text messaging may also be effective ways to reach an AYA audience (IOM, 2013).

“(…life during and after cancer for AYAs is a negotiation of lessons learned and strength gained with struggles to meet expectations of self and others, as well as recovery from the trauma of diagnosis and treatment.”

(Love et al., 2012, p. 557)
SOCIAL MEDIA 101

According to a 2016 Pew Research Center survey, “69% of online adults use social networking sites” (Pew Research Center, 2017). In addition, a 2014 study found that nearly 75% of adults use social media to discuss health (Fox, 2014).

Social media represents a unique opportunity to reach a large audience of both consumers and professionals. It is more important than ever that online medical and health information is “trustworthy, engaging, and accessible to digitally empowered consumers” (Hootsuite, n.d., p. 2).

When designing and thinking about your social media strategy, consider your audience, the channel(s) you want to use, your objective(s), or what you are trying to achieve, as well as how you will measure success. Remember that your social media activities should ultimately support your organization’s goals (Hootsuite, nd.).

Looking to establish a social media strategy for your organization or make the case for why it’s important? The Centers for Disease Control and Prevention offers social media tools to create and establish a social media strategy. The site also offers guidelines and best practices as well as evaluation strategies, tools and templates.

Remember to tailor messaging to your intended audience or audiences. Your organization offers unique strengths and expertise. Make sure to capitalize on them to make your campaign effective.

SOCIAL MEDIA CHANNELS

Twitter, Facebook, Instagram, LinkedIn, Snapchat, Pinterest and more—social media are growing every day, along with opportunities for outreach.

TWITTER BEST PRACTICES

- Keep Tweets below the 280 character limit. This allows other users to Retweet while adding their own comments. Note that @names no longer count toward the 280 character limit on Twitter.
- Add photos or videos. Adding a photo boosts Retweets by 62% on average (Twitter Government and Elections Team, 2014).
- Tweet at author or organizational Twitter handles when possible. Note that Tweets that begin with a username will now reach all your followers, but they will be categorized as “replies.” If you want the Tweet to be seen on your timeline, use the “.@” convention at the beginning.
- Twitter, Tweetdeck, Sprout Social and Hootsuite all have options to shorten links as you write Tweets. Other options for shortening links are provided under Additional Tools and Resources.
- Promote engagement with other organizations by liking or Retweeting their content. You can even add your own comment before Retweeting.
- Be responsive and recognize Retweets, @ mentions and when others share your content. It doesn’t take much, but a simple “thank you” goes a long way toward building engagement.
- Remember that Tweets cannot be edited once they are posted, so proofread before you post!
FACEBOOK BEST PRACTICES

- Shorter posts (around 250 characters) get up to 60% more distribution than longer posts (CDC, n.d.).
- Use photos or videos to make your posts stand out. Posts with photos receive up to 50% more likes than non-photo posts (Hershkowitz & Lavrusik, 2013). However, be aware of Facebook’s policies about what can be posted and identifying people in photos without consent (CDC, n.d.).
- Use a conversational tone and explain to your audience why the content should matter to them (Hershkowitz & Lavrusik, 2013).
- Posts that start conversations by asking questions and responding receive approximately 70% above-average engagement (Hershkowitz & Lavrusik, 2013).
- Vary your post type. Users don’t engage the same way with every post (Hershkowitz & Lavrusik, 2013).
- Track your results and act on them. Facebook offers analytic data that you can use to find out what posts are being “liked” or shared and which ones aren’t. Focus your efforts on what is working (CDC, n.d.).
- More information about Facebook best practices is available from CDC.

BEST PRACTICES FOR COMMUNICATING ABOUT AYA CANCER

AYA survivors have distinct needs that are different from those of childhood cancer survivors and older survivors. Limited awareness of AYA risk, treatment and other unique care needs hampers research, education and communication efforts tailored to this population (U.S. Department of Health and Human Services (HHS) & LIVESTRONG Young Adult Alliance, 2006). Raising awareness about AYA cancer issues is a first step toward increasing national focus and resource allocation to address gaps in care (HHS & LIVESTRONG Young Adult Alliance, 2006). Spread the word about AYA cancer issues to educate and inform your audience.

Your organization’s communication efforts can be most effective when they:

- Treat AYA survivors as a distinct group with unique needs
- Acknowledge and address psychosocial support needs
- Emphasize survivorship follow-up and resources
- Promote quality physician training to support AYA survivors
- Refer AYA cancer patients to clinical trials
Treat AYA survivors as a distinct group with unique needs

- Some of the issues that are particularly salient for AYA patients are self-esteem and identity development, returning to normalcy, psychological distress, psychosexual identity and fertility, financial strain and insurance concerns (Zebrack, 2009, Institute of Medicine (IOM), 2013, Morgan et al., 2010). **Promote resources that address these unique concerns.**
- AYA patients often report an unmet need for age-appropriate websites (Zebrack, 2009). **Assess your content for health literacy, numeracy and whether it is appropriate for your target age group.**
- Zebrack (2009) found that 75% of respondents who desired peer support programs had not been able to benefit from them. AYAs use online forums to exchange support, cope with emotions, describe their experiences and establish their identity as a member of the community (Love et al., 2012). **Emphasize peer support groups, whether online or in-person, to meet this need (IOM, 2013).**
- **Highlight resources that encourage return to work or school since this appears to mitigate distress in AYA patients** (Kwak et al. 2013).
- **Sponsor casual social activities as these may be preferable to formal support group settings for AYA patients** (Morgan et al., 2010).

Acknowledge and address psychosocial support needs

- Survivors who report any psychosocial care are more likely to report satisfaction with how their needs are met (Forsythe et al., 2013). Despite this fact, over 50% of survivors report not receiving this form of care (Forsythe et al. 2013). **Educate patients about how to obtain psychosocial support and services.**
- AYA patients experience high levels of distress at diagnosis and when they transition to survivorship (Kwak et al., 2013). Unmet needs are strongly associated with less than optimal physical health status (Zebrack, 2009). **Refer patients to psychosocial support services during the time of this transition, not just at diagnosis.**
- Psychosocial interventions should “include programmatic components that alleviate distress but also promote potential for positive growth and successful achievement of normative developmental tasks” (Zebrack, Kent, Keegan, Kato & Smith, 2014, p. 8). **Focus on AYA-specific concerns like vocational rehabilitation, social re-integration and involvement.**
- “Feeling normal again” is a common desire among AYA patients (IOM, 2013). **Encourage survivors to take part in activities that restore a sense of normalcy to life whenever possible.**

Emphasize survivorship follow-up and resources

- Having a written survivorship care plan may help AYA cancer survivors, especially when they switch to a new provider (Institute of Medicine, 2013). **Inform patients that they can ask their doctor or other health care professional about survivorship care plans.**
- Zebrack (2009) found that almost all (96.7%) patients expressed a need for information about their illness, treatment and long-term effects. AYAs also desired information about exercise, diet/nutrition,
health insurance, disability and social security (Zebrack, 2009). Make sure patients are provided with information about their illness as well as their practical follow-up care needs.

- AYA patients and survivors (91%) also want websites that offer cancer education and support for their age group (Zebrack, 2009). Tailor survivorship care resources for your audience.
- Survivorship care can include more than just treatment effects and screening recommendations. It can also include information about managing long-term financial toxicity. Provide patients with resources on financial assistance, whether through a patient navigator, social worker or other appropriate health care professional.

Promote quality physician training to support AYA survivors

- “Medical follow-up and management of late effects may reduce survivors’ actual needs for services and possibly the proportion of those indicating that their needs are unmet” (Zebrack, 2009, p. 355). Educate primary care providers about late and long-term side effects, particularly for AYA survivors.
- Less than 5% of adult patients newly diagnosed with cancer are enrolled in clinical trials (Virani, Burke, Remick & Abraham, 2011). Given that physician involvement is a key factor in whether or not a patient participates in a clinical trial, ensure that providers are aware and up-to-date on appropriate clinical trials that may benefit their AYA patients (HHS & LIVESTRONG Young Adult Alliance, 2006).
- AYA cancer survivors are more likely to smoke and report lower levels of physical activity than those who have no history of cancer (Tai et al., 2012). Provide targeted information on modifiable risk factors to reduce cancer risk (HHS and LIVESTRONG Young Adult Alliance, 2006).
- Age-based cancer care can support developmental milestones of adolescence and young adulthood (Morgan et al., 2010). Remind providers about the unique needs of AYAs and encourage specialized training to meet these needs.
- Including parents, family members or caregivers in care decisions may be important for some AYA patients (IOM, 2013). Ask patients who should be involved in decision-making and make every effort to honor those requests.

Refer AYA Cancer Patients to Clinical Trials

- AYAs have lower rates of clinical trial enrollment than younger or older patients with cancer. Refer AYA cancer patients to centers that offer clinical trials (Albritton & Coccia, 2014).
- Improve AYA enrollment in clinical trials. Research shows that decreased enrollment in clinical trials is an important factor in AYA oncology patients having lower cancer cure rates than patients in other age groups (Shaw, Hayes-Lattin, Johnson & Bleyer, 2014).
- Increase the number of clinical trials available to AYA cancer patients. (Gupta & Indelicato, 2014).
- Psychosocial barriers and facilitators can affect an AYA’s decision to enroll and adhere to a clinical trial. Address barriers by promoting clinical trials through peer-to-peer support networks, balancing autonomy and dependency in decision making and making sure consent forms are clear and meet the needs of AYA patients. (Buchanan, Block, Smith & Tai, 2014).
### Sample Tweets and Facebook Posts

<table>
<thead>
<tr>
<th>Tweets</th>
<th>Facebook Posts</th>
</tr>
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<tbody>
<tr>
<td><strong>#AYACancer survivors have unique needs &amp; concerns, like fertility, financial issues &amp; social support. @CancerCare has resources to help:</strong> <a href="http://bit.ly/2DRGXEM">http://bit.ly/2DRGXEM</a></td>
<td>Adolescent and young adult cancer survivors have unique needs, from fertility issues to financial concerns, age-appropriate content is critical. These resources from CancerCare can help: <a href="http://bit.ly/2DRGXEM">http://bit.ly/2DRGXEM</a></td>
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<tr>
<td>Age-appropriate resources are critical for #AYACancer survivors. These from @LLSusa can help: <a href="http://bit.ly/2BIW4L7">http://bit.ly/2BIW4L7</a></td>
<td>Did you know that many adolescent and young adult cancer survivors report a lack of age-appropriate resources? This list from the Leukemia and Lymphoma Society can help: <a href="http://bit.ly/2BIW4L7">http://bit.ly/2BIW4L7</a></td>
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<td><strong>#BreastCancer</strong> is one of the most common cancers in women 25-39. Learn more from @YSCBuzz: <a href="http://bit.ly/2DANeob">http://bit.ly/2DANeob</a></td>
<td>Did you know that breast cancer is one of the most commonly diagnosed cancers among 25 to 39 year-olds? Young Survival Coalition has more information: <a href="http://bit.ly/2DANeob">http://bit.ly/2DANeob</a></td>
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<td>You may have heard about BRCA genetic testing—but could it be right for you? Learn from Amy’s story &amp; talk w/ your doc: <a href="http://bit.ly/2n6UXQy">http://bit.ly/2n6UXQy #BringYourBrave</a></td>
<td>“Cancer runs in Amy’s family: her grandmother had both breast and ovarian cancer, and encouraged her family to learn about their risk.” Learn more about genetic testing for BRCA gene mutations from Amy’s story and talk to your doc about whether it’s right for you: <a href="http://bit.ly/2n6UXQy">http://bit.ly/2n6UXQy</a></td>
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<td>This video from @theNCI covers what adolescents &amp; young adults need to know after a cancer diagnosis: <a href="http://bit.ly/2DjnKUU">http://bit.ly/2DjnKUU #AYAcancer</a></td>
<td>What do adolescents and young adults need to know after a cancer diagnosis? This video from the National Cancer Institute covers the basics. Number one? You’re not alone: <a href="http://bit.ly/2DjnKUU">http://bit.ly/2DjnKUU</a></td>
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<td>Finding out you have cancer is overwhelming at any age, but especially if you’re young. This guide from @heycriticalmass tells you what to ask after a diagnosis: <a href="http://bit.ly/2E59zY0">http://bit.ly/2E59zY0</a></td>
<td>“Yes, you are too young for cancer... But you aren’t alone.” This guide from Critical Mass can help you figure out where to start—with questions for your doctor and a simple document you can print and take to your next appointment: <a href="http://bit.ly/2E59zY0">http://bit.ly/2E59zY0</a></td>
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<td>Janna was 32 when she was diagnosed w/ cervical cancer. Her advice? Your annual checkup can save your life: <a href="http://bit.ly/2E3QSUF">http://bit.ly/2E3QSUF #AYAcancer</a></td>
<td>“I was scared and angry when I received my diagnosis, but I decided to face it head on.” Janna was just 32 when she was diagnosed with cervical cancer. Her advice? Take your regular OB/GYN appointments seriously—it could just save your life: <a href="http://bit.ly/2E3QSUF">http://bit.ly/2E3QSUF</a></td>
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<td>Looking for work during or after cancer treatment can seem daunting, but @CancerAndCareer resume review service can help you move forward: <a href="http://bit.ly/2GfDZrw">http://bit.ly/2GfDZrw</a></td>
<td>Do you have questions about looking for work after a cancer diagnosis? Cancer and Career’s resume review service can help polish your resume, answer your questions and build your confidence: <a href="http://bit.ly/2GfDZrw">http://bit.ly/2GfDZrw</a></td>
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<tr>
<td>Tweets</td>
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<td><strong>Treatment side effects can impact you at work. These tips from @CancerAndCareer can help you cope:</strong> <a href="http://bit.ly/2rBqn6r">http://bit.ly/2rBqn6r</a> #youngadultcancer</td>
<td>“Cancer can drain you physically and mentally, but there are ways to bolster your inner reserves. Specially tailored food and fitness plans can ward off fatigue and other side effects. Plus, there’s your psyche – the most important weapon in your arsenal against the disease”: <a href="http://bit.ly/2rBqn6r">http://bit.ly/2rBqn6r</a></td>
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<td><strong>You’re not alone. @theNCI has tips for confronting some of the challenges of #AYAcancer:</strong> <a href="http://bit.ly/2Bq5lSB">http://bit.ly/2Bq5lSB</a></td>
<td>A cancer diagnosis as an adolescent or young adult can leave you feeling alone, but this info from the National Cancer Institute can help you find support: <a href="http://bit.ly/2Bq5lSB">http://bit.ly/2Bq5lSB</a></td>
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<tr>
<td><strong>Looking for a support group to meet others dealing w/#AYAacancer? @StupidCancer has you covered:</strong> <a href="http://bit.ly/2E7ppBA">http://bit.ly/2E7ppBA</a></td>
<td>Hanging out with other adolescent or young adult cancer survivors can make you feel less alone. Stupid Cancer can help you locate a support group in your area: <a href="http://bit.ly/2E7ppBA">http://bit.ly/2E7ppBA</a></td>
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<tr>
<td><strong>Young women w/#BreastCancer have unique concerns. @YSCBuzz has meet up groups just for you:</strong> <a href="http://bit.ly/2BrI4WM">http://bit.ly/2BrI4WM</a></td>
<td>Local Young Survival Coalition’s Face 2 Face networks are support and social networks that bring together young women at all stages of a breast cancer diagnosis, treatment or recovery to learn from each other: <a href="http://bit.ly/2BrI4WM">http://bit.ly/2BrI4WM</a></td>
</tr>
<tr>
<td><strong>Looking for people who understand what you’re going through? @StupidCancer’s mobile app can help you connect w/other #AYAacancer survivors:</strong> <a href="https://stpdcn.cr/2F7HZcc">https://stpdcn.cr/2F7HZcc</a></td>
<td>“Stupid Cancer’s mobile app connects you to a network of peers who understand what you’re going through. They’ve been there, too.” Learn more: <a href="https://stpdcn.cr/2F7HZcc">https://stpdcn.cr/2F7HZcc</a></td>
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<tr>
<td><strong>Eating well &amp; getting active are especially important for #AYAacancer survivors. Get started today w/these resources from @AmericanCancer:</strong> <a href="http://bit.ly/2rCCUXm">http://bit.ly/2rCCUXm</a></td>
<td>Taking the first steps toward eating healthy and getting active can seem overwhelming, especially if you’re a cancer survivor. But don’t worry, the American Cancer Society has resources to get you started on the path to wellness: <a href="http://bit.ly/2rCCUXm">http://bit.ly/2rCCUXm</a></td>
</tr>
<tr>
<td><strong>Cancer is something you should never have to face alone. @StupidCancer discussion boards can help you connect &amp; get support:</strong> <a href="http://bit.ly/2E58Ype">http://bit.ly/2E58Ype</a></td>
<td>Facing a cancer diagnosis in the prime of life can bring up lots of emotions and fear. Message boards from Stupid Cancer can help you process these feelings by finding others who understand what you’re going through. Learn more: <a href="http://bit.ly/2E58Ype">http://bit.ly/2E58Ype</a></td>
</tr>
<tr>
<td><strong>Group Loop is a safe space for teens affected by cancer. Learn more from @CancerSupportHQ:</strong> <a href="http://bit.ly/2DwLb0o">http://bit.ly/2DwLb0o</a></td>
<td>Group Loop from Cancer Support Community is a safe place for teens touched by cancer to find support, education and hope. Learn more: <a href="http://bit.ly/2DwLb0o">http://bit.ly/2DwLb0o</a></td>
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### SAMPLE TWEETS AND FACEBOOK POSTS

<table>
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<th>Tweets</th>
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<tr>
<td>#AYAcancer treatment comes w/a lot of questions. This doc from @heycriticalmass can help you talk with your doc: <a href="http://bit.ly/2GdVBny">http://bit.ly/2GdVBny</a></td>
<td>Going through cancer treatment as an adolescent or young adult can seem overwhelming. This resource from Critical Mass can help you organize your care by asking the right questions with your care team: <a href="http://bit.ly/2GdVBny">http://bit.ly/2GdVBny</a></td>
</tr>
<tr>
<td>#DYK adolescents and young adults w/cancer have unique needs? @NCCNnews has a resource guide for patients: <a href="http://bit.ly/2n9eK1S">http://bit.ly/2n9eK1S</a></td>
<td>Adolescents and young adults (AYAs) with cancer are often lumped in with pediatric patients or older adults, but they have unique needs. This guide can help AYA patients take charge of their care: <a href="http://bit.ly/2n9eK1S">http://bit.ly/2n9eK1S</a></td>
</tr>
<tr>
<td>Looking to find a clinical trial for #AYAcancer survivors? This guide from @theNCI can help: <a href="http://bit.ly/2msvYo4">http://bit.ly/2msvYo4</a></td>
<td>Thinking about joining a cancer clinical trial? This guide from the National Cancer Institute can help you take the first steps: <a href="http://bit.ly/2msvYo4">http://bit.ly/2msvYo4</a></td>
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<tr>
<td>#AYACancer survivors have unique concerns when it comes to the sexual impacts of cancer. This toolbox can help clinicians address these important needs: <a href="http://bit.ly/2GgAd10">http://bit.ly/2GgAd10</a></td>
<td>Providers: Adolescent and young adult cancer survivors have unique needs when it comes to the sexual impacts of cancer. This toolbox for clinicians can help assess and treat these concerns: <a href="http://bit.ly/2GgAd10">http://bit.ly/2GgAd10</a></td>
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<td>Intimidated by information about clinical trials or unsure where to start? @ProjectInno has resources to get you started: <a href="http://bit.ly/2nc77aq">http://bit.ly/2nc77aq</a></td>
<td>Cancer clinical trials are at the heart of delivering breakthroughs to patients and saving lives. However, fewer than 5% of adult cancer patients enroll in a clinical trial. This information from Project Innovation aims to spread the word and increase participation: <a href="http://bit.ly/2nc77aq">http://bit.ly/2nc77aq</a></td>
</tr>
<tr>
<td>What's being done to close the gap &amp; improve #AYAcancer care? This strategic plan aims to move the conversation forward: <a href="http://bit.ly/2E9vFcd">http://bit.ly/2E9vFcd</a></td>
<td>Adolescent and young adult cancer survivors haven’t seen the same gains in treatment and care as other groups. This report from LIVESTRONG provides strategic steps to close the gap: <a href="http://bit.ly/2E9vFcd">http://bit.ly/2E9vFcd</a></td>
</tr>
<tr>
<td>There are lots of myths out there about clinical trials. Learn to separate fact from fiction w/this fact sheet from @ProjectInno: <a href="http://bit.ly/2GaCmeu">http://bit.ly/2GaCmeu</a></td>
<td>Clinical trials can be a valuable opportunity for cancer patients, but there’s a lot of misinformation out there. This fact sheet from Project Innovation helps bust some myths and start the conversation with your doctor: <a href="http://bit.ly/2GaCmeu">http://bit.ly/2GaCmeu</a></td>
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</table>
OTHER IDEAS TO PROMOTE ADOLESCENT AND YOUNG ADULT CANCER AWARENESS

Host or Participate in a Twitter Chat or Twitterview

Twitter chats are a great way to expand your audience and promote engagement with other partners and organizations. You can organize a Twitter chat yourself or simply participate in another one. Twitter chats are live moderated Twitter conversations focused around a specific topic using a single hashtag. They usually last an hour and involve a list of pre-circulated questions to participants. If you are organizing a chat, reach out to partners early and provide the list of questions as far in advance as possible.

A Twitterview is an interview conducted through Tweets. For a Twitterview, typically an interviewer asks questions directly to the interviewee and participants can follow the conversation through an event hashtag. You may also open up the interview to questions from the audience. Potentially influential speakers might include researchers, cancer survivors or caregivers, health care providers or other subject matter experts.

Consider using a website to help manage the Twitterview or Twitter chat such as TweetChat or TWUBS.

Promote the event to your followers. Host the event, running it similarly to how you would host a live in-person meeting (introduce topic, speaker or participating organizations, your organization). Number your questions starting with a “Q” for question. For example: Q1: What’s the #1 thing providers should know about caring for #AYAcancer survivors? #AYACC. Your speaker(s) can either “reply” to the question you Tweet or Tweet starting with an “A” and the corresponding number. For example: A1: #AYAcancer survivors have unique needs. Don’t treat us like pediatric or older adult #survivors #AYACC.

Retweet or favorite the best questions posed by your followers and answers by your speaker(s) and be sure to share relevant links and resources. After the event, archive an event summary and share with participants and your other followers. Consider using Storify to create a visual transcript of the Twitterview or Tweet chat.

Below are some regular AYA Twitter chats you can participate in to build audience engagement:

<table>
<thead>
<tr>
<th>Hashtag</th>
<th>Description</th>
<th>Frequency</th>
<th>Associated Twitter Handle(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>#MAYACC</td>
<td>Metastatic and Advanced Young Adult Cancer Community</td>
<td>Second Tuesday of every month at 8PM ET</td>
<td>@EK_Drake @CancerFightClub</td>
</tr>
<tr>
<td>#ayacsm</td>
<td>Adolescent and Young Adult Cancer Societal Movement</td>
<td>First Tuesday of every month at 8PM ET</td>
<td>@EK_Drake @maureensweet @ukfann00 @StupidCancer @Hope4YAWC @CancerFightClub</td>
</tr>
<tr>
<td>#YAPchat</td>
<td>Young Adult Program at Dana Farber</td>
<td>Periodically</td>
<td>@DanaFarberYAP</td>
</tr>
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Live Tweet an Event or Conference

Consider live Tweeting a conference or other event around AYA cancer issues. Live tweeting is a form of notetaking which is online and interactive. During an event, conference, speech or webinar, organizers and attendees can live tweet and use established hashtags so that everyone following the event hashtag can see the tweet and reply. During the event you can tweet quotes from speakers, share pictures of attendees, and
retweet messages from the attendees. When quoting speakers, make sure to include their twitter handles to let them know you are promoting their sessions. You can also pre-write tweets and schedule them to go out during the event if you know when certain parts of the event are planned to occur.

**Host a Facebook Live Event**

Facebook Live is a live video streaming service that can be used to connect with your followers in real time. Facebook Live offers the opportunity to conduct live Q & A’s through the comment function where followers can ask questions or post commentary during the livestream. You can also use this livestream service to host an interview or broadcast an event, enabling people to participate even if they are not able to attend in person.

**Pick a date and time.** Tell your followers about your livestream event ahead of time. Live broadcasts can last for up to 4 hours.

**Promote the event to your followers.** Write a compelling description for your event which will show up on your followers’ newsfeeds along with the video to help people understand what your event is about. You can also add your location to the broadcast to increase discoverability. Keep track of your audience’s reactions to gauge how your broadcast is being received.

**Share Event Photos on Instagram**

Instagram is a photo sharing application that allows users to share pictures, videos, and messages with their followers. Instagram can be a great platform for increasing engagement with your audience and sharing your mission through photos. You can use Instagram to share photos from your events and feature individuals involved with the events such as speakers or volunteers. You can also share video clips from the events by posting them to your Instagram story. Encourage followers to share their photos of your events by using a hashtag.

**Pick a hashtag.** Using hashtags is a way to group and organize photos together. Many users search for photos in Instagram using hashtags. If you use an established hashtag, your Tweets may reach audiences that you usually do not reach. If you would like to create your own hashtag, make sure it is short and intuitive. You can increase visibility of your event by having followers post their photos to Instagram with a hashtag.

**Connect your Instagram** to your other social media accounts to cross-promote your activities and increase engagement with your audience.

**Share Your Event on Snapchat**

Snapchat is another social media platform to help you share photos and videos with your followers. Snapchat has over 158 million users with a majority of users under 30 years old (SproutSocial, 2017). You can share photos and videos individually with followers or share them in your Snapchat story. Photos and videos in your Snapchat story are visible to followers for 24 hours. You can use the story feature to promote your event, provide exclusive content such as behind the scenes footage or send a call to action. Share your story to your local “Our Story” to be featured on Snapchat’s map of stories and gain more visibility.

**Utilize Snapchat’s unique features** to promote your organization and events. Geofilters are location-based filters than can be used on photos and videos to further promote your cause as followers can then use these geofilters in their own posts. In the past, Snapchat has created geofilters for Giving Tuesday and donated to a designated charity every time someone posted using one of those geofilters. Snapcash is a feature that allows users to send money through Snapchat which could be a useful tool for soliciting online donations.
Check out this [Snapchat guide](#) for more information.

**Promote Your Cause on Pinterest**

Pinterest is an online tool that can help users discover and organize creative ideas by serving as a vison board. Pinterest can be used to drive more traffic to your website by adding eye-catching images, infographics, or quotes to your Pinterest boards and linking them to your website. Pinterest boards function as albums or folders in that they categorize pins for users to peruse. If you are just starting out with Pinterest it may be good to include general boards showcasing your organization’s mission in addition to adding event or fundraising boards for AYA cancer awareness.

[Link](#) your website and other social media accounts to your Pinterest by including them in the profile header to expand your exposure. If you have a YouTube channel or photo sharing page consider sharing those videos and photos on Pinterest as well.

**Publish a Blog Post**

Publishing blog posts can be a great way to highlight the successes of your organization and promote your events. Consider writing a post with a call to action for your readers to attend your AYA awareness events. Personal stories of patients or survivors, for example, can make for powerful blog posts by connecting with the reader emotionally. Use visuals such as photos and videos to illustrate your narrative and engage readers.

**Create dialogue.** Use your blog not only to share stories but also to communicate with your readers and increase engagement. Ask for audience feedback on your content and promote a space to discuss issues and share success stories.

**Host a Reddit Ask Me Anything**

Reddit is a social news aggregation, content rating, and discussion website. An Ask Me Anything (A.M.A.) is a feature on Reddit where users can interview someone with a notable trait such as a researcher or other expert through posting questions to the Reddit message board. The A.M.A. begins with the interviewee posting an introduction about themselves and then users respond with questions and comments. Users can “upvote” posted questions to indicate that are also interested in knowing the answer to those questions. A.M.As can be scheduled to start and stop at certain times or be open-ended in duration. Consider hosting an A.M.A with an AYA cancer expert or survivor.

**Publicize your A.M.A through your other social media channels to draw more participants.**

**Host an AYA Survivors Meetup Event**

Consider hosting a meetup for local AYA cancer survivors. It doesn’t have to be a formal support group setting or even have cancer survivorship as the main focus. It could simply be a social activity intended to gather AYA survivors, caregivers or family members who have been affected by cancer.

[Consider reaching out](#) to local organizations to solicit donations or prizes for the event. Organize a giveaway or prizes to encourage people to use your hashtag and engage with your content. Twitter and Instagram photo contests are another a great way to get your followers involved and engaged.

You might also consider hosting a special webinar or panel to promote AYA cancer awareness. Make sure to reach out to potential partners early to ensure support. Check out [Communication Training for Comprehensive Cancer Control (CCC) Professionals 101](#) for more information on working with local media.
Best Practices for Engagement Events and Activities

- Plan early and well
- Expand your audience and reach by partnering with another organization
- Make sure you use an original hashtag (unless it makes sense to use an established hashtag)
- Involve well-known local figures to help raise the profile of your event(s) and increase participation and engagement

MEASURING SUCCESS

Looking to measure the success of your social media campaign? Twitter, Facebook, and Instagram both offer free analytic tools to allow you to demonstrate the impact of your social media efforts.

**Twitter Analytics** allows you to see and download detailed tracking information about Tweet activity, engagement, audience and trends over time. Log in to [analytics.twitter.com](http://analytics.twitter.com) with your Twitter username and password to learn more.

**Facebook Insights** allows users to track page likes, post reach, number of visits, specific posts as well as who is following your page. According to Facebook, “posts that get more likes, comments and shares show up more in News Feed and are seen by more people. Posts that are hidden, reported as spam or cause people to unlike your Page reach fewer people.”

**Instagram Insights** is available in the app for users who have an Instagram Business Profile. This tool allows you see overall account metrics, follower demographics, and metrics for your Instagram stories such as impression, reach, and replies.

**Viralwoot** helps track Pinterest analytics, schedule pins, promote pins, and gain new followers. This analytics tool provides statistics about your reach, activity, and engagement scores. It also provides you with an influence score and tells you what you need to do to boost your Pinterest presence.

**Snaplytics** allows users to manage their Snapchat stories, Instagram stories, and Instagram accounts and can help identify the most engaging content across platforms.

**Klout** tracks the influence and reach of your social media profiles and provides a score based on how others are interacting with your content across multiple networks. It also provides information on your top posts so you can see what content is generating action from your networks.

ADDITIONAL TOOLS AND RESOURCES

**Canva**: Allows users to create visually appealing graphics and photos for social media and print materials; includes a collection of low-cost or free stock photos and backgrounds

**CDC Public Health Image Library (PHIL)**: Free image library.

**CDC "photostream" on Flickr**: Website designed for public image sharing. CDC images include public health photos and graphics developed for public health events that users can comment on and share.

**CDC Infographics**: Gallery of CDC-designed infographics to visually communicate data or information

**Goo.gl**: Link shortener that allows for tracking of clicks
Guide to Making Communication Campaigns Evidence-Based: Covers the process of planning, implementing and evaluating an evidence-based communication campaign

Hootsuite, Sprout Social: Online platforms that allow organizations to schedule Tweets and Facebook posts, keep up with their feed (the posts of those they follow), and collect basic analytics for evaluation

Klout: Service that tracks your organization’s level of online social influence

Media Planning and Media Relations Guide: In-depth guide to working with media and establishing a media and communications strategy

Owly: Link shortener from Hootsuite

Periscope: Live-streaming video app so you can show events or videos live to your audience on social media

Social Media Toolkits: Additional social media toolkits from the GW Cancer Center

Thunderclap: Social networking tool that allows you to “crowdsource” your social media campaign to increase its impact

TinyURL: Link shortener that allows for customization of URLs to make them more memorable

Tweetdeck: Platform from Twitter that allows for pre-scheduling Tweets, including pre-loading photos

GLOSSARY

Ask Me Anything (A.M.A): A feature of Reddit where users can interview someone through posting questions to the Reddit message board

Facebook: A social networking site that allows people to create personal profiles and stay connected with others (www.facebook.com)

Facebook Live: A live video streaming service provided through Facebook

Feed: News feeds which you receive straight into your account

Followers: People who have agreed to receive your Tweets or Facebook posts

Hashtags (#): A form of metadata tag that makes it possible to group messages

Instagram: A photo sharing application that allows users to share pictures and videos to their followers either publicly or privately to pre-approved followers (https://www.instagram.com/)

Live Tweet: To post comments about an event on Twitter while the event is taking place

Pinterest: A website where users can discover information mainly through images, GIFs (animated images), and videos (https://www.pinterest.com)

Reddit: A social news aggregation, content rating, and discussion website (https://www.reddit.com)

Retweet (RT): Re-posting of someone else’s Tweet

Snapchat: an image messaging application where messages auto-delete after set amount of seconds

Tweets: 280-character text messages
**Twitter**: An online social networking and microblogging service that enables users to send and read short 280-character text messages, called “Tweets” (www.twitter.com)

**Twitter chat**: A live moderated Twitter conversation focused around a specific topic using a single hashtag

**Twitter handle**: Your Twitter name that begins with the “@” sign. For example: @GWCCancer

**Twittersphere or Twitterverse**: The total universe of Twitter users and their habits

**Twitterview**: A combination of the terms Twitter, a popular microblogging platform, and interview. It is a type of interview for which the medium restricts the interviewer and interviewee to short-form responses. See Twitter’s “Twitter Glossary” for more.
REFERENCES


