National Cancer Survivors Day®
Social Media Toolkit

June 5, 2016
# National Cancer Survivors Day® Social Media Toolkit

## June 5, 2016

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ABOUT THIS TOOLKIT

This toolkit is designed to help stakeholders establish a National Cancer Survivors Day® social media strategy, manage social media accounts, implement Facebook and Twitter best practices, disseminate National Cancer Survivors Day® messaging and evaluate their social media efforts.

WHO SHOULD USE THIS TOOLKIT?

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

WHAT IS NATIONAL CANCER SURVIVORS DAY®?

National Cancer Survivors Day®¹ is an annual observance held the first Sunday in June. “It is a celebration for those who have survived, an inspiration for those recently diagnosed, a gathering of support for families and an outreach to the community” (National Cancer Survivors Day Foundation, n.d.). According to the National Cancer Institute (NCI), “a person is considered to be a survivor from the time of diagnosis until the end of life” (NCI, n.d.). With nearly 14 million cancer survivors in the United States and over 1.5 million new cases diagnosed each year, cancer continues to affect almost every American, whether through a family member or through their own experience (CDC & NCI, 2015).

SOCIAL MEDIA 101

According to a 2014 Pew Research Center survey, “74% of online adults use social networking sites.” (Pew Research Center, 2014). In addition, Hughes (2010) found that, “one-third of adults access social media related to health” (p. 3).

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, n.d.).

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 “SocialMediaWorks,” an online step-by-step tool to create and establish a social media strategy. The site also offers pre-tested and effective messages as well as evaluation strategies, tools and templates.

¹ National Cancer Survivors Day® is a registered service mark of Media America, Inc.
Remember to tailor messaging to your target 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, YouTube, Pinterest and more: Social media is growing every day, along with opportunities for outreach.

**TWITTER BEST PRACTICES**

- Keep Tweets short, between 100-110 characters. This allows other users to Retweet while adding their own comments.
- 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. If you are mentioning a person/organization at the beginning of a Tweet, add a period (.) before the Tweet, unless you only want the Tweet to be seen by people who are following both of you.
- 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.).

**BEST PRACTICES FOR COMMUNICATING ABOUT CANCER SURVIVORSHIP**

The first step in any communication campaign is to define your audience. When communicating about cancer survivorship, your audience may be survivors or caregivers; or health care providers and other practitioners providing cancer survivorship care. The messaging in this toolkit is organized around these two main audiences, each with their own unique strategies for outreach and framing. Remember to tailor
messages to your organization, since each audience may have subgroups with different needs (for example, survivors who are undergoing active treatment vs. five-year survivors who may be out of active treatment but have distinctive screening and follow-up needs).

In its landmark 2005 report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, the Institute of Medicine identified four key components of survivorship care:

- Prevention of recurrent or new cancers that can result from cancer and its treatment
- Surveillance for cancer spread, recurrence, or second cancers and assessing medical and psychosocial late effects
- Intervention for side effects of cancer and its treatment, including physical and psychosocial effects as well as non-medical concerns, like employment or financial issues
- Coordination between specialists and primary care providers

**WHEN COMMUNICATING WITH SURVIVORS…**

**Consider health literacy and numeracy**

- Use simple language and avoid terms not often used outside of the scientific community. Explain how data influences your audience and why it’s relevant (NCI, 2011).
- Organize information so the most important points are first (U.S. Department of Health and Human Services, n.d.).
- If presenting data, use integers instead of decimals as they are more convincing and easily recalled (Witteman et al., 2011). Visual representations of data, like icon arrays are most effective.
- Where possible, point consumers to supporting materials, visuals and reliable sources of information such as trusted websites or physicians.

**Understand the unique perspectives and needs of survivors**

- Cancer patients and survivors often face “cancer information overload” and may feel overwhelmed by information and unable to process it (Chae, Lee & Jensen, 2015).
- Survivors should be aware of the importance of quitting smoking, increased physical activity, good nutrition, getting their flu and pneumonia vaccinations and regular cancer screenings as appropriate (Underwood et al., 2012).
- Narratives can be an effective tool for communicating with survivors. Storytelling can overcome resistance, facilitate information processing, provide social connections and represent emotional or existential issues (Wen-Ying et al., 2007).
- Let patients know about specific resources they can request, such as survivorship care plans or long-term recommendations about screening and follow-up.

**WHEN COMMUNICATING WITH PROVIDERS OR PRACTITIONERS…**

**Make content accessible on the networks where providers are searching for information**

- 70% of physicians reported using social media on at least a monthly basis as of 2012 (McGowan et al., 2012), and a 2009 survey found that 81% of physicians reported using a mobile device to access the web (Cooper et al., 2012).
- Providers often use social media daily to scan or explore medical information and 14% of providers report contributing new information via social media on a daily basis (McGowan et al., 2012).
- Many providers use physician-only sites like Doximity, Sermo, Ozmosis or medical society membership sites like the American Academy of Pediatrics or the American Medical Association.
Emphasize the importance of communication between oncology and primary care providers

- In the past decade, more than 60 anti-cancer drugs have been approved by the FDA, each with its own short- and long-term side effects and potential impacts. Resources aimed at primary care providers should emphasize this information and make it more easily accessible.
- Decreased involvement by primary care providers is associated with worse overall care and outcomes, particularly for preventive services and non-cancer-related health conditions (Earle & Nevile, 2004; Snyder et al., 2009).
- Collaboration among providers can be facilitated by improving role clarity, communication and knowledge exchange between providers (Sussman & Baldwin, 2010).
- Survivors have special follow-up care needs after active therapy is completed. Survivorship care plans can help facilitate this transitional care.

Promote survivorship care resources

- The American College of Surgeons requires Commission on Cancer (CoC)-accredited programs to “provide a summary of treatment and a follow-up plan to all patients completing cancer treatments” (American College of Surgeons, n.d.).
- CDC recommends that follow-up care to cancer survivors should focus on tobacco cessation, increased physical activity, good nutrition, ongoing vaccinations, regular cancer screenings and pain management (Underwood et al., 2012).
- Providers may not be aware of the CoC requirement or may not be aware of follow-up care guidelines for cancer survivors available from the National Cancer Survivorship Resource Center as well as the Cancer Survivorship E-Learning Series for Primary Care Providers that covers follow-up care for survivors of adult-onset cancers. Long-term follow-up guidelines are also available for survivors of childhood cancer.
- Remind providers that patients and survivors are often looking for more information. A 1997 study found that patients reported their greatest need as information, including feedback on the progress of the cancer, information about the probable future of their illness and more information about their illness in general (Butow et al., 1997).
<table>
<thead>
<tr>
<th>Tweets</th>
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<tr>
<td>Who are #cancer survivors and how can you promote health after a diagnosis? Learn more: <a href="http://goo.gl/olAUE5">http://goo.gl/olAUE5</a> #LifeAfterCancer #NCSD2016</td>
<td>Get basic information about cancer, including the definition of a cancer survivor and how to promote your health after a diagnosis. Learn more from CDC: <a href="http://goo.gl/olAUE5">http://goo.gl/olAUE5</a></td>
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<td>What is follow-up #cancer care &amp; why is it important? This fact sheet can help you start a conversation with your doc: <a href="http://goo.gl/71h5nm">http://goo.gl/71h5nm</a></td>
<td>Follow-up cancer care is unique for every patient. This guide from the National Cancer Institute helps explain why it’s important and can help you start a conversation with your health care provider: <a href="http://goo.gl/71h5nm">http://goo.gl/71h5nm</a></td>
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<td>Going from #cancer patient to cancer #survivor can be difficult. This video can help w/what to expect: <a href="https://goo.gl/cXFHBy">https://goo.gl/cXFHBy</a> #NCSD2016</td>
<td>Making the transition from “cancer patient” to “cancer survivor” can be difficult. This video helps explain what to expect and how to manage life after cancer: <a href="https://goo.gl/cXFHBy">https://goo.gl/cXFHBy</a></td>
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<td>A wellness plan after cancer can help improve your health. Learn more about follow-up care from @NIH: <a href="http://goo.gl/x02etA">http://goo.gl/x02etA</a> #LifeAfterCancer</td>
<td>Many of the same general tips for a healthy lifestyle also apply after cancer and can help address some of the long-term issues that may arise after a diagnosis. Get more information on follow-up care from NIH: <a href="http://goo.gl/x02etA">http://goo.gl/x02etA</a></td>
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<td>A good plan for healthy living can improve your quality of life after #cancer. Learn more from @LIVEStrong: <a href="http://goo.gl/7yLO1C">http://goo.gl/7yLO1C</a> #NCSD2016</td>
<td>Did you know that good nutrition, exercise and other healthy behaviors can help your body heal after a cancer diagnosis? Get started today on your plan for healthy living with these resources from LIVEStrong: <a href="http://goo.gl/7yLO1C">http://goo.gl/7yLO1C</a></td>
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<td>Cancer survivor George Hilliard shares his “personal prescription” for surviving cancer. Read more: <a href="http://goo.gl/1EkujU">http://goo.gl/1EkujU</a> #NCSD2016</td>
<td>Learning from and talking with other cancer survivors can help provide social support. Read George’s story and “personal prescription” for surviving cancer today: <a href="http://goo.gl/1EkujU">http://goo.gl/1EkujU</a></td>
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<td>What should you ask your doctor after #cancer treatment ends? Start with these questions: bit.ly/NCSRCPatients #NCSD2016</td>
<td>It’s important to ask your doctor questions after treatment ends. But where do you start? These checklists from the National Cancer Survivorship Resource Center Toolkit can help get the conversation going: bit.ly/NCSRCPatients</td>
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<td>Surviving #cancer can bring up a range of emotions. Learn how to cope and what to expect: <a href="http://goo.gl/D2dC0t">http://goo.gl/D2dC0t</a></td>
<td>Surviving cancer affects physical health, as well as the way you feel and act. While everyone’s experience is different, survivors often experience, fear, depression, stress and loneliness. Learn how to cope and what to expect: <a href="http://goo.gl/D2dC0t">http://goo.gl/D2dC0t</a></td>
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<td>Communicating after cancer can be tricky. @CancerAdvocacy can help you get the support you need: <a href="http://goo.gl/xn3tIQ">http://goo.gl/xn3tIQ</a> #NCSD2016</td>
<td>Communicating after a cancer diagnosis can be difficult. Develop the skills you need to better meet and understand the challenges of cancer with this Cancer Survival Toolbox: <a href="http://goo.gl/xn3tIQ">http://goo.gl/xn3tIQ</a></td>
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<td>Learn about the things you can do to stay healthy once your cancer treatment is completed: <a href="http://goo.gl/FJT0sd">http://goo.gl/FJT0sd</a> #LifeAfterCancer</td>
<td>The end of treatment can bring a range of emotions, from excitement to stress. Learn how you can stay healthy after treatment, including nutrition, lifestyle changes and moving on after treatment: <a href="http://goo.gl/FJT0sd">http://goo.gl/FJT0sd</a></td>
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<td>Currently undergoing #cancer treatment? Start here: <a href="http://goo.gl/tw4c1H">http://goo.gl/tw4c1H</a> via @CancerSupportCm</td>
<td>It can be tough to know where to begin when going through cancer treatment. These resources from Cancer Support Community can help: <a href="http://goo.gl/tw4c1H">http://goo.gl/tw4c1H</a></td>
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## SAMPLE TWEETS AND FACEBOOK POSTS FOR PROVIDERS

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<th>Tweets</th>
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<td>Providers: #DYK there’s an e-learning series just for you? Get the latest on #cancer survivorship care today: <a href="http://goo.gl/PvGdmc">http://goo.gl/PvGdmc #NCSD2016</a></td>
<td>Primary care providers: It can be challenging to get the latest info on caring for cancer survivors. Luckily, there’s an e-learning series designed just for you. Access it today: <a href="http://goo.gl/PvGdmc">http://goo.gl/PvGdmc</a></td>
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<td>Providers: #Cancer survivors have questions, you’ve got answers. Share this helpful book to get started: <a href="http://goo.gl/YTGi8p">http://goo.gl/YTGi8p #NCSD2016</a></td>
<td>Providers: Cancer survivors have questions, you’ve got answers. This helpful book, Facing Forward: Life After Cancer Treatment, can help patients understand what to expect and how to cope. Share it today: <a href="http://goo.gl/YTGi8p">http://goo.gl/YTGi8p</a></td>
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<tr>
<td>Providers: Communicating with #cancer survivors can pose unique challenges. This guide from @theNCI can help: <a href="http://goo.gl/XRyUJH">http://goo.gl/XRyUJH</a></td>
<td>Cancer patients and survivors have unique information needs. Get the latest information from NCI on how to communicate and provide quality patient-centered care: <a href="http://goo.gl/XRyUJH">http://goo.gl/XRyUJH</a></td>
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<td>How can providers coordinate care for #cancer survivors? Register for a free @Medscape account to read more: <a href="http://goo.gl/kl9ji2">http://goo.gl/kl9ji2</a></td>
<td>Care coordination between oncologists and primary care providers is a central challenge for cancer survivors. Create a free account to learn about best practices for communication between primary and oncology care providers: <a href="http://goo.gl/kl9ji2">http://goo.gl/kl9ji2</a></td>
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<td>Providers: This checklist can help you provide resources to cancer survivors in your office. Get it today: <a href="http://goo.gl/fOmubC">http://goo.gl/fOmubC #NCSD2016</a></td>
<td>The amount of information for cancer survivors can be overwhelming. Providers: This handy checklist can help you give patients the latest info without feeling overwhelmed: <a href="http://goo.gl/fOmubC">http://goo.gl/fOmubC</a></td>
</tr>
<tr>
<td>#DYK @CancerDotNet has care &amp; treatment recommendations for patients and #cancer survivors? Learn more: <a href="http://goo.gl/doQfGE">http://goo.gl/doQfGE #NCSD2016</a></td>
<td>ASCO offers care and treatment recommendations for patients and cancer survivors. Access the resources, including short summary videos and info: <a href="http://goo.gl/doQfGE">http://goo.gl/doQfGE</a></td>
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<td>Providers: @CancerAdvocacy offers tools to help plan your patients’ #cancer care and treatment summary. Read more: <a href="http://goo.gl/IrVHHL">http://goo.gl/IrVHHL</a></td>
<td>Providers: Did you know the National Coalition for Cancer Survivorship offers tools to help you plan your patients’ care and create survivorship care plans? Learn more: <a href="http://goo.gl/IrVHHL">http://goo.gl/IrVHHL</a></td>
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<tr>
<td>Providers: @JourneyForward offers a custom #survivorship care plan builder for your patients. Access it here: <a href="http://goo.gl/HNnbh">http://goo.gl/HNnbh #NCSD2016</a></td>
<td>Providers: Wish you could build customizable survivorship care plans for your patients? This free Survivorship Care Plan Builder from Journey Forward can help you get started: <a href="http://goo.gl/HNnbh">http://goo.gl/HNnbh</a></td>
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<tr>
<td>Learn more about the health issues many cancer survivors face: <a href="http://goo.gl/Jl1l6K">http://goo.gl/Jl1l6K #NCSD2016 @CDC_Cancer</a></td>
<td>Are you interested in learning about the health issues cancer survivors face? Get info for survivors in your state and learn more: <a href="http://goo.gl/Jl1l6K">http://goo.gl/Jl1l6K</a></td>
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OTHER IDEAS TO PROMOTE NATIONAL CANCER SURVIVORS DAY®

Host or Participate in a Twitter Chat

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.

Host a Twitterview

A Twitterview is an interview conducted through Tweets. A Twitterview is a form of Twitter Chat where individuals participate in a live moderated Twitter conversation focused around a specific topic using a single hashtag.

For a Twitterview, typically an interviewer asks questions directly to the interviewee and followers can follow the conversation through an event hashtag. You may also open up the interview to questions from the audience. The benefits of a Twitterview include the creation of relevant and interesting content, dissemination of accurate and evidence-based information, increased visibility of your organization and increased engagement with followers.

Pick a hashtag. Using hashtags is a way to group and organize messages together. In Twitterviews, hashtags are used to distinguish your interview from regular Tweets in the feed. Your followers will also be able to filter and track your Twitterview posts by searching your hashtag. Symplur amalgamates popular and established Tweet Chat hashtags on health care topics. 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. Don’t be afraid to use abbreviations and acronyms, because your questions and answers including the hashtag must be under 140 characters.

Pick a date and time, then secure a speaker or speakers to be interviewed. Potentially influential speakers might include researchers, cancer survivors or caregivers, health care providers or other subject matter experts. Provide your speaker(s) with a list of what questions will be asked before the event, so they can prepare their answers in under 140 characters, which can take time and editing. Decide in advance whether you are going to open up the interview to your followers and let your speaker(s) know what to expect. Consider using a website to help manage the Twitterview 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, your organization). Number your questions starting with a “Q” for question. For example: Q1: What questions should #cancer survivors ask their doc? #NCSDChat. Your speaker(s) can either “reply” to the question you Tweet or Tweet starting with an “A” and the corresponding number. For example: A1: Start w/questions about short- and long-term side effects & screening #NCSDChat.
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.

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)
- Prepare as many questions and responses in Tweet format as possible in advance
- Involving well-known local figures may 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 and Facebook 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/about 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.”

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

Survivorship Resources

Journey Forward Survivorship Care Plan Builder: Helps create customizable survivorship care plans for patients.

ASCO Survivorship Care Planning Tools: Sample templates and resources for survivors’ long-term care needs.

LIVESTRONG Care Plan: Provides cancer survivors with information on their long-term follow-up needs

National Cancer Survivorship Resource Center: Information on treatment and follow-up care for patients and providers.

General Social Media Resources

Owly: Link shortener from Hootsuite

TinyURL: Link shortener that allows for customization of URLs to make them more memorable
Goo.gl: Link shortener that allows for tracking of clicks

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

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

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

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

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. Search “cancer,” “survivorship” or “healthy living” for relevant results on cancer survivorship.

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. Search “cancer survivors” for relevant results.

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

GLOSSARY

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

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

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

Tweets: 140-character text messages

Twitter: An online social networking and microblogging service that enables users to send and read short 140-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: @GWCancerInst

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


[http://dx.doi.org/10.1093/jncimonographs/lgq007](http://dx.doi.org/10.1093/jncimonographs/lgq007)


