

How can social media improve oncology care?

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Social media is a broad term that can include many types of “media.” Broadly speaking, media may be defined as “tools used to store and deliver information or data,” and social media is “media disseminated through social interaction.”¹ So social media is more than just Twitter or Facebook posts, it includes all sorts of socially interactive information exchange. Kaplan and Haenlein described 6 types of social media (see Table 1).² A similar social media organizational structure is used on the HowTo.gov site (<http://www.howto.gov/social-media>), a US government Web site best described as a resource to help government workers deliver a better customer experience to citizens (see Table 2 for a glossary of social media terms³). Many physicians have been hesitant to join social media for real and imagined concerns. However, despite such concerns, the Mayo Clinic has embraced social media because “our patients are doing it, so this is where we need to be.”⁴ Similarly, Ed Bennett, director of Web Strategy for the University of Maryland Medical Center, supports the use of social media because “that’s where people are. That’s the bottom line.”⁵ Social media is a tool for interacting with a changing community – of colleagues, the public, and patients – in a changing world.⁴ In addition, Timimi (@FarrisTimimi, medical director of the Mayo Clinic Center for Social Media, #MCCSM) writes in the preface to *Bringing the Social Media Revolution to Health Care* that “we must crowd-source the change we want to see in the world. Social media allows that to happen . . .”⁶

A study by McGowan and colleagues analyzed oncologist and primary care physician use of social

media.⁷ Data from that 2012 study were collected in March 2011 and showed that about a quarter of physicians used social media at least daily to obtain medical information (passive/reading). Fewer of the study participants (14%) contributed information to social media daily (active/contributor). Users at least weekly were: passive (61%) and active (46%). Another study⁸ linked physician social media properties to the national provider identifier (NPI) database, and the findings showed that physician Twitter account creation peaked in 2009, that most physicians present themselves as health professionals, that most physicians follow fewer than 1,000 people, and that the ratio of following to followers is 1:1. This information was further analyzed by Vartabedian (@Doctor_V) in his blog 33 Charts.⁹ Twitter account creation may have peaked, but I still see new oncologists joining Twitter and an increasing use of social media by them. This is encouraging as I believe that social media can improve oncology care by helping to improve practitioners’ knowledge of their highly specialized, rapidly changing field; networking among peers within the oncology community; and education of patients, the public, and colleagues.

Oncology is changing

Health care is changing. Oncology is changing. There is increasing discussion within the specialty about patient engagement, value-based care, and transparency. A few years ago, this was the language of minority voices such as advocacy groups and health policy analysts. Today, change is in everyone’s lexicon. In an article by Cosgrove and colleagues, the authors assert that patient-centeredness is the “idea that care should be designed around patients’ needs, preferences, circumstances, and well-being” and that it is “a central tenet of health care delivery.”¹⁰ That tenet is now becoming a business value that is tied to

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Disclosures The author advises or has advised the following entities in the social media space: Best Doctors, Doximity, and HealthTap, and was a member of the American Society of Clinical Oncology’s Integrated Media & Technology Committee.

Commun Oncol 2013;10:212-217 © 2013 Frontline Medical Communications
DOI: 10.12788/j.cmonc.0048

TABLE 1 Types of social media²

Type	Example ^a
Collaborative projects	Wikipedia
Blogs and microblogs	Twitter
Content communities	YouTube
Social networking sites	Facebook, Google+
Virtual game worlds	World of Warcraft
Virtual social worlds	Second Life

^aTechnologies include blogs, picture-sharing, vlogs, wall postings, e-mail, instant messaging, music-sharing, crowd sourcing, and voice-over IP, to name a few. Many of these social media services can be integrated through social network aggregation platforms.

patient satisfaction, engagement, and outcome measures that ultimately lead to better value of care.^{11,12}

To connect with “patient-engaged care” to improve quality and reduce costs, McClanahan has suggested that we need to change strategies and think about how medicine used to be practiced and how that practice has changed: “The traditional practice of medicine is a paternalistic affair – the patient goes to the doctor, the doctor tells the patient what to do, and the patient does as ordered (or more often, doesn’t do exactly as the doctor ordered). The doctor plays the part of parent. Over the past century, this accepted medical practice did much to foster the “god complex” many doctors are perceived to have to this day. Health care delivery has morphed through the decades, and we are in the infancy of a new and exciting phase – the age of patient empowerment.”¹³ In the same article, McClanahan discusses other concepts: patients need to own responsibility for their health, and as a step in that direction they need to understand their personality and decision making tendencies to aid in collaborative communication with health care providers; reliable information is clear, concise, complete, unbiased, and patient friendly; the limitations of medical care include an understanding of probabilities (and absolute vs relative risk); patient-centered homes would be a move toward prevention and wellness; and patient- disease-oriented social networks have an important role in improving quality of care and reducing costs of care (eg, Aetna and PatientsLikeMe collaboration).

In a post on the KevinMD blog,¹⁴ Ireland discussed the results of the “Better health through better communications” survey for which 1,001 adults in the United States were polled in August 2012.¹⁵ The findings showed that 80% of the respondents thought it was their doctor’s job to keep them healthy – not just to treat them when they are sick. In addition, 50% noted that an e-mail, text, or smart phone app with tips could have helped them

avoid a past health issue, suggesting that patients want more – not less – interaction with physicians. This likely will not be in the form of “open” (unencrypted) social media tools, but the trends of increased communication for social media use are in parallel.

Health care satisfaction, costs, and value will not be solved by social media alone, but it is a newer tool that we need to use to address those issues. This was realized by the National Cancer Institute’s Myeloma Steering Committee Accrual Working Group when it identified 10 possible barriers to accrual for clinical trial enrollment,¹⁶ one of which included education for patients and providers. The group now includes the use of social media in education.¹⁷ Clearly, the concepts in social media will be major drivers in oncology practice, even if specific social media tools will evolve over time.

Twitter in oncology

The styles of social media use are as varied as the people who use social media. Twitter is a useful vehicle for sharing “small feedings” of information and linking to the original manuscript or Web site through tiny uniform resource locator (URL) links – that is, long URL links that are shortened to save characters in the Twitter microblog, which limits posts to 140 characters. Twitter is used for a range of reasons: some users are thought leaders; some cross-leverage related platforms, publicize clinical trials, or network; and others are patient educators or patient advocates. Journals, institutions, the government, and cooperative groups also use Twitter as a tool to disseminate information and connect or network with other like-minded individuals or entities.

Table 3 provides a list of people one might consider following on Twitter.¹⁸⁻²⁰ It is not comprehensive, but is a good selection of Twitter people (tweeps) in various disciplines related to oncology and social media. Follow Twitter users who interest you. That may lead to a narrow focus, for example, breast cancer oncologists and breast cancer research, or your interests may evolve over time. If you are feeling overwhelmed, you can always “unfollow” or just stop checking Twitter. Using social media should not be another chore on your daily to-do list but rather a natural extension of your interests and daily information gathering. Once you follow people, you can see who follows them and who they follow for more ideas. In addition, you can see Twitter user “lists” or other online recommendations. An archive of *Oncology Times* profiles in social media is one such example.²¹ Organizations to follow may include: @AACR, @ALLIANCE_org, @ASCO, @ASCOPost, @CancerDotNet, @iConquerCancer, @theNCI, @NCITrialsatNIH, @OncologyTimes, @ASH_Hematology.

TABLE 2 Glossary of terms^{3,a}

Social media-related
App Popularized in the general lexicon by the iPhone, an app, short for application, is a software program that performs a specific function on a computer workstation or a portable device. Apps run the gamut from Web browsers and e-mail clients to specialized programs such as games, online chat clients, or music players.
Blog A shortened form of “web log.” A blog is an online journal composed by a single author or a group of authors that is updated on a regular basis. Blogs typically represent the author’s opinion and may contain comments by other readers, links to other sites, and permalinks.
Crowdsourcing Refers to harnessing the knowledge base, skills, and enthusiasm of a community of users external to an individual or organization for the purpose of collaboratively solving problems, gaining knowledge, or garnering opinions.
The cloud (cloud computing) An Internet-based computing structure whereby digital data reside on remote network servers and are provided to client computers and other devices on demand using wireless connectivity. In cloud computing, private files are not stored on the owner’s terminal but rather in a remote location, so they can be accessed from any location regardless of the physical location of the client device.
Meme A discreet representation of a concept or culturally defined behavior that is spread through the Web. An internet meme typically involves humor or satire, and its propagation is often both instantaneous and inexplicable.
Metadata or “data about data” refers to information – including titles, descriptions, tags, and captions – that describes a media item such as a video, photo, or blog post. Some kinds of metadata – for example, camera settings such as exposure, aperture, focal length, and ISO speed – can be captured automatically from the device without the need for human data entry.
Microblogging The act of broadcasting short messages to other subscribers of a Web service. For example, Twitter entries are limited to 140 characters.
Podcast A digital file consisting of audio content or audiovisual content made available for download to a portable device or PC (personal computer) for later playback. A podcast uses a continuously updated feed that lets the end user subscribe to it so that when a new file is published online, it is automatically pushed to the end user’s PC or portable digital device.
RSS (Really Simple Syndication) Sometimes also called a Web feed. It is a Web standard for the delivery of content such as blog entries, news stories, headlines, images, or video that is automatically pushed to the end user’s PC or portable digital device without requiring the user to browse from site to site. Most blogs, podcasts, and video blogs contain an RSS feed.
SMS (Short Message Service) A system that allows the exchange of short text-based messages between mobile devices. Most often, these are referred to as “texts.”
Tags Keywords added as a form of metadata to a unit of content, such as blog post or photo. Tags help users to find related topics or media, either through manually browsing on the site or by using the term with an Internet search engine.
Widget Sometimes called a gadget, badge, or applet, it is a small block of content corresponding to a piece of software code, typically displayed in a small box on a web page, for a specific purpose. Examples include weather forecasts or news headlines that are constantly updated, typically via RSS.
Wiki A wiki is a collaborative web.
Twitter-related
Tweet A post on Twitter, a real-time social messaging system and microblogging service.
Handle The unique username selected by the user, designated by an “@username” identifier, and its accompanying URL, for example, http://twitter.com/username .
Follow To subscribe to another user’s tweets or updates on the Twitter.com Web site or using a dedicated application.
Mention To refer to another user in a tweet by including that user’s @username handle.
Timeline A collected stream of tweets listed in real-time order. For example, when users log in to Twitter, their home timeline is a long stream showing all tweets from other users they follow, with the newest messages at the top.
Retweet (noun; RT) A tweet by another user that has been forwarded to you by someone you follow. RTs are often used to spread news or share valuable findings on Twitter.
Retweet (verb; RT) To rebroadcast another user’s tweet to all of your followers by adding the RT tag to the beginning of the tweet.
Modified tweet (MT) Metadata that indicates that the user has added some additional text to the original tweet being rebroadcast, typically commentary or an indication of approval/disapproval.
Partial retweet (PRT) A tweet that has been edited, usually to fit a username within the character limit.
HT Short for “heard through” or “hat tip,” a piece of metadata added to a tweet to signify that content originated with another user external to Twitter.
Hashtag A community-driven convention to allow users to add additional context and metadata to a tweet. Hashtags are added in-line to a Twitter post by prefixing a word with a hash symbol (or number sign). Hashtags (eg, #followFriday) may be used to aggregate, organize, and discover relevant tweets.
Reply A tweet posted in reply to another user’s message, usually created by clicking the “reply” button next to the tweet of interest using the Twitter Web site or a dedicated Twitter app. A reply always begins with @username.

TABLE 2 (continued)

<i>Direct message (DM)</i> Also known simply as a “message,” these tweets are private messages between the sender and recipient. DMs begin with “d @username” to specify to whom the message is directed. Only the designated recipient can read the content.
<i>List</i> A list is a grouping of Twitter users typically sharing some common attribute. For example, one user can create a list of other Twitter users that share a particular interest.
<i>Trending topic</i> A subject algorithmically determined to be one of the most popular on Twitter at the moment.
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How to get started on Twitter

Explaining Twitter is like explaining how to ride a bike – it’s easier to just do it, and once you know how to do it, you don’t forget it! I’ll offer 2 scenarios, 101 for beginners and 339 for advanced users.

Twitter 101 (Beginner)

- Sign up on Twitter (<https://twitter.com/>) and Choose a name based on your personal name or your interest/expertise (see what names are already in use by similarly minded people),
 - Adjust settings (eg, Tweet Privacy, Password, mobile, etc),
 - Include in your profile: interests, what you tweet, potential conflicts of interest,
 - Link to more information, such as Web site or profile.
- Search for and “Follow” a few interesting people or groups
- Log on to HootSuite (with established Twitter account, it allows easier following of multiple streams of information).
- Observe
- Retweet (RT)
- Tweet or Reply
- Repeat steps from Observe to Repeat

Twitter 339 (Advanced)

- Check followers and remove/block unwanted followers
- Link to other forms of social media, such as blog posts, Facebook (professional account), LinkedIn, Pinterest, or organizational Web sites to cross-leverage different platforms
- Optimization – read *The Tao of Twitter*,¹⁹ watch what others are doing, try different engagement techniques, and attend TweetUps at national meetings (eg, #ASCO13Tweetup)
- Use analytics to understand tweet impact, what works and what doesn’t for your audience
- Follow and potentially create hashtags (eg, #hpm, which act as flag/markers to content) and tweetchats (eg #hldr)

Risks, benefits, alternatives

Timimi has noted that “the biggest risk in health care SM [social media] is not participating in the conversation”²² and he has succinctly summed up the policy for participating in health care social media in 12 words: Don’t lie, don’t pry/don’t cheat, can’t delete/don’t steal, don’t reveal. Of course administrators and physicians have trouble keeping things that simple. For example, Dizon and colleagues in a working group from the ASCO IMT committee have provided background on many previous social media policies as well as commentary on pragmatics in an article on social media in oncology practice.³ The authors reviewed institutional social media policies and examples of problems encountered by physicians. They found that the risks usually involve not observing HIPAA (Health Insurance Portability and Accountability Act of 1996 Privacy and Security Rules, <http://www.hhs.gov/ocr/privacy/>).

Redfern and colleagues have published a study in which the findings suggest that Twitter “has excellent potential to connect people and organizations to enhance education, awareness and overall management of cardiovascular disease.”²³ This strategy can similarly be applied in the area of oncology. Woo in the KevinMD.com blog commented on “Why doctors should use their real name on social media.”²⁴ The full post is worth reading but the introduction is critical: “What we say on Twitter as doctors, particularly with medically related topics, carries weight. By saying we are doctors gives our tweets a greater level of authenticity that is not commonly afforded to other users. Not only do we hold power with knowledge, we are respected for the judicious use of our knowledge which has been painstakingly acquired over many years and enhanced by a responsibility for lifelong learning. It is incumbent upon us to not abuse this privilege.”

Shaywitz wrote an article about clinicians’ enthusiasm for social media while at the same time “most [of them] were not prepared to embrace it, and many were poignantly struggling to come to terms with a phenomenon they recognized as important, yet which viscerally troubled them.”²⁵ He wrote that the top concerns were more about the “internet

TABLE 3 People to follow on Twitter

Name	Twitter handle	Specialty	Known for
Tom Beer, MD	@TomBeer	Onc, GU	Author of <i>Cancer Clinical Trials</i>
Sally Church, MBA, PhD	@MaverickNY	Onc marketing consultant	Extensive Twitter coverage; blogs for national oncology meetings
Lorenzo Cohen, PhD	@DrLCohen	Integrative medicine	Director of integrative medicine at MD Anderson Cancer Center
Don Dizon, MD, FACP	@DrDonSDizon	Onc, gynecologic	ASCO <i>Connection</i> ; social media guidelines – <i>J Clin Oncol</i> ; past chair of ASCO IMT committee
Raymond Dubois, Jr, MD, PhD	@RNDubois	Onc, GI	Former president of AACR
Michael Fisch, MD, MPH	@FischMD	Onc, community practice	Palliative care; past chair of ASCO IMT
Julie Gralow, MD	@jrgralow	Onc, breast	Breast cancer and global oncology
Clifford Hudis, MD	@hudisc	Onc, breast	ASCO president, 2013-2014
Tapan Kadia, MD	@TapKadia	Onc, leukemia	A top tweeter at #ASH12
Matthew Katz, MD	@SubAtomicDoc	Radiation onc	MCCSM advisory board. Developing oncology hashtag classification system
Daniel Kraft, MD	@Daniel_Kraft	Onc, BMT	Executive director at FutureMed; chair of medicine at Singularity University
Howard Luks, MD	@hjluks	Orthopedic surgeon	Prominent social media proponent; authored a chapter of <i>Bringing the Social Media Revolution to Health Care</i> ; advisory board member for the MCCSM
Brian McGowan, PhD	@BrianSMcGowan	–	Author of #SOCIALQI: Simple Solutions for Improving Your Healthcare; CME
Robert S. Miller, MD ¹⁸	@rsm2800	Onc, breast	Analysis of Twitter usage at #ASCO10, #ASCO11; <i>J Oncol Pract</i> podcasts; editor of <i>Cancer.Net</i> ; past chair of ASCO IMT
Robert Orlowski, PhD, MD	@Myeloma_Doc	Onc, myeloma	Myeloma tweets; chair of @SWOG
Sunil Patel, MD	@CommunityOnc	Onc, community practice	Patient communication, improving access to clinical trials in the community
Kevin Pho, MD	@KevinMD	Internal medicine	KevinMD.com; known as “social media’s leading physician voice”
Mark Ragan	@MarkRaganCEO	–	CEO of Ragan Communications
Mark Schaefer ¹⁹	@markwschaefer	–	Author, <i>Tao of Twitter</i>
Farris Timimi, MD	@FarrisTimimi	Cardiologist	Medical director, MCCSM
Naoto Ueno, MD, PhD	@teamoncology	Onc, breast	Frequent tweeter, cancer survivor
Bryan Vartabedian, MD	@Doctor_V	Pediatrician, GI	33charts.com blog
Jack West, MD	@JackWestMD	Onc, lung	Global Resource for Advancing Cancer Education (cancergrace.org)
Bill Wood, MD	@WoodDB	Onc, BMT	<i>HemOnc Today</i> editorial board member
Anas Younes, MD ²⁰	@DrAnasYounes	Onc, lymphoma	Integrating FB-Twitter-etc; clinical trials outreach
Peter Yu, MD	@YupOnc	Onc	ASCO president, 2014-2015; chair of ASCO HIT work group

Abbreviations: AACR, American Association for Cancer Research; ASH, American Society of Hematology; BMT, bone marrow transplant; ca, cancer; GU, genitourinary; GI, gastrointestinal; GU, genitourinary; HIT, health information technology; IMT, integrated media & technology; MCCSM, Mayo Clinic Center for Social Media.

culture” and information sources rather than social media specifically and he noted that physicians may need “familiar, well-established processes as a way of coping with things that seem so new. At the same time, it’s hard not to get the

feeling that organized medicine is effectively solemnizing the vitality out of social media. From reading all of the dry documentation discussing social media, you’d struggle to come away with any real sense of why it’s so exciting and

TABLE 4 ASCO 10 tips for use of social media^{3,a}

1. *Get involved.* Take advantage of the greatest opportunity to disseminate credible information and influence both our peers and our patients.
2. *Engage often.* To increase your profile, provide input, respond to others, and create new content.
3. *Always identify yourself.* Everything is discoverable; anonymity is a myth.
4. *Protect patient confidentiality and privacy.* When activities involve your role as a clinician, make sure that anything done respects all relevant state and federal laws, including the Health Insurance Portability and Accountability Act of 1996.
5. *Contextualize your activities.* This enables online activities to be viewed in the appropriate context (i.e. personal opinion versus institutional viewpoint).
6. *Avoid impropriety.* Ensure that any potential conflicts of interest are readily disclosed.
7. *Give credit where credit is due.* Respect copyright, always.
8. *Professionalism is critical.* Online conduct should reflect your profession at all times.
9. *Separate the personal from the professional.* Maintain professional distance between you and your patients, in person and on line.
10. *Be aware of your institutional guidelines on social media.* If you have any questions, seek guidance.

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engaging.” A group of ASCO staff and IMT committee members created a list of 10 tips for using social media (Table 4).³ Social media is here, it is growing in use by the public, health care companies, and by health care providers. It is manageable in terms of time use and overall risk of “adversity.” It is highly relevant as a way to obtain and communicate information. Find a chaperone and take the plunge.

Acknowledgements

The author thanks Don S. Dizon, MD, David Graham, MD, Lisa J. Johnson, MHS, Claire Johnston, BA, Michael J. Fisch, MD, MPH, and Robert Miller, MD, for allowing him to use their “10 tips” list and for previewing the manuscript.

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