

Practical Guidance: The Use of Social Media In Oncology Practice

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Abstract

The penetration of social media into modern society has become a worldwide cultural phenomenon. Social media use widely accessible Web-based and mobile technologies to facilitate the creation and sharing of user-generated content in a collaborative and social manner. The uptake of social media in medicine provides new opportunities for health care professionals and institutions to interact with patients and other professionals. Oncologists may use social media as a platform for patient education and authoritative health messaging, for professional development and knowledge sharing, and for direct patient interaction, although this may be fraught with important legal and privacy concerns. In this article, a working group of the ASCO Integrated Media and Technology Committee explores how oncologists might responsibly use social media in their professional lives. Existing

social media policies from hospitals, health systems, and pharmaceutical industries are examined to identify common concepts informing the development of future guidelines. Key principles identified include establishing institutional ownership of social media activities and safeguarding protected health information. Furthermore, oncologists must not confuse the roles of provider of information and provider of care, must understand regulations related to state licensure and medical records, and must recognize the importance of transparency and disclosure of potential conflicts of interest. Social media may be particularly useful for raising the awareness of and recruitment to clinical trials, but compliance with federal and state regulations and areas under the purview of a local institutional review board must also be ensured. Examples of constructive use of social media in oncology with Facebook, Twitter, and YouTube are provided.

Introduction

Social media encompass a variety of Web-based and mobile technologies. For oncology professionals, social media may be used for professional networking, interfacing with colleagues and patients, and clinical trials activities. However, these opportunities can be accompanied by important pitfalls and risks. At present, there is little published guidance for oncologists on the appropriate use of social media in clinical practice and research, and what is available is intended for a more general audience. The aim of this article is to address this area of need for oncologists and related specialists. Of note, ASCO develops official clinical guidelines using specific methodology based on a comprehensive literature review, complemented by expert consensus opinion where necessary, but this article does not reflect that process.¹ Rather, it represents the impressions and consensus opinions of a working group composed of members of the ASCO Integrated Media and Technology Committee as it relates to the responsible use of social media for the oncology professional. We also provide a glossary of social media terminology to aid the reader in understanding social media applications (Appendix 1, online only).

We recognize that the use of social media extends far beyond the individual practitioner and is of interest to, and within reach of, health care organizations, including hospitals, small physician practices, and cancer centers. As an example, National

Cancer Institute–designated comprehensive cancer centers have at least one social media site, with most having a Facebook site, Twitter account, and YouTube channel (Appendix Table A1, online only). However, the objective of this article is to provide specific guidance to individual practitioners on how to engage in social media, keeping in mind the regulatory, personal, and professional factors associated with any online presence.

What Are Social Media?

Social media comprise a number of online and mobile resources that provide a forum for the generation, sharing, and discussion of individualized ideas and content. Social media are commonly defined by specific applications and/or Web tools, most of which are widely accessible and free to use or available at minimal cost. These applications may be categorized by purpose, including such functions as professional networking (LinkedIn, Doximity), social networking (Facebook, Google+), recommending/filtering (Yelp, Delicious), media sharing (Flickr, YouTube), content production (blogs, Twitter), knowledge/information aggregation, and location-based services (Foursquare), among others.

Physician use of social media may fall into one of three categories: professional education/continuous professional development, public health messaging or education, and direct

engagement with specific patients for purposes of clinical care. Although each of these categories provides for unique opportunities in practice development, there are inherent risks as well.

Social media can provide the platforms to relay new information (ie, research presented at medical conferences) and encourage the exchange of ideas. In a study of the use of Twitter at the 2010 and 2011 ASCO Annual Meetings, Chaudhry et al⁴ concluded that tweets often contained robust and clinically accessible information useful for both patients and clinicians. Another example of professional education is crowdsourcing, which refers to the process by which an individual or organization uses social media to harness the knowledge base, skills, and enthusiasm of a community of external users for the purpose of collaboratively solving problems, gaining knowledge, or garnering opinions. Thus, social media provide a new communication channel, enabled by Internet technology, for physicians to share and exchange medical information at a pace that was never before possible.⁵

Physicians are also using social media to educate the public. Tweets, blog posts, or comments on disease-specific discussion forums provide a more targeted form of social media education. In more interactive social media forms, the public has the opportunity to actively participate in these discussions. This represents a tremendous opportunity for physicians to disseminate legitimate, evidence-based information and counter the proliferation of inaccurate and/or anecdotal material prevalent on the Internet. However, attention to potential conflicts of interests is crucial, particularly if mentioning specific treatments (eg, drug X is a treatment for breast cancer). Fortunately, the limited research available suggests such conflicts of interest are not common.⁷

Direct patient care is probably the least-used area in social media, and depending on which social media applications are being considered, it is not clear to us that this can be done in a manner consistent with the principles of patient privacy and compliance with regulatory requirements. In addition, the use of general online social media channels for physician-patient communication in this manner raises significant issues as noted in Table 1. At a minimum, considerable thought would need to go into the disclaimers and patient consents as well as research into applicable state laws before use of social media in this manner.

However, many patients often attempt to initiate communication with their physicians on social media sites.⁶ An example of this engagement can be found in the “e-patient” movement.⁷ E-patients are defined as individuals who are “equipped, enabled, empowered, and engaged in their health and health care decisions,”⁸ with the additional implication that most e-patients are Internet-savvy consumers who use online health resources, particularly disease-specific online patient communities, for knowledge seeking and sharing. It is highly likely that with the proliferation of smart phones and other remote monitoring devices, the drive toward virtual health-related interactions will increase. We recognize the urgency to develop and refine guidelines for appropriate use.

The use of social media for patient-related interactions in online social networks is generally not advisable. In a survey of approximately 480 medical professionals (medical students,

Table 1. Issues of Concern With the Use of Social Media Channels for Physician-Patient Communication

Issue	Relevant Question
Physician licensure	Is the physician practicing medicine in the states where the patients are logging on from?
Liability protection	Does the physician's malpractice coverage reach this activity?
Abandonment	Does a physician-patient relationship come into being during social networking that must be followed through? Is there an obligation to respond to urgent communications within a set time frame?
Medical records laws	Is the social networking communication a part of the designated record set? Does it need to be made part of the chart?

resident physicians, and practicing physicians), 68% felt it was ethically problematic to interact with patients for either social or patient-care reasons.⁶ Such interactions run the risk of unintentionally violating state and federal privacy laws. For example, following patients on social media sites (eg, Facebook) may be construed as a violation of the Health Insurance Portability and Accountability Act (HIPAA) if others can “reasonably infer that person was ‘friended’ because the individual is a patient of that specific physician or is being treated for a disease of shared interest.” In such cases, HIPAA-compliant authorizations by the patient may be necessary before participation in a specific physician’s or medical organization’s social media sites.⁹ Thus, direct engagement with patients for purposes of clinical care should be avoided.

Oncology and Social Media

Whereas the above considerations are applicable to all patients and medical specialties, what are the special implications for oncology? After a cancer diagnosis, a significant proportion of cancer patients seek information about their diagnosis, prognosis, and treatment options, and in today’s society, this has largely occurred online, as well as from other patients and family members.¹⁰ Social media represent a key teaching opportunity for oncology professionals to disseminate credible, evidence-based information. Social media could also provide a key mechanism to heighten awareness of clinical trials in oncology and drive participation. Finally, social media can be useful tools for physicians to disseminate and share information with other health care professionals, such as the Twitter example from the ASCO Annual Meeting described above.⁴

Summary of Existing Guidelines/Policies

In an effort to characterize the framework on the use of social media for oncologists, we reviewed social media policies and guidelines by the American Medical Association, British Medical Association, and those publically available from 35 entities (Appendix 2, online only). Common important concepts on the application of social media are listed in Table 2.

A majority of guidelines recommend establishing institutional ownership of the social media activities. Having a central clearinghouse for all new activities is commonly required, most often through marketing departments and designation of an institutional representative. This can provide an assurance of

Table 2. Common Concepts in Social Media Policies and Guidelines

Concept
Establish ownership of activity.
Establish patient–research subject authorization and consent.
Respect confidentiality of individuals and institutions and compliance with state and federal privacy laws.
Respect copyright.
Separate personal from professional.
Disclose role, relationships, and conflict of interest.
Review state professional licensure requirements.
Review medical records policies and laws.
Review malpractice insurance coverage.
Use disclosures to reinforce that the social media communications do not constitute medical advice, responses may not be timely, accuracy of information is not assured, communications are not confidential, etc.

continuity of style and an organizational oversight of social media activities.

Respect of HIPAA concepts and protected health information were almost universally cited. Several institutions require a signed HIPAA authorization before any posting or tweeting of patient-specific information that could reasonably be traced back to the patient. Other institutions, particularly medical schools, expand this concept to include consents from or about research subjects, volunteers, and even cadavers. The connection to an oncologist on social media sites can, intentionally or unintentionally, broadcast private information (ie, diagnosis or prognosis) to third parties. As such, it is essential that any contact (including any patient-specific information) be initiated and disclosed solely by the patient. Regardless of situation, all health care providers must vet the information posted as the dissemination of erroneous or nonauthoritative information could reflect poorly on the provider, even if done in a private capacity. Privacy disclosure concerns also extend to proprietary information. Although most often cited in industry policies, this concern was also reflected in larger health system organizations.

Being mindful of privacy considerations is not the same thing as accounting for security risks. The security risks inherent in Web-based portals and platforms hosting the social media raise another concern. From the institutional perspective, social media sites create risks to otherwise secure information systems through Web-based mail (which is not always vetted through enterprise mail-filtering) or “phishing” attacks through open or public comment platforms on blogs.

The separation of personal and professional social media activities is addressed in a majority of policies. Most institutions recommend not using institutional graphics or logos on personal social media pages and encourage (if not require) a disclaimer separating personal activity from institutional activities. While most social media sites require an e-mail address to establish activity, many institutional policies disallow the use of work e-mail addresses in this manner, reflecting a concern for Internet technology security and the importance of separating personal and professional activities.

Acknowledgment of conflicts of interest is also a concern. There are occasionally arrangements made for social media postings and activity in exchange for money or other considerations. Most policies prohibit these arrangements and required full disclosure of relationships in conjunction with disclaimers.

As a matter of education, many policies discuss the potential risks to reputation and the global nature of social media. Recognition that postings made under your account can be copied by “friends” and widely disseminated without your approval or even knowledge is important. In addition, even though personal connections and networks may appear to be local, these activities can have global access and reach. The best discussions relate to the fact that social media postings can have long-lasting impact on professional or personal reputations. Mechanisms to monitor one’s online reputation are available through professional firms and online services. As an example, the American Medical Association partnered with Reputation.com in 2011 to provide online reputation-management services.

Many social media sites include “friending” other members to establish and grow one’s personal network. The friending of patients, or even ex-patients, is strongly discouraged in many policies in an effort to preserve the boundaries of the professional physician-patient relationship. A large online database of social media policies includes: <http://socialmediagovernance.com/policies.php>.

We believe it is critical that a provider’s own social media policy be followed, and review of the institution’s policy on a regular basis is prudent. Examples of the negative and positive use of social media in medicine are found in Appendix Table A2 (online only).

Social Media and Clinical Research

The timeliness of any clinical trial is dependent on its ability to enroll patients efficiently. The consequences of either not meeting accrual goals or extending recruitment time are many: delays before a potentially active therapy becomes widely available; requirement for more financial resources than were originally expected; and ultimately, diversion of funds need to launch other studies.¹⁰ Unfortunately, for phase III randomized trials, the degree of uncertainty with treatment arms and the process of randomization generally result in slower recruitment compared with other study designs.

Social media have the capacity to become a very useful tool for clinical researchers, but their use must be in compliance with regulatory laws at the federal, state, and local levels. Strategies that aim to inform and educate the public on the condition being studied have been linked to improvements in recruitment. This was shown in one systematic literature review, in which the following mechanisms were associated with higher recruitment: use of an interactive computer program (relative risk [RR] 1.48, 95% CI, 1.0 to 2.18), attending an education session (RR 1.14, 95% CI, 1.01 to 1.28), addition of a health questionnaire (RR 1.37, 95% CI, 1.11 to 2.74), and watching a video about that condition (RR 1.75, 95% CI, 1.11 to 2.74).¹¹ All four of these strategies lend themselves to social

media technology by use of Web sites like YouTube, professional blogs, and even Twitter.

In addition to their potential use as tools for recruitment, sites such as Facebook, Twitter, LinkedIn, and Google+ provide an infrastructure that allows investigators to interact with the public in new ways: to create interest in new clinical trials, to enable screening on a real-time basis, to communicate with enrolled subjects, to collect data, and to publicize the release of completed studies.

Along with these opportunities to engage the public are risks and considerations that all oncologists must be aware of. As an example, communicating with an individual about whether he or she might be eligible for a particular trial can give reveal personal health information. Other examples include information that could serve to “un-blind” a trial or reveal results before the data are properly analyzed. Researchers should be mindful of their confidentiality obligations under clinical trial arrangements.

The institutional review board (IRB) is a panel that reviews and is authorized to approve, require modification, or disapprove all research activities covered by the Department of Health and Human Services (DHHS) Code of Federal Regulations.¹² It is important to remember that a study begins at the point of recruitment, and any activity related to the conduct of the research project is potentially subject to IRB review.^{12,13}

With respect to patient recruitment, the IRB has the duty and the responsibility to review all study recruitment material, including any advertising. Specifically, the Office for Human Research Participations suggests that Web sites must be subject to the same requirements as print media.¹⁴ Although this seems clear, it does not address what types of communication are under the scope of IRB review and which ones are not. The question, then, becomes: when is patient communications advertising?

To address this basic question, as well as other concerns, the Office of the Inspector General (OIG) released guidance regarding the use of clinical trial Web sites.¹⁵ In the report, the OIG determined that “current guidance does not require IRB review if the clinical trial listing is limited to the following basic trial information: title, purpose of the study, protocol summary, basic eligibility criteria, study site location(s), and how to contact the study site for further information. This is a sound policy that we do not propose to change.”^{15(p16)} Thus, it appears clear that clinical trial registration Web sites (eg, www.clinicaltrials.gov) do not require IRB review for entries posted. The OIG went on to note undefined areas where IRB review may be needed. In the report, mention was made of Web sites that “provide more than the prescribed basic trial information mentioned in current guidance.” For these areas, uncertainty exists

Table 3. Social Media and Clinical Trials: Considerations

Platform	Question	Response
Facebook		
Before creation of the page	Who owns the page (you, sponsor, or institution)?	The creator of the trial page is responsible for content.
	Is your Institution aware the page will exist?	Engage your institution's media department so you are aware of guidelines.
	Is the trial sponsor aware you plan to do this?	Ensure the page is allowed under the clinical trial agreement.
	Is IRB review required?	Consult local research administration to determine whether the page meets institutional or state definitions of advertising.
Placing content on the site	Are you placing content on that is consistent with the trial?	Refrain from providing significant details of any trial. Only basic study information should be available.
	Where is the content coming from?	Beware of using proprietary information.
	Is there a potential for liability or claims of false advertising?	Avoid making claims of treatment efficacy or side effects. Use disclaimers to reduce risk.
Controlling access	Who is your audience?	Will it be publicly available for the general public to “like” and follow?
Security monitoring	Who will monitor posts?	A mechanism to protect against HIPAA violations and inappropriate posting must be in place.
Communication	Do you plan to interact with individuals who post?	What type of information will be shared? Avoid using social media to screen for eligibility; always refer to your institution.
		Be aware that you cannot be assured that people are using their true identity when posting.
Twitter		
Communication	What is the purpose of using Twitter?	If raising awareness of trial, make sure to link to a site where more information can be found (eg, clinicaltrials.gov). If protocol specific communication method, make sure it is allowed per protocol. Avoid disclosure of preliminary results or nonpublic information.
Blogs		
Communication	Are you involved in the study?	Bloggers involved in the conduct of a study should not write about that trial or drug because such commentary (depending on the writer's role) may be reasonably viewed as advertising.
	What will you write about?	Avoid discussing specifics related to the trial or patients treated on the trial, particularly if there is a reasonable chance this information could lead to identification of the patient.

Abbreviation: HIPAA, Health Insurance Portability and Accountability Act.

regarding whether or not they require review by an IRB. As such, local institutional policy must take precedence in this area of uncertainty regarding IRB approval—as well as approval by an institution's legal and compliance departments—before using social media for participant recruitment is advised.

Table 3 provides principles that we encourage investigators to consider on the appropriate use of social media and the Internet as it relates to the conduct of clinical research. Our aim is not to supplant the guidelines in place at the individual institution level, but to address the real concerns researchers have when it comes to the use of the Internet. We propose that any actions that may risk patient autonomy, respect, and confidentiality are inappropriate to take on independently. Such activities warrant the review of the IRB.

An attractive application of social media pertaining to clinical research in oncology is the creation of a trial-specific interactive page by an investigator or clinical research organization. This page can be used in multiple ways: to publicize the trial itself, as a platform for education about the disease being studied, and as a means of collecting data such as patient-reported outcomes. As exciting as these possibilities seem, we do not suggest they represent an appropriate use of social media, principally on the basis of privacy concerns. There is currently no way to either verify information posted by prospective participants or to ensure the accuracy of postings. Most important, neither the investigator nor the institution owns their Facebook page, and as such, data may be collected without their awareness or permission.

Should one entertain the idea of a trial-specific Facebook page, IRB review of the content and design to ensure they meet institutional guidelines with respect to both noncoercive content and the assurance of privacy should be strongly considered. Of note, these considerations about Facebook and similar sites are not just applicable to the clinical trial situations; they are equally applicable to the kinds of engagement discussed earlier in this article.

Summary

Social media hold the promises for a more interactive educational experience and enhanced opportunities to influence care delivery as well as expanding and speeding the dissemination of information both inside and outside the oncology community. Given the popularity and almost universal appeal of social media we encourage oncology providers and institutions to learn more and engage in this ongoing evolution.

Protection of patients as well as physicians is critical. Regulations that exist to protect patients' privacy and care should also be considered to apply to the use of social media. The protection of both the institution's and physicians' reputations as well as patient privacy needs to be carefully held. Physician protection would ex-

tend to the separation of personal and professional use of social media. In addition, the importance of transparency cannot be overestimated. Any involvement by physicians in social media, whether it is personal or professional, if not entirely transparent, can lead to repercussions from institutions or to professional reputations. The explosion in the use of social media inside medical care is without precedent. Social media provide another avenue for community development that patients, particularly those with cancer, are often seeking. Even though a number of uses for social media have come to the forefront, it is wholly expected that new and unforeseen uses, benefits, and potential concerns will arise in the future.

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Appendix

Appendix 1: Glossary of Social Media Terms

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 like games, online chat clients, or music players.

Blog. A blog, a shortened form of “web log,” 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. 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). The cloud is 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 meme is 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. 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.

Micro blogging. Micro blogging is the act of broadcasting short messages to other subscribers of a Web service. For example, Twitter entries are limited to 140 characters.

Podcast. A podcast is a digital file consisting of audio content or audiovisual content made available for download to a portable device or personal computer (PC) 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. RSS (Really Simple Syndication), sometimes called a Web feed, 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. SMS stands for 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. Tags are 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. A widget, sometimes called a gadget, badge, or applet, 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 site that can be directly edited by anyone with access to it.

Twitter Related

Tweet. A post on Twitter, a real-time social messaging system and microblogging service.

Handle. The unique username selected, 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 a user logs 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, 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.

Direct message (DM). 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.

List. 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.

Trending topic. A subject algorithmically determined to be one of the most popular on Twitter at the moment.

Appendix 2: Institutional Policies on Social Media Reviewed

Beth Israel Deaconess Medical Center – Web Site Terms of Use
 British Medical Association – Social Media Guidance
 Carolina Health Care System – Social Media Guidelines
 The Centers for Disease Control and Prevention – Social Networking Comment Policy
 Cleveland Clinic – Social Media Policy
 Compass Medical PC – Social Media Policy
 Danbury Hospital – Blogging Policy
 Duke University Health System – Facebook Guidelines
 Fairfield Medical Center – Social Media Guidelines
 Hospital Sant Joan de Deu, Barcelona – Social Media Policy
 Inland Northwest Health Services – Social Media Policy
 Kaiser Permanente – Social Media Policy

Lehigh Valley Health Network – Social Media Guidelines
 Massachusetts General Hospital – Social Media Policy
 Mayo Clinic – Sharing Mayo Clinic
 Methodist Healthcare – Social Media/Online Communications Guide
 Ministry and Affinity Healthcare – Social Media and Employee Guidance
 Mount Sinai School of Medicine – Social Media Guidelines
 The Ohio State University Medical Center – Social Media Policy
 Pfizer – Corporate Responsibility
 Roche – Social Media Guidelines
 Sentara Healthcare – Social Media Policy
 Sutter Health – Social Media Tip Sheet
 University of California, San Francisco – Social Media Guidelines
 University of California, Irvine – Employees Participation Policy/Social Media
 University of Minnesota – Social Networking
 University of Missouri Health Care – Social Media Guidelines
 University of Texas MD Anderson Cancer Center – Social Networking Guidelines for Employees
 US Medical Supplies – Social Media Policies
 Vanderbilt University School of Medicine – Social Media Policy
 Vertex Pharmaceuticals – Twitter Guidelines
 Washington University – Social Media Policy
 West Virginia University Health Sciences Center – Social Media Guidelines
 Wright State University School of Medicine – Social Media Policy

Table A1. Social Media Presence in National Cancer Institute–Designated Comprehensive Cancer Centers

Institution	Facebook	Twitter	YouTube	Other
Abramson Cancer Center	Pennmed	Pennmedicine	Pennmedicine	Blog
Alvin J. Siteman Cancer Center	SitemanCancerCenter	SitemanCenter	SitemanCancerCenter	
Arizona Cancer Center	Arizonacancercenter	AZCancerCenter		
Case Comprehensive Cancer Center	CaseCCC			
Chao Family Comprehensive Cancer Center	UCI-Chao-Family-Comprehensive-Cancer-Center	UCICFCCC		
City of Hope Comprehensive Cancer Center	Cityofhope	Cityofhope	Cityofhopeonline	Flickr
Dana-Farber Cancer Institute	Danafarbercancerinstitute	Danafarber	DanaFarberCancerInst	Google+ Blog
Duke Cancer Institute	DukeCancerInstitute	Dukecancer	DukeCancerInstitute	
Fox Chase Cancer Center	FoxChaseCancerCenter	FoxChaseCancer	FoxChaseCancerCenter	LoveVersusCancer.org
Fred Hutchinson/University of Washington Cancer Consortium	HutchinsonCenter	HutchinsonCtr	HutchinsonCenter1	Wordpress
Georgetown Lombardi Comprehensive Cancer Center	GeorgetownLombardi	LombardiCancer		
H. Lee Moffitt Cancer Center & Research Institute	Moffitt-Cancer-Center	MoffittNews	MoffittNews	
Herbert Irving Comprehensive Cancer Center	Columbiamednews	Columbiamednews	Columbiaps	
Holden Comprehensive Cancer Center	University-of-Iowa-Hospitals-Clinics	Uihealthcare	UIHC	
Huntsman Cancer Institute	Huntsman-Cancer-Institute	Huntsmancancer	Huntsmancancervideos	Vimeo
Jonsson Comprehensive Cancer Center	Uclafightscancer	Uclajccc	UCLAJCCC	
Masonic Cancer Center	University-of-Minnesota-Medical-Center-Fairview		UofMMedicalCenter	
Massachusetts General Hospital Cancer Center	Massgeneral	MassGeneralNews	MassGeneralHospital	FourSquare LinkedIn
Mayo Clinic Cancer Center	MayoClinic	Mayoclinic	Mayoclinic	Mayo Clinic Social Media Network LinkedIn Google+ Flickr Pinterest Blogs
Memorial Sloan-Kettering Cancer Center	Sloankettering	Sloan_kettering	Mskcc	
Moores Cancer Center	UC-San-Diego-Moores-Cancer-Center	UCSDHealth	UCSDMedicalCenter	LinkedIn
Norris Cotton Cancer Center	Dartmouthcancer	CancerDartmouth	DartmouthHitchcock	Podcasts
Robert H. Lurie Comprehensive Cancer Center	Chicago-iL/Lurie-Cancer-Center		luriecancercenter	
Roswell Park Cancer Institute	Roswellpark	roswellpark	Rpicreative	CancerConnect
Sidney Kimmel Comprehensive Cancer Center, Johns Hopkins University	Johns.hopkins.medicine	Hopkinsmednews	johnshopkinskimmel	Blogs Podcasts ShareCare
St Jude Children's Research Hospital	Stjude	Stjude	Mystjude	
Stanford Cancer Institute-Stanford Medicine	Stanfordmedicine	Sumedicine	Stanfordhospital	Blog
	Stanfordhospital	Stanfordhosp		Flickr
The Barbara Ann Karmanos Cancer Institute	Karmanoscancer	Karmanoscancer		Wordpress
The Cancer Institute of New Jersey	TheCINJ		CancerInstNJ	
The Ohio State University James Cancer Hospital and Solove Research Institute	TheJamesOSU	Thejamesosu	OSUTheJames	
The University of Texas MD Anderson Cancer Center	MDAnderson	Mdandersonnews	Mdandersonorg	Podcasts and video

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Table A1. (Continued)

Institution	Facebook	Twitter	YouTube	Other
UAB Comprehensive Cancer Center	UABComprehensiveCancerCenter	UABCancerCenter	UABLifestories	
UC Davis Comprehensive Cancer Center	UCDavisCancer	UCD_Cancer		
UCSF Hellen Diller Family Comprehensive Cancer Center	DillerCancerCenter	Ucsfcancer		
UNC Lineberger Comprehensive Cancer Center	Unclineberger	Unc_lineberger	Unclineberger	Flickr
University of Chicago Comprehensive Cancer Center	University-of-Chicago-Comprehensive-Cancer-Center	UCCancerCenter	UChicagoMedCenter	
University of Colorado Cancer Center	Coloradocancercenter	Cocancercenter		
University of Michigan Comprehensive Cancer Center	UniversityofMichiganComprehensiveCancerCenter	UMCancerCenter	UMCancerCenter	Flickr
University of Pittsburgh Cancer Institute	UPMC-Cancer-Centers		Upmc	
USC Norris Comprehensive Cancer Center	Keck-Medical-Center-of-USC	USCHealthNews	USCKeck	
UW Paul P. Carbone Comprehensive Cancer Center	Uwhealth	Uwhealth	Uwhealthwi	Google+ Pinterest Blogs Flickr
Vanderbilt-Ingram Cancer Center	VanderbiltIngram	VUMCancer	Vanderbilthealth	ENewsletter
Wake Forest Comprehensive Cancer Center	Wakehealth	Wakehealth	Wakeforestbaptist	
Yale Cancer Center	Yale-Cancer-Center			Podcasts

Table A2. Examples of the Use of Social Media in Oncology

Social Media Platform	Example
Facebook	
Patient disclosure in Facebook posts	<p>A Rhode Island physician found herself in legal trouble after she posted her clinical experiences attending in an emergency room [Doctor busted for patient information spill on Facebook]. Although she did not mention names or willingly disclose personal health information, a description of the injuries sustained by one patient was of sufficient detail that it allowed a third party to identify that patient. The physician was subsequently fined by the state and had her privileges terminated at that hospital.</p> <p>Source: Conaboy C: For doctors, social media a tricky case. <i>Boston Globe</i>, April 20, 2011. Available at: http://www.boston.com/lifestyle/health/articles/2011/04/20/for_doctors_social_media_a_tricky_case/?page=full.</p>
Facebook posts to spur action	<p>"Earlier this year, [Dr. Thomas] Lee used Facebook to promote his practice's annual fitness challenge. More than 100 people-patients, employees, and affiliated hospital staffers-posted Facebook photos of themselves taking part in weekly challenges, like climbing 20 flights of stairs, and posted updates on their progress. . . Lee says, "People posted their numbers, and they kept getting higher and higher. . . The sense of competition was very motivational."</p> <p>Source: Haupt A: How doctors are using social media to connect with patients. Available at: http://health.usnews.com/health-news/most-connected-hospitals/articles/2011/11/21/how-doctors-are-using-social-media-to-connect-with-patients?</p>
Facebook and YouTube to create an online community of cancer survivors	<p>At the Mayo Clinic in Florida, Dr Herbert Wolfson's group aimed to establish an online Facebook community to help in recovery following surgical treatment for esophageal cancer. It has allowed connection between families who would never have met and serves as a resource to exchange medical information, share coping strategies, and learn more through links to educational material presented on YouTube. Dr Wolfson also notes that many patients that met through Facebook go on to establish offline connections.</p> <p>Source: Wolfson H: Social media for survivors of esophageal cancer. Presented at the 2011 Annual Meeting of the American College of Gastroenterology, Washington, DC. Available at: http://download.abstractcentral.com/ACG2011/proofs/P3.html.</p>
Twitter*	
Sharing cancer-related information	<p>In a report on the use of Twitter at the 2011 ASCO Annual meeting, several physicians cited it as an opportunity to contextualize the data being presented. This allowed for a less solitary experience and the opportunity to gain real-time feedback on data by following what others were saying in their tweets.</p> <p>Source: Scientific meetings through the lens of Twitter. <i>NCI Cancer Bulletin</i>, May 2011. Available at: http://www.cancer.gov/ncicancerbulletin/053111.</p>
Declarations to inspire or influence providers and/or the lay public	<p>For Dr Christian Sinclair (@ctsinclair), Twitter helps him "inform the public. . . and if there are patients or families who need this knowledge, [he] can help them because of this network." In this example, Dr Sinclair describes the use of Twitter to help individuals connect with local hospices.</p> <p>Source: Chen PW: Medicine in the age of Twitter. <i>New York Times on the Web</i> June 11, 2009. http://www.nytimes.com/2009/06/11/health/11chen.html.</p>
Highlighting clinical trials and special causes	<p>Many organizations and physicians use Twitter as a means to highlight research interests and current clinical trials. However, one of the top social media stories from 2011 was the "bucket list" of 15-year-old Alice Pryne (#alicebucketlist). Faced with terminal lymphoma, she wrote of her own bucket list of things she wished to accomplish before she died, one of which was to encourage as many people as possible to become bone marrow donors. Her bucket list became an Internet phenomenon, and one of the top Twitter trends in oncology for 2011 and has increased the awareness of bone marrow registries worldwide.</p> <p>Source: O'Neill M: "What is Alice's Bucket List & Why Is It Trending?" <i>Social Times on the web</i> June 9, 2011. http://socialtimes.com/alice-bucket-list_b65803.</p>

* Although tweets tend to be informal and more personal than many other forms of communication, use of profanity or negative judgments about colleagues reflects poorly on any health professional regardless of whether the Twitter account is for personal or professional use.