Review Article

# Social Media and Health Policy

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## ABSTRACT

The current era is characterized by the vibrant and rapidly evolving communication technologies. Communication in any form has evolved and now includes media such as Facebook, Twitter, and Instagram to report a few. Communicating and consuming information has shifted from the more traditional ways to new ones as part of this communication evolution. Cancer is an area of healthcare where such social media have been championed either to promote public awareness and drive campaigns or influence political decision-making. Although health-care lags behind many other industries in adopting social media as a part of a business or policy strategy, the increasing engagement of patients, the public, and the policymakers in social media raised the need for integrating these tools as a part of an overall program to support the strategic imperatives of the health care. As these and other new ways to communicate are introduced to the world and injected into our cultural and political systems, the question that raises here is: "How successful are social media in influencing health policy?"

**Key words:** Cancer, Facebook, health policy, social media, Twitter

## Social Media Definition

The context of social media is broad and constantly evolving with new ways of communication emerging rapidly. The term social media mostly refers to internet-based tools that allow individuals and communities to gather and communicate, to share information, ideas, personal messages, images, and other content, and in some cases, to collaborate with other users in real time.[1]

## Why People Use Social Media?

There are many varying reasons that people choose to integrate social media in their lives. For example, patients and caregivers can be active on social media channels. Their activities include tweeting, blogging, and building peer-to-peer communities on Facebook and Twitter where they openly share and discuss information (usually in the form of a positive or negative experience) regarding their contact with the health-care services.[2] These social media

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tools have also increased the ability of patients to find others with their conditions and to discuss treatment options, suggest lifestyle changes, and to offer support.

Social media are not exclusively used by the patients and caregivers but also by health-care professionals. These tools can be used to improve or enhance professional networking and education, organizational promotion, patient care, patient education, and public health programs.[3] The value of social media tools has also been acknowledged in research dissemination.[4]

The use of social media within the political arena context has become increasingly apparent in recent years. For example in the United States, members of the Congress have been encouraged to use Twitter (through the tweet congress initiative) as a means to encourage government transparency, communication, and engagement with the public.[5] In an evaluation of this initiative, the Congressional Research Services concluded that the use of Twitter increased the ability to collect and transmit real-time information from constituents that could be influential for policy or voting decisions.[6]

## Why Influencing Cancer Policy is Possible?

Social media platforms such as Facebook, Twitter, or Instagram have an increasing user base across the world. It is estimated that these three social media platforms had, respectively, more than 1.86 billion, 317 million, and 500 million monthly active users in December 2016.[5,7] The increasing embracement of social media platforms by users with a health agenda and within the health-care context conveys the message that social media can be a valuable tool for disseminating and consuming information, promoting public awareness and influencing policymaking about health. Public policy referred to government policy such as any statement or position taken by the government or government departments.

The power of the internet to disseminate information is reflected on the fact that is the second highest source of science news.[7] This power of disseminating information has contributed to the potential of social media tools to support behavioral change, participation encouragement, and self-engagement,[8] and it fosters patients' autonomy by complementing the information provided by health-care professionals.[9]

Political disengagement in various contexts (including health) has become somewhat a serious problem in countries around the world. This is partially attributed to the rapidly declining levels of trust between policymakers and the public (policy end users). However, this is a threat to the foremost duty of any legislative person: that of representing and promoting the interest of the public. Furthermore, this ultimately leads to a misalignment between the expectations of the public and those of the policymakers which further fuels political disengagement. Since this issue has been identified by policymakers as an important problem that needs urgent and well-thought attention, ways have been explored how to promote public engagement in various and sustainable ways. Policymakers' role in public engagement has developed to such a point that in some cases, it has been integrated into their more traditional roles of legislation, scrutiny, and representation.[10] The past decade has marked the shift from the rather traditional model of parliaments simply as institutions that represented the public without the necessity to actively communicate and engage with this same public.[11] In the new era, the use of social media has provided a direct access to citizens (without the mediation by the media or parties), direct access to younger members of the public that were previously considered a hard-to-reach group, the possibility provided to the public to generate the conversation on specific areas of concern to report a few. Particularly, in the context of citizen engagement, it has been argued by health-care researchers that "engagement of average citizens and civic leaders is leading to a grassroots restructuring of local environments to be conducive to health and well-being."[12] Social media engagement offers the potential to improve societal and global health by involving individuals in the health research and the actual policymaking process.[13] Successful public engagement needs to focus explicitly and directly on health content, with the social media engagement being driven by conversational, collaborative, socialized, and decentralized messaging.[13]

Through the shaping of public opinion, social media can also influence policymakers.[10] As policymakers abide to the needs of the public, it becomes apparent that the shaping of public opinion on a specific topic will call for the policymakers engagement and appropriate response. This has been a popular strategy in the context of public health where it has been utilized as the means to increase public awareness and mobilizing decision-makers for policy change.[14]

Similarly, to the people's role in influencing public policymaking, health-care professionals are also in a unique position to actively design and create health policy. The reasons lie in the fact of having positive role models, the insightful experience of frontline health care, personal connections, undertaking research and implementing research in practice, or gaining direct experience in strategy development.[15] O'Connor[16] advocates in favor of information technology including social media as another potential avenue to encourage nurses to participate in policy

design, by enabling them to network and communicate with senior leaders and legislators.

## Threats to Using Social Media

The use of social media tools is not without risks in the health-care arena. As many cases in social media highlight, the information disseminated through social media platforms can involve high levels of self-disclosure (e.g., patient disclosing information on her experiences during the chemotherapy session). Murthy and Eldredge[2] claim that this creates different sociological expectations of health-related behavior on social media. Other ethical questions to be considered are whether there is violation of patients' privacy by listening in or soliciting comments online. The presence of using social media platforms is not universal, so the question raises here of whether health-care professionals or policymakers are ignoring the people who do not participate (or are not as active) in social media? Following, the most frequent and important threats to the users of social media tools are briefly presented.

As with traditional online media, the main limitation of health information found on social media is a lack of quality and reliability.[17] Issues such as the unknown identity of medical authors of medical information found on social media sites are often unknown or are identified by limited information, which poses as a threat to the validity and reliability of the information being conveyed. In addition, there appears to be a paradox when comparing evidence-based medicine to social media in regard to anecdotal reports. While these reports are emphasized in social media relying on individual patient stories, evidence-based medicine de-emphasizes anecdotal reports. Despite the value that these anecdotal reports bare, the way and level of their utilization need to be made with caution.

Health-care professionals as popular users of social media can also experience negative outcomes as a result of their presence in such media platforms. Perhaps one of the greatest risk associated with the use (or misuse) of social media is the posting of unprofessional content. This can, in turn, have a negative impact on the health-care professionals and affiliated institutions.[1] Whereas behavior in social media can be perceived by medical and nursing boards as unprofessional, this can lead to imposing restrictions or suspending or revoking licenses.

The risk that health-care professional might unintentionally disseminate sensitive proprietary patient data existed before social media. However, with social media and the rise of international hacking, the potential for widespread of private information following a breach poses much greater risk to patients. The lack of a clear understanding of privacy in the context of social media and health-care organizations can threaten patient's autonomy and the therapeutic relationship of trust.[18] What is fundamental in maintaining the patient's autonomy, and dignity is their right to control the collection, use, and disclosure of personal information.

## Conclusion

With the inexorable growth of social networking in health care, and the rising influence of social media on individual health care, social media is attracting the attention of researchers, clinicians, health-care organizations and policymakers intrigued by its affordability, influence, and virtually universal reach. Policymakers in the health-care context view social media as a valuable tool to increase public's engagement to devise and implement policies to deliver public services that meet the needs of society. In the same light, the engagement of health-care professionals in the process of policy developing is equally important and needs to be pursued by the policymakers so that valuable input from frontline nursing staff, whose clinical, educational, and research expertise could add value to policy's scope and direction. Social media hold a great potential in disseminating health-related information as they provide the public, patients, and health professionals with a platform to exchange on different health matters potentially affecting population health outcomes. Furthermore, the use of media platforms as a real-time learning resource will potentially provide actionable insights into patients' and caregivers' needs and preferences across the continuum of care. Online storytelling by patients and caregivers active on social media can complement traditional methods of capturing a range of perspectives on the quality of care. Finally, social media can promote awareness, health promotion, provide peer support, and extend access to health interventions all of which bring a new dimension to health care. Despite its great potential, social media when used carelessly, the dangers these technologies pose to patients and health-care professionals are formidable.

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