SOCIAL MEDIA: A COMPREHENSIVE KNOWLEDGE SYNTHESIS AND CASE STUDIES OF APPLICATIONS IN MEDICINE AND HEALTHCARE

by

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ABSTRACT

Social media are dynamic tools that have allowed virtual socialization and dialogue to emerge on the Internet. Although the term is often used synonymously with social networking and web 2.0, social media have penetrated intra-personal and professional communication extensively and their use has become essentially tacit knowledge among teenagers, and increasingly in the general population. To date, the value of social media to health professionals as a tool for clinical activity and in public health has not been extensively studied.

Blogs, Facebook, Twitter, Wikipedia, YouTube, Flickr, Mashups and Second Life are no longer obscure words in the vocabularies of highly technical people. These spaces are starting to replace face-to-face interaction in a large majority of populations and institutions.

Healthcare has not been isolated from this trend. The evidence base for the use of social media is rising exponentially, with applications in medical education, collaboration, surveillance, clinical trials, public health, and health services research. However, the comprehensive documentation of how, where and why these tools are affecting health(care) is not well documented.

This thesis provides a comprehensive review of the impact of social media in medicine and health(care). Chapter 1 provides an overview of the conceptual and theoretical frameworks, along with the assumptions, that guide the use of social media in the health domain. Chapter 2 synthesizes the what, where, when, how and why social media are being adopted, structured according to the different functionalities of social
media. These include blogs, microblogs, social networking, professional and thematic networking, wikis, media sharing tools, mashups, collaborative filtering/bookmarking and other social media (e.g., Second Life). Chapter 2 also discusses a series of clinical implications and recommendations for stakeholders wishing to engage these dynamic spaces. Chapter 3 reviews three recent administrative and judicial cases that have emerged from the inappropriate use of social media and Chapter 4 concludes with the main implications of and significance of the findings. Further research is clearly required to solidify the evidence on the use of social media in health care and to explore and document its economic, clinical, governance and tactical impact and utility.
PREFACE

The third case study in Chapter 3 was published by Francisco J. Grajales III as a letter entitled *One Step Forward, Two Steps Back: Why Can’t We Protect Doctors Who Put Patients First*? This work can be found in the Journal of Participatory Medicine under the Creative Commons Public License. It has also been archived and curated at http://www.jopm.org/opinion/letters/2011/08/08/one-step-forward-two-steps-back-why-can%E2%80%99t-we-protect-doctors-who-put-patients-first/
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
<td>i</td>
</tr>
<tr>
<td>PREFACE</td>
<td>iv</td>
</tr>
<tr>
<td>TABLE OF CONTENTS</td>
<td>v</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>vi</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>vii</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>viii</td>
</tr>
<tr>
<td>DEDICATION</td>
<td>ix</td>
</tr>
<tr>
<td><strong>CHAPTER 1: A Review of the Foundations for this Research</strong></td>
<td></td>
</tr>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Conceptual Frameworks</td>
<td>3</td>
</tr>
<tr>
<td>Theoretical Frameworks</td>
<td>12</td>
</tr>
<tr>
<td>Objectives</td>
<td>17</td>
</tr>
<tr>
<td><strong>CHAPTER 2: A Review of the Where, How, and Why Social Media are Being Used</strong></td>
<td></td>
</tr>
<tr>
<td>Introduction</td>
<td>18</td>
</tr>
<tr>
<td>Method</td>
<td>19</td>
</tr>
<tr>
<td>Results</td>
<td>25</td>
</tr>
<tr>
<td>Discussion</td>
<td>61</td>
</tr>
<tr>
<td>Clinical Implications</td>
<td>71</td>
</tr>
<tr>
<td>Conclusion</td>
<td>73</td>
</tr>
<tr>
<td><strong>CHAPTER 3: A Selection of Recent Judicial and Administrative Case Studies</strong></td>
<td></td>
</tr>
<tr>
<td>Introduction</td>
<td>75</td>
</tr>
<tr>
<td>Case Study 1</td>
<td>76</td>
</tr>
<tr>
<td>Case Study 2</td>
<td>77</td>
</tr>
<tr>
<td>Case Study 3</td>
<td>79</td>
</tr>
<tr>
<td>Discussion</td>
<td>80</td>
</tr>
<tr>
<td>Conclusion</td>
<td>87</td>
</tr>
<tr>
<td><strong>CHAPTER 4: Conclusions</strong></td>
<td></td>
</tr>
<tr>
<td>What We Know</td>
<td>88</td>
</tr>
<tr>
<td>What We Would Like to Know</td>
<td>90</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>92</td>
</tr>
</tbody>
</table>
LIST OF TABLES

Table 2.1: MEDLINE Search String.................................................................23
Table 2.2: Categorical Definitions of Social Media........................................24
Table 2.3: MedGadget Top Medical Blogs for 2010........................................29
Table 2.4: A Selection of Common Twitter Terminology...............................31
Table 2.5: 140 Healthcare Uses for Twitter (Synthesized).............................33
Table 2.6: 61 Medical Wikis...........................................................................46
Table 2.7: Some Well Known Health-related Mashups..................................50
Table 2.8: Types and Descriptions of Different Media Sharing Sites..............55
Table 2.9: A Summary of Health Related Spaces in Second Life..................61
Table 3.1: Royal College of Physicians of BC Position on Social Media..........84
Table 3.2: Excerpts from the CMA’s Rules of Engagement with Social Media...85
LIST OF FIGURES

Figure 1.1: The Evolution of Media.................................................................2
Figure 1.2: The Spectrum of Medical Informatics......................................4
Figure 1.3: Understanding Network Effects...............................................5
Figure 1.4: Worldwide Mobile Broadband Subscriptions..........................6
Figure 1.5: Worldwide Fixed Broadband Subscriptions.............................6
Figure 1.6: Understanding the Chasm.........................................................11
Figure 1.7: Number of Articles Published in PubMed Related to Social Media.16
Figure 2.1: A Sample Rounding Blogging Case..........................................28
Figure 2.2: The HealthSeeker Diabetes Education App on Facebook........41
Figure 2.3: A Public Profile on LinkedIn....................................................43
Figure 2.4: CureTogether’s Page on Chronic Fatigue Syndrome..............45
Figure 2.5: North American Outbreaks in the HealthMap Mashup............51
Figure 2.6: An Avatar Inside a Virtual Operating Room in Second Life.......58
Figure 3.1: Doyle Byrnes’ Facebook Picture.............................................78
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CHAPTER 1

Social Media in Medicine and Health(care):
A Review of the Foundations for this Research

INTRODUCTION

What is social media and web 2.0? Why has the use of social media become nearly ubiquitous in contemporary society so quickly? What theoretical and conceptual frameworks guide the use of social media in medicine and health(care)? What gaps exist in our knowledge regarding the use of social media? This chapter will address important questions for clinicians, researchers, and decision-makers who are trying to make sense of the evolution and adoption of social technologies. In particular, this chapter will review the history of social media, and their conceptual and theoretical frameworks.

The History of Social Media

Humans are social entities who have found innovative ways to communicate with one another throughout history. Although orality\(^1\) has been and will remain a primary form of communication, socialization in the graphic form dates back to prehistoric times - in the form of cave drawings. With new technologies, new social, and socialization media emerged, such as stele and papyri.\(^1\) Later, with the immense work of monks in scriptoria and other elites all over the world, albeit in arcane languages that only a relatively few in the general population could understand, this trend continued.\(^2\) Then came the Gutenberg Revolution, which allowed books and news in the form of

\(^{1}\) Orality is thought and verbal expression in societies where the technologies of literacy (especially writing and print) are unfamiliar to most of the population.\(^3\)
print/texts in the vernacular to reach the masses and several centuries later the electronic age (first with the telephone and telegraph, an early form of tweets), followed shortly by television as a form of mass communication and computers as a form of mass participation and recursively to smart phones as multimedia instruments of mass communication and participation. [1]

With the dawn of the Internet, a new information and communication revolution occurred. The near ubiquitous access to information and communication technologies (ICT), and later on, mobile forms of ICTs led to the adoption of social media as we know it today (e.g., Facebook, Twitter, and Wikipedia). This evolution has been well documented in media studies; most notably by Herbert Marshall McLuhan in 1964 in the book *Understanding Media: The Extensions of Man*. [4] Figure 1.1 summarizes the technological evolution of media. [4]

**Figure 1.1: The Evolution of Media**

![Diagram of the evolution of media from orality to electronic](image)
CONCEPTUAL FRAMEWORKS

Social Media and Web 2.0

Today, social media are a vehicle for “social interaction, using highly accessible, and scalable, communication techniques. The term refers to the use of web-based and mobile technologies to turn communication into interactive dialogue”. [5] These include a spectrum of digital content including, but not limited to: videos, images, print-based materials, status updates, websites, and hyperlinks to other types of media. Social media, often semantically linked with web 2.0, is a term used by industry in the Silicon Valley (California, USA) to denote the new Web of the early 2000s, the key feature of which is that high levels of technical skill were no longer required to make new websites. Today, some of the most prolific social media websites include: Facebook, Twitter, YouTube, Second Life, Wikipedia, LinkedIn, Flickr, FourSquare, among many others.

In medicine, social media have been used for massive collaboration (e.g., the Type II Diabetes page on Wikipedia was written by more than 800 contributors [6], to catalyze the speed of information exchange (e.g., a tweet-like update sent by the World Health Organization reaches over 400 000 followers [7], for medical education (e.g., the Clinical Cases and Images Blog hosts virtual rounding cases [8]), among others. Conceptually, social media lie at the nexus of information age healthcare and industrial age medicine because they encompass a branch of medical informatics with a broad

2 Conceptual frameworks outline the tenets and assumptions of research as it is operationalized within a broader context.
range of applications from bench-side research, to peer-to-peer support, to clinical medicine. These concepts are illustrated on Figure 1: The Spectrum of Medical Informatics. [9]

**Figure 1.2: The Spectrum of Medical Informatics [9]**

![Diagram of the Spectrum of Medical Informatics](image)

**Contemporary Society and Social Media**

The evolution of technology over the last fifty years can be characterized by two trends, which are exemplified by Moore’s and Metcalfe’s “Laws” (see below), respectively. These may be used to understand the exponential adoption of innovations, including social media.

In 1965, Gordon Moore, the co-founder of Intel Corporation observed that the number of transistors in computers were doubling every year. [10] Simply put, this meant that, due to a doubling of processing power, a laptop bought in 1996 was twice as fast as one bought in 1995. Roughly illustrated, this means that the GameBoy (a handheld game released in 1989 by Japan’s Nintendo Corporation [11]) has more processing power than the computers that took man to the moon (these were housed in air conditioned warehouses with an area of several hundred square feet). Thus, computers have become so cheap (and powerful) that lower and middle-income
households have access to one, at the very least, along with a mobile phone device, which is, in effect, a dramatic democratization of computing power.

The second law illustrates a rough empirical description of the power of networks. In essence, Metcalf’s Law states that the number of cross-connections (e.g., connectivity) between actors in a network grows in near exponential fashion whenever new users are added to a network (see Figure 1.3). Similarly, the value of the network grows when new users are added; however the notion of value is not articulated by Metcalfe and the mathematical expression of the law is highly debated, a concept which has been highly discussed in academic discourses. [12-14]

**Figure 1.3: Understanding Network Effects [12]**

These two laws, when combined, explain the exponential adoption of broadband Internet subscriptions, in both mobile and fixed (e.g., desktop-computer) forms, are the reason why social media have been adopted to a near ubiquity among the general population. These trends are best seen through the International Telecommunications
Union\(^3\) (ITU) connectivity data, which can be found on Figures 1.4 and 1.5 (units are per 100 inhabitants for the 2000 to 2010 calendar years). [15] Further extrapolated into Canadian terms, research shows that 26.2 Million Canadians have access to the Internet (World Bank Development Indicators, 2010) [16] and 79% of these use social media at least once a month. [17]

**Figure 1.4: Worldwide Mobile Broadband Subscriptions**

**Figure 1.5: Worldwide Fixed Broadband Subscriptions**

**Functionalities of Social Media**

The expansion in connectivity over the last decade has also resulted in social media evolving to acquire a number of functionalities and although various classification schemes exist for categorizing the spectrum of social media tools; the most pragmatic way to stratify them is based on their initially intended function. Thus, for the purposes

\(^3\) The ITU is the United Nations agency responsible for governance and coordination of global telecommunication services.
of this thesis, social media will be categorized using the International Medical Informatics Association⁴ (IMIA) Social Media Working Group (SMWG) classification [18], using eleven categories: 1) Social Networking (e.g., Facebook, MySpace); 2) Professional Networking (e.g., Linked In); 3) Microblogs (e.g., Twitter, Identi); 4) Video Sharing (e.g., YouTube, Vimeo); 5) Blogs (e.g., Wordpress, Tumbler, Blogger); 6) Wikis (e.g., Wikipedia, Wikigenetics, Wikicancer); 7) Forums/Listservs (e.g., Equidad); 8) Photo Sharing (e.g., Flickr, Picassa); 9) Thematic networks (e.g., Sermo, Osmosis); 10) Collaborative filtering (e.g., RSS, Delicious, Mashups); and 11) Other (e.g., MUVE, Aggregators, Wolfram Alpha).

**Important Premises About Social Media in the Medical and Health(care) Domains**

Given the above, there are four caveats which define the operational context in which this research and medical/health(care) practitioners use social media. They are important, despite being general observations from the field (not just the clinical world), because they illustrate the fluidity of the environments in which social media is used that may require special considerations (e.g., privacy) and are not necessarily an issue in broader contemporary contexts.

First, there is a significant vacuum of evidence regarding the use of social media in all spectrums of healthcare - from the bedside to the decision-maker level. However the digital interactions that occur through social media are, by and large, analogous to telephone/video-based telemedicine. However, one does not necessarily need to

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⁴ IMIA is the global association of national medical informatics associations with a Non-Governmental Organization seat at the World Health Organization.
perform a triple blind, randomized controlled trial (RCT) to understand that picking up the phone and asking the most readily-available subject expert, for advice, on the possible treatment options for a patient will result in a beneficial patient outcome. At the end of the day, the attending clinician will be responsible for his/her patient, and must make a decision based on their evaluation of the disease and what they know about effective treatments. Social media thus provide a new manifestation, similar to the telephone, that must be evaluated both empirically and qualitatively, but waiting out for “gold standard” level evidence may be problematic given the rapid speed with which social media are being adopted.

Second, there are no “traditional experts” in the use of social media as its applications are highly contextualized and the rate of change in tool functionality and prominence varies tremendously and rapidly. A pediatrician, for example, may blog often and have thousands of followers on their blog; however that does not mean, that s/he understands the risks of blogging anonymously, or how a virtual community of patients that use YouTube for peer-to-peer support operates. [19] Indeed, erroneously people often confuse the number of readers and views in social media with expertise, which are not necessarily analogous.

Third, no single semantic categorical definition can be applied to a social media tool or service due to the diversity of ways in which social media may be used, applied and interpreted. This tendency is a product of the interconnectivity between services through the use of APIs or Application Programming Interfaces, which allow social media services to interconnect with each other, expand their functionality, and reach an
exponential number of users. (Think, for example, of asking the question: what is iTunes best for? The answer to this question will vary on whether the user buys music, rents movies, buys apps, downloads lectures, listens to the radio or podcasts, or watches TV shows.) Notwithstanding, it is a fact that functionalities in the social media domain often merge and change (e.g., When Facebook added its location functionality to compete with FourSquare, did it become a thematic social network based on the location where information was shared? Or; did it remain a social networking site?).\(^5\)

Finally, social media have the potential for viral adoption and reach. This is why the rate of growth for Twitter users in early 2009 exceeded 1,334 percent \([20]\), a figure that would be an anomaly in other media. Similarly, this is also what allows a person or an organization to be in contact (and interact) with millions of people despite being one or many degrees of physical separation apart, on instant basis (e.g., think of a broadcaster asking questions through Twitter to its viewers during an interview with Dr. Phil - millions may be watching passively, but Twitter feeds allows the connectivity and interaction that passive watching does not, even with call-in shows or email questions).

**Conditions Influencing the Use of Social Media**

When users of social media interact with each other they subject themselves and their organizations to four conditions - either consciously or subconsciously. These are described below and are inherent in a number of theories, including: Social Network Analysis Theory, Rogers Diffusion of Innovations, Economic Theory, and the Theory of Risk Perception.

\(^5\) The explanations of these concepts are further expanded upon in Chapter 2.
First, Social Network Analysis Theory [21] suggests that, when social media are used to find or disseminate information, the information can reach a finite number of people, and this number will be determined by: 1) the size of an individuals’ social network (e.g., the number of friends they have on Facebook); 2) the number of connections that those users have with other users (e.g., how many friends those friends have); and 3) the location of those users on social and organizational strata. For example, if a student meets Bill Gates at a conference and Bill follows the student back on Twitter then the student is more likely to impact more people or find the information s/he is looking for because Bill Gates may re-tweet the question or other people may follow the student simply because bill gates is following him thereby increasing reach..

Second, users adopt social media at a rate that follows the normal distribution [22] and the area under the curve, that is, the different types of users who use social media, can be understood through Rogers’ Diffusions of Innovations. [23] Nevertheless, there is a chasm between two general types of users: 1) those who favor technology and performance; and, 2) those that prefer solutions and convenience. The first of this group (the left of the curve) is composed of innovators, technology enthusiasts, early adopters and visionaries, while the second (the right of the curve) is composed of pragmatists, conservatives, laggards and skeptics. This is illustrated in Figure 1.6: Understanding the Chasm. [24]
Third, Economic Theory denotes that all behavior is guided by incentives; that is, any action on behalf of a person can be due to a naturalistic (e.g., curiosity), moral (e.g., a calling to do the right thing), economic (e.g., financial remuneration), or social (e.g., to connect with others) incentive. [25] Thus, a health provider may answer a patient request on Facebook or Twitter for a variety of reasons beyond financial remuneration; it can be because s/he is getting paid to do it, because it can help them build social capital, or because they may feel it’s the right thing to do.

Finally, there is a formal or informal risk mitigation strategy, or the user/clinician is unconcerned (or ignorant) of the risk of using social media in a medical or health(care) context. Examples that denote some of the case law on this issue are discussed in Chapter 3, including the case of a world renowned blogger and pediatrician, Dr. Flea, who used anonymity to rant about a personal malpractice lawsuit and ended up having to pay a large settlement due to his lack of due diligence in his blog posts. [26]
THEORETICAL FRAMEWORKS

Positivism

There are two primary philosophies of science that are used in medicine. These guide the validity, robustness, and appropriateness of measurement in research. Generally, the majority of medical interventions are evaluated using positivistic paradigms, which assume “an external [knowable] reality which can be measured; that phenomena such as ‘project goals’, ‘outcomes’ and ‘formative feedback’ can be precisely and unambiguously defined, that facts and values are clearly indistinguishable, and that generalizable statements about the relationship between input and output variables are possible, [regardless of the context]” [27]. Indeed, this is the mindset of the gold standard, the RCT, which measures the effect of an intervention on a small, often, homogenous sample and later on tries to extrapolate its results to a large, often, heterogeneous population.

In this research, the positivistic approach is not appropriate to synthesize the evidence on the use of social media as I am not trying to measure, prove, or generalize what social media are within the context of medicine and health(care). Rather, my intent is to question why social media are being used; to uncover and explain what tools are being used and for which purposes; as well as to understand how different actors may use and enable change through the use of social media.

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6 Theoretical frameworks outline the theories where this research is situated in the academic literature.
**The Critical-Interpretivist Approach**

Thus, this research will use narrative reviews to synthesize and reflect on the dialogue that has emerged around the use of social media in medicine and health(care). Methodologically, the critical-interpretivist approach will be used, which uses the context and conflicts that have emerged within the peer review literature and traditional and social media to critically appraise and interpret, from a variety of perspectives, the impact social media are having within the health sector, its workers, and institutions. As a method, the critical-interpretivist approach assumes that all research is perspectival (e.g., that it follows a particular person’s point of view) and that complex social phenomena, such as the adoption of social media tools, are open to multiple interpretations and, as a consequence, the findings of this research are likely to be challenged based on the perspective of the person reading and appraising this research, which further continues the dialogue and therefore compliments the research. [27]

**Medicine 2.0**

In December of 2006, Giustini published the first editorial describing the impact of web 2.0 on medicine. The publicity surrounding this trend continued in the following months and was finally conceptualized as a theoretical framework in 2008 by Dr. Gunther Eysenbach. This is framework [28], which is now recognized as Medicine 2.0, identifies five emerging and recurrent themes that have affected medicine and health(care), from the bench to the bedside, and it also takes into account how clinicians and patients look for, and access, information on the social web; these themes
are: 1) Social Networking; 2) Participation; 3) Apomediation; 4) Collaboration; and 5) Openness. [28]

Social Networking denotes the use of social tools, like YouTube, which allow anyone with basic computer skills to upload digital media (a video in this case) and commence a discussion with multiple users through a comments’ feature. Participation allows multiple user interaction (e.g., a wall posting on Facebook), which connects the author of the initial post with others interested in the information posted. Apomediation, is a middle ground for information access; it is a categorical term which lies between mediation and disintermediation (the removal of mid-level actors) and can be defined as a state where credible information is not delivered to a consumer through traditional sources (like the Encyclopedia Britannica). Rather, someone who looks for information through apomediation uses less traditional pathways and sources (e.g., rather than looking up a traditional encyclopedia, a user may ask their social capital or virtual friends for help and advice). [28] Collaboration is the opportunity for very large numbers of users to work towards a common goal (e.g., the population of content in Wikipedia). Finally, Openness, which stands for the transparency, interoperability (through the aforementioned use of APIs), and the general trend for the masses to “open up” private data, and knowledge, for the benefit of the general population.

Ongoing Research Questions

A number of studies have evaluated various facets of social media’s impact to medicine and health(care). These are thematically centred on public health and health services research, virtual communities, medical education, information quality, and
ethics. Some of the research questions that have been explored, under these categories, can be found below:

**Public Health and Health Services Research:** How do social media users respond to public health catastrophes (e.g., H1N1)? [29] How can Twitter be used in an emergency department to improve human and bed resource flow? [30] What is the best way to recruit clinical trial participants using social media? [31]

**Virtual Communities:** What elements determine the development, growth, and transformation of a virtual community? [32] What incentives drive clinicians to socialize in a virtual environment? [33] What influence does a virtual Community of Practice have on medical practices? [34]


**Information delivery and quality:** What is the accuracy of drug information on Wikipedia? [39] How do health information consumers appraise online information resources? [40] What design elements attract or repel web visitors to a web page? [41]

**Governance and Ethics:** What sorts of privacy and confidentiality violations do residents and medical students portray in their Facebook profiles? [42] How should web information be safeguarded online and by whom? [43] How should online pharmacies be regulated? [44]
The Need for a Collective Synthesis

Since 2005, the number of articles published in PubMed on social media has doubled every year (Figure 1.7) and the diversity of research themes on the use of social media in medicine and health(care) is likely to continue expanding at an exponential rate. [45] Although a large number of editorials and scientific studies which identify changes in the landscape have been published over the last seven years, to date, there has been no single comprehensive synthesis of the evidence, or lack thereof, for or against using social media in medicine and health(care).

Figure 1.7: Number of Articles Published in PubMed Related to Social Media
OBJECTIVES OF THIS THESIS

Given the several set of issues, assumptions and applications of social media noted above, health services researchers, clinicians, and other medicine and health(care) stakeholders would benefit from an evidence synthesis, which is the overarching objective of this thesis. More specifically, using a mixed methods approach, this research will synthesize:

1. The contexts – the where, how and why – in which social media has been used in medicine and health(care) by different actors, including: (but not limited to) clinicians, managers, and health organizations;
2. Recommendations on how social media may be used appropriately, safely, and ethically; and
3. Prominent legal and ethical dilemmas that have emerged from the adoption of social media in medicine and health(care) contexts;
4. The trends and key issues that must be evaluated in the coming years.
CHAPTER 2

Veni, Vini, Tweeti: A Review of the Where, How, and Why Social Media are Being Used Medicine & Health(care)

INTRODUCTION

In the previous chapter, I reviewed the history of social media and the conceptual and theoretical frameworks that are being used to guide this research. In this chapter, I tackle the second and third objectives of this thesis: to critically review the context in which social media are used; and to provide recommendations for their safe and ethical use.

Social media are web-based tools that are used for computer-mediated communication. In healthcare, they have been used to improve and maintain peer-to-peer and clinician-to-patient communication, as well as to promote institutional branding, and to improve the speed of interaction between and across different healthcare actors. More specifically (and to name a few applications), they have also been used to educate clinicians and patients [46], to generate content rich resources (e.g., Wikipedia) [47]; to evaluate real-time flu trends [48]; to catalyze outreach for (public) health campaigns [49]; and to recruit patients in clinical trials. [50]

A number of indicators also suggest that the evidence for using social media in healthcare is growing; for example: the number of articles indexed on PubMed has nearly doubled each year for the last four years [45]; social media policies are being adopted [51] and tested in various healthcare settings [52]; subspecialty-based journals
are continuously revealing how social media facilitate knowledge-sharing and collaboration within medical specialties [53]; and theories on the social changes resulting from their adoption are being developed. [18]

Despite these increasingly useful insights however, our collective understanding of how social media can be used in different medical and healthcare contexts has not been synthesized into a single document.

**Objective**

I conducted a narrative review to gain a better understanding of how social media are being used in healthcare. Using a mixed methods approach, I illustrate the where, how, and why social media are being used. Ultimately, the intent of this review is to allow different healthcare actors the opportunity to see, understand, and make informed decisions, on how to use social media and similar electronic-mediated communication tools as part of their daily activities.

**METHOD**

A research question may be evaluated using a number of methods and traditions. Most commonly, these are grounded on a philosophy of science, which outline the conceptual and theoretical frameworks of the research, ultimately providing a lens and a method of inquiry to shape the results presented.

**Positivism**

In medicine and healthcare the *gold standard* review method follows positivistic epistemology, which assumes that “there is an external reality that can be objectively measured; that phenomena such as “project goals”, “outcomes”, and “formative
feedback” can be precisely and unambiguously defined; that facts and values are clearly distinguishable; and that generalizable statements about the relationship between input and output variables are possible.” [27]

In the positivistic tradition, reviews are operationalized using robust methodologies often with a peer review procedure at key steps in the research process. Cochrane Reviews and some meta-analyses primarily use this approach, where even the titles and protocols are published in advance of results. Meta-analyses, Cochrane, and systematic reviews are resource-intensive and follow standardized procedures, which have been developed by physicians, knowledge management experts, archivists, and curators. [54] Their procedures/protocols span from the formatting of a title, to the parameters of a research question (e.g., PICOS - Population, Intervention, Control, Outcome, and Secondary gains), to specific consortia for reporting results (e.g., the Checklist for Reporting Results of Internet E-Surveys).

A number of other review methods also stem from positivism. These include the Realist Review [55], which is used in evaluation research for the design and implementation of complex social interventions; the Rapid Review [56], which is an adaptation of Systematic Reviews and is executed when there is an urgent need for evidence, such as during public health crises (e.g., during the H1N1 avian flu epidemic); Scoping Reviews [57], which aim to map the breadth and depth of the peer review literature within a field; and Narrative Reviews [54], which are most commonly written by field experts and are usually based on evidence and personal experiential knowledge.
An Alternative to Positivism

Although positivism is the most commonly used epistemological lens in healthcare, it is not the most appropriate for many topics, including eHealth, where computer-mediated communication tools like social media are situated. The reasons for this have been extensively documented by Greenhalgh and Russell’s [27] Why do evaluations of eHealth programs fail? They can be summarized in four premises. First, eHealth programs most often have multiple goals, which are perceived differently by different actors (e.g., the goal of Electronic Medical Records as seen by health administrators vs. clinicians); thus no single set of goals can serve as a fixed reference for comparison between inputs and end results. Second, outcomes are not stable; they change in different contexts and evolve over time (e.g., a hospital may start a Facebook page, but users may use it for a different purpose than the hospital originally intended). Third, the link between processes and outcomes in eHealth are typically interrupted by many variables and confounders; therefore generalizing “success” to a single number of variables is unreliable. Fourth, program success may not necessarily be articulated in a vocabulary of outcomes that can be reliably measured (e.g., think of measuring the governance of different social media tools across different actors, such as a hospital, the Royal College of Physicians and Surgeons, and a health region). It is important to note that these recommendations resulted from the evaluation of the UK’s National Health Service £12.7 billion Connected for Health Initiative, which sought to modernize public-healthcare services with state-of-the-art information technology using eHealth.

7 The WHO defines eHealth as application of information and communication technologies for health and healthcare. [59]
This review follows Greenhalgh’s conceptual recommendations, collectively known as the critical-interpretivist approach [27]. First, the critical-interpretivist approach is an interpretative model that assumes a socially constructed reality acknowledging that people perceive issues in different ways and assign different values (and significance) to facts or events. Thereby, “reality” is assumed to be unknowable both objectively and unproblematically because the research process cannot be isolated from the identity and values of the researcher or subject (they are both inevitably implicated). Second, the critical-interpretivist approach also assumes that critical questioning can generate new, and different, knowledge that cannot be generated using a Positivistic (hypothetico-deductive approach).

**Mixed Methods**

This review will draw upon the critical-interpretivist approach not with an intent to measure, quantify, or generalize its results, but with the intent to illustrate, explain, and provide the contextual knowledge of why social media are being used in medicine and health(care). Ultimately, it will allow decision makers and clinicians alike to decide for themselves where, how and why they may use and implement these computer-mediated communication tools in their work and (potentially) their personal lives too.

**Data Sources and Knowledge Synthesis**

This non-exhaustive review [9] used a number of traditional and non-traditional reference sources. It is non-exhaustive due to inherent limitations that occur when trying to assess the medical and health-related grey literature, which is situated within social media itself; that is, it would be impossible to keep track of new posts and
updates on Facebook and Twitter-like tools, as they occur in the thousands every minute, of every day. Medline was searched using the search string in Table 2.1. Additionally, data from the Cochrane list of web 2.0 resources, the Health Librarianship Canada (HLCanada) Wiki, the Pan-American Health Organization’s Equity and Human Development Listserv, the 2008-2011 proceedings of the International World Congress on Social Media and Web 2.0 in Health, Medicine and Biomedical Research, and award winning blogs (e.g., Scienceroll.com) were used to supplement peer-reviewed resources. Where necessary, results were further supplemented with an environmental scan of the Google and Bing search engines.

Table 2.1: MEDLINE search string (modified from [45])

|"second life" AND (virtual OR 3d OR immersive) | OR |"virtual worlds" OR "web 3.0" OR |"medicine 2.0" OR "health 2.0" OR "web 2.0" OR mashup OR "social media" OR digg OR |"del.icio.us" OR "social bookmarking" OR wikis OR folksonomy OR wikipedia OR flickr OR twitter OR youtube OR facebook OR myspace OR Linkedin OR FourSquare |

Results were categorized based on social media service type (see definition below) and, where appropriate, further sub-grouped using the United Nations Foundation Mobile Health for Development Framework [59] which has been used by a number of high-level actors (e.g., the WHO) to stratify digital media. The categories of this framework are: 1) education and awareness; 2) data collection; 3) remote monitoring; 4) peer-to-peer communication amongst healthcare workers; 5) disease and epidemic outbreak tracking; and 6) diagnostic treatment and support.

Definitions

As of May 2012, there was no commonly accepted standard to stratify social media into categories. Thus, in Table 2.2, I expand the functionality strata presented in
Chapter 1 to assign a definition to each social media service type. Examples of the service types are also provided.

**Table 2.2 Categorical Definitions of Social Media**

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Definition</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Blog</strong></td>
<td>Short for ‘web log’ – a blog is a free, easy-to-publish website where bloggers (authors of blogs) post information and essays in sequential order. [60]</td>
<td>WordPress, Blogger</td>
</tr>
<tr>
<td><strong>Microblog</strong></td>
<td>A tiny blog service that allows networks of users to send short updates to each other in less than 140 characters. Microblogs are considered a platform for information dissemination, social networking, and real-time communication. [60]</td>
<td>Twitter, Identi</td>
</tr>
<tr>
<td><strong>Social Networking Site</strong></td>
<td>A social networking site is an online service, platform, or site that focuses on building and visualizing social networks or social relations among people, who, for example, share interests and/or activities. A social network service essentially consists of a representation of each user (often a profile), his/her social links, and a variety of additional services. [61]</td>
<td>Facebook, MySpace</td>
</tr>
<tr>
<td><strong>Professional Networking Site</strong></td>
<td>A professional networking site is a type of social network service that is focused solely on interactions and relationships related to business or a person’s professional career. [62]</td>
<td>LinkedIn, Sermo, Asklepios, Ozmosis, Drs Hangout, Doc2Doc</td>
</tr>
<tr>
<td><strong>Thematic networking sites</strong></td>
<td>Social networking sites centered on a particular theme; for example, disaster response, nursing, etc. These share many aspects of, and operate as a community of practice.</td>
<td>Telehelp, Innocentive, 23andMe, PatientsLikeMe, CureTogether</td>
</tr>
<tr>
<td><strong>Wiki</strong></td>
<td>Wikis are used to denote communal websites where content can be quickly and easily edited. Wikis support collaboration and information sharing; feature multimedia, such as video, slides, photographs, and allow anyone to edit whereas others are password protected. [60]</td>
<td>Wikipedia, Fluwiki</td>
</tr>
<tr>
<td><strong>Mashups</strong></td>
<td>A website that combines data and functionality from two or more services to create a new, value-added, service. [63]</td>
<td>HealthMap, Google Flu</td>
</tr>
</tbody>
</table>
Table 2.2 Categorical Definitions of Social Media (continued)

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Definition</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collaborative Filtering Sites</td>
<td>A website where information is filtered or collected according to patterns. Techniques involving collaboration among multiple agents, viewpoints, and data sources are often used. These agents engage through a variety of sites, through a process called crowdsourcing, where the crowds join forces for a common purpose. [64]</td>
<td>Digg, Delicious</td>
</tr>
<tr>
<td>Media Sharing Sites</td>
<td>A hosting service that allows individuals to upload and create galleries of photos, videos, and other digital media (e.g., slide presentations). The host will then store them on a server and make them either publicly or privately available.</td>
<td>SlideShare, YouTube, Flickr</td>
</tr>
<tr>
<td>Other</td>
<td>Multi-User Virtual Environments, also known as Virtual Worlds.</td>
<td>Second Life</td>
</tr>
</tbody>
</table>

RESULTS

A total of 62 articles, 43 websites, and 11 reports (or policies) were evaluated, reviewed and synthesized to inform the development of this article. Results are presented in the proceeding seven sections, according to social media tool functionality.

Blogs

The first social media were adopted in the late 1990s in the form of web-logs (a term which was later shortened to form the word Blog). Web-based software platforms like Open Diary enhanced accessibility from a technical perspective and allowed the lay public to create a communal website where new (unrelated) users could voice their opinions about any topic and collaborate to create a communal dialogue. Blogs foster open access to information (both opinion and fact), contribute largely to the number of new websites created on the Internet and are often picked up by mainstream media, which makes them an important vehicle for social change. [65] For example, Paul Levy, the former President and CEO of Beth Israel Deaconess Centre in Boston, MA, was one
of the first healthcare executives to run a blog about the aspects of, and his reflections on, his public position and decisions as a public authority with significant power, and on the transparency of clinical outcomes at the hospital for which he had responsibility.[66]

Although the literature on the use of blogs in Medline is growing, only one study has formally evaluated the attitudes, perceptions, and realities of the medical Blogosphere. Indeed, Kovic and colleagues [65] who conducted an online survey of medical bloggers, found that successful medical bloggers are most often highly educated writers (with masters or doctoral-level degrees) who are faithful to their sources and readers, and are motivated to influence how others think by sharing their practical knowledge or skills in a creative manner.

In terms of education and awareness, educational institutions in healthcare have used blogs to foster reflective peer-to-peer learning, which allow for open discussions and a formal log of medical training; as well as the implementation of new protocols. [67] Many hospitals also use blogs for community outreach to: 1) feature their “first class” facilities [66] (e.g., a story of the newest device or test not owned by a competitor); 2) positive patient experiences [68] (e.g., Mayo Clinic’s Piano Foyer Video, where two unrelated patients meet and play the piano together while in hospital); or 3) feature celebrity-type physicians who operate on famous people or athletes. [69] Blogs are also used by hospitals to disseminate disease-specific information as an electronic form of the patient education leaflets handed out at the bedside. [70]

Blogs have been used in clinical research for clinical trial recruitment and data collection, allowing patients to ask questions about the trial procedures, risks, and
incentives while maintaining an anonymous, non-threatening environment. [71] Mayo clinic has also used blogs focused on Major Depressive Disorder to request feedback on the patient experience, and some of the Integrative Medicine practices they follow. [46]

For remote monitoring, patients have been creative in their use of blogs. SixUntilMe\(^8\), for example, features the life of a patient living with type 1 diabetes (Kerri Morrone Sparling), insulin pumps, continuous glucose monitors, and diabetes advocacy. [72] Cancer patients have also used blogs as a narrative of the patient experience with chemotherapy. Dave deBronkart, who is a well-known e-patient\(^9\) advocate, used his blog to inform family members and his attending (family) physician of changes in tumor growth from a self-created spreadsheet of radiology reports of tumor size data. [73] Also, in May of 2011, the Vancouverite Derek K. Miller had a friend post his auto-obituary after dying from stage 4 metastatic colorectal cancer. What is most interesting about this particular example is that his self-obituary blog post (http://www.penmachine.com/) “went viral”, receiving more than four million views in the four days after his death – a rather startling example of the potential reach of health related social media.

In peer-to-peer communication among healthcare workers, blogs have been used for (virtual) rounding. The Clinical Cases Blog (http://casesblog.blogspot.com) is a model for this in the medical blogosphere, as it features cases in Allergy and Immunology, Cardiology, Pulmonology, Gastroenterology, Nephrology, Endocrinology,

\(^8\) The name for this blog stems from age at which the author was diagnosed with Diabetes.

\(^9\) ePatients are patients that are internet savvy, empowered, and engaged in their own care. [74]
Haematology, Rheumatology, Infectious Diseases, Neurology, Geriatrics, and Pain Management. Moreover, this blog also has a special section on admission note templates (e.g., Congestive Heart Failure), procedure guides, and similar material. Figure 2.1 (below) displays an example case from this Blog.

**Figure 2.1: A Sample Rounding Blogging Case**

Hepatitis C and Alcohol Abuse - What is the Treatment Plan?

Author: V. Dimov, M.D.
Reviewer: B. Rashchina, M.D.

A 51-year-old African American male (AMA) with a past medical history (PMH) of hepatitis C, alcohol (ETHOH) abuse, and hypertension (HTN) is referred to the GI clinic because of elevated liver function tests (LFTs). He has no complaints.

**Past medical history (PMH)**

Intravenous drug abuse (IVDA) with heroin and cocaine abuse 30 years ago, hepatitis C, heavy alcohol abuse, HTN. Recital bleeding for 2 months - a colonoscopy showed 9 benign polyps (one tubular adenoma and 9 hyperplastic polyps).

**Medication**

Tamsulosin (alpha-1 blocker), Lisinopril.

**Social History (SH)**

Drug abuse as described above. He told his PCP that he is “in remission” from alcohol. On closer questioning, the patient admitted to long-term alcohol abuse in binging sprees, drinking 3-6 bottles of beer whenever he can afford it. The last binge was just 2 weeks ago. He financed his ETHOH abuse with the money he is receives for disability because of his liver disease.

**Physical examination**

ADAM 12: No signs of chronic liver disease.
HEENT: no rash (just in brows as per patient).
The rest of the examination was normal.

With regard to disease and epidemic outbreak tracking, citizen-report photo blogs have been used to inform hospitals of incoming mass casualty events (e.g., Hudson River plane landing). Equally interesting, is how the US military has used natural language processing to automatically filter and retrieve information on blog posts by military servicemen as a means to monitor emotions and Post-Traumatic Stress Disorder after operational deployment. [75]

There are many other examples of medical blogs, which lie outside of the aforementioned categories. However, both the Medgadget and iMedicalApps Blogs are
well known for their annual (winter) competitions, which feature the best medical blogs and (mobile device) application reviews based on a public voting system. (Table 2.3 features a brief description of the 2010 Medgadget Blog Award Winners.)

**Table 2.3: Medgadget Top Blogs for 2010**

<table>
<thead>
<tr>
<th>Blog Category</th>
<th>Site Name</th>
<th>Site Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Best Medical Blog</td>
<td>EMCrit blog</td>
<td>This blog by an Intensivist from New York City exposes interesting issues in the practice of Emergency Medicine. The site also features podcasts discussing procedures, checklists, and other factoids about the ER.</td>
</tr>
<tr>
<td>Best New Medical Blog</td>
<td>ZDoggMD</td>
<td>This humorous blog by a hospitalist in Silicon Valley features music videos, poems about Santa with gout, and other funny things for clinicians in an emotionally tense environment.</td>
</tr>
<tr>
<td>Best Literary Medical Blog</td>
<td>StorytellERdoc</td>
<td>This anonymous blog is written by an ER physician who writes about the grace, passion, and sadness of medical practice and the shared humanity between practitioners and patients in the ER.</td>
</tr>
<tr>
<td>Best Clinical Blog</td>
<td>GeriPal</td>
<td>This group blog about geriatrics and palliative care features evidence-based reviews. The site also invites (new) qualified authors to contribute their content and has developed into a community with passion and focus.</td>
</tr>
<tr>
<td>Best Health Policies/Ethics Blog</td>
<td>Covert Rationing Blog</td>
<td>This blog discusses the various facets of health care rationing; including causes, effects, and how to address underlying factors. The author is a retired professor and researcher in cardiology and cardiac electrophysiology.</td>
</tr>
<tr>
<td>Best Medical Technologies / Informatics Weblog</td>
<td>Science Roll</td>
<td>This blog features news and brief reportage-style commentaries on everything from computers to patients and doctors. Other resources are also available on medical informatics and genetics.</td>
</tr>
<tr>
<td>Best Patient’s Blog</td>
<td>Wheelchair Kamikaze</td>
<td>This patient blog covers a spectrum of issues from living with Multiple Sclerosis to research news and lifestyle articles. The author is regarded as an authority for patients with MS and fosters a support community with his blog posts.</td>
</tr>
</tbody>
</table>
This section on blogs cannot conclude without an acknowledgement to the Really Simple Syndication (RSS) web standard. RSS allows software, known as RSS readers, to pull content and create an email-like inbox of blogs and other websites (e.g., PubMed) that are frequently updated. This is useful when a user wants to create a customized “feed" of information that is relevant to their interests and classify them accordingly, for easy retrieval in the future. Among the most notable RSS readers are Google Reader, iGoogle, and Bloglines.

Overall, Blogs are the oldest; most established and evaluated form of social media, with the earliest articles as early as 2004, noting their use in medicine and family practice. [76] A number of peer-review articles on Blogs have also been published; these mainly note their effectiveness how they can be used to disseminate best practices [77]; their applications in assessing clinical knowledge learned [78]; and how they can be used to promote reflection and professional development. [67]

**Microblogs**

The most dynamic and concise form of information exchange on social media occurs on microblogs (e.g., through tweets). Consisting of 140 character-long updates, these short 21st century telegrams, allow users to view large amounts of content over a short period of time. Today, a large number of microblogging platforms exist, which cater to audiences varying from the corporate world to teenagers, however Twitter is and has remained the most prominent service on the market. Twitter updates are known as tweets.
Newcomers to Twitter often perceive the update-length as a barrier to communication. This misconception usually decreases with repeated use, as tweets are easily supplemented with shortened hyperlinks to other digital media, such as videos or websites. “Tweeps” (people who tweet) also often use other services that connect to the Twitter platform (e.g., TweetDeck, HootSuite), which allow them to organize their tweets, manage information, and see website previews or pictures without having to click on a link and open a new web browser window. Some of these services also sort, filter, and curate tweets, allowing a user to see updates related to a particular topic, such as healthcare. In turn, this has caused a new technical language to emerge, a glossary of which can be found on Table 2.4.

Table 2.4: A selection of common Twitter terminology (adapted from [79])

<table>
<thead>
<tr>
<th>Terminology</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>@</td>
<td>The @ sign is used to call out other users within a tweet. When a username is preceded by the @ sign, it becomes a link to a Twitter profile.</td>
</tr>
<tr>
<td>Avatar</td>
<td>The personal image uploaded to a Twitter profile.</td>
</tr>
<tr>
<td>Block</td>
<td>To block someone on Twitter means they will be unable to follow you or add you to their lists, and will not deliver their mentions (see below) to your mentions tab</td>
</tr>
<tr>
<td>Direct Message (DM)</td>
<td>These are private Tweets between two users.</td>
</tr>
<tr>
<td>Favorite</td>
<td>A tweet marked as favorite saves the message for later viewing.</td>
</tr>
<tr>
<td>Follow Count</td>
<td>The number of people that follow a user, as well as how many people that user follows.</td>
</tr>
<tr>
<td>Follower</td>
<td>A follower is a separate Twitter who follows “you”.</td>
</tr>
<tr>
<td>Follow Friday</td>
<td>The most commonly used hashtag #FF, it recommends who other users should follow based on personal experience and interactions with other users. #FF is used on a Friday and it is a form of social courtesy.</td>
</tr>
<tr>
<td>Following (verb)</td>
<td>The act of following another user.</td>
</tr>
<tr>
<td>Geotagging</td>
<td>Tagging (metadata) added to a tweet, which denotes the geographical location from where the message was sent; enabling this feature allows users to disclose where they are in real-time.</td>
</tr>
<tr>
<td>Terminology</td>
<td>Definition</td>
</tr>
<tr>
<td>-----------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Handle</td>
<td>A user's &quot;Twitter handle&quot; is the username they have selected and the respective accompanying URL (e.g., <a href="http://twitter.com/username">http://twitter.com/username</a>)</td>
</tr>
<tr>
<td>Hashtag</td>
<td>The # symbol is used to mark keywords or topics in a Tweet. It serves to search the twitter sphere on a particular topic.</td>
</tr>
<tr>
<td>Listed</td>
<td>To be included in another Twitter user’s list.</td>
</tr>
<tr>
<td>Lists</td>
<td>These are publicly or individually curated groups of Twitter users. They are often used as a filter to find tweets of users who follow a particular topic (e.g., Cardiologists)</td>
</tr>
<tr>
<td>Mentions</td>
<td>Mentioning another user in a tweet by including their handle.</td>
</tr>
<tr>
<td>Reply</td>
<td>A Tweet posted in reply to another user’s message, usually posted by clicking the &quot;reply&quot; button next to their Tweet within a timeline. If the users’ twitter timeline are public, it allows people to follow the tweet conversation and response thread.</td>
</tr>
<tr>
<td>Retweet (noun)</td>
<td>A Tweet by another user, forwarded to you by someone you follow. Often used to spread news or share valuable information and allows it to spread virally.</td>
</tr>
<tr>
<td>Retweet (verb)</td>
<td>The act of forwarding another user's Tweet to a user's personal followers</td>
</tr>
<tr>
<td>Search</td>
<td>A function of twitter (found at <a href="http://search.twitter.com">http://search.twitter.com</a>) to search for usernames, hashtags, or a particular subject. (This function is generally limited to the past 2 weeks of public tweets.)</td>
</tr>
<tr>
<td>Short URL (SURL)</td>
<td>URL shorteners are used to turn long web addresses (URLs) into shorter URLs.</td>
</tr>
<tr>
<td>Spam</td>
<td>Unwanted messaging or following on Twitter.</td>
</tr>
<tr>
<td>Timeline</td>
<td>A real-time list of Tweets on Twitter.</td>
</tr>
<tr>
<td>Tweet (noun)</td>
<td>A message posted via Twitter containing 140 characters (or fewer).</td>
</tr>
<tr>
<td>Tweeterer</td>
<td>An account holder on Twitter who posts and reads Tweets.</td>
</tr>
<tr>
<td>Unfollow</td>
<td>To cease following another Twitter user. This will cause their Tweets to no longer show up in a user’s home timeline.</td>
</tr>
<tr>
<td>Widget</td>
<td>A discrete code that allows a twitter user to feature their “tweets” in real time on a different website (e.g., a blog).</td>
</tr>
</tbody>
</table>

Tweets and tweeting styles can be classified in three broad categories. [80]

Substantive tweets are independently understandable (e.g., a tweet with an abridged title or author of a paper, a brief comment, and a link to the publication; or a headline teaser to a blog). Conversational tweets are fragments of a new or ongoing conversation.
and draw on professional or personal interests or comment on current events (e.g., I am doing research with my supervisor, Dr. Kendall Ho, at the Vancouver General Hospital Emergency Department). Finally, there are hybrid tweets, which are substantive and conversational at the same time (e.g., discussing my supervisor’s newest Nature publication at the Mahoney and Sons pub http://examplehyperlinktopicture.com).

In medicine and healthcare, there have been over 140 reported uses for Twitter, a synthesis of which can be found on Table 2.5. [81]

Table 2.5: 140 Healthcare Uses for Twitter (Synthesized)

| 1. Tissue recruitment (blood, kidneys, etc.) | 14. Promoting Domestic Violence awareness |
| 2. Epidemiological data collection (e.g., [http://www.sickweather.com/](http://www.sickweather.com/)) | 15. Raising Child Abuse awareness |
| 3. Disaster alerting and response | 16. USMLE preparation for medical licensing |
| 4. Emergency response team communication and management | 17. NCLEX for preparation for nursing licensing |
| 5. Supportive care for patients and family members (including weight, exercise, and smoking cessation support) | 18. Recruitment of health care staff |
| 6. Diabetes management (blood glucose tracking) | 19. Alcohol and other substance abuse support |
| 7. Health diaries | 20. Triage management in emergency rooms |
| 8. Adverse event reporting in the clinical setting and related pharmacovigilance | 21. Census management/monitoring |
| 9. Silent code alarms (e.g., psychiatric emergencies, security incidents) | 22. Crowdsourcing health care resources |
| 10. FDA Drug safety alerts | 23. Shift-bidding for nurses and other health care professionals |
| 11. Amber (and related) alert notifications | 24. Mood tracking (for patients with bipolar and other mood disorders) |
| 12. Biomedical device data capture and reporting | 25. Patient care reminders in the clinical setting |
| 13. Coordinating preoperative, perioperative and postoperative care (among pharmacy, nursing and surgical services) | 26. Prescription management, including pharmacy refill reminders |
| | 27. Daily health tips from authoritative sources |
Table 2.5: 140 Healthcare Uses for Twitter (continued)

| 28. Location awareness during crises | 53. Connecting genetic researchers with physicians |
| 29. Occupational safety response | 54. Publishing the latest advances in biomedical devices |
| 30. Hazardous materials communication | 55. Issuing asthma alerts |
| 31. “Quick and dirty” diagnostic brainstorming between physicians (e.g., ‘symptom clustering’) | 56. Data collection for tracking facility patterns (process-performance, supply-chain and staffing problems) |
| 32. Clinical case education (residents following attendings) | 57. Live-tweeting medical conferences (so they can be followed by non attendants) |
| 33. Physician opinion-sharing | 58. Keyword-tracking of health-related topics via Twitter search (and API connected applications) |
| 34. Environmental alerts: pollen counts, pollution levels, heat waves, severe weather alerts | 59. Improving medical rounding systems |
| 35. Remote wound care assistance | 60. Clinical trial awareness, recruitment, and participant invitations (e.g., Trial-X) |
| 36. Rural area health care communication | 61. Sharing peer-to-peer reviews of articles of interest |
| 37. Micro-sharing of pertinent patient information | 62. Connecting patients with similar disease processes |
| 38. Micro-sharing of diagnostic results (blood tests, echocardiography, radiological images) | 63. Enhancing health-related support groups (e.g. buddy-systems for depression) |
| 39. Customer service interactions | 64. Medical appliance technical support (e.g. at-home: colostomy care, infusion-pumps, wound-vacs) |
| 40. Publishing health-related news | 65. Reporting medical device malfunctions |
| 41. Psychiatric “check-ins” for patients | 66. Arranging appointments with health care providers |
| 42. Nursing mentoring and collaboration | 67. Product, and food safety alerts |
| 43. Publishing disease-specific tips | 68. Information on women’s health |
| 44. Childcare support | 69. Pain management |
| 45. Fund raising for hospitals and health-related causes | 70. Community health outreach |
| 46. Updating patient family members during procedures | 71. Bioterrorism awareness and preparedness |
| 47. Live-tweeting surgical procedures for education | 72. Patient-sharing of health-related experiences |
| 48. Rare diseases tracking and resource connection | 73. Community management and development between patients of related conditions |
| 49. Reporting hospital staff injuries | 74. Mental health awareness |
Table 2.5: 140 Healthcare Uses for Twitter (continued)

| 75. Food bank resource management | 85. Publishing vaccination/immunization services (e.g., locations, hours and reminders) |
| 76. Exposing medical quackery       | 86. Obtaining information on Medicare and Medicaid |
| 77. Discussing public health care policy | 87. Clinical education coordination |
| 78. Developing stronger patient-provider relationships | 88. Whistle blowing (e.g., reporting breeches of universal precautions in health care facilities) |
| 79. Following health marketing     | 89. Posting daily nursing tips |
| 80. Exchanging/soliciting scientific validation of alternative health claims | 90. Exchanging physician humor |
| 81. Interprofessional (logistical communication and collaboration) | 91. Coordinating allied health care services during patient admissions |
| 82. Public safety announcements    | 92. Post-discharge patient consultations and follow-up care |
| 83. Tracking the progress of developing pharmaceuticals | |
| 84. Broadcasting infant care tips to new parents | |

In terms of medical education, there have been some interesting applications of Twitter. The Pennsylvania State College of Medicine has used Twitter to augment peer-to-peer and instructor-to-student learning [82] by stimulating topic discussions, providing feedback on critical thinking, conducting course evaluations, disseminating writing prompts, soliciting class responses, and monitoring student progress. Second, a junior doctor and a medical student started a Twitter Journal Club [83] that functions in the same manner as traditional journal clubs, except that the means for discussion is Twitter. By using a combination of blog posts, where the paper and discussion questions are posted in advance, along the hash tag \(^{10}\) #TwitJC, students, doctors, and anyone interested in the subject can engage and interact in a meaningful way. The club meets on Sunday fortnights at 2000h (GMT).

\(^{10}\) See Table 2.4 for the definition of a hashtag.
In terms of health service delivery, two physicians have used @tweetspreekuur since October of 2009 for primary care consultations. [84] Using the concept of learning by doing, the service was launched with little planning. After one year, their tweeting practice has shown that consultations encompass all areas of primary care though the main reasons for contact are advice, reassurance, and triage. Typically, questions and answers vary from one to eight tweets in length and about one third of the communication takes place publicly, while the other two-thirds takes place through direct messages. Pictures of skin and genital related problems have also been sent to the service.

Presently, @tweetspreekuur is run on a voluntary basis (there is no reimbursement to the physicians who run the service) and the attending physicians who run the service stipulate that their success is due to language (consultations take place in Dutch, limiting their audience), and the option for patients to continue the consultation through a secure online platform, which is only available in the Netherlands. Today, preliminary research [85] suggests that Twitter has been effective at providing access to care at a low cost, running the service is fun and entertaining for the providers, and the level of user satisfaction is high.

In this section, it is important to draw attention to hashtags, which are a form of information curation that allow people to find tweets related to a particular discussion or topic. Among the most common are #HCSM or Health Care Social Media and its Canadian (#HCSMCA), European (#HCSMEU) and Latin American (#HCSMLA) variants, #Med2, #MDChat, and #Health20. For example, a tweet that has both the #Med2 and
#HCSMCA hashtags will be read by people who filter tweets because of their interest in information related to social media in Canada; as well as the Medicine 2.0 conference series.

On the negative end, there are a large number of bots (e.g., Robots) that retweet and spam Twitter users who use particular words, phrases, or hashtags in order to increase their user reach and digital footprint; however these phony users are typically removed by the Twitter service relatively quickly due to the “report spam” feature on the site. Also, due to the limited size of a person’s profile, it is essential that Twitter users double check the identity of the person whom they are communicating with, as it is easy to create a fake profile and communicate with an unknown charlatan on the service.

**Social Networking Sites**

Although different types of social media are often categorized as social networking sites, for the purposes of this research, social networking sites will be defined as web-browser accessible services, which allow users to create social connections in a public or semi-public form (through the use of profiles) in order to share information updates with other site users. Wikipedia, the online user-generated encyclopaedia, further expands on this definition with a number of concepts, as can be seen below [61]:

* A social networking service is an online service, platform, or site that focuses on facilitating the building of social networks or social relations among people who, for example, share interests, activities, backgrounds, or real-life connections. A social network service consists of a representation of each user (often a profile), his/her social links, and a variety of additional services. Most social network services are web-based
and provide means for users to interact over the Internet (through) instant messaging. Online community services are sometimes considered as a social network service, though in a broader sense, social network service usually means an individual-centered service whereas online community services are group-centered. Social networking sites allow users to share ideas, activities, events, and interests within their individual networks.

A large number of peer-reviewed articles have been published under the MESH headings of Social Networking Sites and Web 2.0 [45], with much of the literature centered on issues around maintaining professionalism, ethical practices, identity, and privacy. However, given that these subjects apply to all types of social media, they are addressed in the discussion section.

An iconic paper by Farmer and colleagues (2009) [86] evaluated the relationship between Facebook groups and common medical conditions. They found that the most common type of groups on Facebook were centered on specific medical conditions (e.g., malignant tumors), peer-to-peer support, and fundraising for support groups, organizations, and individuals. Farmer and colleagues also found that researchers used Facebook to aggregate themselves into a “network” for dissemination of their research to other researchers and health care providers. They also identified the existence of self-aggregated negative-behaviour support groups, mainly centered on the promotion of excessive alcohol consumption.

Similarly, in July of 2011 Bender and colleagues [87] found that the majority of those who use social networking sites use them to form self-aggregated interest groups. Within a single disease, Breast Cancer, a search on Facebook revealed over six hundred support groups organized around four central themes: fundraising, awareness,
marketing, and general support. General support groups were not used as an adjunct to supportive care nor served as a general form of patient-to-patient support; rather, they were most often created by a user (or family member) with cancer as a means to keep friends and family members updated on their treatment and, at the same time, receive supportive feedback. Bender et al. also noted the fact that their results may be skewed due to the fact that they were only able to analyze public groups, which had very few user contributions as a whole, and that the technical architecture of Facebook, which makes it difficult to have a fictitious profile when compared to other (more open) social media, such as twitter, may be responsible for skewing the data. This is a general limitation of research on social media sites, all closed profiles and private conversations cannot be evaluated unless the patient him or herself discloses the content of these interactions. This literature review did not find any formal research comparing “closed” groups on Facebook.

Another interesting use of Facebook group occurred in Taiwan [88], where a well-known emergency physician blogger created a public group to ask his collages as to how they could improve patient wait times in the emergency room. In less than a month, the group grew virally, with the majority of emergency department staff from around Taiwan proposing solutions. Eventually, the group received so much attention that the Minister of Health himself (and his staff) joined the group and commented directly, using the comments from its fifteen hundred plus group members to make policy decisions. This culminated with the minister making visits to emergency departments in ten different cities and promising to initiate a dialogue to improve
funding and reduce wait times in emergency departments in collaboration with the
Taiwanese Bureau of National Health Insurance.

A less documented facet of social networking sites is the third-party applications
that can be created within these services. Third party applications work through the
integration of application programming interfaces (APIs) that allow outside software
and data to be visualized. In Facebook, the most prominent of these is Zynga’s Farmville
Game, which allows people to create a virtual farm and, by interacting with other
Facebook friends, acquire a virtual currency that can be used to buy virtual goods, such
as tractors or animals.

Similar examples within health can be found in an article by Fernandez-Luque
and colleagues [89] that searched for, and evaluated, these “apps” within Facebook.
This research found that less than 30% of listed applications were real and the
remaining 70% were non-functioning “spam.” In their evaluation of the 56 working
applications Fernandez-Luque and colleagues found that these software were
thematically centered around: fitness and weight loss, specific health conditions (e.g.,
diabetes) education, smoking cessation, and fundraising for health and research-related
activities. The most notable included “Get up and move” which allows people to
challenge their friends to engage in physical activity and report on it after they have
completed it; the American Heart Association’s “START” application, which was part of a
heart portal and allowed users to answer questionnaires on cardiovascular health and
upload the data to a health portal; and HealthSeeker a diabetes management education
app (See Figure 2.2) allowing users to learn how to better manage their diabetes and
gain “points” that could be used for incentive draws in the process. Although not specifically named, two other applications were also described, these allowed users to make appointments for blood donations. Only one application was made for physicians, which was used as a forum to answer patient questions.

**Figure 2.2: The HealthSeeker Diabetes Education App on Facebook**

Within the research realm, Bull and colleagues published a reflective case study that discusses the ethical questions that emerged during a randomized controlled trial of preventative HIV education for high-risk teens in the United States. [90] They found that maintaining ethical principles was the most difficult part of using Facebook for research purposes. In particular, maintaining beneficence, improving knowledge and information comprehension, ensuring equity of special populations, and safeguarding confidentiality and security were the largest challenges to the study’s implementation.
To overcome these problems, Bull and colleagues referred study participants from a Facebook fan page to an external website, which was congruent with the US Health Insurance Portability and Accountability Act (HIPAA) and their Institutional Review Board’s requirements. Bull and colleagues concluded by recommending that researchers who plan to collect data from social networking sites consider whether the social networking service is the appropriate vehicle for participant recruitment, that they offer multiple venues for participants to provide informed consent, and that all data are safeguarded behind secure firewalls, preferably outside the original social networking site.

**Professional and Thematic Networking Sites**

Professional networking sites are aimed solely for interactions related to a person’s professional career or business. LinkedIn is the most popular and does not solely focus on medicine or healthcare; it allows people to publicly display a curriculum vita along with personal and institutional affiliations. Unlike Facebook, which allows people to “friend” each other, LinkedIn uses connections, which publicly show people that may have worked together or know each other. Should a person be new to the site, connections can also be used to visualize the number of degrees of separation between two or more people. Figure 2.3 displays a public profile on LinkedIn.
A number of healthcare specific professional networking sites also exist; these include Sermo, Asklepios, Doctors’ Hangout, Ozmosis, Doc2Doc, and others, which try to recreate the intimacy of the “physicians’ lounge” in an online environment. These sites most often require the clinician to submit their credentials to a site gatekeeper, thus creating the perception of an elitist forum that is “safe” from patient’s eyes. Discussions in these sites typically range from dating in a medical environment, ethics, clinical trial and medication reviews, biostatistics, and specific treatment options. A combination of business models are also used by these sites, which vary from financial sponsorship by a professional association (e.g., Asklepios by the Canadian Medical Association), advertisement, anonymized data vending to external stakeholders (e.g., insurance companies, pharmaceutical companies, etc), commission on prizes offered by
companies trying to solve a particular problem (e.g., InnoCentive), and research by external stakeholders (e.g., surveys on physician medication prescription habits).

Thematic networking sites are analogous to professional networking sites, but centered on a particular theme. These include telemedicine (e.g., Telehelp), informatics (e.g., Health Informatics Forum), nursing (e.g., SocialRN), genomics (e.g., 23andMe) and patients (e.g., PatientsLikeMe), among others. Of particular interest are patient thematic networking sites, as a number of these sites collect, aggregate, and visualize patient data to promote patient-driven research (research that was initiated by a patient and used to collaborate with other patients with the same or a related disease). [91]

One site that promotes patient-driven research is CureTogether; it collects a number of health metrics including weight, caloric intake, sleep, exercise, and other disease-specific indicators. [92] Although the site is not meant to constitute medical advice, it allows patients to summarize statistics on treatment efficacy, side effects, and causes of disease, ultimately helping people make more informed treatment decisions. For example, on its chronic fatigue syndrome page, CureTogether has amalgamated responses from over thirteen hundred patients, encompassing nearly seven thousand data points on effective treatments. Indeed, it is this “crowdsourced” or collective wisdom from large numbers of patients approach what is believed to combat single stakeholder bias – a concept that remains contested by experts today, as it is difficult to prove, in terms of accuracy and validity, that a third parties have not intervened in how
results are displayed to users. Figure 2.4 displays a summary page on different treatment effectiveness for chronic fatigue syndrome.

**Figure 2.4: CureTogether’s Page on Chronic Fatigue Syndrome**

![CureTogether’s Page on Chronic Fatigue Syndrome](image)

**Wikis**

Wikis\(^\text{11}\) are easy-to-publish websites that can be quickly and easily edited by multiple users; they feature both text and multimedia content. Within medicine, the most commonly cited and used wiki is Wikipedia, which receives over 150 million page views per month, with the top 200 medical articles receiving over 100,000 monthly page views.\(^\text{[93]}\) Additionally, the Health Library Wiki of Canada (a UBC Library initiative) lists over 61 medical wikis and wikibooks available to healthcare professionals and patients alike. These can be found on Table 2.6.

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\(^{11}\) The term wiki was borrowed from the Hawaiian language; and it stands for quick; it is a metaphor of the speed with which information can be accessed, added, and edited on a wiki.
### Table 2.6: 61 Medical Wikis

<p>| | |</p>
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<tbody>
<tr>
<td>1.</td>
<td>AIDS Wiki</td>
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<td>2.</td>
<td>Ask Dr Wiki</td>
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<tr>
<td>3.</td>
<td>Clinfowiki</td>
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<tr>
<td>4.</td>
<td>Clinical Research Informatics Wiki</td>
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<tr>
<td>5.</td>
<td>Demystifying Depression (wikibook)</td>
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<td>6.</td>
<td>Diabetes Wiki</td>
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<td>7.</td>
<td>Diagnostic Radiology (wikibook)</td>
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<tr>
<td>8.</td>
<td>EBHC Search Strategies Wiki</td>
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<td>9.</td>
<td>EBM Librarian</td>
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<td>10.</td>
<td>ECgpedia</td>
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<td>11.</td>
<td>Emergency Medicine (wikibook)</td>
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<td>12.</td>
<td>EyeWiki</td>
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<td>13.</td>
<td>FluWiki</td>
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<tr>
<td>14.</td>
<td>Ganfyd - Get A Note From Your Doctor (U.K.)</td>
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<tr>
<td>15.</td>
<td>Handbook of Genetic Counseling (wikibook)</td>
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<tr>
<td>16.</td>
<td>HealthGrid wiki</td>
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<td>17.</td>
<td>Health++</td>
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<td>18.</td>
<td>HLWIKI Canada</td>
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<tr>
<td>19.</td>
<td>Human Physiology (wikibook)</td>
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<td>20.</td>
<td>Immunology (wikibook)</td>
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<td>22.</td>
<td>Medical Imaging</td>
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<td>23.</td>
<td>Medpedia</td>
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<tr>
<td>24.</td>
<td>MedSkills wiki project</td>
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<tr>
<td>25.</td>
<td>MIGHEALTHNET (Migrant Health)</td>
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<tr>
<td>26.</td>
<td>MLA-HLS Wiki</td>
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<tr>
<td>27.</td>
<td>NAHRS/MLA Nursing Resources wiki</td>
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<tr>
<td>28.</td>
<td>Neurodegeneration Research Wiki</td>
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<td>29.</td>
<td>NursingWiki</td>
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<td>30.</td>
<td>Open Anesthesia</td>
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<td>31.</td>
<td>Open Medicine</td>
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<td>32.</td>
<td>OpenWetWare</td>
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<td>33.</td>
<td>Onco Wiki</td>
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<td>34.</td>
<td>Orthopaedic Surgery (wikibook)</td>
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<td>35.</td>
<td>Pathology Informatics wiki</td>
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<td>36.</td>
<td>Pathpedia</td>
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<td>37.</td>
<td>Pharmacology (wikibook)</td>
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<td>38.</td>
<td>Physiopedia</td>
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<td>39.</td>
<td>Psychology wiki</td>
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<td>40.</td>
<td>Quality of Medical Data</td>
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<td>41.</td>
<td>Radiation Oncology (wikibook)</td>
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<td>42.</td>
<td>Radiopaedia.org</td>
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<tr>
<td>43.</td>
<td>Street Medic Wikia</td>
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<td>44.</td>
<td>Surgical Procedures (wikibook)</td>
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<td>45.</td>
<td>Toronto Public Library Health &amp; Wellness</td>
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<td>46.</td>
<td>UCLA Radiology Residents</td>
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<td>47.</td>
<td>Urgencyclopédie</td>
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<td>48.</td>
<td>WardWiki</td>
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<td>49.</td>
<td>WebHealth</td>
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<td>50.</td>
<td>Wellness Wiki</td>
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<td>51.</td>
<td>wikiCancer</td>
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<td>52.</td>
<td>WikiDoc</td>
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<td>53.</td>
<td>Wikiecho</td>
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<td>54.</td>
<td>WikiHealth</td>
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<td>55.</td>
<td>WikiHealthCare</td>
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<td>56.</td>
<td>Wikikidney.org</td>
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<td>57.</td>
<td>WikiMD</td>
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<td>58.</td>
<td>WikiPatient</td>
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<td>59.</td>
<td>Wikisurgery</td>
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<tr>
<td>60.</td>
<td>WikiTox</td>
</tr>
<tr>
<td>61.</td>
<td>Wikiversity School of Medicine</td>
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</table>

Although Wikipedias’ accuracy and completeness are often debated, as is the content of many wikis, research by Clauson and colleagues [39] compared Wikipedia’s drug information with the Medscape Drug Reference.\(^\text{12}\) This research found that Wikipedia had very few factual errors and that it included approximately 76% of the

\(^{12}\text{Medscape.com}\) is an advertisement-funded health care professional information site. It features content on drugs, research articles, and medical specialties.
content found Medscape (a validated and trusted information source). [39] Wikipedia was also found to foster quality/accuracy of information improvements over a period of ninety days, due to crowdsourcing, which was not the case with Medpedia due to their more restrictive editorial process. [39] In their concluding remarks, Clauson et al. noted that Wikipedia was a good starting point for health information consumers, despite being narrower in scope, less complete, and with more errors of omission than Medscape.

In terms of its editorial membership, a recent article published by Wikipedia’s medical editorial board [93] noted some of the dilemmas faced on this digital space. Among the weaknesses noted is the fact that some people and organizations (e.g., the pharmaceutical industry) have used the site to advance their personal and corporate mandates. Also, Wikipedia’s knotty user architecture uses a pseudonym whenever content is written or edited, which makes it very difficult to verify the expertise or credentials of content authors and editors. Among its strengths, Wikipedia’s medical editors noted the promotion of an article to Good Article Status, which requires the independent review by at least one editor, and a group of editors for promotion to Featured Article, a process that is analogous to peer review. Becoming an editor on Wikipedia is also no easy task, as user rank promotion\(^\text{13}\) is subject to a public voting system where the date, and number of articles edited and authored are evaluated by other Wikipedia users and editors; also IP addresses are cross checked, to prevent a

\(^{13}\) Wikipedians (people who contribute to Wikipedia) are democratically promoted and ranked based on the number of contributions (e.g., new articles, edits, etc.) that they provide to the Wikipedia site and community in general.
single person from voting themselves in. Wikipedia has a style manual [93], which, for example, prevents drug dosages from being added to the site in order to prevent patient harm from an unqualified person or charlatan with initiative to (self) diagnose and prescribe the wrong medication. There is also an elaborate process of content verifiability, should disputes arise between editors, to ensue successful conflict resolution and neutrality of the information.

Other notable wiki use for public health include the WHO’s International Classification of Diseases 11 update experiment [94], which opened the IDC classification system that is used around the world to clinicians for them to add new codes, that they thought should be considered, before the WHO ratified the new classification strata through its internal processes. Along similar lines is the Medskills wiki, which is a wikibook that compiles physical assessment techniques, a tool that allows students to learn without having to buy expensive textbooks. Wikisurgery, a free surgical encyclopedia; and OpenWetWare, which features a number of laboratory procedures to facilitate the learning steps of complicated laboratory techniques (e.g., a DNA polymerase chain reaction).

It is important to note that a large variety of wiki-like software exist on the Internet. These include Google Documents (GDocs), which is a word processing program analogous in functionality to Microsoft Word but with the added benefit of simultaneous synchronous user collaboration, and automatic document publishing as a web-page. [95] Similarly, etherpad, is a an open source, low bandwidth, massive user (>30) collaborative writing tool, particularly suitable for simultaneously working on a
This wiki section cannot end without mentioning one of the largest problems with wikis. These are attracting and maintaining a critical mass of content contributors and editors; as well as dealing with wiki damage, which occurs through (human or robot) spam, link rot, deletion of information such as medication side effects (despite the ability to see a history of changes, similar to Microsoft Word’s Track Changes feature), and the deliberate insertion of misinformation (e.g., neutraceutical companies noting that their products can cure cancer and other similar claims [93]).

**Mashups**

Mashups are portmanteaus (e.g., hybrids) of two or more web services, which use APIs to create a new service or functionality. The term was borrowed from the music industry, where separate music tracks are combined by DJs to create a new song. The first medical mashups originated in the form of analog Geographical Information Systems, similar to John Snow’s map of the Cholera outbreak in London in 1854. [97] Today, a large number of medical mashups exist (see Table 2.7) ranging from infection disease visualization (e.g., HealthMap.org) to PubMed search engines, which use semantic technologies to find peer-reviewed articles, which closely match an author’s written block of text (e.g., ETBlast3).
### Figure 2.7: Some Well Known Health-related Mashups

<table>
<thead>
<tr>
<th>Site Name/Address</th>
<th>Brief Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Google Earth</td>
<td>Typically known as a world visualization website, Google Earth allows time-enabled maps in order to track worldwide flu trends by using google.com symptom search queries.</td>
</tr>
<tr>
<td>2. Healthmap.org</td>
<td>Healthmap, which is led by a multidisciplinary team in Boston’s Children’s Hospital, uses informal data sources for real-time world-wide disease surveillance and outbreak monitoring.</td>
</tr>
<tr>
<td>3. Sickweather.com</td>
<td>Sickweather uses a patent-pending algorithm to aggregate data from Facebook and Twitter along with self-reported data in order to forecast, track and map a number of illnesses around the world.</td>
</tr>
<tr>
<td>4. Whoissick.org</td>
<td>Whoissick aims to provide current and local sickness information to the public. Although it was one of the first disease visualization mashups, today the site has little data and is likely to be defunct in the near future. The main reason is a lack of a community, which provides data to the site. Who is sick also does not reveal which data sources it uses to visualize disease and symptom outbreaks.</td>
</tr>
<tr>
<td>5. etest.vbi.vt.edu/etblast3</td>
<td>eTBLAST is an article search engine which looks for peer reviewed articles, such as those on PubMed, which resemble any block of text. Thus, one can write a paragraph and look for articles, which will support the premises noted. This mashup is a project of the Innovation Laboratory at Virginia’s Bioinformatics Institute.</td>
</tr>
</tbody>
</table>

An example, which illustrates both the importance and need for mashups by large organizations, is Healthmap. Financed by the Google Foundation and supported by the Canadian Institutes for Health Research, US Centers for Disease Control and the National Library of Medicine, HealthMap uses Fisher-Robinson Bayesian\(^{14}\) filtering to aggregate information from the World Health Organizations’ Information System.

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\(^{14}\) Fisher-Robinson Bayesian filtering is a technique which uses degrees of belief for statistical inference, rather than the (more widely known) frequentist approach for hypothesis testing which uses confidence intervals. [98]
(WHOSIS), the Food and Agriculture Organization (FAO), the Program for Monitoring Emerging Diseases (ProMED-mail) databases, Geosentinel (the global surveillance program from of the International Society of Travel Medicine), the World Organization for Animal Health, the European Centre for Disease Prevention and Control, Baidu and Baidu News, and Google News. HealthMap is interesting because it combines a very large variety of data sources and APIs (e.g., Google Maps, Google Translate and Xajax) to create a highly powerful information resource that can be “zoomed” all the way to relatively small geographic regions (e.g. suburbs). When looking for disease outbreaks all details are dependent on the source data, which means that while some geographic regions may display a high level of information, others may not; a general weakness of the site. Figure 2.5 displays the HealthMap Mashup for North American Disease Outbreaks.

**Figure 2.5: North American Outbreaks in the HealthMap Mashup**
Collaborative Filtering

Collaborative filtering sites are websites that allow multiple users to tag or classify and crowdsourced information to create a user-based, bottom up, folksonomy (a user generated, unstandardized, taxonomy). Today, a collaborative filtering feature can be found in most blogs (e.g., to classify blog posts into one or more subjects or themes), microblogs (e.g., through the use of hashtags), wikis (e.g., to find related articles), and media sharing sites (e.g., to find similar pictures or videos). Content tags are used to facilitate information filtering and when combined with a semantic algorithm, which prevents typos from being incorporated into the folksonomy as a new classification term, are powerful data curating tools. Three prominent collaborative filtering sites are Delicious, Digg, and Connotea. [100]

Digg is a social news site, which allows registered users to give a “thumbs up or down” on a news story. By doing so, articles are pushed up or down on the site’s landing page, allowing readers access to the “best” content as voted by the community. Users also have a comment and follow feature, allowing them to access other user’s views and subject interests. Moreover, Digg also integrates a number of APIs, such as Facebook Connect, allowing users to share articles and their views on them to other social media sites. In healthcare, Digg can be particularly useful to policymakers and hospital administrators who wish to get information on the latest outbreaks and health-related news in their local community, as the site allows access to the “highest regarded sources” as voted by the Digg user community.
‘Delicious’ is a social bookmarking service, which allows users to store, share, and discover web bookmarks. Its primary allure is a user-chosen tagging system, which allows people quickly to filter through large amounts of bookmarks in a short period of time. Also, due to its web-based nature, users can access their bookmarks from any computer with Internet access. Other features include public and private bookmarks, groups, and similar and popular link suggestions, which allow for collaboration. In medicine and health(care), Delicious can be used to create high quality collaborative knowledge repositories (e.g., with resources from WHO, CDC, Health Canada, etc) that are centered around a particular topic (e.g., a treatment) and can be easily accessed and by a select (or open) group of people (e.g., a hospital department).

Connotea is a free online reference management site for clinicians and scientists. It allows users to share and organize their references and receive updates as to what colleagues are reading and adding in their reference libraries. [101]

Unfortunately alexa.com, the popular web traffic rating site, shows that despite collaborative filtering sites’ usefulness, they are losing popularity and market-share in attracting new and maintaining old users due to the rising integration of a tagging feature in other social networking sites.

**Media Sharing Sites**

Media sharing sites comprise a large palette of social media tools that are optimized for viewing, sharing, and embedding digital media on other web services;
they share a large number of attributes with other social media – profiles\textsuperscript{15}, friends, comments, and private messaging/sharing of content – but their success is determined by the type content uploaded and shared. Views are often not necessarily related to the quality of the media or its accuracy, as viral content sharing may be erroneous or have poor resolution. Most often, a site’s catchy title \({102}\), amusement level (e.g., a baby panda sneezing and the mother panda being scared by the baby) \({103}\), or relevance to current affairs is what affects its ‘virality.’ \({104}\)

Media sharing sites, nevertheless, are great resources for knowledge translation (e.g., the Ken Jong CPR video), community building (e.g., multiple sclerosis patient-to-patient videos), marketing (e.g., Viagra commercials and information pamphlets), research (e.g., video explaining patient rights), education (e.g., medical skill demonstration videos and summary sheers), and branding (e.g., Mayo clinic patient playing piano video). They are also easy to use, have no cost (for non-premium accounts), and are accessible from both desktop and mobile devices. Table 2.8 illustrates the different types of media sharing sites, a common example, and their description.

\textsuperscript{15} A profile page in a media sharing sites is often referred to as a channel; however individuals and organizations may have more than one channel, as a way to organize content around a theme (e.g., Tuberculosis vs. Diabetes).
## Table 2.8: Types and descriptions of different media sharing sites

<table>
<thead>
<tr>
<th>Media Sharing Site Category</th>
<th>Example</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Video sharing</td>
<td>YouTube</td>
<td>Video sharing site where users can upload, view, share and comment an unlimited number of videos in both analog and high definition resolutions.</td>
</tr>
<tr>
<td>Photo Sharing</td>
<td>Flickr</td>
<td>Image and video hosting site with an online community centred on its users and the theme of uploaded photos.</td>
</tr>
<tr>
<td>Presentation Sharing</td>
<td>SlideShare</td>
<td>Slide sharing site where users can upload presentations in MS PowerPoint, Keynote, Open Office, and .pdf formats.</td>
</tr>
<tr>
<td>Document sharing</td>
<td>Scribd</td>
<td>Document sharing site where users can upload different types of document, presentation, and spreadsheet formats.</td>
</tr>
<tr>
<td>Music Sharing</td>
<td>MySpace</td>
<td>MySpace was the largest social networking site until 2008; however, today MySpace is primarily used as a niche media-sharing site for musicians and emerging artists, which allows them to upload and sell single music tracks and entire albums in MP3 format.</td>
</tr>
<tr>
<td>Education Sharing</td>
<td>ITunesU</td>
<td>A podcasting service provided through the Apple Corp. iTunes Store which grants free and paid access to educational documents, audio, and video. Content is multidisciplinary and available from kindergarten all the way through university; it includes course lessons, lectures, labs, and lab demonstrations.</td>
</tr>
<tr>
<td>Video and Images in Medicine</td>
<td>Medting</td>
<td>A web and mobile platform that allows physicians to share medical images and build clinical cases to foster inter and intra institutional collaboration.</td>
</tr>
<tr>
<td>Theme Specific</td>
<td>The Doctors Channel</td>
<td>Medical video site that offers free CME, medical news, and physician education videos from experts in over 50 specialties.</td>
</tr>
</tbody>
</table>

A number of articles have been published on the use of media sharing sites; these primarily focus on the use of audio and video podcasts\(^\text{16}\) for health professional education, patient-to-patient communication, and public health campaigns.

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\(^{16}\) A podcast is an audio or video recording of episodic nature that can be subscribed to, syndicated, and downloaded via the web or through a digital media store, such as iTunes. Podcasts can be played in mp3 players and iPods.
Within the patient-to-patient communication realm, Fernandez-Luque and colleagues (2009) evaluated the comments from a random sample of YouTube videos created by patients with Multiple Sclerosis. [105] They found that virtual communities emerged through the “comment” feature of the site, with patients responding to each other’s videos, documenting the progression of their disease, and endorsing certain medications that should be used as a last resort for the treatment of a disease (e.g., Tysabri). Of concern was the interaction with patients directly with the pharmaceutical industry, requesting patients to contact companies to become champions and public advocates for particular medications.

Similar research by Keelan and colleagues at the University of Toronto featured a characterization of available immunization information in YouTube. [106] They found that the most commonly discussed vaccine topic was childhood vaccines (accounting for 25% of the total vaccine videos) with the most specific vaccine topic being HPV. Overall, negative videos (e.g., those that contradicted the Canadian Immunization Guide) were more likely to receive a higher number of views and user ratings, and accounted for approximately 50% of total YouTube immunization videos.17

Media sharing sites have also become encyclopedic resources. Among the most notable are the Khan Academy, which hosts over three thousand videos and practice exercises in everything from algebra to medicine and healthcare; the Doctors’ Channel, which hosts online videos for a variety of healthcare professionals featuring content.

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17 YouTube does not discriminate video ranking based on content unless the video violates copyright policy (in which case, it is removed). Generally, the number of times a video is viewed is the main driver behind search result rankings.
about continuing medical education, medical news, and healthcare-related entertainments.

Negative effects from media sharing sites have also been reported [105]. In YouTube, copyright infringements are common. Today however, copyright owners can opt in to receive a share of advertisement revenue to keep the content online. Also, few child protection initiatives have been implemented on these services. For example, if one types “proana” and “thinspiration” on YouTube, over twenty seven thousand collective videos can be recalled. These can lead individuals to cause self harm by providing information on how to support anorexia and bulimia, as well as finding other equally ill individuals who become supporters in maintaining a disease-prone lifestyle.

Finally, it should be noted that not all content available on media sharing sites is available to anyone with an Internet connection; some countries block their access to these sites (e.g., China). Notwithstanding, it is also important to consider that the high prevalence of mobile phones has broken the capture and upload barrier for these sites, which means that if an organization or individual is not constantly monitoring their online presence, it is simple for an individual to take a video of themselves complaining about the care they have received and upload it onto the web, damaging an individual or a hospital’s online reputation very quickly and with very little relative effort.

**MUVEs and Other Social Media**

Although a large number of social media sites and functionalities are likely to continue emerging, the only remaining category of social media which have not yet been discussed are Massively Multiplayer Online Games (MMOG), more recently
branded as Multi-User Virtual Environments (MUVE). These 3-dimensional ecosystems are analogous to a mashup of video games and wikis, which allow users to interact with each other through a virtual representation of themselves known as an Avatar. Figure 2.6 displays an avatar inside a virtual operating room in Second Life.

**Figure 2.6: An avatar inside a virtual operating room in Second Life**

MUVEs can be classified in two general categories: general purpose and healthcare specific. The most prevalent general purpose MUVE is Linen Lab’s Second Life, which can be used for gaming or healthcare education with equal ease. Healthcare specific MUVEs are less common, typically focusing on particular activities such as medical education (e.g., CliniSpace), simulation (e.g. OpenSim), and psychiatric treatment (e.g., InWorldSolutions). A large body of research exists on the use of MUVEs and is summarized below, particularly focusing on SecondLife.

Historically, MUVEs evolved from early role-playing games. These were text-based and played by multiple users through networked computers; however, computer
graphics today allow live rendering that “feels” quite life-like. Also, MUVEs are programmed to simulate many aspects of “real life” that are possible in 3 dimensions. Thus, when two avatars walk closer together, the computer’s user will experience the opposite character’s voice getting increasingly louder, as it happens in real life. This effect is also mimicked graphically; that is, other avatars (and their surroundings) are rendered with increasing sharpness and become more life-like in their interactions as they become closer together.

Some special-purpose MUVEs can even integrate the use of external sensors (e.g., built in webcams in laptop computers) to replicate the user’s emotions on their avatars (e.g. smiling) [107] and experiments are already underway to incorporate scent, temperature, robotics, and even remote-controlled haptic devices.\(^\text{18}\) These extra gadgets have the goal of expanding current MUVE capabilities to add a “fourth dimension” (4D). [108]

Evidence for the use of MUVEs in medicine is growing rapidly with applications in, e.g., health care [109] and patient education [110], epidemiology [111] mass prophylaxis simulation [112], psychotherapy [113], and research [114].

A paper by Margaret Hansen at the University of San Francisco [115] has summarized the major strengths and weaknesses of these environments, which are applicable to both general purpose and healthcare specific MUVEs. Their strengths lie in their ability to be accessed from the comfort of a user’s own home at any time,

\[^{18}\text{Haptic devices give real-time feedback that can be felt, through the sense of touch; for example, a haptic intra venous cannula will decrease resistance once the bevel of the needle is in the “vein” on the screen.}\]
their pedagogical flexibility allowing users and content creators with knowledge of the Linden Scripting Language to design and construct a unique environment that mimics “real world” architecture. Their dynamic nature also supports collaboration at a distance, analogously to telemedicine. This is not without cost however, as the technical barrier to entry in terms of usability often prevents and frustrates most users of these tools (e.g., users have a hard time manipulating the avatar on the system and teleporting it to a virtual hospital). Other weaknesses of MUVEs also include the large amount of time required to build a 3D rendering of a physical place and the low efficiency associated with sharing text, images, and videos to an avatar, when compared with standard web browser-based interfaces of other social media. Finally, the fact that MUVEs are often perceived as computer games, rather than serious clinical and social environments, can also affect their adoption within healthcare institutions.

Beard and colleagues also conducted research that surveyed health-related activities on Second Life [116]; they found sixty-eight health-related locations, which are summarized in Table 2.9, along with their description. Other notable findings of this paper include the fact that research has demonstrated that using MUVEs can have real-life behavior implications. Indeed, this is the premise behind US CDC education center on Second Life, which aims to engage visitor to influence real-life health decision making.
Table 2.9: A summary of iconic health-related spaces in Second Life

<table>
<thead>
<tr>
<th>Category</th>
<th>Site Name</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education &amp; Awareness</td>
<td>Health Info Island</td>
<td>A site run by librarians and medical experts that offers education, awareness and access to a variety of health information resources.</td>
</tr>
<tr>
<td></td>
<td>Gene Poole</td>
<td>A genomics educational facility with 3D tutorials, videos, and other resources on chromosomes, DNA, RNA, laboratory techniques, and chromosomes.</td>
</tr>
<tr>
<td></td>
<td>Virtual Hallucinations Lab</td>
<td>This walking hallucinations lab educates people about the abnormalities of living with Schizophrenia.</td>
</tr>
<tr>
<td></td>
<td>Virtual Ability Island</td>
<td>A virtual island which provides a place for social support and education about disabilities.</td>
</tr>
<tr>
<td>Training &amp; Simulation</td>
<td>Imperial College London</td>
<td>This training hospital features a series of wards and patient simulation cases.</td>
</tr>
<tr>
<td></td>
<td>Play2Train</td>
<td>Emergency preparedness training. Teaches physicians how to manage patients and drug doses in emergency situations.</td>
</tr>
<tr>
<td></td>
<td>RL Education</td>
<td>The Heart Murmur Simulator allows people to auscultate virtually and learn normal and abnormal heart sounds.</td>
</tr>
<tr>
<td>Marketing</td>
<td>American Cancer Society</td>
<td>The Virtual Relay for Life is a fundraising event, which aims to sensitize people about cancer &amp; cancer research.</td>
</tr>
<tr>
<td></td>
<td>Palomar West Hospital</td>
<td>This virtual hospital simulates the patient experience and state of the art technologies used at Palomar West Hospital in Escondido, California.</td>
</tr>
<tr>
<td></td>
<td>FasterCures</td>
<td>An organization focused on changing the culture of medical research, it provides information about clinical trials and new treatments.</td>
</tr>
<tr>
<td>Research</td>
<td>Human Health &amp; Performance Lab</td>
<td>This is a University of Houston site, which pays people to fill out surveys, participate in research &amp; others studies.</td>
</tr>
</tbody>
</table>

**DISCUSSION**

This synthesis of results has yielded a number of issues, challenges and drivers for and against the adoption of social media in medicine and health(care). These are
summarized under the following three subheadings: ethics, professionalism, privacy, and confidentiality; information quality; and unanswered questions.

**Ethics, Professionalism, Privacy, and Confidentiality**

The potential violation of ethical standards, patient privacy, confidentiality, and professional Codes of Practice, along with the misrepresentation of information, are the most common contributors to individual and institutional fear against the use of social media in medicine and healthcare.

Equally important but less well understood is the notion of how these issues vary according to geographical and cultural norms, and how clinicians may protect themselves during internet-based interactions. A simple example of this is the Tweetsprekuur Dutch primary care consultation service on Twitter, which is considered to be an unethical use of technology by most professional bodies in North America (e.g., the Royal College of Physicians and Surgeons) who discourage or prohibit the use of social media for patient-clinician interactions altogether. [51] [117]

More specifically, there are varied philosophical views by professional bodies both supporting and condoning the use of social media. If this was not nebulous enough, these contradictions are further perplexed by regional (e.g., health authority) and institutional (e.g., Hospital) variations in policy. Fundamentally however, it can be said that the fear of the unknown is a major barrier against the adoption of social media in clinical settings. This “unknown” is likely due to the conservative nature of healthcare institutions and practitioners, a lack of understanding of the true risks and liabilities that could result, as well as the question of whose recommendations and best practices
should be followed (e.g., the CMA [118] supports the conservative use of social media while the BMA [117] and AMA [51] condone it).

Despite this uncertainty, Hrynaszkiewicz and colleagues [119] recommend that if information is posted publicly, it should not include patient identifiers (e.g., patient names, insurance numbers, photos) without written consent. However, if permission is not obtained, clinicians can remain on solid ethical grounds by disclosing up to a maximum of three indirect patient identifiers (e.g., sex, disease, treatment).

In general, there is a trend in the literature that recommends all clinicians to ignore patient requests sent through social media. [117] This is important because one could argue that, by not responding to these requests, clinicians are committing an Act of Omission, as there would be implied consent to respond through the medium given that the patient started the dialogue on social media (e.g., Twitter).

In terms of social media policies, socialmediagovernance.com [120] is the most comprehensive public database of institutional policies on the subject. As of June 2012, this resource included 194 social media policies, of which, 21 were from healthcare institutions, including big stakeholders like the Mayo Clinic, Kaiser Permanente, and Roche. In 2010, research by Kind and colleagues [121] evaluated all US accredited medical schools (n=132) for their social media presence. They found that although 95% (n=126) of American Medical Schools had a Facebook presence only 13 had social media policies and only 7 of those encouraged the thoughtful and responsible use of social media.
Research has shown [42] [122] that the numbers of privacy and confidentiality violations committed by physicians who use social media are relatively minimal. For example, Thompson and colleagues at the University of Florida [42] evaluated 1023 student and medical residents Facebook profiles in 2007 and 2009. They found that medical students were more likely than residents to violate privacy; however the only privacy violations that were found were photos of medical mission trips where clinicians were interacting with patients. Even then, out of the thousand plus profiles evaluated only 12 ethical violations were found, which accounted for less than 2% of physician profiles. Similar research using content analysis was also conducted with self-identified physicians on Twitter by Katherine Chretien [122], who found that out of 314 physicians, each with more than 500 followers only 3% of their total tweets could be considered unprofessional and 0.7% of them represented potential privacy violations.

**Information Quality**

The notion of health-related information quality has been a heated topic of discussion since the mid 1990s when Internet became accessible to the public. Of concern are not only child protection and anti-pornography initiatives but also quackery and e-pharmacies, which often use social media for direct to consumer advertising (DTC).[^19] Equally important are questions of identity theft, misrepresentation of identity (e.g., a charlatan claiming to be a Medical Doctor) and the validity of information that is provided within and through social media.

[^19]: Although DTC is only legal in the United States and New Zealand, pharmaceutical DTC practices reach the majority of web consumers due to the technical architecture of the World Wide Web, which makes it nearly impossible to block social media interactions across (arbitrary) geographical boundaries.
To establish the validity of the information provided, clinicians who use social media use one or more of the following tactics. First, they take pictures of themselves in a clinical environment and upload them publicly using a service such as Flikr or Picassa, so that any user with access to the internet can see them. Second, they complete a (public) professional networking site profile, such as LinkedIn, which denotes the location and year of their medical training, professional connections and affiliations, and other credentials or interests. (It is important to remember that professional connections or “friendships” on Professional Networking Sites rightly or wrongly give a sense of validation from third parties.) Third, they apply to and are congruent with one or more information quality policy consortiums such as the Healthcare Blogger Code of Ethics (MedBloggerCode) [123] or the Health On the Net (HON) [124] Foundation’s information quality initiative, which allow people to display a digital “ribbon” on their websites with a link to a third party site which verifies compliance with their principles of information quality.

The principles of information quality, as agreed by HON and MedBloggerCode are questionable, because inaccurate and false information is difficult to monitor and police; nevertheless, they should be noted as these principles have been in existence for over a decade. “Verified” websites displaying approval ribbons must voluntarily provide the following information: 1) [professional] perspective (e.g., Is the blogger a cardiologist or a cardiac surgeon?); 2) confidentiality (e.g., Is patient privacy being protected?); 3) conflicts of interest (e.g., Is the writer being paid by the pharmaceutical industry?); 4) reliability (e.g., Are there citations to peer-reviewed material?); 5)
courtesy (e.g., Is third party content attributed?); 6) purpose (e.g., Is the purpose of the site clearly stated?); 7) justification of claims (e.g., What is the level of evidence behind the information provided?); and 8) contact information (e.g., Are the contact details of the article author and website publisher accurate?). [123-124]

In contrast, clinicians who use social media anonymously typically use the quality of their content and the minute details provided in their rants to prove the validity of their claims and (to a point) credentials. The most famous case of anonymous blogging is that of Dr. Flea [125] which is discussed in Chapter 3.

At the time of this study, at the World Health Organization headquarters in Geneva, Switzerland, Dr. Joan Dzenowagis is leading a request to the Internet Corporation for Assigned Names and Numbers (ICANN), which manages all domain names on the Internet, for a new specific .health domain. The acquisition of this domain would be strictly legislated and monitored according to quality criteria, such as those noted above, and later prioritized by a consortium of industry partners (e.g., Google) to come up as the first search results when people look for health-related information. [126] Theoretically, this would improve consumer confidence with regard to the quality information from the get go and improve information trust as a whole because one could validate content from social media sites directly from their web address. However, whether this initiative will happen is a political issue that requires the support of at least 99 of 198 Member States at the World Health Assembly (WHO’s Governing Body) and will likely not be resolved in the near future.
Validated information sites have also existed since the dawn of the Internet. In social media, wikis like Medpedia (a Harvard, Stanford, University of Michigan and UC Berkley initiative), which verify author’s credentials before allowing them to generate content, have tried to improve information quality and “validity.” However, when the majority of articles by these “author verified” sources are compared with open initiatives like Wikipedia, they tend to be shorter, of equal or less quality, and have fewer references due to the restriction of users that can add and democratize the amount of content available on the Internet [127-128].

Unanswered Questions

Developing an appropriate Standard of Care involving digital interactions, particularly those over social web tools are likely to remain a misty ether of agreements due to the range of philosophical, cultural, social, and political values that can be found in the health sector. Professional standards, outlining whether to separate or merge clinical and personal identities are a reoccurring issue, as health providers have different levels of digital literacy and educational credentials (e.g., Should nurses have different digital interaction standards from physicians?). [129] For example, while some professionals may deem it acceptable to use one Facebook profile for both work and personal purposes, by using due diligence and monitoring their privacy settings carefully (e.g., with whom they share specific information; patients vs. close friends), others may lack the technical knowledge necessary to separate their personal and professional life and may have more than one profile or will avoid interactions with current and former patients altogether. [19]
There is also a question of whether legal frameworks from telemedicine can or should be adapted to social media. In telemedicine, for example, the standard practice is for clinicians to be licensed in the location where the patient is receiving treatment. However, the Internet transcends geographical boundaries making it nearly impossible to follow the same precedent. Even so, if the patient discloses their address of residence but is physically in a different geographical location when receiving treatment, it is debatable whether this principle should be maintained.

Other issues that need to be addressed, in terms of liability and malpractice, is whether a health care provider, layman, or digital platform should be held liable for health-related recommendations provided through social media. The articulation of policies that are adaptive to the rate of newly evolving social technologies will also continue to be a challenge for decision makers. At the core, is the question of whether professional organizations (e.g., the Royal College of Physicians of Canada) would prefer to monitor and enforce every digital interaction or whether they will grant the discretion necessary for their members to exercise their professional judgment and due diligence and only undertake an investigation when they receive a complaint.

Furthermore, there is a need for an urgent evaluation of policies by key actors (e.g., Public Health Agency of Canada, the Canadian Medical Association, Provincial Ministries of Health, etc.) that are responsible for safeguarding computer-mediated communication in healthcare. Should, for example, standardization and verification of medical licensing be implemented on the web? If so, it would need to be operationalized in such a way that provincial colleges of physicians, nurses, and other
care providers can link to a database or web-ribbon to prove their licensed clinician status. Ensuring the highest possible safety and effectiveness of digital interactions is a mutual responsibility of industry, professional associations, and government; however no hierarchy of responsibility and accountability presently exists and the gaps in policies must be harmonized through a multi-stakeholder meeting or clinicians will continue to operate in a conflicting policy environment which may ultimately lead to legal action as a result of their social media use.

Governments also need to identify what business models are appropriate in the health sector. For example, is it appropriate to sell patient information? Traditionally, it has, so long as the patient is informed of the transaction and the data are anonymized. However, given that users seldom read the Terms of Service when signing up for a social tool and that they are not allowed to modify them, an ethical question remains about whether they are being de facto coerced to give their data away when joining a specific service. This issue is further complicated by the notion that interacting through social media is an increasing social expectation. [131]

An additional issue is that few web companies and social media service providers are fully transparent, from the moment a user signs up for a social service, as to how they will use a user’s data. Even if they are transparent in how they will use the data, the Terms of Service, which are legal binding documents, often change without the end user having any say in the matter or even being aware of the changes. It is important to consider whether or not users and industry would be willing to open a pay-for-privacy business model, which could potentially allow social media to become an ecosystem for
safe and secure digital interactions in healthcare by allowing clinicians and patients to use services they already use (e.g., Facebook) for a safe and ethical healthcare-related encounter. Alternatively, the question of whether governments should institute a legal requirement for user privacy in these sites will be important to ponder in the future, as secure messaging platforms in the healthcare space are expensive and even sometimes even subject to privacy and confidentiality breeches themselves. [132]

To date no longitudinal evaluations of the full economic effects of social media, both with regard to health care and in other domains, have been conducted. Though this is due to the novel nature of social media, such evaluations would help determine the appropriate incentives (e.g., CME vs. money), who should provide them, the return on investment, total cost of ownership, scalability, and long-term financial feasibility of using social media. [133]

Other theoretical and pragmatic questions must also be addressed; these include (but are not limited to: 1) Will Wikipedia and other medical wikis which use crowdsourcing and open structures of community-regulated validation become more powerful and sustainable than UpToDate-like resources that have traditionally used a small (paid) group of individuals to create clinical information summaries? (If so, what are the ethical and legal responsibilities of the Wikipedia-like actors towards health consumers?); 2) How biased are social media in providing medical information to users and is it leading to near-infinite segregation of users around a specific belief (e.g.,

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20 Near-infinite segregation can be conceptually understood as the idea that the internet can provide nearly limitless data storage and socialization spaces for people with deviant behavior (e.g., quacks) to maintain their practices, interact with like-minded
quackery); 3) What are the sociocultural, ecologic, and architectural considerations that must be contemplated over the next decade in the use of social technologies in healthcare?

Limitations

This study has a number of limitations. First, results were limited to the English language. Second, during the environmental scans and grey literature queries snowballing was used, which is subject to friendly and frequent author bias. Third, due to the complexity of the data synthesis process, there was a three-month lag between the data collection and the completion of this manuscript (despite efforts to monitor new applications and tools during this time, it is possible that I may have missed new developments during this time period). Finally, there was a high-reliance on self-reported data from blogs and primary users, which opens the possibility to incorrect, fabricated, or invalid data.

CLINICAL IMPLICATIONS

This research has demonstrated that clinicians may use social media as part of their professional duties in health service delivery. Thus, the following four guidelines may be used to mitigate risk during such interactions.

Principle 1: Maintain professionalism at all times: Clinicians must remember and follow their institution’s and professional association’s social media guidelines in all digital interactions. If such bodies have not yet created a policy on the use of social media, clinicians must assume that all information exchanged is public and posted in a medium individuals and promote their practices without being confronted by an a recognized authority (e.g., Health Canada). [134]
no different than a newspaper. If in doubt about whether the information to be posted is appropriate, it should not be posted. It is also essential to remember that just because a message is private (e.g., a direct message on Twitter or Facebook) this does not mean that the information being exchanged is secure and protected. Clinicians and organizations may also use disclaimers to note that the information provided through social media does not indicate any form of endorsement or validation by third parties; and that all views expressed are solely those of the author and not those of the institution that the clinician is affiliated with. Indeed, although disclaimers in general have no legal weight in court [107], they do inform the public of separate personal and institutional identities.

**Principle 2: Be authentic, have fun and do not be afraid:** the only way to create meaningful relationships over social media is to be genuine. Clinicians should not be afraid to be themselves, so long as they keep in mind Principle 1 and remember the public nature of social media, as well as who their audience is.

**Principle 3: Ask for help:** People who use social media are very enthusiastic about new members joining their community; thus, clinicians should look for people with similar interests, both professional and personal, and ask for help. Attention to detail should also be placed on how people interact (e.g., netiquette) and mimic the social media service and community’s practices (so long as they are professional).

**Principle 4: Focus, grab attention, engage, and take action:** One of the most useful models for the successful engagement of an online audience with social media is the Dragonfly Model [135]. By using the analogy of a dragonfly which needs all four wings
to work in concert, equally this model uses the following principles: 1) focus (e.g., identify a single, concrete, and measurable goal for using social media); 2) grab attention (e.g., make others look at content by saying or posting something interesting); 3) engage (e.g., foster personal connections by discussing your interests with like-minded people); and 4) take action (e.g., enable and empower others).

CONCLUSION

The role of social media in the healthcare sector is far-reaching and this article has discussed which, what, where, how and why different social media are used in a spectrum of healthcare-related settings. Questions and debates in terms of governing social media and applying it to medicine and healthcare are likely to remain contentious.

Although research has shown that few physicians who use social media violate privacy and confidentiality standards, it is unclear as to whether it is appropriate to delegate discretion to the physician and allow him or her to decide if social media is appropriate in specific medical contexts; indeed, this is the case in the Netherlands with the primary care Twitter consultation service @tweetspreekuur, where Dutch telemedicine policies allow physicians to make the call of whether a particular technology is appropriate for patient care. Understanding which actor or actors are responsible and liable, as well as how ethics, confidentiality, privacy, and information quality should be managed will remain central issue that must be resolved in the coming years.

The four guidelines provided herein provide a starting point for healthcare professionals who wish to use social media in a safe and ethical manner. However,
much work remains to be done in understanding the pertinence of social media in public care when contrasted with their use in private systems where social media is principally used as a marketing technique to supplement concierge-medicine. Finally, more research will allow us to understand the synergies between social media and evidence-based practice, ultimately allowing for evidence-based policies and economic analyses on the return of investment of using social media.
CHAPTER 3
A Selection of Recent Judicial and Administrative Case Studies that Emerged from the Adoption of Social Media in Medicine and Healthcare

INTRODUCTION

In the previous chapter I reviewed the literature regarding the where, how and why social media have been adopted in a variety of medical and health(care) contexts. However, there is no question that legal and ethical issues also emerged during the adoption process. Indeed, many stakeholders today not only fear the implications that could result from the use and adoption of social technologies, but they are also highly skeptical and unaware of the administrative and judicial processes that could follow when social media are misused.

Questions including: “How can social media affect physicians during a malpractice lawsuit?” “How should academic institutions respond to students who violate patient confidentiality?” “Should physicians interact with their patients through social media?” illustrate the many actors and controversies faced by clinicians, patients and the public alike. Indeed, it is the objective of this chapter to use case studies to explore these questions.

The first case study is entitled Dr. Flea; it will review a famous malpractice lawsuit of an anonymous pediatrician blogger. The second case study is entitled Facebook in Nursing Practice; it explores a nursing student who was dismissed from Johnson Community College for uploading the picture of a placenta and umbilical cord

75
during a maternity placement. The third and last case study is entitled *Friend or Foe*; it discusses the case of a physician and a patient who were “friends” on Facebook and had to stop their virtual relationship (e.g., their Facebook friendship status) due to hospital policy.

Since these cases were all in the public domain, it is important to understand the background story, what has happened, how institutions have reacted, and how the issues were dealt with. Indeed, these examples are real-life illustrations that have been discussed in both social and traditional media (e.g., print and TV) and have created a great deal of public interest, anxiety, as well as a potential legal precedent.

**Case Study 1: Dr Flea**

Pediatric Pulmonologist Dr. Robert Lindeman was a world-renowned anonymous medical blogger and, conjointly, the winner of the 2006 Medical Weblog Awards. His Blog, “Flea”, covered topics from childhood obesity to anti-vaccination perspectives. In an interview [26], Lindeman noted that he blogged anonymously because “there were things that [he] could not say publicly because [he] was a doctor [and] his colleagues would judge him.” These included things like malpractice and the “sorry state” of his subspecialty. Unfortunately however, his blogging led to the most notorious settlement due to medical blogging known to date.

In 2002 Dr. Lindeman had a patient who suddenly and unexpectedly died from complications of diabetes. The mother of the deceased decided to sue Dr. Lindeman for wrongful care. After consulting with his malpractice insurance, the matter went to trial,
as Dr. Lindeman, his attorney, and the insurance company believed no malpractice occurred.

During the trial Dr. Lindeman decided to provide a play-by-play summary of what happened under his nom de plume “Flea”, a blog he had been running for a number of years prior to the court case, anonymously. Inappropriate details, including the videotaped preparation sessions with his attorney and the coaching process of how to answer questions in a manner appealing to the jury were discussed in his blog. Flea also noted which clinical materials his attorney had told him to read [[136], that the judge was “dozing” during the trial, and that Dr. Lindeman himself was a “cocky bastard.” [43]

Half way through the trial a colleague of the plaintiff’s attorney, who read medical blogs, came across Flea’s blog and informed the plaintiff. The next day, while on the stand, Dr. Lindeman was asked if he was Flea, which resulted in a substantial financial settlement with the plaintiff due to “prior inconsistent statements.” (This is basically a legal term noting that Flea’s account on the blog and his testaments in court were contradictory.) That day, the Dr. Flea blog was taken offline and since, Dr. Lindeman has never blogged again. Despite this however, the story was on the front page of the Boston Globe the next day resulting in numerous social and professional consequences.21

Case Study 2: Facebook in Nursing Practice

Doyle Byrnes was a 22 year old 4th year nursing student at Johnson Community College [137] when, during one of her placements at Olathe Medical Center’s maternity

21 These consequences are presented in the discussion section.
ward, she asked one of her nursing instructors if she could take a picture of a patients’ placenta and umbilical cord. Doyle was excited and wanted to share the excitement with her family and friends. The instructor replied 'oh you girls', so she proceeded to take the picture and post it on Facebook (Figure 3.1 [138]). Three hours later, the instructor called Doyle and asked her to take the picture off the social media site. Doyle happily complied. Asking the instructor if she was in trouble, the instructor replied that she was not. In fear of being reprimanded, Doyle also closed her Facebook account. Despite this however, the next day Doyle was dismissed from nursing school with a letter from Jeanne Walsh, director of nursing at the college, noting: “Your demeanor and lack of professional behavior surrounding this event was considered a disruption to the learning environment and did not exemplify the professional behavior that we expect in the nursing program.”

Figure 3.1: Doyle Byrnes’ Facebook Picture
A few months later, the Doyles sued the school and the case went to court. In particular, Clifford Cohen, Doyles’ attorney noted that the Johnson Community College’s Code of Conduct did not address photographs or social media. A federal judge noted that the school had no right in dismissing the student, and ordered the school to issue a reprimand and reinstate Doyle into the nursing program. Doyle completed her degree and moved states to look for a job in nursing. It is unknown if she was able to find a job due to her inappropriate use of Facebook.

Case Study 3: Friend or Foe

I am a patient, researcher, and healthcare professional. I have worked with the World Health Organization and the World Bank as an “expert” in social media. I believe that we can use social media to humanize medicine and empower patients. Recently, I was shocked to receive an email from my physician. He had to “unfriend” me from Facebook because of a new hospital policy.

Last May, the British Medical Association (BMA) issued a statement condemning patient relationships on Facebook. Their rationale is that social technologies “increase the potential of clinical exploitation” because a physician may gain access to information that was not disclosed during a clinical encounter. [117]

At the core of this issue is defining professional boundaries on digital spaces and, as a corollary, our expectations of privacy. My doc and I, whom I haven’t named to protect his identity, had a mutual agreement. Our “friendship” outside the clinical space

22 This case study was published under the Creative Commons Public License in the Journal of Participatory Medicine on August of 2011. [139]
would serve, in our view, to complement rapport, and the Facebook platform was not to be used for medical purposes.

At last, I had found a positively deviant doctor. He put patients first.

It took less than two months for the system to condemn our behavior. (The BMA policy was adopted by my physicians’ hospital, reprimanding all physician-patient contact on social media.)

I fully supported and understood my doctor “unfriending” me. However, when are we going to protect those doctors who want to go above and beyond the standard of care? Perhaps in the future the BMA will not sanction our connection through a Google+ circle, which allows physicians to separate personal and professional connections, but perhaps the system will never change and will only see risk when they hear the words “social media”.

**DISCUSSION**

These three cases exemplify the difficulties patients and clinicians face when setting boundaries on digital spaces; they also illustrate the institutional and public repercussions that may result when personal boundaries are evaluated through an institutional and organizational lens.

*Anonymous Blogging*

The case of Dr. Flea exposes the risk and lack of anonymity that can be found on the social web. Today, the medical blogging community condemns anonymous blogging, yet a few prominent blogs of unknown authorship remain (e.g., Storytell ER Doc: A peek behind the curtain [140]). Medical professionals who wish to blog must always evaluate
the risk vs. benefits of using social media. Common incentives for blogging can vary from financial (e.g., remuneration by hospitals and other healthcare institutions on a by post basis), to social (e.g., receiving respect from the medical community), or moral (e.g., creating a communication forum for patient-physician interaction) reasons.

After the settlement, Dr. Flea was interviewed by the New York Personal Injury Law Blog where he noted the following advice to medical bloggers [136]: 1) Every time you post, recite the following to yourself as though it were a mantra: “I am cutting rope with which to hang myself. I am cutting rope with which to hang myself”. 2) Any time you write anything, anywhere, recite the following to yourself as though it were a mantra: “I am cutting rope with which to hang myself. I am cutting rope with which to hang myself”; and 3) Don’t blog anonymously.”

The response of the patients in Dr. Lindeman’s practice subsequent to the lawsuit was also interesting, as Dr. Lineman described the segregation of patients in his private practice into three groups [136]: fugitives, supporters, and everybody else. The fugitives called as soon as they found out about the case and demanded that their records be transferred to a different practice. The supporters called Dr. Lindeman to express their support, they told him that they respected him and appreciated him being their doctor. Finally, everybody else was the third group, which includes everyone who did not know about the case or what to think of the situation, resulting in never making any mention of it. Despite this, some colleagues, once they found out Flea was Dr. Lindeman, stopped speaking with him altogether; illustrating the ripple effect that inappropriate medical blogging can have on a medical professional and his practice.
The case was also widely discussed by the medical blogosphere. Dr. Ves Dimov, an allergist and professor at the University of Chicago, provided a summarized account of the event along with the following recommendations [141]: 1) write as if your boss and your patients are reading your blog every day; 2) comply with Healthcare Insurance Portability and Accountability Act or corresponding legal statute in your jurisdiction (AKA Do not blog anonymously); 3) list your name and contact information; 4) if your blog is work-related, it is probably better to let your employer know; and 4) use a disclaimer, such as: "All opinions expressed here are those of their author(s) and not of their employer. Information provided here is for medical education only. It is not intended as and does not substitute for medical advice."

**Posting Inappropriate Pictures**

The story Doyle Byrnes exemplifies the range of expectations for privacy, confidentiality, and professionalism that vary with age, culture, and across healthcare institutions. It raises an important question of whether or not the healthcare establishment will be able to create policies that can keep up with the dynamic nature of online environments. For example, the question of whether a placenta is an unequivocal patient identifier, bad taste or simply stupid is at the crux of the ramifications that could follow if this case were to repeat itself.

Although Byrnes’ case has received much attention in the media, it is unlikely that this event is isolated. Different social media sites have different privacy settings, many of which can be customized, but often change, many times without notice or time for a user to adapt. [19] Indeed, it is difficult for institutions to know if a picture that
violates professional codes of conduct has been uploaded since “private” update timelines are common and social media privacy site settings vary. [42]

Should healthcare institutions police their employees for appropriate conduct? Generally, a violation of patient privacy occurs when identifiable information is shared with people outside the patients care circle [43] and although a patient picture is considered a direct patient identifier, could one claim that a placenta is equally identifiable? Drawing the line is an issue that must be addressed in all policies, and at present, the horizon remains unclear as to what is inappropriate behavior, who should sanction individuals, and who is responsible to monitor social media.

The use of pictures is common in learning environments. Thus, one should ponder what would have happened if a less publicly visible technology were used. Say for instance, if Doyle Byrnes used a Polaroid camera and the picture was displayed at a family member’s desk, would Johnson Community College and other academic institutions consider the offence to be of equal or lesser magnitude?

At present, there are no ethical frameworks in the peer-reviewed literature addressing social media issues. Furthermore, it is also unclear, once a real violation of patient privacy and confidentiality has occurred, how healthcare institutions should respond when renewing or hiring new personnel who have committed these “infractions”, given the lack of legal and related policies.

Digital Friends

The unfriending case in Facebook illustrates the evolving understanding of professional boundaries, as well as the present turf wars about who should govern
social media in clinical realms. This scenario is analogous to who should own the
electronic medical record (e.g., the patient, the government, or the physician) that is
still under debate. Clinicians wishing to augment the therapeutic relationship with
digital tools are subject to a number of codes of practice, ethics, and legal statutes -
most of them with conflicting perspectives. This contrast is illustrated in the social
media policies of the College of Physicians and Surgeons of British Columbia [142] and
those of the Canadian Medical Association. [118] Excerpts of these policies are displayed
in Tables 3.1 and 3.2, respectively.

Table 3.1: Royal College of Physicians of British Columbia Position on Social Media Use

<table>
<thead>
<tr>
<th>The College proposes the following guidelines for physicians who participate in social media and online networking forums:</th>
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<tbody>
<tr>
<td>1. Do not initiate an invitation to patients or patients’ family members to be your online friends.</td>
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<tr>
<td>2. Carefully consider an invitation from a patient to become an online friend. In general, avoid entering into dual relationships with patients by becoming online friends but be considerate of patients’ feelings when declining the invitation.</td>
</tr>
<tr>
<td>3. Respect patients’ privacy by carefully managing information acquired about them from online sites or other sources. Consider whether it is medically necessary to view patients’ websites or online profiles and, if so, seek permission to access these sites. Do not enter collateral information about patients in your records without their knowledge.</td>
</tr>
<tr>
<td>4. Exercise restraint when disclosing personal information on social media or online networking forums. Assume content on the Internet is public and accessible to all.</td>
</tr>
<tr>
<td>5. Read, understand, and use the strictest privacy settings in order to maintain control over access to your personal information. Be aware that privacy settings are imperfect and can be compromised.</td>
</tr>
<tr>
<td>6. Be mindful of your own Internet presence and be proactive in removing content, which may be viewed as unprofessional.</td>
</tr>
<tr>
<td>7. Be aware of the potential for establishing online therapeutic relationships through medical advice and discussion posted to the Internet. Also be aware of the potential for breaching patient confidentiality by conveying medical information in anecdotal form in an Internet post.</td>
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</table>
Table 3.2: Excerpts from the CMA’s Rules of Engagement with Social Media

<table>
<thead>
<tr>
<th>Background</th>
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<tr>
<td>• The reality is that individual doctors and medical organizations have to consciously decide if, why and how to use the various social media platforms.</td>
</tr>
<tr>
<td>• While use of social media could potentially increase the exposure of physicians to disciplinary and medico-legal issues, those physicians who choose to use social media can help shape how these tools can improve health care in the future.</td>
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<tr>
<th>Patient Confidentiality</th>
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<tr>
<td>• When using social media, physicians should endeavour to use the most stringent security and privacy settings available for the particular platform.</td>
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<tr>
<th>Professionalism</th>
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<tr>
<td>• Having an online profile or identifiable presence on social media can have the same degree of positive or negative impact on a physician’s social reputation as being active in any other public venue. In fact, having access to a global audience can magnify this reputation.</td>
</tr>
<tr>
<td>• The most effective use of social media often involves communicating information that is both personal and professional. However, physicians must retain the appropriate boundaries of the patient-physician relationship when dealing with individual patients. The same standards of professionalism that would apply in face-to-face physician-patient interactions also apply in electronic interactions.</td>
</tr>
<tr>
<td>• If a physician is an employee of a health care institution or organization that has social media guidelines in place, he or she should review these and act accordingly.</td>
</tr>
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</table>

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<tr>
<th>Potential Benefits</th>
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<tbody>
<tr>
<td>• More frequent communication with patients and the public improves the quality of medical care and satisfaction with physician care. Social media can enhance the role of traditional media in delivering important public health messages.</td>
</tr>
<tr>
<td>• Use of social media can provide patients and the public with quicker and easier access to medical expertise, often in a way that is more current, clear and concise than traditional media sources.</td>
</tr>
<tr>
<td>• Posting (with copyright permission) evidence-based medical information on social media sites can improve the quality of health information made available to patients and the public.</td>
</tr>
</tbody>
</table>

As it can be seen from Tables 3.1 and 3.2, the perspectives from the CMA and the College of Physicians and Surgeons of British Columbia are conflicting. While the College believes that physicians should avoid interactions with their patients on social media sites, the CMA accepts that social media is a public space that can improve the quality and satisfaction of medical care. At present, each provincial College of Physicians
and Surgeons is responsible for licensing medical practice and subspecialty, however if a member is unaware of their provincial college policy and follows the CMA policy, should they be considered to be at fault in the eyes of the public, when what they are doing is in the best interest of the patient? Traditionally yes, but whether it is the best approach is important to consider.

Understanding if different technical platforms should be governed differently and by which stakeholder is at the crux of social media governance. Traditionally, secure messaging platforms like mydoctor.ca along with secure email platforms used by health maintenance organizations (e.g., Kaiser Permanente) have been deemed appropriate for patient-clinician communication though open social media platforms have not. Perceiving whether there is an actual vs. a real threat to patient confidentiality is also an issue of perspective, as it could be argued that if a patient contacts a clinician through a social platform s/he is inherently giving permission for the clinician to respond through that medium. Even so, research also shows that secure platforms can be subject to privacy and confidentiality breaches despite robust security training and the compliance of good information safeguarding practices, as it happened to Kaiser Permanente’s “KP Online” platform, which during a server patch installation concatenated 800 email messages and publicly revealed the confidential health information of a large number of patients. [132]

Nevertheless, institutions must consider whether instating policies that force clinicians to ignore patient contact on social media are innately violating the principle of patient autonomy and/or might cause an act of omission. For example, if a clinician
receives a suicidal ideation note on a social site, he has a legal duty to act and inform the authorities. Yet, if this is considered a valid exception for action when interacting in social media sites, what other exceptions are acceptable on these social digital spaces?

**CONCLUSION**

In conclusion, this chapter has presented a review of three recent judicial and administrative cases that affected, both directly and indirectly, clinicians and institutions that use social media. The question however remains in who should be responsible for the governance of social media, and where should personal and professional boundaries be drawn. Much research and work will need to be done before ethical and governance frameworks can be harmonized across and between healthcare actors to ensure the safe, ethical, and responsible use of social media in clinical environments and a positive addition to the therapeutic patient relationship.
CHAPTER 4

Conclusions

[Social Media] are like Pink Floyd lyrics; they mean different things, to
different people depending on their state of mind – Kevin Maney

What We Know

Social media are increasingly being adopted in medicine and healthcare. Although their use is perceived to be risky by a large majority of healthcare stakeholders, it has not stopped many clinicians and institutions from adopting and implementing social media as a means to improve hospital efficiency, efficacy, equity, visibility and improve the patient experience. However, comprehensive, high quality, evidence on these implementations remains relatively scarce and it is primarily found in the grey literature.

The cases and applications reviewed suggest that social media has become and will continue to be a major venue for computer-mediated communication in medicine and health(care). Furthermore, this research has also demonstrated that patient information privacy and confidentiality breeches on tools like Twitter and Facebook are relatively uncommon.

From an academic perspective, more work is required to document the theoretical and conceptual frameworks that can be used to evaluate social media in research and practice. Media studies, Medical Informatics, and Medicine 2.0 may be used as a lens to operationalize research, but when combined with the critical-
interpretivist approach are not often well accepted within the traditional positivistic realm of evidence-based medicine.

The question of who should govern the use and adoption of social media remains nebulous in the world beyond academic discourse. Although policies on the use of social media are being crafted and adopted by academic, healthcare, and professional institutions, views are often conflicting across actors, and policy violations are difficult to police due the vast differences in user knowledge on social media site privacy, as well as the differing perception of what is appropriate and inappropriate behaviour.

Identifying appropriate frameworks with which to guide the safe, ethical, and appropriate use of social media in the healthcare space will be a challenge in the years to come. Understanding how security, patient confidentiality and risk should be mitigated and attenuated will be increasingly important as social media has evolved much more quickly than policy can be created or adapted. Exploring, disseminating, and translating “best practices” for both private and public healthcare institutions (and the general public itself, as there are users with differing perspectives on this issues) will allow further adoption and decrease institutional resistance to the continued adoption of social media.

To my knowledge, this is the first comprehensive synthesis of the evidence, assumptions, conceptual and theoretical frameworks, and ethical and administrative dilemmas that have been experienced in medicine and health(care) in adopting social media. However, as stated in Chapter 1, the intent of this research was not to prove, measure, or generalize; its intent was to use narrative and dialogue to question and
explain, to uncover, as well as to understand how different actors may use and enable change through the use of social media. The dissemination of this work will be essential for healthcare actors in optimizing their governance, clinical, administrative, and public engagement procedures in their day to day activities.

Although a number of safeguards have been implemented to ensure the robustness of this research, the dynamic nature of social media provides an inherent limitation of this work. Unfortunately the majority of the evidence for the use, adoption, and implementation of social media remains outside of the peer-reviewed literature. This makes it difficult for decision makers to accept and value the intrinsic contributions that social media can provide to their organizations and health(care) practices.

**What We Would Like to Know**

Understanding how social media tools and technologies impact quality, access, and cost of healthcare delivery will and should remain a top priority for health(care) actors and institutions. Further research is necessary to develop new (or adapt existing) frameworks on the ethics, effectiveness, impact, and return of investment of digital social spaces. It is also key that we understand the appropriate incentives that support clinicians and institutions in augmenting the therapeutic relationship that can emerge through social media; this will not only help improve healthcare delivery, but it will also ensure that new emerging tools are used in the safest, most ethical, and effective possible manner.

Finally, understanding the benefits, functionalities and contextual applications that social media can provide to the healthcare establishment are vitally important.
Although this work has provided the what, where, when, how, and why social media may be safely and appropriately adopted, it is necessary to formally document established practices across the spectrum of healthcare actors using these tools. Furthermore, it is important to ponder whether clinical trials are necessary before the healthcare establishment accepts that social media has penetrated its “safety” walls. Widely available mobile devices (e.g. smart phones, iPads, etc.) make it nearly impossible to prevent access to social media in virtually any context. Convincing different actors however, of the benefits of social media will likely remain a challenge due to the conservative nature of medicine and the healthcare establishment as a whole. However, a much clearer picture of benefits and risk must be developed thorough research to make progress and ensure that the safest practices possible are followed when healthcare is delivered through computer-mediated communication tools like social media.
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