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Consumer Informatics and Digital Health

Solutions for Health and Health Care

Springer

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Chapter 4
Healthcare Social Media for Consumer Informatics

Check for updates

Mandi Bishop

Introduction

If you're reading this, chances are you're a digital native—born in the Information Age, raised on smartphone apps, speaking fluent text acronyms and emoticons. It's likely that the internet is the first source you turn to for research on every topic from "how to apply the perfect smoky eye makeup" to the nuanced politics of the Middle East.

It may be tough to imagine a time when instant information access was not available, any time, on demand, at your fingertips. But I was born in such a time: when research had to be done at a physical library, during library hours, using the Dewey decimal system to navigate rows of shelves and find encyclopedias that were only updated once a year, and whose entries referenced other physical books that I then had to go back to Dewey to locate (see Fig. 4.1). Crowd-sourced information stores, such as Wikipedia, existed in different forms within communities—but they were called opinions or rumors, not facts.

As you read, try to remember that the road to digital culture acceptance was a long one—and that, for many individuals and organizations, we aren't there yet. Healthcare, as an industry, has traditionally been a Luddite, lagging a decade or more behind most major industries in the adoption of new technology.

However, in recent years, the industry has been accelerating its technology proliferation—with social media playing a large part in propelling healthcare forward into its inevitable digital future. Consumers have come to expect and demand the digital native experience, and social media gives them a powerful, global voice to ensure these demands are heard and met.

M. Bishop (✉)
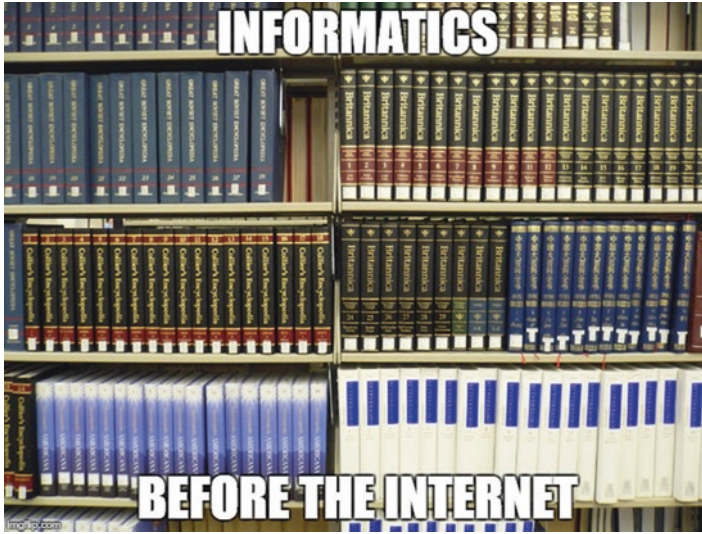Gartner, Jacksonville, FL, USA

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Fig. 4.1 Informatics before the Internet = Encyclopedias. Source: Meme

Historical Context

It could arguably be said that the dawn of consumer informatics corresponded with the birth of the internet, and that increased attention to healthcare consumerism principles and practices over the past decade are partially a result of the rapid proliferation and adoption of social media networks. After all, the internet is a seemingly infinite source of living documents encompassing research and treatment advancements, as well as performance scorecards—enabling instant access to information and expert analysis that once took years, if not decades, to make available to the public.

The rise of what we think of now as "social networks" began in earnest in the 1980s with the introduction of the personal computer and online meeting places called "Bulletin Board Systems" (BBS), which were typically local hubs for file and message-sharing. They were local because the connections between computers used analog phone lines, and long-distance rates would apply for out-of-area calls. CompuServe's consumer market growth in the late 1980s and 1990s further democratized social networking by enabling public access to email and a vast array of discussion forums. In 1993, when America Online created a Windows version of its software and offered internet access in addition to personalized email and member profiles, it paved the way for web-based social networking: Classmates.com and MySpace.com to Facebook and beyond.

Today, merely a decade after Facebook launched to the general public, the majority of US consumers across age groups, genders, races, geographies, and income levels use one or more social networks. According to Pew Research Center's report, "Social Media Update 2016" (Greenwood, Perrin, & Duggan, 2016), 86% of all

adults in the USA are online, and most of them are active on at least one social media network. Figure 4.2 provides a timeline of some of the major events leading up to the current state of social media adoption.

Although platforms like Facebook, Twitter, and Instagram are most likely the platforms that come to mind when considering the question, "what IS social media," there is a much broader definition that is more contextually appropriate in consideration of its position as a modern cornerstone of consumer informatics. *For purposes of this chapter, we define social media as any online resource that is designed to facilitate engagement between individuals.* Social media networks can be available for the general public, such as Facebook, or can be private, such as Yammer, which restricts use to communications within organizations. Worldwide, there are dozens of social media networks vying for users and advertising market dollars (see Fig. 4.3).

For the purposes of this chapter, the focus will be on those networks most heavily used in the USA.

Industry Context: Why Healthcare Is Different

Healthcare has always been a laggard in technology-based innovation adoption, in comparison with other industries, for a number of reasons. First, health care is highly complex and constitutes nearly 18% of the economy in the USA (CMS.gov, 2018), and has many stakeholders with competing ideas about how care should be accessed and provided. In addition, the regulatory landscape for healthcare offers a maze of complexities, with differences between often-conflicting local, state, and federal legislation creating comprehension and compliance challenges.

Due to the intensely personal nature of medical records, the prevailing industry paradigm, until recently, was that information created within the walls of the hospital was to remain within the walls of the hospital. The systems managing information were designed with proprietary programming languages specifically to be incapable of exporting health information to the outside world. Plus, Americans are uniquely litigious; any breach of privacy or the social contract resulting from adoption of technology could result in a lawsuit.

Yet, even with those challenges, healthcare is making its way online.

Platforms

Facebook

Of the online adults in the USA, 68% use Facebook—a user base which transcends age, gender, income, and geography barriers, with 74% of Facebook users accessing the network every day (Pew Research Center, 2018).
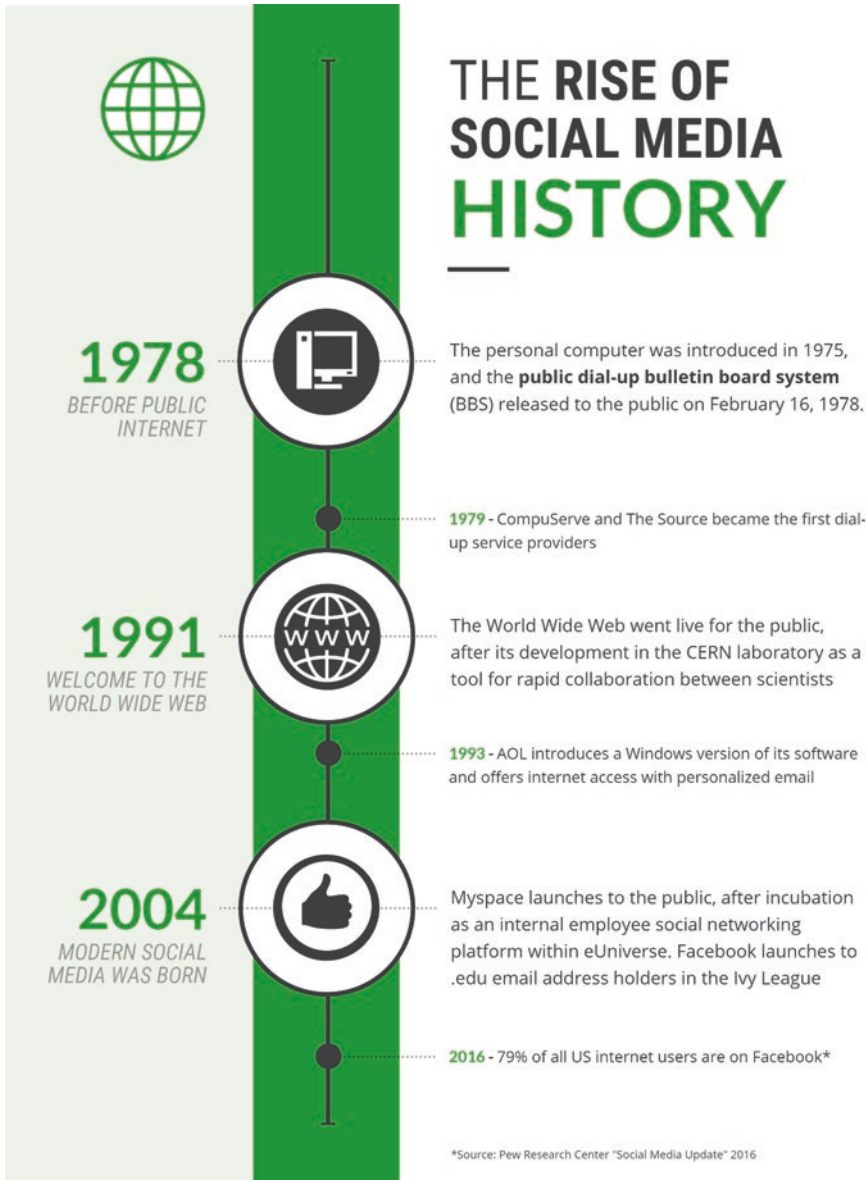
Fig. 4.2 The rise of social media: history. Source: Original graphic created by author using the following sources: 1975 personal computer—Altair 8800 http://historycomputer.com/Modern Computer/Personal/Altair.html; 1978 BBS birth—https://www.theatlantic.com/technology/archive/2016/11/the-lost-civilization-of-dial-up-bulletin-board-systems/506465/; 1979 Compu Serv—https://www.wired.com/2009/09/0924compuserve-launches/; 1991 WWW launch—https://thenextweb.com/insider/2011/08/06/20-years-ago-today-the-world-wide-web-opened-to-the-public/; 1993 AOL personal email—http://time.com/3857628/aol-1985-history/; 2004 MySpace—https://www.huffingtonpost.com/2011/06/29/myspace-history-timeline_n_887059.html; Pew Research Center, Facebook remains the most popular social media platform, "Social Media Update," 2016 http://pewinternet.org/2016/11/11/social-media-update-2016/

Most popular social networks worldwide as of April 2018, ranked by number of active users (in millions)

Social Network	Active users (millions)
Facebook	2 234
YouTube	1 500
WhatsApp	1 500
Facebook Messenger	1 300
WeChat	980
Instagram	813
Tumblr**	794
QQ	783
QZone	563
Sina Weibo	392
Reddit	330
Twitter	330
Baidu Tieba*	300
Skype*	300
LinkedIn**	260
Viber*	260
Snapchat**	255
LINE	203
Pinterest	200
Telegram*	200

Number of active users in millions

Sources
We Are Social; Kepios; SimilarWeb;
TechCrunch; Apptopia; Fortune
© Statista 2018

Additional Information:
Worldwide; We Are Social; SimilarWeb; TechCrunch; Apptopia; Fortune; Fortune; as of April 12, 2018; social netw
app/voip included

Fig. 4.3 Most popular global networks as of April 2018. Source: (Statista 2018). Downloaded from https://www.statista.com/statistics/272014/global-social-networks-ranked-by-number-of-users/ Used with permission

Quantitatively speaking, approximately 179,000,000 people are engaging with Facebook content on a daily basis. That means 68% of all US adults, inclusive of the entire population—including those with and without internet access—are Facebook users. They are online, engaging with each other and with companies (or brands) via Facebook profiles, pages, groups, events, and messages—and a growing number of them are actively seeking and sharing health and healthcare information.

The volume of content Facebook users create, curate, and engage with on a daily basis is staggering. According to TechCrunch (Constine, 2016), Facebook had over 2.5 trillion posts in 2016. When Facebook introduced keyword search capabilities across its entire content base in 2015, it opened a Pandora's Box of possibilities for consumers searching for healthcare-related information. Regardless of the search term applied, it is likely that there is a related public post available for the user to view and potentially share with her family, friends, neighborhood, or physician.

While these billions of users may post or read health-related content in the course of their Facebook newsfeed browsing, features allowing users to create private groups and events, giving individual administrators the control to restrict membership and moderate content, have provided the opportunity for thousands of specific healthcare-related virtual communities to grow. Bloomberg reported in 2016 (Frier, 2016) that over one billion people use Facebook groups, with users leaving ten billion comments and "liking" 25 billion-plus pieces of content. Newer features, such as file-sharing and member solicitation via email rather than Facebook interface, are expected to further increase group and event product use in 2017 and beyond.

Group engagement increases both site visits and the length of each visit, both desirable conditions for increased marketability to advertisers and shareholders. According to Statista, a research aggregator, in February 2018 (Statista, 2016), Facebook accounted for 42% of all social media visits, with Twitter at a mere 5.2%. LinkedIn, a professional networking site, garnered a mere 1.2% (see Fig. 4.4).

Given these usage statistics, it shouldn't be surprising that it is likely that there is at least one Facebook group dedicated to the specific type of information a healthcare consumer might seek. Facebook's market dominance, in addition to its searchable content features, makes it one of the top online resources. Rare disease sufferers and their caregivers can find groups to search and share details about treatment regimens, such as those seeking information about epidermolysis bullosa, a disease affecting approximately 20,000 people in the USA, and with no fewer than 5 dedicated Facebook group resources. Physician mothers sharing tips and tricks have over a hundred groups available to join. Health systems, individual physicians, and insurers all have the opportunity to create individual profiles, pages, groups, and events, which can address a particular topic (such as a diabetes management program) or a particular function (customer service).

New social media platforms are introduced regularly. However, the market share discrepancy between Facebook and its competitors is so large, it would take a disruptor of Amazon proportions to overtake them.

Twitter

Twitter, founded in 2006, was designed as "the text-messaging of the internet" (Wikipedia, 2017a, 2017b), a platform from which registered users could share "short bursts of inconsequential information" in 140 characters or less. Posts are called "tweets," and the action of posting is called "tweeting."
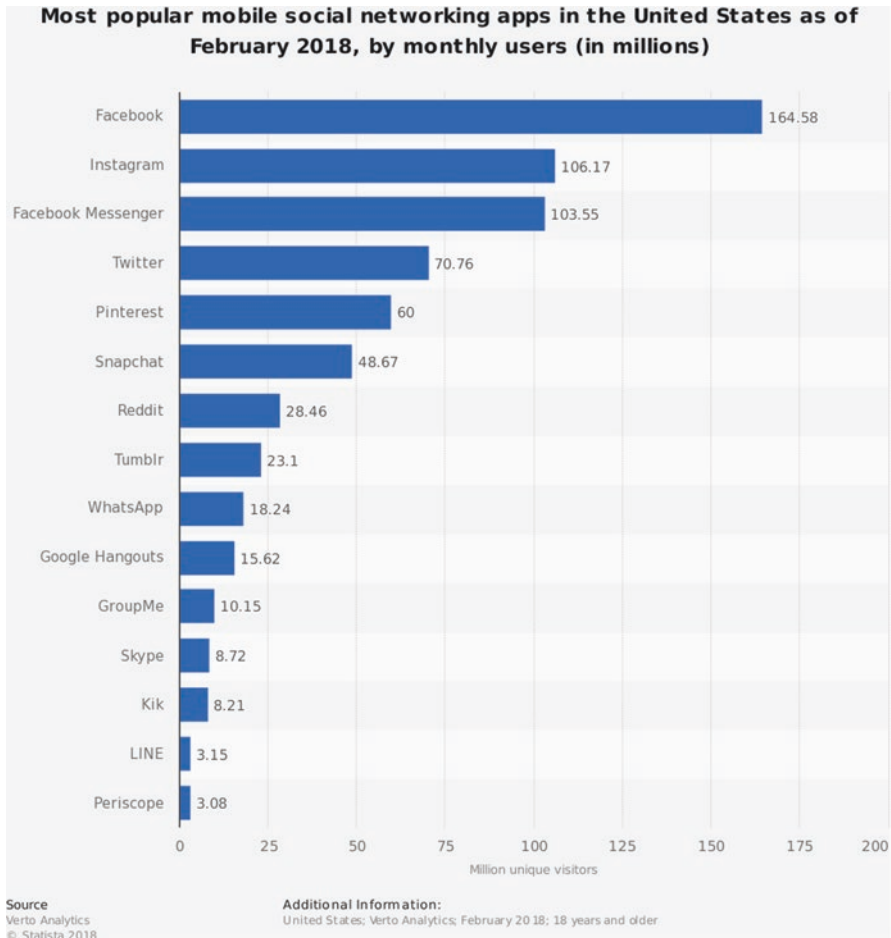
Most popular mobile social networking apps in the United States as of February 2018, by monthly users (in millions)

App	Million unique visitors
Facebook	164.58
Instagram	106.17
Facebook Messenger	103.55
Twitter	70.76
Pinterest	60
Snapchat	48.67
Reddit	28.46
Tumblr	23.1
WhatsApp	18.24
Google Hangouts	15.62
GroupMe	10.15
Skype	8.72
Kik	8.21
LINE	3.15
Periscope	3.08

Source
Verto Analytics
© Statista 2018

Additional Information:
United States; Verto Analytics; February 2018; 18 years and older

Fig. 4.4 Most popular mobile social networking apps in the USA by visits, February 2018. Source: Statista 2018. Downloaded from https://www.statista.com/statistics/265773/market-share-of-the-most-popular-social-media-websites-in-the-us/. Used with permission

Tweeting is popular. According to research from Omnicore (Aslam, 2017), in 2017, it boasts over 317 million active monthly users, with 100 million active daily users sending over 500 million tweets per day. Although the founders said the initial intent for Twitter use was the sharing of the mundane moments of life, the platform has become a veritable force for information (and, unfortunately, disinformation) delivery. A 2015 survey conducted by the American Press Institute (Tom Rosensteil, 2015) indicated that the most prevalent uses for Twitter involve news (see Fig. 4.5).

Early Twitter users wanted to find ways to group-related tweets, within the content of the tweet, itself. Thus, the hashtag was born in 2007 (Edwards, 2013), to become a content curation and indexing strategy that has permeated cultural consciousness and all other social media platforms. Hashtags link tweets together, and

Why Do People Use Twitter?

Source: American Press Institute survey "How People Use Twitter in General" - September 2015

- ■ To find out about breaking news
- ■ To keep up with general news
- ■ To pass the time
- ■ To tell others what you're thinking or doing
- ■ To see what others are saying while watching live events
- ■ To keep in touch with people
- ■ To follow famous people
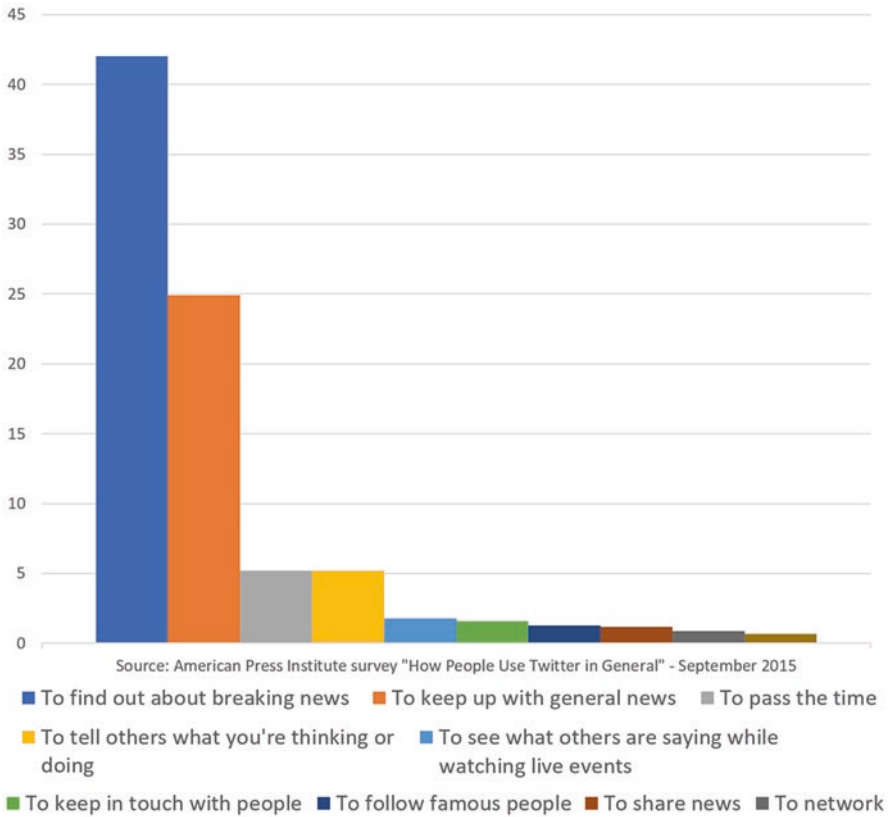- ■ To share news
- ■ To network

Fig. 4.5 Why people use Twitter, September 2015. Source: American Press Institute. Used with permission

can be used to create communities, targeted topic discussions, and marketing campaigns. Users can search content based on any combination of hashtags, keywords, profile handle, content type (image, link, etc.); these query parameters can also be used to create lists to curate targeted content automatically (see Table 4.1; Figs. 4.6 and 4.7).

Twitter has become a uniquely rich environment for healthcare information seekers and sharers, with hashtag themes connecting individuals across the globe of all walks of life—leveling the playing field between physician and patient, policymaker and constituent. It spawned a dedicated research platform, Symplur (2017), that curates public user-provided hashtags and archives related content so that citizen scientists and academic researchers, alike, can analyze tweet and user profile text in addition to complex network connection patterns between users and topics.

Table 4.1 Healthcare hashtag reference guide

Healthcare hashtag	Description
#HCSM	Healthcare social media
#HITsm	Health IT social media
#MedEd	Medical education
#FOAMed	Free open access medical education
#BCSM	Breast cancer social media
#LCSM	Lung cancer social media
#SPSM	Suicide prevention social media
#Migraine	Migraine community support
#ChildhoodCancer	Childhood cancer community support
#HCLDR	Healthcare Leaders community
#MentalHealth	Topics related to mental health
#SDOH	Topics related to social determinants of health
#DigitalHealth	Topics related to health apps, wearables, remote monitoring, VR/AR
#ED	Topics related to eating disorders—and not necessarily related to overcoming them

Source: Original table created by author

Fig. 4.6 Influence of #BCSM on Twitter-10,300+ Participants, 52,500+ tweets over 5 month period December 2016–April 2017. Source: Symplur Signals, a healthcare social media analytics platform. Used by permission

Blogs

One of the most popular social media constructs that does not fall under the typical platform definition is the "blog," a term coined in 1999 by Peter Merholz (peterme. com, 2002) as a shortened form of the term "weblog." Blogging become one of the most popular forms of content-sharing and engagement on the internet, with more than 180 million individual blog sites in existence.
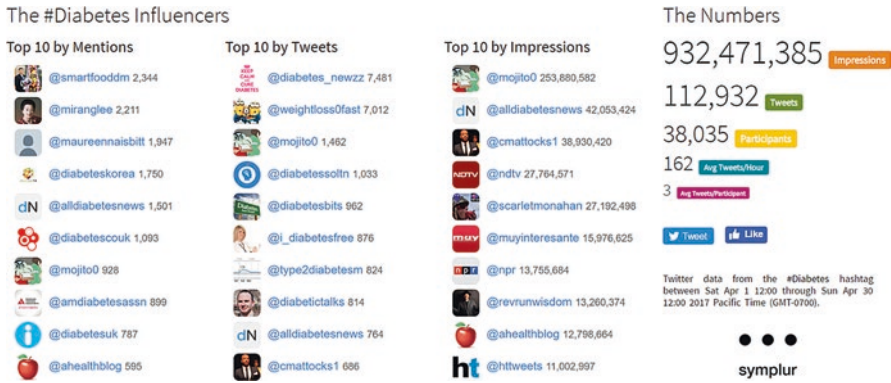
Fig. 4.7 Influence of #Diabetes hashtag on Twitter-30K+ participants, 112K+ tweets over 30-day period in April 2017. Source: Symplur Signals, a healthcare social media analytics platform. Used by permission

According to W3Techs Web Technology Surveys data from April 2017, more than 25% of all websites on the internet are powered by WordPress (W3Techs, 2017), a content management system introduced in 2003 that quickly became the market-leading blogging platform. Popular with website developers and consumers alike for their extensible architecture and low cost, competing content management systems have proliferated, and with them, the popularity of blogs has exploded.

WordPress, the market leader in blog content creation and viewership, now boasts more than 400 million people viewing more than 26 billion pages of blog content per month on its platform (WordPress, 2017), with more than 87 million new posts accruing more than 44 million comments.

Regardless of the type of health or healthcare-related information one seeks, there is a blog dedicated to the topic (see Table 4.2). Healthcare bloggers run the gamut from patients and caregivers documenting their experiences navigating the healthcare system to doctors and nurses providing answers to some of the most frequently asked, or uniquely interesting, questions they hear. Internet users can subscribe to blogs, receiving updated content when it becomes available, and can often engage with the blogger and the other readers within the comments section of the individual blog entries.

YouTube and vLogs

When a blog's content primarily consists of videos, it is called a "vlog"—and video is the fastest-growing internet content type. Cisco's, 2016 "Visual Networking Index" whitepaper (Cisco, 2016) forecasts that video traffic will be 82% of all consumer internet traffic by the year 2020, tripling between 2015 and 2020.

Table 4.2 Healthcare blogs for all audiences

Healthcare blog title	Website URL	Target audience
The Health Care Blog	Thehealthcareblog.com	Industry professionals
Healthcare Scene	Healthcarescene.com	Health IT professionals
Blog for a Cure	Blogforacure.com	Cancer patients and caregivers
Bitter-Sweet Diabetes	Bittersweetdiabetes.com	Diabetes patients and caregivers
Blogabetes	Dlife.com/diabetes-blog	Diabetes patients and caregivers
Dr. Oz Blog	Blog.doctoroz.com	Consumers and patients
Medscape	Medscape.com	Industry professionals
Dr. Phil Blog	Community.drphil.com	Consumers and patients
Life as a Healthcare CIO	Geekdoctor.blogspot.com	Industry professionals
Health Populi	Healthpopuli.com	Industry professionals, activated patients
e-Patient Blog	e-patients.net	Patients, caregivers, and industry professionals
Caring Bridge	Caringbridge.com	Patients, caregivers
The Hurt Blogger	Thehurtblogger.com	Autoimmune disorder patients, caregivers
The Doc Smitty	Checkupnewsroom.com/thedocsmitty/	Parents of pediatric patients
Kevin, MD	Kevinmd.com/blog/	Professionals, consumers and patients
Dr. Jen Gunter	Drjengunter.wordpress.com	Consumers and patients of OBGYN
e-Patient Dave	epatientdave.com/blog/	Consumers and patients, professionals

Original table created by author

While other social media platforms like Facebook, Twitter, and Instagram have introduced support for pre-recorded and live streaming video, the market leading user-generated video platforms is YouTube, a Google property which, according to the website's most recent published statistics (YouTube, 2018), has over one billion users and reaches more 18- to 49-year-old consumers than any cable network in the USA—as well as reaching exponentially more than any other online video platform, according to comScore's, 2017 Desktop and Mobile Video Rankings (comScore, 2017).

Video is a powerful tool for sharing and consuming information, with individual or corporate vloggers—as well as entire channels of related vlogs—providing content from personal diary-style entries to short films designed to advertise a brand or product launch. One of the most popular video content types is the "how to" video, with 2015 statistics supplied by Google and aggregated in a study by Search Engine Land (Gesenhues, 2015) stating that searches for "how to" videos are growing 70% year over year, representing more than 100 million hours of YouTube viewing annually.

For healthcare, this equates to users being presented with video tutorials on such topics as, "how to complete a Medicaid application," "how to appeal a health insurance decision," or "how to calm a crying baby" (Hamilton, 2015). The latter example represents a vlog entry demonstrating an infant holding technique from a

Fig. 4.8 "I Am A Patient and I Need to Be Heard" Morgan Gleason vlog, January 2014. Used by permission

pediatrician, Dr. Robert C. Hamilton, that "went viral," receiving more than 23 million views in less than 18 months.

Patient stories captured on video can resonate far, as well. In January of 2014, Morgan Gleason was a 15-year-old hospital patient who was fed up with the lack of respect for rest that her care team exhibited. She recorded a short vlog entry (Gleason, 2014) decrying the constant wake-ups, reiterating the phrase, "I am a patient; I need to be heard," and uploaded it to YouTube (see Fig. 4.8).

The video went viral and received national media attention, including an article in Forbes (deBronkhart, 2014) and numerous healthcare industry speaking engagements. With the support of her mother, CareSync executive Amy Gleason, she was encouraged to share her experience with healthcare executives—and the online world—and her story became a rallying cry for patient empowerment.

Yelp and Local Business Review Sites

In addition to blogs and vlogs, user-generated social media content contributing to healthcare consumer decisions increasingly includes ranking sites such as Yelp, which allows users to search for and review local businesses (see Figs. 4.9 and
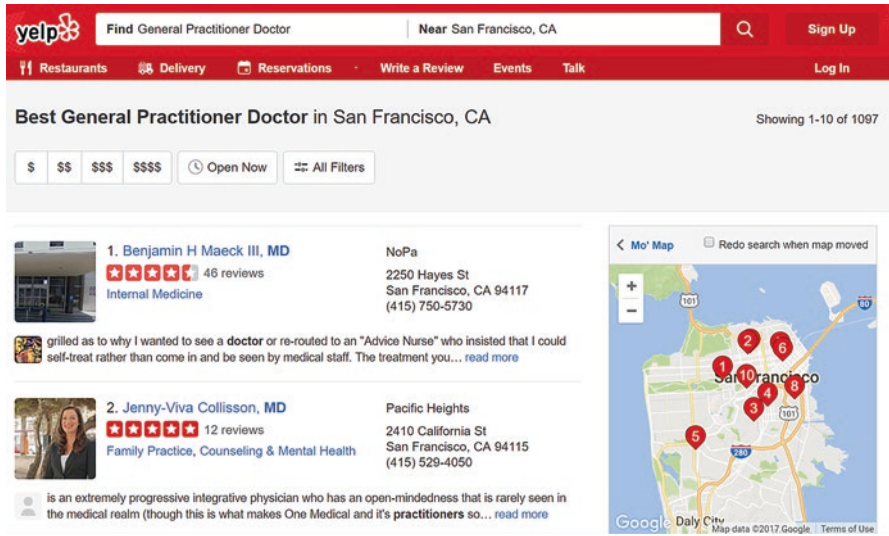
Fig. 4.9 Yelp results for "General Practitioner Doctor" near San Francisco, CA, April 2017. Used by permission

4.10). Leveraging your device's location services, Yelp responds to inquiries regarding "what's near me," encouraging users to "check in" then rate and review the businesses once visited.

As of December 2017, according to its published statistics (Yelp, 2017), the service boasted 73 million unique average monthly visitors accessing the site via desktop, with 24 million monthly mobile app unique visitors, contributing a cumulative total of over 121 million reviews. Although health-related businesses only comprised 7% of Yelp's businesses reviewed in 2017, as the healthcare industry increases its adoption of omnichannel communications and social media that number can be expected to substantially increase.

Yelp, and similar sites like Angie's List, provides familiar ranking criteria—such as stars—as well as user-submitted reviews (and, often, the business responses to reviews). In addition to the specialized business review sites and apps, the most heavily trafficked review and rankings are now aggregated and curated by more general giants, using proprietary weighting criteria, and presented to users searching for a particular business or type of business: Google and Facebook.

As more than 70% of all internet searches are performed by Google, according to NetMarketShare's, 2017 Search Engine Share report (NetMarketshare, 2017), the business star ranking is now prominently displayed on search results (see Fig. 4.10), and Facebook reviews are integrated into Google's local pages, the likelihood that an online healthcare consumer will see a company equated with a stars ranking is very high.

Consumer reviews of healthcare service providers are aligned to patients and caregiver requirements; the types of information provided by Yelp are vastly differ-
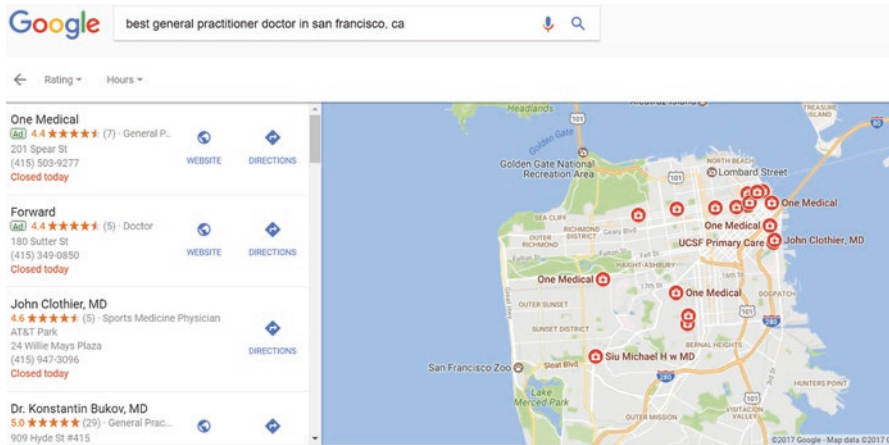
Fig. 4.10 Google results for "Best General Practitioner Doctor in San Francisco, CA," April 2017. Source: Google and the Google logo are registered trademarks of Google, Inc., and are used with permission

ent than that provided by the results of traditional patient satisfaction surveys, such as those routinely collected from Medicare patients. When searching Yelp for healthcare providers, users frequently see comments pertaining to bedside manner, patient's perception of the doctor's knowledge, and the patient's satisfaction with the results (Miller, 2017a, 2017b).

Unlike some social media platforms, blog sites, or online communities, the user-generated content isn't automatically available for others to read and isn't moderated by a human administrator: Yelp purports to leverage proprietary algorithms to determine which reviews to display in what order, weighting frequent reviewers as more reliable and reducing the number of "fake" postings.

Community Websites and Networks

Websites dedicated to health and healthcare-related causes and industries that include social engagement features such as discussion forums and private messaging have proliferated across the internet since the earliest days of public dial-up access. These resources may have blog and content curation components, but their primary focus is community development and member collaboration.

One of the most widely recognized examples of this type of social media network is *PatientsLikeMe*, which launched its first online community for ALS patients in 2006 (Wikipedia, 2017a, 2017b) and eventually has become the largest online population of ALS members in the world. PatientsLikeMe now provides support for

over 2800 conditions (http://news.patientslikeme.com/about/background), and the community's cooperation with researchers and clinicians has led to changes in how the community members' conditions are reported and measured, such as the development of the MS Rating Scale to determine how MS is progressing over time (Wicks, Vaughan, & Massagli, 2013).

Another growing online community is the Society for Participatory Medicine, a membership organization that promotes shared decision-making between patients and providers and supports SPM Connect, a collaboration platform for member discussions about participatory medicine.

Healthcare Social Media Audiences and Use

While there are distinct user roles for those engaging in social media for health and healthcare, there is substantial overlap and fluidity between roles as a user engages, especially among individuals participating organically in social media as a human and not as a brand (see Fig. 4.11). In this context, for individuals, the role assignment is reliably applicable to a single engagement, only; the role represented may change over the course of a series of engagements. Brand personas are less complex, although the individuals engaging on behalf of the brand are often challenged to follow the constraints of role-appropriate representation. Healthcare's social media audiences include: consumers, patients, caregivers, providers, insurers, and researchers.
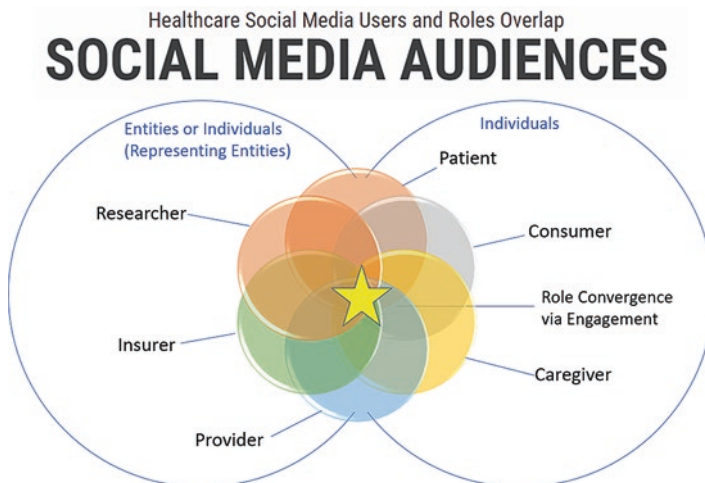

Fig. 4.11 Healthcare social media audiences. Source: Original graphic created by author

Patients and Caregivers

Patients and caregivers are individuals engaging in social media networks for information regarding the diagnosis, prognosis, treatment plan, and impacts of health conditions. Their roles are closely related, and their engagement behaviors are similar. A patient is the individual experiencing the health condition, and a caregiver is the person caring for the individual experiencing the condition. These roles are not mutually exclusive: a patient can be a caregiver to another individual, or to herself.

Patients and caregivers are also consumers of healthcare services; however, interactions as consumers follow a different pattern. To paraphrase Jeff Margolis, CEO of Welltok (Jayanthi, 2015), in an interview with "Beckers Hospital Review" in 2015: consumers make choices while patients receive care.

To extend that definition to address how patients engage in social media: patients, and their caregivers, seek information about the diagnosis, treatment, and management of health conditions. Anyone can become a patient at any time: experiencing unfamiliar symptoms accompanied by an inability of her peers to diagnose her illness, a physician may research social media resources for people discussing similar symptoms. A new mother experiencing post-partum depression while nursing her baby may become actively engaged in an online support group. An elderly research scientist caring for his wife who suffers from Alzheimer's finds himself diagnosed with diabetes, and he seeks help from diabetes groups on Facebook in optimizing his self-care regimen to maximize the time and energy required for his caregiver responsibilities.

According to Rock Health's report, "Digital Health Consumer Adoption: 2015" (Wang, 2015), 71% of all adults with internet access use the internet to search for health information. Of those, 40% who search act directly on the information they find. Beyond searching, increasingly, patients are sharing their stories on social media—proffering clinical and deeply personal details about their experience, and those stories serve to inform and educate others dealing with similar circumstances.

This phenomenon of sharing and commiserating within an online community has been of especially high value to those affected by rare diseases, which affect more than 30 million people in the USA, according to CG Life's recent article, "Rare Diseases: The Role of Social Media in Patient Recruitment" (CG Life, n.d.).

The internet removes geographic boundaries, with freely available translation tools enabling multi-lingual conversation, allowing patients and caregivers without peers in physical proximity to benefit from connections worldwide. By leveraging the internet and its social media communities, patients are able to more effectively find clinical trials, find events or specialized support resources, as well as learn and evaluate tips and tricks for managing conditions from others living with it.

Consumers

Frequently, the terms "patient" and "consumer" are used interchangeably when discussing the roles played in the healthcare system. Often, an individual is playing both roles simultaneously. However, there is a distinction: in the role of "consumer,"

an individual is shopping for, buying, and rating products and services received. While clinicians remain trusted information sources, social media "shopping" allows for instant answers and anonymous acceptance or rejection of the results.

Social media-enabled healthcare consumerism is rapidly increasing. An oft-cited 2012 report from PwC, "Social media 'likes' healthcare: From marketing to social business" (Health Research Institute of PwC, 2012), indicated that 42% of all consumers surveyed search for health-related consumer reviews via social media.

Three years later, in 2015, the Rock Health report (Wang, 2015) indicated that 50% of all online consumers search for reviews of doctors or healthcare services (see Fig. 4.12). And, again, 40% of those act on the information immediately.

For healthcare consumers, social media content provides a smorgasbord of decision support material. In addition to the reviews of providers and services, people share pricing information that isn't readily available through any other means. Patients upload bills, letters from providers or insurers, and tell the story of their financial progression along the care continuum.

This transparency and willingness of consumers to share price data online created a cottage consumer informatics industry specialization, with companies like ClearHealthCosts collecting, aggregating, analyzing, and sharing the data with other consumers. Similarly, the public availability of data sets from the Food and Drug Administration as well as the Centers for Medicare and Medicaid Services supercharged the healthcare data journalism and related consumer decision-support initiatives, such as ProPublica's Vital Signs project (Wei, 2017) (see Fig. 4.13).

Providers

Healthcare providers have a unique and complicated relationship with online information sources, including social media networks (see Fig. 4.14). The regulatory environment, in conjunction with many institutions' discomfort with the fact that there is virtually no surefire way to control information flow once it is released on the internet, creates a delicate balancing act for organic social media engagement.

Although a growing number of providers, both individuals and institutions, are becoming active on social media, engagement between a physician and a patient, specifically directing the care of that patient, is still rare. A number of constraints represent barriers to the use of public social media platforms for clinical diagnosis and treatment.

The Health Insurance Portability and Accountability Act (HIPAA) privacy rule (US Department of Health and Human Services, 2003) is the most oft-cited reason why providers should be cautious—if not downright avoid—social media engagement: yet, HIPAA as prohibitive of this type of communication is flawed rationale. Although the HIPAA privacy rule does set standards for handling Protected (sometimes referred to as Personal) Health Information (PHI) (US Department of Health and Human Services, n.d.), and defines penalties for failure to comply, it does not prohibit engagement or limited information-sharing—provided that the patient involved has explicitly given consent.

INTERNET-FOR-HEALTH STATISTICS

IN THE US

ADULTS ONLINE

According to Pew Research Center in 2016, 86% of all US adults are online. Rock Health's "Digital Consumer Adoption Survey: 2015" indicated 71% of them were searching for health information.

TAKING ACTION

Rock Health's 2015 survey found that 50% of all US online adults sought reviews of doctors or healthcare services. Of the 71% searching for healthcare information, and the 50% searching for reviews, 40% act on the information immediately.

86%   71%   50%   40%

Fig. 4.12 Internet-for-Health Information and Actions Taken Statistics, 2015–2016. Original graphic created by author, based on the following sources: Greenwood et al. (2016) and Rock Health (2015)

Patients and caregivers frequently share detailed condition information on social media networks with the hope that the collective hive-minds of clinicians online may be able to help them better assess and address their health concerns. This information is voluntarily proffered, and frequently leads to expansive conversation about
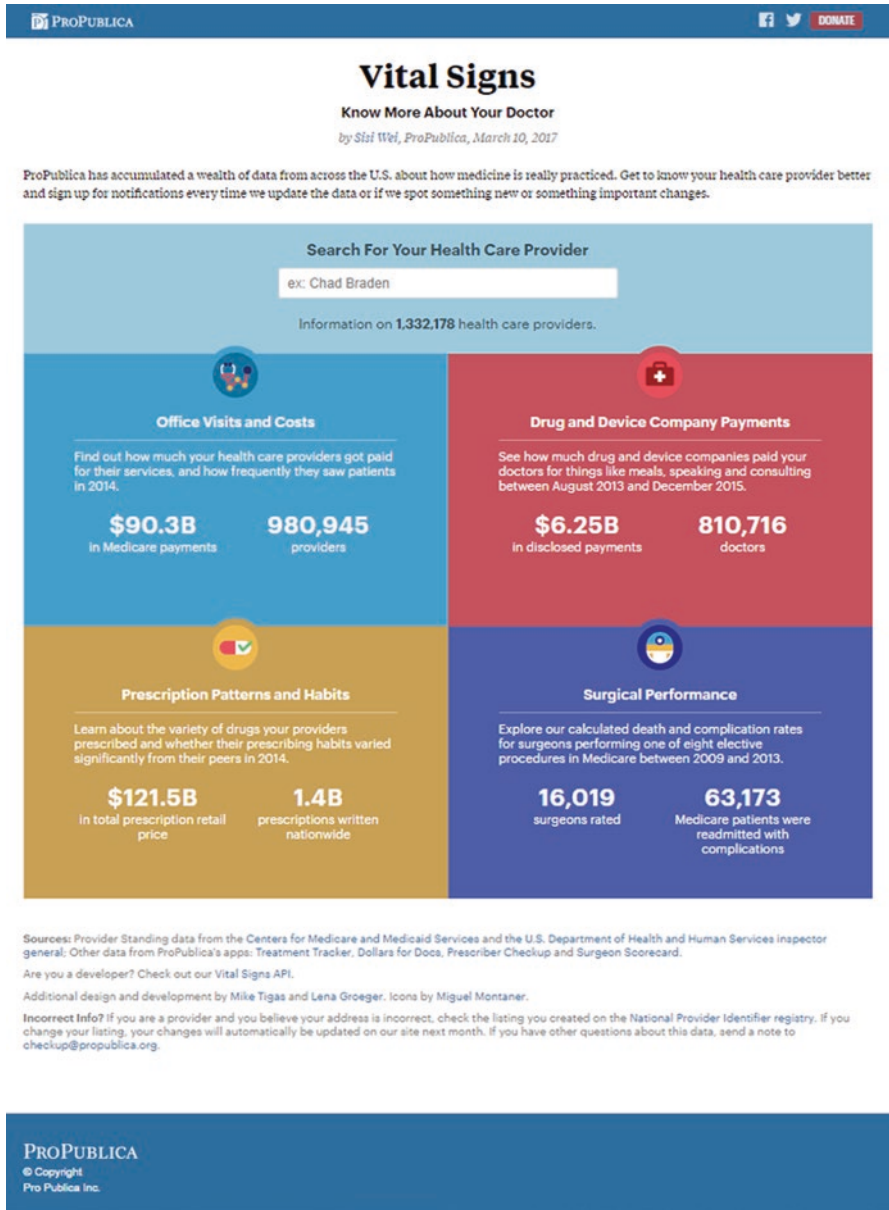
Fig. 4.13 ProPublica vital signs project—cost, quality, and performance data for healthcare consumers. Used courtesy of ProPublica

Fig. 4.14 Healthcare providers and social media—relationship status? It's complicated. Source: Meme

diagnosis possibilities, the experiences of others in managing the disease, and clinical research related to the condition and treatment. These interchanges offer valuable insights to provider participants, who have an opportunity to view the patient and caregiver perspective as they navigate the care continuum—and who may learn from the vast experience of the global community of clinicians who engage.

Many providers and institutions are prolific in their online information dissemination, garnering community support and trust through thought leadership and allowing a broad audience to learn from their expertise. Dr. Zubin Damania, the co-founder of the Health 3.0 movement and more commonly known as ZDoggMD (Damania, 2017), creates rap parody videos to make clinical language and healthcare processes accessible. Each video has a hashtag label, so that its pattern of proliferation across social media platforms can be easily captured and studied. One of his most popular, "EHR State of Mind (#LetDoctorsBeDoctors)" (Damania, 2015), gives voice to the pain many clinicians feel with their electronic medical records systems—making the provider experience of being de facto data entry clerks relatable for their peers and the patients they serve.

An institutional provider example of effective provider social media engagement is a video released by Cleveland Clinic, "Empathy: The Human Connection to Patient Care" (Cleveland Clinic, 2013), which showed the hidden stories behind each person encountered in a hospital. It went viral, accumulating more than three million views in a matter of months after release, and receiving thousands of positive accolades in the form of public comments.

Conversely, this effectiveness at social media engagement can also backfire, as evidenced by the public relations firestorm created (Boodman, 2017) when the Medical Director and Chief Operating Officer of the Cleveland Clinic Wellness Institute, Dr. Daniel Neides, posted an anti-vaccination missive (Neides, 2017) on the institution's blog site. Outrage from the medical and patient community swiftly ensued, with widespread media coverage from Forbes (Haelle, 2017) to NBC News (Fox, 2017) addressing the incident available online in a matter of hours from the

post, culminating in Dr. Neides issuing a public apology, and receiving disciplinary action from the institution (Wadman, 2017).

Beyond outreach and education, provider institutions often practice brand protection through social media surveillance (called "listening"), in which online posts are monitored for certain keywords: the name of the organization, an affiliated doctor or place of service, an ad campaign tagline, or other identifying phrase. Positive social feedback can be amplified, and negative sentiments can be addressed, through the strategic application of social media listening and response.

Insurers

Much like providers, health insurance organizations and their employees face a heavily regulated environment with strict compliance standards that must be considered when engaging in social media. Additionally, insurers typically face an uphill trust battle: conventional wisdom is that health insurance is one of the least liked industries in the USA second only to the airline industry. Members don't typically engage with their insurance plan unless there is a health or financial problem, making the relationship dynamic more challenging and adversarial than in a trusted provider/patient scenario.

Yet, there are a number of ways in which savvy insurers are making the most of the opportunities to get social online. One of the most common ways insurers leverage social media is to educate and inform their members and communities on myriad subjects: the benefits that are available with insurance coverage, local health and wellness-related events, clinical thought leadership, and legislative or policy impacts to the marketplace. The content pieces that are distributed on social media can be tracked, so that insurers can better understand how to influence the customer lifecycle and how to produce and disseminate the information items that will most resonate.

Many insurers protect their brand through listening, and some have added the component of timely incident intervention and resolution. Dedicated customer service accounts, often actively monitored 24 h per day, respond instantly to social media posts reporting a specific member's problem: claim or service authorization denial, payment system failures. While few of the insurer's social media accountholders have the authority (or access) to resolve situations, the immediate response and routing to the appropriate channels for resolution is frequently enough to defuse a potential public relations bomb before it can explode.

And explode, it can. As more Americans go online for news and shopping, an inability to adequately provide timely response to or resolve a negative situation that presents on social media networks can result in measurable reputational damage and financial losses. For example, in 2017, Florida Blue, a Blue Cross and Blue Shield network insurer with over four million members, experienced a "glitch" with a third-party payment vendor (Miller, 2017a, 2017b): member bank accounts were debited multiple times, on the same day, for 1 month's premiums.

The uproar from affected members spread across the internet like wildfire, with news organizations reaching effortlessly and immediately into the fray to pluck potential interviewees from the pool of available complainants, while Florida Blue's social media team manning the Twitter handle and Facebook page apologized and urge members to contact the generic email address used for all social media inquiries. An ideal crisis response would have had dedicated and empowered team members managing the communications, and proactively controlling the messaging about the organization's handling of the situation.

Overcoming Healthcare's Objections to Social Media Adoption

As with any type of external communication, there are plenty of pitfalls that healthcare can experience in its journey to widespread social media adoption. However, there are very few that cannot be mitigated, if not entirely dismissed.

"My company doesn't allow it." For some providers, payers, or researchers, in addition to the regulatory constraints previously listed, there may be institutional rules prohibiting the use of social media (although, the number of healthcare organizations who have not, in some way, implemented a social media acceptable use policy to empower their employees and harness influencers is rapidly dwindling). As healthcare consumer decisions continue to become measurably influenced, if not outright made, by social media content, organizations will respond with social media policies and guidelines that will allow, and in many cases encourage, institutional and individual participation.

"I went to medical school. Google did not. I'm not addressing internet diagnoses." Armed with the knowledge that the vast majority of the adult population is online searching for health information, the "Dr. Google" phenomenon is here to stay—and a negative attitude about patients appearing in the office armed with a sheaf of printed websites is not going to change that fact. Instead, ask the patients what social media resources they've used, creating the opportunity to build a library of resources that the practice can verify as valuable (or discredit and educate their patients, accordingly).

"There's no way to validate the information offered on social media." This is a valid concern. An online culture so steeped in fibs that the term "alternative facts" entered the lexicon in 2017 is prone to absorb inaccuracies, if not outright lies. Social media posts do not function like peer-reviewed journals; there is no mandatory verification of the information presented by expert third parties. Old wives' tales and outright falsehoods are commingled indiscriminately with facts, and each audience type is left to their own devices to validate or discount the information presented. However, the fact is that patients and consumers are online, they are engaging with these information sources—and the most significant opportunity to

separate wheat from chaff is to engage, understand the landscape of sources that are resonating with them, and offer truthful variations as necessary.

"I don't want to open myself up to a negative review." Unfortunately, there's no way to prevent this. Doctors, hospital systems, and insurers with the highest quality ratings from government agencies and consumer watchdog groups will experience the occasional negative review. By engaging and building a trusted presence in thought leadership, in addition to continually striving for excellence in service delivery, the positive reviews—and the positive commenters on any negative review received—should outweigh the occasional ding. Negative reviews offer the most growth opportunities, however, and the learning gleaned from them should not be discounted. The grievances expressed on Yelp may mirror issues that will directly impact a health system's patient experience survey ratings for government programs, which would decrease their government reimbursement rate.

"Not everyone uses the internet." This is true. Although internet access, inclusive of all connection speeds, is nearly ubiquitous, high speed internet access, as defined by an internet connection at or equal to 25 megabits per second download and 3 megabits per second upload speeds, is not available to millions of people across the USA. The 2016 Federal Communications Commission Broadband Progress Report (Federal Communications Commission, 2016) found that 10% of all Americans, and 39% of rural Americans, lack access to high speed internet.

Given the rising prevalence of streaming video and image-based content, one's connection speed determines the scope of the social media information available for inquiry or consumption. While blogs and most social media platform content could feasibly be accessible without a broadband internet connection, albeit with limited functionality, resources like YouTube would not.

Additionally, beyond internet access, there is the concern of overall digital readiness for the individual and population served. A 2015 Pew Research Center study on "Digital Readiness Gaps" (Horrigan, 2016) analyzed respondents' comfort and trust with the use of digital tools for learning, and found that 52% of the adults surveyed were "relatively hesitant" to fully adopt digital platforms for education—which serves as an indicator for these personas to engage in social media for healthcare purposes.

Each of these objections is overcome by healthcare organizations every day. None are insurmountable.

Conclusion

We live in an online social world, and the healthcare industry players ignore that at their peril. I am a prime example of the power of consumer informatics via social media: I would not have been invited to write this book chapter if it weren't for my online presence, which allowed my content to proliferate rapidly on a scale not possible without the internet, creating a number of research citations referencing my work in this space, eventually catching the attention of my future editor.

Fig. 4.15 "Like" it or not,
social media is
democratizing healthcare.
Source: Meme
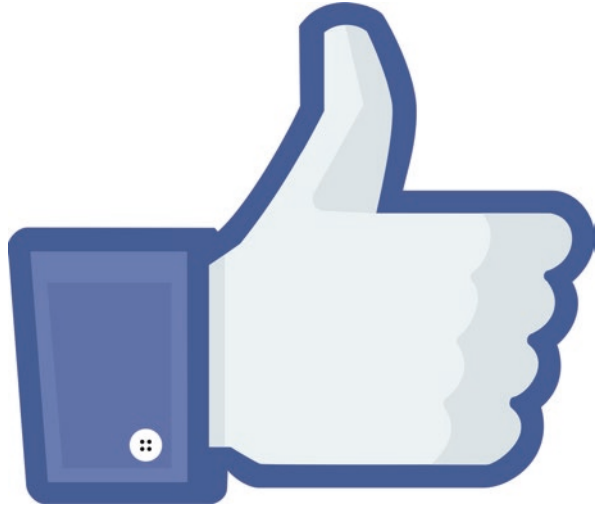
With internet access approaching ubiquity, and social media content-based deci-
sion support playing an increasingly large role in our daily lives, the field of con-
sumer informatics—and the healthcare industry—must take the "Likes" and reviews
seriously (see Fig. 4.15). Social media is democratizing healthcare, and we, as pro-
fessionals, must adapt or die.

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