



A REPORT ON THE USE OF SOCIAL MEDIA TO PREVENT BEHAVIORAL RISK FACTORS ASSOCIATED WITH CHRONIC DISEASE



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Executive Summary

This report describes the ways in which social media tools and technologies are being utilized by adults to alleviate mental health conditions and prevent behavioral risk factors associated with chronic disease through enhanced health education, communication, and behavior change.

Health behavior is fundamentally influenced, shaped, and defined by social networks composed of friends, colleagues, family members, caregivers, and others. Daily lifestyle decisions impact our overall health and wellness, and consistently unhealthy choices can lead to the development and progression of chronic disease. In the face of a chronic disease, individuals must often alter routine behavior, actively monitor their health and activity on a daily basis, and cope with significant disabilities, comorbidities, and psychosocial effects. Although risk factors associated with chronic disease are preventable, many populations often experience barriers to appropriate healthcare and information.

This report examines the impact of social media and role of online communities in enhancing health education and behavior change efforts to promote wellness, healthy eating, and active living to prevent chronic disease. As Internet broadband and wireless connectivity have spread across the United States, our society has embraced new forms of online communication. Sometimes referred to as Web 2.0 or the interactive web, social media platforms and tools allow people to create, control, and share their own content. By upending the traditionally opaque, top-down field of healthcare, social media is empowering Internet users with information and social support to lead healthier lives.

Key Challenges

Significant challenges to the widespread acceptance and use of social media in healthcare were identified through this study. As discussed in greater detail in the report, barriers include:

- **Digital divide among elderly and minority populations**, although wireless connectivity is narrowing the gap.
- **Balancing transparency and anonymity** with the creation and sharing of personal content online.
- **Concerns about privacy and HIPAA compliance** among healthcare organizations and providers inhibit the adoption of social media into daily practice and operations.
- **Quality, validity, and authenticity of information online** can come into question because content is almost always user-generated.
- **Limited theoretical or evaluation models for social media exist**, given that the majority of interventions conducted today are feasibility or pilot studies that have yet to promulgate gold standard methodologies.

Key Benefits of Social Media

In spite of the barriers above, social media offers an array of benefits to the prevention of risk factors associated with chronic disease. As discussed in greater detail in the report, social media enables health education and enhances behavior change by:

- **Breaking down the walls of patient-provider communication** to make information about a chronic condition or treatment more personable and timely.

- **Improving access to health information** in a scalable, low-cost approach capable of targeting specific populations that are otherwise hard to reach.
- **Providing a new channel for peer-to-peer communication** among healthcare consumers, caregivers, and family members to share and discuss their experiences with similar health conditions or treatments.
- **Developing meaningful relationships** that can provide psychosocial support and motivation to cope with chronic conditions.
- **Establishing communities** of patients, caregivers, and/or family members with shared experiences to combat isolation, fear, and stigma.
- **Engaging and empowering people** to be accountable and achieve their goals and objectives through online peer support.

Strategies for Promoting Health and Wellness through Social Media

The incorporation of social media tools into chronic care and prevention is expected to grow in practice and importance as more people communicate online. As our society becomes increasingly connected through wireless devices and accustomed to sharing private matters such as health with others online, new challenges and opportunities will arise to leveraging this information in a safe, dynamic, and timely manner. A robust review of the literature and interviews with experts reveals that social media holds great potential to combat chronic disease and promote health and wellness. Successful strategies and best practices in social media are identified in this report, including:

- **Develop multiple synchronous and asynchronous functionalities** to allow flexible 24/7 communication among users.
- **Include online roles for trained health providers and caregivers** to mitigate concerns about misinformation without breaking users' trust.
- **Provide dynamic privacy controls and use requirements** that encourage users to share as much or as little information as they prefer.
- **Incorporate user-centered design** to ensure not only that the platform is developed appropriately for the intended user audience with relevant features.
- **Provide an open, safe environment** for users to comfortably share information about health issues which may be heavily stigmatized.
- **Apply evidence-based behavioral theory** to leverage social networks for peer support and motivation.
- **Redefine the role of patients** by empowering healthcare consumers with information and opportunities to be involved in patient-centered care and research.
- **Leverage long-lasting community ties** to sustain user engagement.

In studying current trends and developments, this report provides a series of vignettes that demonstrate how social media can be successfully used across occupational, behavioral, personal, community, and public health settings and beyond to prevent mental health conditions and behavioral risk factors associated with chronic disease.

Preventing Risk Factors Associated with Chronic Disease Through Social Media

Introduction

This report describes the ways in which social media tools and technologies are being utilized to alleviate mental health conditions and prevent behavioral risk factors associated with chronic disease through enhanced health education, communication, and behavior change. Over the past several years, eHealth Initiative has researched how technology can support patients and providers to prevent and manage chronic conditions across the continuum. By illustrating case studies in a variety of contexts, this report demonstrates how social media can support chronic disease prevention among adults at an individual and community level.

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This report examines the impact of social media and role of online communities in enhancing health education and behavior change efforts to promote wellness, healthy eating, and active living to prevent chronic disease. As Internet broadband and wireless connectivity have spread across the United States, our society has embraced new forms of online communication. Sometimes referred to as Web 2.0 or the interactive web, social media platforms and tools allow people to create, control, and share their own content. Social media is upending the traditionally opaque, top-down field of healthcare to empower Internet users with information and social support.

Methodology

This report was informed by qualitative mixed-methods research between March and August of 2013. Under the oversight of a multi-stakeholder Technical Advisory Group composed of experts in behavioral health, chronic care, and social media, eHealth Initiative (eHI) conducted an environmental scan of the field to identify and assess best practices in the use of social media for healthcare. After attending relevant conferences and reviewing online and peer-reviewed publications, eHI interviewed 29 key informants to obtain more information and fill in gaps where literature was sparse. Summaries of these interviews and case studies are incorporated throughout the report, which focuses on social media use within adult populations aged 18 and older. A list of the Technical Advisory Group members and key informants can be found in the Appendix.

Burden of Chronic Disease

Chronic disease is the most common, costly, and preventable health problem in the United States. More than 133 million Americans currently have one or more chronic conditions, and 50 million of these individuals are disabled as a result.¹ The leading cause of death and disability nationwide, chronic disease significantly increases the risk of health-related complications, hospitalizations, readmissions, and productivity loss in the workforce.² Chronic care accounts for approximately 75 percent of total healthcare expenditures, and the annual cost of chronic disease is projected to rise by five trillion dollars over the next forty years.³ While advances in medical science and technology have enabled chronically ill individuals to live longer, the healthcare system is currently unable to effectively manage and treat their conditions in a sustainable manner. The prevention of chronic disease thus becomes an issue of fundamental importance not only to the healthcare system, but the national economy.

Chronic disease poses an enormous mental health burden for many people. A chronic disease diagnosis frequently throws patients into a world that they are entirely unfamiliar with, characterized by a persistent need to alter routine behavior, monitor health, manage food intake, and adhere to complex treatment and medication regimens. Most individuals must not only manage their condition and associated disabilities for the rest of their lives, but also cope with common symptoms such as grief, fear, anxiety, anger, and depression. As a significant source of comorbidity, mental health conditions can further compound the challenges associated with chronic care. Approximately one in four adults suffers from a mental disorder such as alcohol abuse, trauma, depression, or anxiety, leading to more than \$113 billion in costs each year. Mental health conditions can complicate chronic disease management efforts by impairing health behavior change, accelerating the risk and progression of illness, and diminishing an individual's capacity to cope with the demands of day-to-day life. Individuals with mental illness often have poorer health, and lack the ability or access to receive appropriate services.

The increased prevalence of chronic disease is largely attributable to the convergence of an aging population with risk factors such as physical inactivity, poor nutrition, use of tobacco and alcohol, high blood pressure and cholesterol, stress, depression, and overweight and obesity.⁴ Many of these risk factors can be mitigated by health interventions, education, and communication can which support healthy lifestyle and behavior change. However, populations with chronic diseases often experience barriers to healthcare and information, such as stigmatization, social isolation, and fear, which can in turn inhibit access to care, medication adherence, and compliance with disease management protocols. Recognizing the challenges faced by vulnerable populations, innovative public health prevention efforts are leveraging social networks, environments, and communities in new ways to create targeted intervention programs that focus on upstream risk factors. In today's digitally connected society, social media is changing not only how the health system interacts with high-risk populations and individuals with chronic conditions, but also how wellness, healthy eating, and active living can be shared and disseminated among communities.

Overview of Social Media

The rise of the Internet and smartphones has fundamentally transformed the flow of information within the healthcare landscape. Today, people increasingly turn to digital communication platforms to research and learn about healthcare. More than 80 percent of adults in the U.S. use the internet and 59 percent have searched for health information online in the past year. As

internet access and use have become more ubiquitous, the internet itself has evolved into a more interactive and complex space. Sometimes referred to as Web 2.0 or the interactive web, the Internet environment today allows for people to create, control, and share their own content online. Social media includes a wide range of platforms and tools which provide an online channel for interactive capabilities, as displayed in Table 1 below.

Table 1: Taxonomy of Social Media Tools for Chronic Disease Prevention

<i>Tool</i>	<i>Definition/Use</i>	<i>Example</i>
Internet support groups	Online group of people with a common health condition that convenes via internet-based platforms	MendedHearts, DailyStrength
Media sharing	User-generated multimedia is uploaded online for public access and comment	Health-related channels on Youtube, Pinterest
Message boards and forums	Synchronous and asynchronous platforms that allow users to post messages (often short form) and receive responses from other users	CancerCompass, HealthTap
Microblogs	A blogging platform that allows only limited information or characters in each entry	Twitter, Tumblr
Social games and challenges	Mobile- and internet-based games that incorporate social components to share results and progress with a network	Fitocracy, Diabesties
Social networking sites (general)	Traditional social networking sites allow users to create a network of contacts to interact with	Facebook, LinkedIn
Social networking sites (health-specific) and online patient communities	Network of people who can share their health-related information and experience with others online	Treatment Diaries, SmartPatients, HealingWell
Weblogs (blogs)	Online journal for an author to write and share posts (often long-form), and receive comments from other users	DiabetesMine, ItSuxToBeFat

In a very short span of time, social media has fostered a vibrant ecosystem of online communities, discussion, interaction, and relationships, with particularly high participation among individuals with chronic conditions. According to the Pew Research Center, more than 72 percent of adult Internet users engage in social networking to create and share content in text, visual, audio, or audiovisual formats. Approximately 40 percent of cellphone users employ their smartphone or mobile device for social media purposes, and increased connectivity is expected to raise online engagement in the future as devices add new features and grow more sophisticated. However, trends in social media use vary significantly along demographic lines. Social media is primarily used by younger populations between the ages of 18-29 (89%) and 30-49 (78%). While initially slow to adopt social media, the Baby Boomer generation has rapidly begun to catch up, with 60 percent of the 50-64 age group and 43 percent of the 65+age group using social networking platforms today.⁵ Although social media is used predominantly by internet users who are younger, female, and/or live in urban settings, the digital divide is closing as broadband connectivity and smartphones continue to spread across the general population in the United

States. Table 2 below briefly summarizes some of the cultural differences among different subpopulations and their use of social media platforms.

Table 2: Landscape of Social Media Use⁶

<i>Social media platform</i>	<i>% of internet users</i>	<i>Most used by</i>
Any social networking site	72%	Adults ages 18-29, women
Facebook	69%	Women, adults ages 18-29
Twitter	18%	Adults ages 18-29, African Americans, urban populations
Pinterest	15%	Women, adults under 50, Caucasians, people with some college education
Instagram	13%	Adults ages 18-29, African Americans, Latinos, women, urban populations
Tumblr	6%	Adults ages 18-29

The Impact of Social Media on Chronic Disease Prevention

Social media is changing how people interact with the healthcare and public health systems. The participatory, interactive nature of social media platforms allows for information to be generated and shared in a viral fashion. However, the speed of social media interactions also challenges traditional models of health promotion and surveillance to successfully leverage complex information in real-time. Just as personalized medicine uses large datasets to identify an effective treatment plan for an individual, social media data can be mined to identify specific populations engaged in high-risk behavior and target interventions to prevent chronic disease. Social media not only provides new channels for timely communication and trusted information, but also a critical outlet for self-expression. In the context of healthcare, internet users are increasingly turning to their online networks for advice, information, and support. By seeking and sharing information online, health consumers (or “e-patients”) are using social media to become more equipped, enabled, empowered, and engaged in managing their health, care, and wellness. While health professionals continue to be regarded as the primary source of information for diagnoses, medications, and referrals, more Americans than ever value of social networks (e.g. friends, family members, and fellow patients) for emotional support and advice on everyday health issues.

The data that can be collected from social media is equally as important as the services provided. A wide range of demographic, behavioral, geographic, emotional, and psychographic information on users and their interactions can build collective intelligence around health status, behavior, perceptions, and experiences. Data can also be used at an individual level to monitor mental and physical health, such as dietary intake, blood pressure, mood, or physical activity. Efforts to track daily life through technology and data acquisition are often referred to as the Quantified Self. As the Quantified Self movement gains traction among mobile and internet users, interactive web platforms will further engage, empower, and educate people to manage their health. Social networks have long been correlated with improved health and psychosocial outcomes, and recent research has suggested that online communities have a similar impact. Social media can enhance traditional social networks by bridging geographic gaps and providing anonymity to receive real-time assistance, information, and support.

Social media is also an important driver of prevention efforts to reduce the burden of chronic disease. At a primary prevention level, social media is an effective vehicle for education and awareness to encourage healthy behavior. As the internet has matured, social media has also fueled more complex efforts at a secondary level by providing individuals battling early stages of chronic disease with a community to rely upon for timely advice during teachable moments. Finally, social networking creates lasting relationships and communities online to support prevention at a tertiary level and mitigate long-term effects and challenges of chronic conditions such as cancer survivorship. By targeting behavioral risk factors such as smoking, alcohol use, physical activity, weight-loss, and nutrition, social media can effectively promote health and wellness before and after an individual develops a chronic condition. The following sections demonstrate how social media can be utilized to prevent chronic disease across occupational, behavioral, personal, community, public, and geriatric health settings and beyond.

Improving Access to Health Information and Education

Providing patients with appropriate resources and know-how is critical in encouraging healthy behavior. Healthcare organizations can increase the reach of their health-related messaging online by pushing educational materials, self-help resources, and other information out to targeted patient populations through interactive web platforms. More than 30 percent of adults are estimated to use social networking sites for health purposes, and people with chronic conditions frequently turn to the internet to learn more about their disease and complement what they've learned from their provider.⁷ Social media can also enable patients to communicate directly with one another and share lessons from their own experience with chronic disease and behavior change. In some instances, patients have leveraged social media to engage in patient-led research and participatory medicine.

Information Sharing

The amount of information that is available for health consumers is growing exponentially at a time when direct face-to-face communication with providers is decreasing due to financial pressures. Social media can increase the reach of information in a scalable, low-cost fashion.⁸ Although the quality of information found through social media can vary, interactive web channels can be leveraged to deliver evidence-based resources to populations that can otherwise be hard to reach.⁹ As health consumers, caregivers, and their families continue to embrace social media, it will become imperative for healthcare providers to engage in the digital world. Information sharing and education are important components of enabling people to self-manage chronic conditions and change their behavior or lifestyle to improve their health. Many healthcare organizations share information in a variety of formats across social media platforms for health consumers. While some organizations use a more traditional top-down approach to control the production of appropriate and accurate content, others rely on material curated or redistributed

"Social media is changing the paradigm of health communication and smartphones are only making it easier to put information directly in the hands of underserved populations that otherwise may not have internet access in rural or low-income areas."

*- Alice Patty,
National Association of Chronic*

by subject matter experts, and sometimes even healthcare consumers. For example, Swedish Medical Center is a health system in Washington that uses a physician-led blog to actively share information with patients. Providers write about relevant topics, covering both general and niche health information topics. The blog has empowered patients with basic information about their condition that can be accessed before visiting with a provider. Consequently patients ask more detailed questions specific to their circumstances. Dana Lewis, Manager of Digital Marketing and Internal Communications at Swedish, observes that their content-based social media strategy “directly impacts care by allowing providers more time to really focus on a person’s individualized care rather than cover information at a high level. The blog has also been effective at answering patients’ basic questions and providing information that isn’t easily found elsewhere.”

One particularly important feature of social media for educational purposes is the bidirectional nature of social media as a communications medium. Users are not only able to read and digest the information presented to them, they can also directly engage with the information’s source to share their thoughts on the content and/or how it impacted their own lives. Research has demonstrated that social media can improve the relevance of evidence-based medical information for patients by enabling them to participate in its refinement and offer feedback to maximize its effectiveness when presented to others.¹⁰ By engaging patients and offering messaging tailored to their specific interests, social media can increase the effect and reach of communication efforts. Examples include:

Inova Health System

Chris Boyer managed the digital communications and social media strategy at Inova Health System in northern Virginia. Under his guidance, Inova’s social media outreach focused specifically on engaging patients while sharing information for educational purposes. Boyer notes, “a lot of people out in the community are not really interested in health-related messages, but if their friends are commenting about something, then they may participate in the conversation.” Inova’s strategy leveraged social media platforms for different purposes: Facebook served as a hub for engagement and communication about events being held on other channels; Twitter proved useful for providing short, real-time bursts of content to supplement educational events; Google+ and its Hangouts feature allowed for real-time interaction during events; and Pinterest offered visually-driven engagement and a space for curated content. “At the end of the day, successful social media strategies require a human voice.” Feedback from patients at all points in the process was incorporated into future educational offerings to ensure that patients were provided with content they could actually use. “Social media provides a suite of vehicles that allow us to interact with our community in a completely different way than any other kind of communication tools. Social media is designed where people can initiate conversations with us, either directly or indirectly. They can engage with the information that we’re sharing with the community – and it’s changing the way in which we approach healthcare.”

LIVESTRONG Foundation

LIVESTRONG Foundation has also used social media as a way to increase the relevancy of its cancer-related messaging and reduce disparities across the country. In 2009, LIVESTRONG launched an educational campaign with culturally relevant and linguistically appropriate material for Hispanic and Latino populations. During the campaign, Facebook became the second-most important driver of traffic to LIVESTRONG’s resources.

LIVESTRONG chose to use social media because it was deemed an ideal platform for reaching Hispanic populations, facilitating relationships, delivering content, and maintaining high usage rates.¹¹ Echoing this belief, Michael Stellefson, a faculty fellow at the University of Florida's Center for Digital Health & Wellness, suggested that "social media may help patients pay closer attention to current healthcare guidelines. People with chronic disease are becoming more and more accustomed to locating relevant health information from interactive web platforms such as FaceBook, Twitter, and YouTube."

Information dissemination and patient education have quickly grown into one of the primary uses for social media in healthcare. Social media enables providers to reach broad swathes of the population with both targeted and general health information. Engaged patients can use social media to learn about relevant topics, proactively provide feedback, and share and edit content. Furthermore, social media can leverage established online networks to attract internet users with specific messages and health information. Although strategies and techniques are evolving, social media is a robust tool for efficiently reaching populations with accurate, accessible, and impactful content.

Peer-to-Peer Communication

Communication on social media mirrors the norms and patterns of face-to-face interaction. Social media users can find peers with similar needs, share information strategies for coping with their conditions, and develop meaningful relationships within online communities. Patients, caregivers, and family members often provide and solicit advice, exchange tips, and learn from the experiences of others on health-related social media platforms, thereby improving their knowledge and capacity for self-managing chronic disease and associated risk factors. By fostering community, internet-based social networks can encourage behavior change through information sharing, psychosocial support, and peer influence. Peer-generated information is often written in common terms without complex medical jargon, which can be beneficial to those with low health literacy or numeracy. Moreover, information that would otherwise prove difficult to obtain through direct interactions with providers, such as the personal impact of treatment or how daily routines and behaviors will be affected, can be shared among online peers. Finally, peer support can be instrumental in connecting people with resources to achieve their health goals.¹²

In the face of grave diagnoses, patients often make care decisions based on emotion rather than fact – such as opting for a treatment because of anecdotal evidence from a peer, even if their specific circumstances or medical history is substantially different. By helping a patient collect and analyze information, social media can assist individuals in making decisions in a more deliberate manner, incorporating information from both peers and professionals. For instance, access to experiences of other people with the same rare cancer through social media could prompt a patient to incorporate knowledge of potential side-effects of a treatment into their decision-making process instead of arbitrarily selecting a treatment because it worked for someone they know.¹³ Research has suggested that people with chronic conditions seek out specialized knowledge from their online peers.¹⁴ For example, analysis of large diabetes management groups on Facebook revealed that information sharing was common among participants. Sixty-six percent of posts described a user's personal experience with diabetes, which were then integrated with other forms of diabetes-related information by members of the group to develop a more complete portrait of life with diabetes. Experiential information such as adverse side-effects of medication was also used by patients to inform decisions. Nearly 25 percent of posts shared sensitive aspects of diabetes management that were unlikely to come up in traditional doctor-

patient interactions, including strategies for counting carbohydrates while drinking alcohol to prevent ketoacidosis.¹⁵ The collaborative nature of social media such as the example below enables users to access and share practical knowledge relevant to their immediate concerns and real-life experience, which they might not otherwise encounter through typical healthcare settings.

MyHealthTeams

MyHealthTeams builds social networks for chronic disease communities including approximately 49,000 parents of children with autism, 5,200 women with breast cancer, and 8,000 people with multiple sclerosis. Each site is designed to help patients and their caregivers surround themselves with the best people possible to help them as they manage their condition. Incorporating the collective knowledge of MyHealthTeams enables users to assess the quality of the information they receive and make the most appropriate healthcare decisions based on their condition. Eric Peacock, CEO and co-founder of MyHealthTeams, notes that “the basic instinct a patient feels after receiving a diagnosis is ‘I want to find other people that have been in my shoes and learn from them. I don’t want to reinvent the wheel. I know what the doctor has told me, and now I want to hear from other people like me’ – and MyHealthTeam provides a hub for that communication.”

MyHealthTeams leverages social network effects to deliver relevant information to people with chronic conditions. Each MyHealthTeam website leverages social media elements that users are already familiar with to make it easier to navigate; profile pages and an activity feed are similar to those found on Facebook, while the site’s directory of providers and health services resembles Yelp in allowing users to contribute and recommend content to others. “MyHealthTeams is helping patients with different conditions from all walks of life. For example, women are building real friendships and contributing very practical, helpful resources for other users, such as crowd-sourced answers, advice, and real-life stories about how to face breast cancer.” By incorporating health-specific information, users can search for others based on characteristics like diagnosis, stage of disease, type of therapy, and age, and add them to their disease management team.

Active participation in social media is not necessarily a requisite for benefiting from information-sharing aspects. People can glean information on important topics simply by viewing social media and reading content. For example, 19 online support groups dedicated to breast cancer, fibromyalgia, and arthritis were surveyed to determine whether “lurkers” (those that viewed the forums but did not contribute by posting) received the same benefits as posters (those that actively communicate online). Though lurkers were less satisfied overall with online support groups, they did not score differently than posters on key measures of empowerment including “being better informed” and “feeling more confident in the relationship with their physician.” These results indicate that the mere act of consuming content via social media can empower users.¹⁶

Patient-Provider Communication

Given the complexity of their conditions and treatment, many patients with chronic disease(s) need regular access to their providers across the continuum of care to address concerns and comprehend medical information. Patient-provider communication is critical to facilitate patient engagement and ensure that patients are actively involved in making health-related decisions. However, in-person encounters between patients and providers are often short and may not offer

enough time to sufficiently address all the questions of a patient or caregiver; moreover, issues often arise outside of appointments or after business hours. Social media offers the potential for real-time patient-provider communication without the constraints of face-to-face interaction, and research suggests that many health consumers are ready to engage with providers through social media platforms.¹⁷

Although patients are increasingly sharing health information with one another, direct provider-patient communication via social media is still relatively rare. Concerns about patient privacy and Health Insurance Portability and Accountability Act (HIPAA) regulations have largely stifled the use of social media to supplement patient care.¹⁸ However, interactive web platforms can be used to effectively educate, remind, and engage patients; monitor their behavior; and provide feedback in a cost- and time-efficient manner. By enabling patients to become more engaged and empowered partners in their care, social media can substantially improve health outcomes. Dr. Mark Ryan, a practicing physician at Virginia Commonwealth University Health Systems, believes that “connecting through social media is a good way to bring patients back into direct care settings.” Patients can be further engaged in their care by using collaborative tools such as wikis to develop patient-centered care plans, decision aids, and clinical practice guidelines through shared language and common terminology to increase usability and uptake.^{19,20,21} In an effort to reduce concerns about privacy, researchers recommend invite-only online groups for interacting directly with patients with shared conditions and concerns in closed environments such as:²²

University of Maryland Medical System

For example, the University of Maryland Medical System (UMMS) recently established four support groups on Facebook to allow patients to continue meeting after their face-to-face support groups ended. Each group is housed on an invite-only Facebook page, and is managed by a nurse practitioner. Ed Bennett, Director of Web and Communications Technology at UMMS, notes that “patients have conversations about their shared experiences and the types of issues that they have to deal with from a medical and psychological standpoint. Social media platforms allow patients to talk to each other, share information, ask if anybody else has had this particular problem, and help others through what is a very stressful and difficult time.” The nurse practitioner monitors the group, kicks off discussion topics, and answers questions about medical issues to ensure that the patients are receiving accurate information. By nature of the accessibility and ubiquity of the Internet, online groups are an effective means of improving access to care.

Oak Park Behavioral Health

At Oak Park Behavioral Health, Dr. Tiffany Taft utilizes Twitter, Facebook, and a blog to inform patients about a variety of mental health topics. For Dr. Taft, social media is an outlet for breaking down barriers between patients and providers to improve communication, humanize the patient-provider relationship, and overcome stigmas surrounding mental health: “It can be really positive in terms of people learning about what we do as psychologists and mental health providers. Half the time people don’t even know what it’s like to come see a therapist and that may be a barrier to their treatment.” Like Dr. Ryan, Dr. Taft believes that social media engagement can encourage patients to return to care settings where more open dialogue is appropriate. “Social media helps drive the conversation between providers and clients. I learn so much from reading patients’ tweets, Facebook posts, and blog entries to better understand their world.” Providers using

an online web portal with a forum and blog tailored for young diabetics have expressed similar appreciation for being provided with a window into learning how patients think.²³

Participatory Medicine

Health-related social networks such as MedHelp, PatientsLikeMe, DailyStrength, Tudiabetes, CureTogether, and Asthmapolis are online patient communities where users can find and discuss information about conditions, symptoms, and treatments, provide and receive support, enter and monitor data, and join health studies. In fact, patients on these sites have even begun to take care into their own hands by developing, participating in, leading, and reporting the results of clinical research. Crowd-sourced research is a natural extension of the activities of online health social networks and communities, where patients and researchers have access to groups of individuals with shared characteristics and goals. Crowd-sourced research endeavors can build patient engagement, increase transparency, and directly impact the patient community without the delays of more standard study designs. Participatory research findings have already helped improve the characterization and measurement of disease, investigated aspects of prescription drug use including off-label uses, adherence, and patient sentiments, and established evidence for links between diseases and specific genetic traits.²⁴

"Patients will really make a difference in how the body of knowledge on a disease develops through research. If just one percent of consumers become actively engaged and involved in their health, they can change the whole system."

- Jamie Heywood, PatientsLikeMe

Many view participatory medicine as a critical component of healthcare in the future, and see social networks as a foundational step in that direction. Researchers have predicted that technology will transform the traditional patient-provider relationship by simultaneously inserting more people and information into the relationship. As patients and providers both move into virtual spaces, the patient-provider relationship will shift from an authoritative model to a partnership model, where patients are the primary researchers and providers offer alternative therapeutic options and information analysis.²⁵ Jamie Heywood, co-founder of the online social network PatientsLikeMe, expresses similar views: "Social media essentially provides the ability for patients and research subjects to provide robust feedback on how effective a treatment plan is. There's a democratization effect that breaks the traditional subject-researcher modality – and it couldn't have arrived at a better time."

PatientsLikeMe

PatientsLikeMe is one of the most well-known online health social networks. The site functions as both a community for patients and a virtual disease registry for various medical conditions. Upon joining, patients create user profiles detailing their health history with structured and unstructured information, including prescription information, symptom reports, biometric indicators, and test results. Users can view profiles of individual users, as well as aggregated information summarizing treatments and symptoms from patient groups with shared attributes. Patients can communicate with one another via a community forum, private messaging, and comments on profiles. By adding a rich data layer on top of standard communication tools, PatientsLikeMe equips patients to use the information at their disposal to enhance their care and make more informed decisions.²⁶ In

addition to helping care for its users, PatientsLikeMe also operates as a validation tool for patient-centered clinical research that ultimately may better serve the population.

Heywood views social media as the next step in the evolution of crowd relationships. "The modern Internet allows people to draw upon the right information in the right context through the right relationships to more effectively advance their knowledge." Social networks such as PatientsLikeMe combine rich, accessible literature with 24/7 communities to enable users to move from a light understanding to detailed topical knowledge. "By creating a social network, we wrote a new social learning contract that can transform the healthcare system."

Behavioral Change

Access to health-related information can better equip people to improve their lifestyles and overall health. Social support can augment information to encourage self-reflection, strengthen accountability to achieve goals, and ameliorate adverse psychosocial health effects of living with a chronic condition.²⁷ For individuals with stigmatized conditions such as obesity or depression who otherwise would not be comfortable seeking information or support, interactive web platforms can have a transformative impact.

Wellness programs frequently incorporate social media to create a sense of community, coalesce people around shared goals, hold participants accountable to their peers, and offer social and emotional support. Forums, discussion boards, and Facebook groups are the most commonly used forms of social media for preventing high-risk lifestyle behaviors, though independent blogging communities have also emerged around certain risk factors for chronic disease such as nutrition and physical activity. Mirroring many of the advantages of face-to-face support groups and communities, forums and discussion boards also offer additional benefits such as increased accessibility, culturally appropriate information, availability around the clock, and anonymity.

Blogging has long been associated with improved quality of life, self-awareness, and psychosocial support to achieve behavior change. The blogosphere has had a significant impact on the weight-loss and tobacco cessation communities by providing people with a supportive, interactive environment which can encourage and validate each blogger's personal journey. A review of weight-loss blogs found that bloggers share their personal lives to express emotion, develop a therapeutic link with an audience, receive peer support, and increase personal accountability for achieving their weight-loss goals. Bloggers have also described their communities as unique groups with shared interest that can otherwise be hard to find.^{28,29} Active participation in an online community can help smokers obtain information on cessation, manage lapses and withdrawal, obtain social support, and increase accountability.

Content analyses of online support groups such as the Alcohol Help Center reveal that bloggers often shared words of encouragement with each other. Participants used the forum to exchange strategies to reduce alcohol use, request help or advice, and support others as they share their experiences. By providing information and therapeutic value through fellow peers, the Center was able to reduce high-risk behavior and improve wellness.³⁰ Similar results were observed at StopSmokingCenter.net, a web-assisted tobacco intervention which includes a discussion forum moderated by trained health educators. The first posts that individuals made after registering for the forum frequently sought support or advice for quitting. Interestingly, people who had recently quit smoking or had not yet tried to quit made their first post more quickly than those who had

quit smoking for more than a month, indicating heightened informational and supportive needs among those in early stages of the cessation process. Other forum users responded most quickly to first posts soliciting help, demonstrating their eagerness to help their peers through the initial – and most difficult – phases of quitting. The discussion boards thus functioned as an immediate source of support not otherwise available through many traditional interventions. Discussion board use was associated with greater completion of tests for nicotine dependence and engagement in the smoking cessation process.³¹ Analysis of other forums have found that active forum users showed smaller declines in abstinence rates over 70 days, indicating greater success in maintaining their smoking cessation goals. Moreover, user activity was positively associated with better abstinence rates; those who posted more often reported significantly higher rates of abstinence than those who posted less frequently or not at all.³²

As social media evolves, many health interventions are beginning to move from traditional areas of blogging and discussion boards to more advanced, interactive platforms. For example, the FITNET physical activity intervention used Facebook to distribute basic information and tips related to physical activity, with materials designed specifically for young adult cancer survivors. FITNET users also received access to a separate website with tools for goal-setting and tracking physical activity, educational materials with advanced self-help guidance, and the opportunity to participate in guided discussions led by the study administrator on the group's Facebook page. Over the course of three months, the FITNET group and a control group (which received only basic information and tips related to physical activity) used their respective Facebook pages to discuss physical activity, offer encouragement and support, and share resources. Although both groups reported increases in moderate-to-vigorous physical activity levels, participants in the FITNET group reported greater increases in weight loss. The presence of a moderated discussion did not have an impact on the frequency with which participants commented on the Facebook pages, indicating that Facebook is a potentially effective tool for delivering a physical activity intervention even without professionally facilitated discussions.³³ In 2010, one of the first randomized controlled trials testing the health outcome effects of online social networking showed little difference in daily physical activity between a social networking and control group; however, social media users did remain engaged significantly longer than their counterparts and were more likely to complete the program due to social support.³⁴

Incentives and Gamification

Some social media-based interventions are using behavioral psychology to enhance social support and incentivize behavioral change. Commonly referred to as gamification, this approach incorporates game mechanics to engage users.³⁵ Erik Augustson is a Program Director and behavioral scientist at the National Cancer Institute's (NCI) tobacco control branch. In monitoring the evolution of health promotion, Augustson notes that "people have demonstrated that they're willing to engage in social media-based games and work diligently towards goals which only provide virtual rewards in the digital world. By implementing gamification into traditional health interventions online, behavior can be incentivized via social media without having to provide monetary incentives."

Fitocracy

Gamification is one of the hallmarks of Fitocracy, a fitness social network and workout tracking platform with more than one million users. After joining the community, users select fitness-related areas of interest to generate a content feed on their profile. People can view and post comments, photos, videos, and links to other resources. Gamification is

integrated into the fitness tracking component of the site by awarding points when users enter exercises, workouts, or routines that they've completed. As users earn more points, their progress is charted by advancing levels which indicate stages of achieving their fitness goals. Brian Wang, CEO of Fitocracy, explains that "Gamification is a strong tool for the first-time users who become intrigued with the idea of earning points and facing harder challenges." However, gamification may ultimately lose its appeal over time as the informational and social support functions of the community grow more important to users. "The attraction of reaching new levels eventually fades over time – but what keeps people engaged is connecting with the community and forming bonds with other users. It's really a one-two punch; gamification draws users in and the community keeps them engaged."

Like other online communities, members of Fitocracy rely on one another for information and support. The activity feed keeps users aware of workouts shared by the people they follow, enabling them to learn new routines or activities to incorporate into their own fitness plans. New users who haven't spent much time working out will often follow more experienced users to learn the first steps they should take to improve their fitness. "Props" and supportive comments keep people motivated to continue working out. "This establishes a positive feedback loop for physical activity. If you are working out by yourself, no one will really know or care about it. On Fitocracy, the audience is targeted and relevant, and will provide immediate feedback and support."

UnitedHealth Personal Rewards

United Healthcare has also experimented with using real-world incentives to change peoples' behavior. UnitedHealth Personal Rewards was a successful pilot program that leveraged social media channels (including Facebook, Twitter, and online community groups) to encourage participants to check their biometrics and help them better understand and manage risk-factors for chronic disease. In return for taking steps to improve risky behavior, United offered reduced reimbursement premiums. Anya Kirvan, Vice President and Innovation Champion, suggests that "people will make a change if they know their numbers, understand that they're not as healthy as they thought, and have an incentive that really is relevant for them. However, the hardest part is getting them through the front door and social media is a wonderful way of targeting tough demographics to reach." The pilot program achieved an 84 percent engagement rate and demonstrated measurable improvements in biometric indicators. The program's success was attributed in part to robust online communities that shared strategies for managing cholesterol, blood pressure, and blood sugar. Despite barriers to the use of social media in healthcare organizations, Kirvan believes that "Online community groups such as the Personal Rewards program are just as important as going to see the doctor – particularly among high-risk populations in dire need of access to health information and education."

Psychosocial Health

The psychosocial impact of chronic disease may affect an individual's ability to manage their condition, potentially compounding the problem and contributing to further distress. Social media can provide an outlet for individuals with chronic disease to coalesce around a shared experience and offer mutual support as they progress from diagnosis to treatment and management. Information-sharing not only provides people with the knowledge they need to successfully manage their condition and change their lifestyle, it can also provide reassurance and reduce

feelings of isolation. Social media can provide support and replace the loss of face-to-face contact that may result from illness or hospitalization.³⁶ Social support can empower individuals with the knowledge that they can lead a normal and productive life despite their illness.

Social media use is particularly common among individuals experiencing adverse psychosocial effects from chronic disease or in need of support. For example, testicular cancer survivors have reported unmet care needs which impact mental well-being (such as body image, stress management, and anxiety about recurrence) that weren't addressed until they found an outlet through online communities.³⁷ Similarly, online breast cancer communities have been found to improve psychosocial outcomes even when users aren't actively engaged.³⁸ In studying characteristics of patient engagement within an online cancer support group, researchers have found that individuals with lower scores on social support assessments were more likely to actively use the group's discussion forums. Living alone was also correlated with posting on the forums, suggesting that online sharing is an alternative way to receive feedback and support from peer networks.³⁹

Comprised of discussion boards, chat functions, and informational content, the HeartNET community enables heart disease patients to communicate with one another and provide reciprocal support. Interviews with users demonstrate the community's ability to help give the participants' experiences with illness meaning, provide mutual emotional support, and offer therapeutic value through sharing one's experiences. For one participant, the community took the edge off her relentless search for 'answers' and instead offered her a sense of belonging and experience of travelling a difficult path in the company of a supportive group of people who understood the challenges she faced.⁴⁰ Similar benefits were found from synchronous support interventions delivered through online chat rooms for individuals with advanced cancer that joined to find peers with similar experiences. Some participants reported feeling uncomfortable or unwelcome at general cancer support groups that met in person because they had to deal with different issues as a result of their advanced stage of cancer. Joining a group with like-minded peers freed them to express their feelings and reduced their sense of isolation. Because the participants had advanced stage cancer, the groups served different roles for different individuals. Two particular narratives emerged. The dignity narrative was typified by a focus on the future and how the individual could make meaning from their lives as they faced death. The support groups enabled people to discuss difficult issues around the end of life that were hard to talk about with their friends and family. The deferral narrative focused on dealing with the present and coping with cancer, and the support group was more of an outlet for hope, help, and emotional support as they faced life with cancer. Participants expressing each of these narratives reported appreciation of the presence and input of the other.⁴¹

Big White Wall

Recognizing the need to provide a safe environment online where people can anonymously express themselves, receive guided support, and seek information on mental health conditions at any time of day or night, Big White Wall is an evidence-based service that combines social networking and clinical intervention for over 14,000 people in the United Kingdom. Members can access a range of digital therapeutic interventions and interact with other users online through the SupportNetwork forum moderated by trained professionals. Jen Hyatt, CEO of Big White Wall, believes that "social media can break down the walls of behavioral healthcare on two fronts: by providing peer support to influence positive health decisions and reinforce behavior change, and by connecting users

with peers and personalized services online.” Big White Wall seeks to leverage these fronts by “creating a healthcare space where the patient is placed at the center of their own care, surrounded by a community of peers and professionals. Rather than passively waiting alone for an expert opinion, the patient is actively supported by physicians on call and the wider community to pursue their own health goals.”

Hyatt adds, “reducing stigma is one of the keys to tackling common mental health conditions such as depression, anxiety and stress. One of the issues with mental health is that people find it difficult to talk about. At Big White Wall we tackle this through anonymity.” Seventy-three percent of users report disclosing their problems for the first time on the SupportNetwork, and the program has improved mental wellbeing (95%), self-management (80%), and anxiety and depression (50%) among users over a three-month period. Independent cost-effectiveness evaluations estimate that the SupportNetwork service saves an average of £369.35 (\$597.05) per member in direct costs to the National Health Service by reducing face-to-face therapy, afterhours and emergency services, and psychiatric hospitalizations. “The greatest barriers that we face today are an aversion to risk and fear of the new, coupled with the fragmented nature of healthcare,” Hyatt notes. But times are changing. “People are now so accustomed to turning to the internet for their needs to find information, to pay bills – why not also use the internet to take care of their own health in a way that actively empowers them? If we can assure that quality and safety can be guaranteed online as much as offline, the convenience and accessibility of the digital world will continue to revolutionize healthcare.”

In addition to online support groups and discussion forums, other social media tools have also demonstrated psychosocial value for individuals with chronic disease. For instance, health bloggers can use blogs to increase their connections with others, decrease isolation, and release pent-up emotions. Blogs also function to give meaning to experiences with illness and generate personal insights. This can increase a blogger’s understanding of their condition and a sense of purpose for living with and managing a disease.⁴² Moreover, blogging communities can serve as protective spaces for bloggers to challenge social discourses and resist stigma. Members of the “fatosphere,” a fat-acceptance blogging community felt empowered, experienced an increased sense of social connectedness, and perceived improvements in mental and physical health and well-being.⁴³

Treatment Diaries

Treatment Diaries is a social network which utilizes privacy and anonymity to encourage users to share their experiences with a health-related journey. Like other social networks, Treatment Diaries allows users to set up a profile with a personal diary in which they can track their progress with their disease or share their thoughts anonymously. Amy Ohm, CEO of Treatment Diaries, states, “By extending privacy to the patient, caregiver, or healthcare advocate, they are empowered to share more and feel comfortable providing and exchanging details that are very intimate and personal with respect to their health.” Demographically, women tend to participate in online support groups and blog about health at higher rates than men. However, Treatment Diaries’ focus on privacy has helped more men share on the site. Ohm notes, “It can be particularly difficult for men to be open about their health in public.” Diaries are not restricted to discussing a user’s health; men are also using the platform as caregivers for their spouses to express emotions that they couldn’t otherwise express to their peers like resentment, sadness, and even anger about

having to interrupt their lives to care for someone else. Treatment Diaries provides many of the emotional and supportive functions that patients with chronic disease seek through social media. According to Ohm, “patients need to be connected. They need to know that there are others who share their condition and associated challenges. Connecting these individuals offers therapeutic benefits because what all of a sudden feels scary, lonely, or overwhelming is now tied to somebody else who is going through exactly the same thing.” Social media tools such as Treatment Diaries can help people overcome the psychosocial impacts of chronic disease by providing supportive environments typified by mutual understanding which can alleviate feelings of fear, anxiety, isolation, and stigma.

Improving Health, One Community at a Time

Social media tools are not only being integrated across the continuum of chronic care, but also enhancing community-level health promotion.⁴⁴ Traditional public health programs have long disseminated information and interventions online. However, the reach and diversity of interactive web tools allow public health professionals to communicate, educate, and empower previously hard-to-reach and vulnerable population in new ways and mediums. Recently, a number of cities and counties across the country have taken up initiatives to help residents collectively lose weight.

OKC Million Campaign

Oklahoma City was once one of the most overweight and least physically active cities in the U.S. In 2008, the mayor of Oklahoma City launched the “OKC Million Campaign” to motivate residents to lose a combined one million pounds. The mayor’s office engaged the community through outreach to neighborhoods, schools, civic organizations, religious groups, and employers to raise awareness, challenge individuals to create social groups online, and lose weight. The campaign featured a website with tools to help people track their weight loss, access educational information, and expand the scope of participation. Individuals shared their success stories online, becoming local community advocates who could increase the relevance of the campaign to their peers. Steve Hill, the Mayor’s Chief of Staff, noted the echo effect of social media: “It was great that we could Tweet to our followers, but if they then resent messages to their friends and family, we could reach exponentially more people.”

Over the next four years, more than 48,000 participants logged onto a website that acted as a clearinghouse for healthy eating and active living information, a hub for participants to track and monitor weight, diet, and physical activity, and a platform for them to share their stories and progress. In January 2012, the city reached its goal of losing one million pounds and running more than one million miles. Since working on the Oklahoma City initiative, Mike Panas, the founder of Healthwise Champions, has supported similar community-based programs in other cities and counties using effective online tools to promote healthy lifestyles. Looking back over the past several years, Panas observed, “Ultimately, it’s the community that changes from within. The majority of individuals can truly improve their health when given the right direction, tools, and social support. Social media platforms provide an environment and infrastructure for social groups to help people reach their goals, improve their health, and achieve sustainable change.”

Evaluation of Social Media

The examples above have demonstrated how social media impacts chronic disease prevention, including disease-specific knowledge, psychosocial support, patient empowerment, information sharing, and health outcomes. However, there has been relatively little research on how to assess the overall effects of social media in healthcare. Without widespread consensus on an appropriate evaluation framework or set of metrics, it can be difficult for many healthcare organizations to develop effective social media intervention programs. Michelle Hamilton-Page, Manager of New and Social Media at the Center for Addiction and Mental Health in Toronto, observed, “Commonly used social media metrics are the tip of the iceberg because we as researchers still have yet to really figure out what the significance is of the number of posts, followers, likes, or comments even as we measure them.” Some researchers have suggested that established approaches from traditional health promotion simply be adapted to social media. For example, the RE-AIM framework could be repurposed to evaluate the population-based impact of online health promotion programs based on the range and representativeness of participants, outcomes, rates of participation and engagement, consistency of results, and sustainability.⁴⁵ Alternatively, other models have utilized key performance indicators (KPIs) to evaluate health promotion through measurable data points such as consumer feedback, attitudes, exposure, and engagement.⁴⁶

Moreover, analyzing the data that is generated and collected through interactive web platforms has presented the field with new challenges as online tools become more complex and robust. The volume, velocity, and variety of data communicated through social media platforms require new methods of evaluation, surveillance, and research. Social media intelligence, though still a nascent field, incorporates components of machine learning, data mining, and natural language processing algorithms to derive meaning from vast amounts of unstructured content. By identifying patterns and semantic nuances of large data sets with high levels of predictive accuracy, analytic models can be built to scale and provide specific information about targeted user populations and their behavior. Because the discipline is fairly recent, these techniques can be

Text mining is an efficient approach for parsing large amounts of unstructured data communicated through social media. Aiming to discover novel information in a timely manner, text mining algorithms can parse and identify aspects of text (such as sentiment, health symptoms, health behavior, or knowledge) to detect patterns in data. After converting unstructured textual data into machine-understandable format, text mining can filter out data with ontologies and categorize information through domain analysis.

Natural language processing (NLP) has emerged as a highly effective algorithmic approach to decipher the range of complex information that can be communicated and expressed online. While basic NLP techniques can parse text to identify topics and connotation of phrases, some of the most compelling applications of NLP lie around sentiment analysis. Sentiment analysis identifies polarity of subjective information to distinguish between opposing opinions, feelings, and topics. In the context of health, sentiment analysis is particularly useful in determining emotion, mood, and psychosocial status of social media users on platforms such as blogs, message boards, or microblogs.

vulnerable to low specificity and misinformation. For example, analytic techniques may have to differentiate between the word “cold” as a reference to health or temperature to avoid overestimating the prevalence of illness. As predictive models incorporate machine learning and evolve over time, however, data will ultimately drive more accurate insight.

Looking Ahead

The effective design, implementation, and use of interactive online tools can offer unique solutions to respond to the needs and concerns of populations that are at risk of chronic disease or high-risk behavior. While social media has been heralded in some circles as a panacea to communication, its rapid introduction into the world of healthcare has presented new challenges and opportunities on a scale that was previously unimaginable. Social media, like other information technology, was adopted initially by affluent, urban, educated, and younger populations; however, as smartphones proliferate, social media is rapidly penetrating other demographic markets with newfound wireless internet connectivity and access. Nonetheless, a significant digital divide continues to exist, particularly among elderly minority populations. While the divide may have begun to narrow and provide more access to information, it has also been deepened by the speed and ease with which misinformation can spread through digitally connected networks. Without appropriate eHealth literacy regarding issues of the veracity and reliability of information found online, social media may encourage users to diagnose and medicate themselves without seeking professional medical input.

Another major challenge to social media involves consumer trust, privacy, confidentiality, and understanding of the risks of sharing personally identifiable information. The public nature of online platforms can put users at risk of potential harm or misconduct when private data is exposed, particularly when stigmatized health information is breached that may have originally been shared under the guise of anonymity. Younger individuals, who are typically more familiar with social media, are often less careful about what they share publicly. While differences in risk tolerance exist, it is becoming increasingly difficult to navigate privacy and trust online. “Patients should be able to do what they want with their own data. It might be ill-advised for someone to put all their hourly vital signs on Facebook or Twitter, but paternalistic laws shouldn’t tell them that they can’t. What we need to do instead is manage expectations and increase education and transparency about privacy - or lack thereof - on social networks,” advocated Alice Leiter, Policy Counsel at Center for Democracy and Technology. “Individuals need to be aware of privacy challenges on social networking sites, and be left to make their own decisions about assuming that risk.”

As more health consumers engage in social media, healthcare organizations will need to reassess their existing protocols and adopt institutional policies that reflect digital trends. “Social media applications have exponentially expanded the geographic and socioeconomic reach of public health and healthcare,” remarked Dr. Bernard Fuemmeler, Associate Professor at the Duke University School of Medicine and co-director of mHealth@Duke. “But it will be critical to ensure that patient privacy and confidentiality are protected according to HIPAA compliance” when there is dialogue online between a patient and provider. Rather than avoiding social media, some organizations are redesigning the fiduciary role of a health professional to encourage patient-provider communication, evidence-based intervention, dissemination of information, and surveillance of communities for risk of adverse behavior through social media platforms. Because

digitized health information is increasingly being used by entities that fall beyond the traditional jurisdiction of HIPAA, it will behoove newcomers to healthcare from the tech community to identify practical solutions that mitigate potential threats and provide safeguards for dynamic control of information and confidentiality.

In light of the digital divide and privacy concerns, social media is used differently by disparate populations. The interactive web is fairly new, but varying rates of interest and activity among Internet users suggest patterns of sustainable user engagement. Today, people are more than twice as likely to search, access, and consume information through social media for health-related purposes, rather than generate or contribute to content.⁴⁷ While there are a variety of factors leading to this plateau effect, the rapid proliferation of social media platforms has subjected many people to feelings of fatigue and information overload. It is therefore critical for interactive online tools to incorporate user-centered design and adapt to evolving needs, behaviors, and preferences of healthcare consumers without overburdening them. For instance, some social media programs may better cater to people with specific conditions by providing around-the-clock synchronous communication and support, while others may be better served by an integrated asynchronous platform that also offers a forum for ongoing community and discussion. “An ounce of prevention is worth a pound of cure. But once people reach their goal – for example, losing a certain amount of weight – it can be difficult to achieve sustainable results without a long-term gameplan and support community in place. Unfortunately, a lot of tools with social components are not built with a multi-faceted vision in mind, and only target individual use for specific purposes on a short-term basis,” noted Panas. The most successful social media platforms identified in our research were those that were able to create sustainable communities by offering a variety of tools to empower healthcare consumers.

The introduction of interactive web technologies has also had a ripple effect in the public health and health services research community. While emerging data analytic techniques hold great promise to mine large amounts of information, they are vulnerable to inaccurate specificity and false reporting until statistical models are refined. Because social media is user-generated and reported, the vast majority of data can lead to ecologic fallacies and questions regarding authenticity or accuracy of conclusions. “Future public health initiatives should focus on evaluating the source and quality of health information available to the public on social media,” agreed Stelfox. If social media is to truly enhance public health and healthcare, professionals must be better trained with multi-disciplinary skills to bridge the gap between data science and healthcare – and the general public must in turn be better educated about how to safely share their information online without impinging on their desire to express themselves.

Lessons Learned

In examining how social media can prevent chronic disease across occupational, behavioral, personal, community, and public health settings and beyond, this report has discussed the key challenges, benefits, and strategies that are listed below.

Key Challenges

- **Digital divide among elderly and minority populations**, although wireless connectivity is narrowing the gap.
- **Balancing transparency and anonymity** with the creation and sharing of personal content online.

- **Concerns about privacy and HIPAA compliance** among healthcare organizations and providers inhibit the adoption of social media into daily practice and operations.
- **Quality, validity, and authenticity of information online** can come into question because content is almost always user-generated.
- **Limited theoretical or evaluation models for social media exist**, given that the majority of interventions conducted today are feasibility or pilot studies that have yet to promulgate gold standard methodologies.

Key Benefits of Social Media

- **Breaking down the walls of patient-provider communication** to make information about a chronic condition or treatment more personable and timely.
- **Improving access to health information** in a scalable, low-cost approach capable of targeting specific populations that are otherwise hard to reach.
- **Providing a new channel for peer-to-peer communication** among healthcare consumers, caregivers, and family members to share and discuss their experiences with similar health conditions or treatments.
- **Developing meaningful relationships** that can provide psychosocial support and motivation to cope with chronic conditions.
- **Establishing communities** of patients, caregivers, and/or family members with shared experiences to combat isolation, fear, and stigma.
- **Engaging and empowering people** to be accountable and achieve their goals and objectives through online peer support.

Strategies for Promoting Health and Wellness through Social Media

- **Develop multiple synchronous and asynchronous functionalities** to allow flexible 24/7 communication among users.
- **Include online roles for trained health providers and caregivers** to mitigate concerns about misinformation without breaking users' trust.
- **Provide dynamic privacy controls and use requirements** that encourage users to share as much or as little information as they prefer.
- **Incorporate user-centered design** to ensure not only that the platform is developed appropriately for the intended user audience with relevant features.
- **Provide an open, safe environment** for users to comfortably share information about health issues which may be heavily stigmatized.
- **Apply evidence-based behavioral theory** to leverage social networks for peer support and motivation.
- **Redefine the role of patients** by empowering healthcare consumers with information and opportunities to be involved in patient-centered care and research.
- **Leverage long-lasting community ties** to sustain user engagement.

Conclusion: Fish Where the Fish Are

Consumer activism and empowerment has sent a ripple effect through the healthcare industry. Today, more people than ever are taking it upon themselves to steward their own health, track and manage personal health information, make health-related decisions, and share information and experiences with others. The incorporation of social media tools into healthcare is expected to grow in practice and importance as more people communicate online. As our society becomes increasingly connected through wireless devices and accustomed to sharing private matters such as health with others online, new challenges and opportunities will arise to leveraging this information in a safe, dynamic, and timely manner. At the time of publication, there is limited peer-reviewed research demonstrating evidence of how social media can be utilized to improve disease management and health outcomes. Because few theoretical or evaluation models for social media exist, the majority of research conducted today are feasibility and pilot interventions that have yet to incorporate standard methodologies for assessing outcomes.

The most successful examples of social media in healthcare are tools that fish where the fish are by utilizing the most relevant platform for a target population based on their specific needs, characteristics, or preferences. For example, a primary prevention program targeting alcohol abuse or smoking cessation might be best served by an interactive web tool with mobile functionalities to raise awareness and reach younger audiences with age-appropriate educational material. On the other hand, secondary and tertiary prevention of a chronic disease such as an advanced cancer often involve complex psychosocial issues and challenges that are best suited to be addressed through online discussion boards that provide a peer support community. By grounding intervention and education in evidence, patient-centered social media programs offer an effective and attractive medium for patients and providers alike.

This report presents a series of vignettes that only begin to scratch the surface of innovative social media practices. While applications of social media to healthcare are often discussed in the context of infectious disease and emergency preparedness, tools and platforms can also be leveraged to enhance chronic disease prevention by creating new channels for engagement online with both general and targeted populations. Although concerns and barriers remain to be addressed, interactive web technologies can enhance the prevention of high-risk behaviors by improving access to information, behavior change tools, and online communities.

Appendix I: Technical Advisory Group

Name	Organization
Abdul Shaikh, PhD, MHS	National Cancer Institute
Alan Balch, PhD	National Preventative Partnership
Amanda Woodhead, MS	Emdeon
Cecilia Arradaza	FasterCures
Geeta Nayyar, MD, MBA	AT&T
J. Leonard Lichtenfeld, MD	American Cancer Society
James Murray, MS	CVS Caremark
Jay Bernhardt, PhD, MPH	UFL Center for Digital Health & Wellness
Joe Hall, PhD, MS	Center for Democracy and Technology
John Patton	NACDD and NAPHIC
Linda Dimitropoulos, PhD	RTI Center for the Advancement of Health IT
Mark Dredze, PhD	Johns Hopkins
Mike Lardiere, LCSW	National Council for Behavioral Health
Nathan Tatro	American Psychological Association
Patricia MacTaggart, MBA	George Washington University
Phil Baumann	Health Is Social
Richard Birkel, PhD, MPA	Center for Healthy Aging
Steven Stack, MD	American Medical Association
Susannah Fox	Pew Research Center
Todd Evenson, MBA	Medical Group Management Association

Appendix II: Key Informants

Name	Organization
Alice Patty	National Association of Chronic Disease Directors (NACDD)
Alice Leiter	Center for Democracy & Technology
Amy Ohm	Treatment Diaries
Anya Kirvan	United HealthCare
Bernard Fuemmeler, PhD, MPH	Duke University Medical Center
Brian Wang	Fitocracy
Bryson and Mike Panas	Healthwise Champions
Chris Boyer	North Shore LIJ Health System
Dana Lewis	Swedish Hospital
Ed Bennett	University of Maryland Medical System
Eric Peacock	myHealthTeams
Erik Augustson	National Cancer Institute Tobacco Control Research
Flora Vale	ESRI
Jamie Heywood	PatientsLikeMe
Jen Hyatt	Big White Wall
Laura McNulty	ESRI
Mark Dredze	Johns Hopkins University
Mark Ryan	Virginia Commonwealth University Medical Center
Marlene Schwartz	Yale Rudd Center
Matt Longjohn	YMCA
Michael Stellefson	University of Florida Center for Digital Health and Wellness
Michelle Hamilton-Page	Centre for Addiction and Mental Health
Robert Jarrin	Qualcomm
Sean Duffy	Omada Health
Shira Loyer	SeniorBridge / Humana
Steve Hill	Oklahoma City Mayor's Office
Sylvia Chou	National Cancer Institute
Tiffany Taft	Oak Park Behavioral Health
Tom Glynn	American Cancer Society
Wen Dombrowski	Resonate Health LLC

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