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Social Media and Clinical Trials Recruitment: Potential Benefits and Challenges

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Introduction

"...*the use of social media in supporting medical research is rapidly moving from experimental pilots to informed strategies. An increasing number of companies and healthcare stakeholders are exploring how social media can support clinical trials... and as they do so, some interesting trends are emerging...*" [1].

This column examines the potential uses of social media in the recruitment of patients for clinical trials. Its primary purpose is to provide an overview for health librarians, but clinical trial coordinators and researchers may also find the discussion relevant.

Social networking using internet-based media is fundamentally changing how health researchers think about research and engage patients in clinical trials. Since 2009, social media has been touted as an avenue for clinical trial recruitment [2] and for sharing information with participants [3]. Three of the most popular social media tools, Facebook, LinkedIn, and Twitter, have been used to raise awareness about clinical trials [4–6]. Several dedicated Web sites such as Clinicaltrials.gov and the International Clinical Trials Registry Platform have played crucial roles in helping patients find out about clinical trials [7, 8]. However, social media platforms are now seen to be equally important in communicating research and encouraging patients to participate in clinical studies.

As is true with any new information technology, social media has presented early adopters with a number of possible benefits and challenges. Despite concerns voiced by some in the scientific community, research is steadily moving onto the Web and "into the cloud" (for a definition of cloud computing, see Appendix A). For example, clinical trials rely on human subjects for studies but often have difficulties recruiting enough patients [9]. According to Allison, "one-third of trials fail to recruit a single patient, and fewer than 20% of clinical trials are completed on time" [2]. Yet, it seems significant that patients using the Web are more likely than the general population to agree to participate in clinical research [2].

Due to the popularity of Facebook and consumer health Web sites such as PatientsLikeMe, the use of social media in clinical research should be closely evaluated. In 2011, at a Cochrane Collaboration workshop, the top six reasons for using social media in clinical research were: (*i*) to recruit patients for clinical trials, (*ii*) to encourage inter-professional communication and collaboration, (*iii*) to develop virtual patient interactions and training, (*iv*) to set up health advocacy groups, (*v*) to promote funding and fundraising opportunities, and (*vi*) to issue public health alerts [10]. Given the complexity of information ecosystems on the Web, the question is whether health librarians can play advisory roles for research teams who may be interested in using social media. As the relevant issues are discussed in this paper, keep in mind what parts of the discussion might directly apply to health librarians.

Health 2.0: the patient-centred Web

The use of social media in patient care is part of what some experts call Health 2.0, or the patient-centred Web. Health 2.0 can be defined as "...health care that employs social media and other Web-based tools to promote collaboration between patients, caregivers, medical professionals, and other stakeholders" [11]. Patient narratives co-created on the Web are at the heart of Health 2.0 and provide mechanisms for two-way interactivity between patients and providers. Unidirectional practices from a former era in health care seem to be relics of a paternalistic time. Now electronic patients, or e-patients as they are commonly called, are "actively engaged members of health-related social media networks who rely on social media for their health information" [12]. Online patient communities such as MediGuard and ClinicalResearch (for a list of e-patient communities, see Appendix B) are two excellent examples of social tools that promote the awareness of clinical trials and crowd-sourced information exchanges [2].

In any case, a number of concerns must be discussed before the tools can be used by clinical research coordinators [13]. Lack of ethical and regulatory frameworks for

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social media is a major concern in Canada and the United States. Scientists in government agencies such as the US Food and Drug Administration have been grappling with the potential impact of social media on patient privacy and confidentiality [13]. Some experts say Congress' work on new legislation will require issuing warnings about marketing products to patients via social media [14]. Other debates focus on third-party posts about drugs and medical devices and whether pharmaceutical companies can be held liable for patients' comments about off-label uses.

Prior to this revolution in two-way communication on social media, information was regularly presented to patients unilaterally by health providers [4]. Of course, this still exists in many hospitals and doctors' offices today. But with the social tools and information sources now available to patients, this approach to information dissemination is no longer viable. Health 2.0 patients want to move fluidly from interacting with others and sharing relevant information to locating high quality research at the click of a mouse. A critical component of Health 2.0 is the implied collaboration it introduces for doctors and their patients. After all, patients must learn to speak directly to physicians about their problems. Health 2.0 sites assist patients in learning how to talk to (and debate with) doctors [15] and in finding solutions to their problems in collaboration with others.

Other challenges may arise for patients using social media, and they must be dealt with. First, there is the real danger of information overload. The overwhelming amount of contradictory information online is a problem and a major health literacy challenge for consumers [16]. Not only is misinformation worrisome but patient anger at the system is often openly expressed. This is why some physicians are reluctant to engage with patients in conversations on social media without the usual filters that come with face-to-face communication. The need to speak freely and without filters, however, is why patients use social media. Seizing the enormous potential for patient empowerment, clinical trial recruitment firms want to talk directly to patients and have begun to ask patients directly for their participation in clinical trials [17].

As the world gradually moves online, researchers have taken steps to learn about the norms that apply in online patient communities [18]. Obviously, engaging patients online presents a few obvious dangers. Some drug companies are carefully monitoring patient activities online and are gauging whether or not they will participate in such an open environment [14]. In the United States, the Health Insurance Portability and Accountability Act stipulates, for example, that patient information must be "de-identified" before it is transmitted online [2]. However, how many patients truly understand the public nature of these Web sites? Will patients wrongly identify family members in conversations online? Who will monitor and correct this disclosure? In Canada, the Change Foundation in Toronto believes that the main stumbling block in the adoption of social media is the "lack of best practices that might enable organizations to be less risk-averse" [19]. Similar to their American counterparts, Canadian researchers have expressed their concerns about breaches of patient confidentiality in social media spaces as they currently are configured.

The power of social media

The power of social media to reach new global audiences is obvious. Facebook, the most popular social media platform in the world, has attracted more than one billion users, or about 1/7 of the global population [20]. According to at least one study, Facebook was shown to be the most efficient platform in recruiting patients for clinical trials [21]. Companies such as Johnson & Johnson and Pfizer have used YouTube and Facebook, respectively, to reach patients. Social media's reach and on-the-go portability make it very attractive to both researchers and drug companies. The advent of iPads and iPhones makes mass communication via smartphones much easier. However, at least one study suggests that regulators in the European Union are struggling with the global nature of clinical trials and the need to tighten regulations and international standards for the protection of the public and the research process itself [22].

Dozens of pharmaceutical companies are using social media to accelerate their recruitment strategies as most delays in conducting trials stem from recruitment [2]. Clinical trials in oncology also fail to meet their enrollment targets and some never enroll any patients. Some cancer-based LinkedIn groups bring together patients and their doctors and have even been used to find surgeons who will remove inoperable cancers. The Association of Clinical Research Organizations recently announced the launch of its YouTube channel "... to educate the public, media, and policymakers about clinical trials and the growing role of clinical research in drug development" [23]. The power of social media, while undeniable, requires judicious sharing of best practice. Health librarians are advised to share their ideas.

PatientsLikeMe – a 2.0 site with social reach

According to a 2012 study, "PatientsLikeMe (PLM) and 23andMe are the leading [web sites] of ... crowdsourced health research" [24]. What is PLM? PLM is a social-networking site that brings together "patients like me" from around the world; it has about 150 000 registered patients who are organized into 19 disease-specific communities [24, 25]. PLM's business model emphasizes openness and transparency; it is a private company that supports patient recruitment for clinical trials by providing members with a platform for invitations to active clinical trials.

The PLM Web site offers access to several online communities and categorizes patients into five domains: (*i*) amyotrophic lateral sclerosis, (*ii*) Parkinson's disease, (*iii*) HIV/AIDS, (*iv*) multiple sclerosis, and (*v*) mood disorders such as depression. PLM is upfront about its funding model and says it sells aggregated information from the use of its site to drug, device, and insurance companies. According to Sarasohn-Kahn, when "groups of people come together to aggregate opinions and data,

there will be a valuable data stream collected; the value of the data can then be monetized in a variety of ways'' [11].

Some of the patient data sources on PLM, such as symptoms and specific drugs as well as demographic information, are closely tracked. Patients share their stories, views on treatment, and the benefits and side effects of drugs and complementary therapies such as herbal medicine, massage, yoga, and so on. The site is indispensable for anyone needing information about rare conditions and for those wanting to speak to others. Patients are able to find other patients like them by searching the site for specific diseases, conditions, age groups, treatments, and symptoms.

Pfizer's clinical trial "in a box"

Pfizer, which calls itself the world's largest research-based pharmaceutical company, launched a new program in 2011 called "clinical-trial-in-a-box" [26]. The project was said to be the first randomized trial of its kind, allowing patients to participate completely from home. Regardless of geography or proximity to the researchers, patients were able to participate in a virtual trial through the use of a mobile phone [27]. Pfizer stated publicly on its blog, *ThinkScienceNow,* that it wants to "transform the role of the patient as a participant in clinical trials", and is committed to improving the experience for patients [28]. Pfizer hopes its approach to research will ultimately save patients' lives and save the industry time and money.

In early 2012, after so much press, Pfizer decided to discontinue its virtual trials project. Craig Lipset, Head of Clinical Innovation at Pfizer, said in a June 2012 blog post: "*I also want to clarify that [our withdrawal of the virtual trial] does not represent a failure for or withdrawal from the use of the Internet or social media for patient recruitment. We routinely use the Internet as a channel for recruitment in our studies and will continue to do so wherever it is appropriate. Recruitment strategies tend to be very study specific, and we will be working to refine such strategies specific to a virtual trial approach*" [29]. Despite the setback, Pfizer seems to be committed to engaging patients virtually, and to using social media more strategically in future projects.

Suggestions for the future

What lessons can health librarians learn from the Pfizer experience? First of all, one of the most important lessons is to think strategically before using social media [18]. Matching the features of a social media tool to the specifications of a project is important. Second, learn as much as you can about social media and participate in your local CHLA/ABSC chapter's projects. Before developing Health 2.0 strategies for your organization, think about how you might build trust and credibility with a community of e-patients [12]. Where possible, if you venture into Health 2.0, share your personal experiences and expertise with patients as much as possible. The frequency with which you engage should be timely and consistent. Some Health 2.0 Web sites include active

patient navigators who point patients to legitimate Web sites at the National Library of Medicine such as MedlinePlus and PubMed. Health librarians can provide similar referrals, including which libraries locally a patient might visit to find evidence-based information.

Pharmaceutical companies and researchers are advised to respect the private online spaces of patients. Although some companies are waiting to hear from regulatory agencies about social media, this shouldn't prevent them from creating their own in-house codes of conduct and policies [12]. E-patients are very savvy about commercial intrusion into their online lives and may resent some of the inevitable virtual arm-twisting [12]. According to at least one institutional review board (IRB), the number of negatives on social media surpasses the positives, so unless you want to challenge boundaries, try to remember not to make the following mistakes:

- Don't promise positive outcomes for any investigational drug or clinical trial.
- Don't communicate that any drug or product is safe or provides superior results.
- Don't say any medical device or product is approved by any regulatory body.
- Never promise free treatment or emphasize incentive payments.

As much as possible, in using Health 2.0 Web sites, try to use the spaces as information channels and help patients to understand their eligibility for and interest in clinical trials. Many IRBs in the United States do not have policies or guidance in place to resolve misunderstandings that occur online, so it may be prudent to hire a social media expert to help with planning. Keep in mind that once you create a social media presence and identity for a clinical trial, maintaining your accounts in good standing requires determination and a long-range plan.

Just like any library or information service, reference questions received over social media require a timely response. Many of the principles that health librarians apply to reference services also apply online to social media. In fact, there is no reason why health librarians can't stake a legitimate claim to being experts in social media; the tools and trends of the digital age are part of the information literacies we monitor, use, and teach. Finally, given the massive increase in the use of social networking tools in health care, more research is needed – and health librarians should participate. The real and anticipated benefits and potential risks of using social media should be evaluated, especially when our users are affected by them during the course of their research and provision of care.

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Appendix A

Cloud computing is a type of computing where software is accessed and stored out on the open Web "in the cloud", literally "out there in cyberspace"', instead of locally on desktop computers. Cloud computing usually involves common applications that are accessed from within a Web browser while the software and data are stored remotely.

Crowdsourcing in Health 2.0 refers to a distributed form of outsourcing the creation of knowledge. It can be used to refer to finding large groups of people who share similar interests, such as patients who use social media sites to share and create knowledge.

E-patients are health consumers who use the Internet regularly to gather information about medical conditions and/or illnesses and who uses social media to do so. An e-patient can also be defined as an "actively engaged member of health-related social media networks who relies on social media for health information..."

Health 2.0 is a more participatory, patient-centred model of healthcare. It emphasizes online (public or private) interactivity between consumers, health providers, and librarians on social networks and an ability to share medical information, patient data, and anecdote to improve health outcomes on a global scale.

Online (and virtual) health communities: There are many online, virtual health communities available to e-patients on the Web and via social media platforms such as Facebook, Twitter, and LinkedIn as well as via niche Web sites such as PatientsLikeMe and 23andme.

Social media engagement: The direct interaction with e-patients in online health communities is a form of social engagement. A form of social media engagement with patients is currently being pursued to locate participants for clinical trials.

Appendix B

Health 2.0 Web sites

Social media site	Mission	Comments	Successes
Army of Women (Love/Avon) http://www.armyofwomen.org/	Recruits healthy women of all ages and ethnicities, breast cancer survivors, and high risk women to participate in trials	Challenges scientific community to improve breast cancer research conducted on healthy women	In 2012, 300 000 women are registered. Several "calls to action" have been issued for breast cancer research
Clinical Connection http://clinicalconnection.com	325 000 members connect to clinical trials worldwide; facilitates patient recruitment for clinical trials	Online community includes blog, daily news, RSS feeds, e-mail updates, Facebook, and Twitter	Active discussion board and clinical trial recruitment service
Clinical Research http://www.clinicalresearch.com/	Biopharm company created ClinicalResearch.com to increase clinical trial awareness, understanding, and participation	Search for clinical trials near your city or community	Information features clinical trials, daily news, and easy navigation of content
Diabetic Connect http://www.diabeticconnect.com/	Online, caring community; diabetes experts share information and support	Ask an expert, follow friends, and get information about diabetes management including alternatives	50 000 registered users; recruited for trials; mobile apps
Emerging Med Navigator http://www.emergingmed.com/	Since 2000, patients search for cancer trials via patented search service	Patients create profiles used for eligibility in clinical trials in the United States and Canada; phone "Clinical Trial Specialists" for advice and support	Site guides approximately 170 000 patients through searches
MediGuard https://www.mediguard.org/	Since 2007, drug safety, recall, and monitoring service; collects feedback and shares reviews	Free medication alert service – allows patients to take active role in care	2.7 million users in United States, United Kingdom, France, Germany, Spain, and Australia
Inspire http://www.inspire.com/	Since 2005, a national patient organization with partners, patients, and advocacy groups to create online network. Includes clinical trial recruitment model	80 non-profit patient advocacy organizations as partners. Members are notified of trials.	120 000 members and 1 million posts. Community with ten times the number of members who meet inclusion criteria
PatientsLikeMe http://patientslikeme.com	A privately funded social networking site where patient communities share experiences and post experiences and health data; supports patient recruitment for clinical studies	Share medical histories; health records no identifying information; PLM sells information to drug, device, and insurance companies; buyers mine data	150 000 patients, registered with over 1000 conditions in 19 disease-specific communities

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Appendix B (*Continued*)

Social media site	Mission	Comments	Successes
Social Heart Study https://socialheartstudy.org/	A new social network based project and research study that recruits patients on the Internet	Aims to discover how social networks such as Facebook contribute to cardiovascular health; ways of preventing cardiovascular disease	Collaboration between two California university medical schools. Recruit target is one million.
Sermo http://www.sermo.com/	Since 2006, an exclusive community for physicians who post observations and questions arising in their practice	68 medical specialties discuss treatment options, network for expert advice; share opinions once credentials are verified	More than 125 000 physician members. Anonymity if you want it. American Medical Association endorsed Web site until 2009.
TrialX http://trialx.com/	Connects patients to clinical trials and develops innovative technologies and media to facilitate patient recruitment	Web-based platform that uses algorithms and social networks to help patients find clinical trials matching health conditions	17 000 + clinical trials approved by US Food and Drug Administration; 100 000 + trial searches; 15 000 + volunteers; 10 000 + connections made
23andme https://www.23andme.com/	Genetic testing for health, disease and ancestry DNA analysis system.	Discover your personal genetric profile; global origins, trace your ancestry, access 200 health traits reports, disease risks.	Testing done in certified lab; includes collection of educational materials to guide you on personal journey of genetic discovery

Source: Allison M. Can web 2.0 reboot clinical trials? *Nature Biotech*. 2009;27: 895–902.