

USING SOCIAL MEDIA TO IMPROVE HEALTHCARE QUALITY

A Guide to Current Practice and Future Promise

June 2011

PART 1

Introduction and Key Issues in the Current Landscape



innovation cell

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ABOUT THE CHANGE FOUNDATION

The Change Foundation is an independent policy think tank, intent on changing the health-care debate, health-care practice and the health-care experience in Ontario.

A charitable foundation established in 1996 and funded through an endowment, The Change Foundation leads and leverages research, policy analysis, quality improvement and strategic engagement to enable a more integrated health-care system in Ontario designed with individuals and caregivers top of mind.

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ABOUT THE HEALTH STRATEGY INNOVATION CELL

The Health Strategy Innovation Cell is a health policy think tank based at Massey College in Toronto. We test new business models for the delivery of excellent healthcare. We use Web analytics and build online tools to guide our consumer-focused solutions.

www.innovationcell.com

INTRODUCTION BY THE CHANGE FOUNDATION

In the fall of 2009, the Health Strategy Innovation Cell's CEO Neil Seeman and his Chief Imagineer Carlos Rizo brought us a unique proposition

to explore the potential of social media as a tool to advance a more responsive, patient-centred healthcare system in Ontario. Social media refers to collaborative and interactive online communication and community-building tools.

Though neophytes in social media, we recognized that the core question fit well with The Change Foundation's work: supporting the creation of a more integrated and innovative healthcare system responsive to the needs and lived realities of those it serves.

MORE AVAILABLE IN THE ETOOLKIT

COMING LATE JUNE 2011 AT INNOVATIONCELL.COM

- If you are new to social media, you can learn the basics from our *social media glossary*.
- If your organization is currently using social media, you can post information about what you're doing on our *editable online directory* and use the directory to connect with other Canadian healthcare organizations.
- To stay up to date and see what's trending in discussions about social media use in healthcare, visit the *What's Hot* and *Further Reading sections*. These dynamic tools will work like a real-time literature review on emerging issues and leading practices.
- Please contribute to this discussion and share your insights, experiences and feedback through the *Comments* section at the bottom of every page in the eToolkit.
- In the eToolkit we will offer the ability to discuss the content via Facebook and Twitter so that the eToolkit itself emerges as an example of *social media in action*.

The resulting project, *Using Social Media to Improve Healthcare Quality*, was a two-year collaboration (2009-2011) between The Change Foundation and the Innovation Cell, an independent think-tank based at Massey College in the University of Toronto. We decided to fund and partner on this endeavour, working closely with the Innovation Cell to mold and frame the objectives and principles of the project. We wanted to ask a meaningful and forward-looking question that aligned with emerging policy issues – the *Excellent Care for All Act*, for example, and the province's evolving quality improvement agenda – and we saw the opportunity to test the question in the field with provider partners. We wanted our findings to be practical, useful and transferable to other healthcare institutions in Ontario and beyond.

This guide is one of the products of our collaboration. Content for the guide was amassed and compiled by the Innovation Cell, with input and support from The Change Foundation.

WHAT WE LEARNED

Patients and caregivers are everywhere on social media channels. They are busy blogging, tweeting and building peer-to-peer communities on Facebook and other websites where they openly share and discuss their experiences with healthcare. But, compared to other sectors, healthcare organizations have been relatively slow to be comfortable with social media as a way to connect with patients. Although the use of social media in healthcare is growing by leaps and bounds – the dynamic directory created for this project shows that the number of Facebook, Twitter and YouTube accounts by Canadian healthcare organizations has quadrupled in the past year – few have begun to tap this rich reservoir of real-time, real-life stories to improve the delivery of care.

Why is healthcare a slow adopter?

- The main stumbling block is the lack of a set of accepted best practices that would enable organizations to become less risk-averse.
- Ethical questions are a major concern. Are we violating patients' privacy by listening in or soliciting comments online? Are we ignoring the people who don't participate in social media?

“Healthcare organizations in Canada are not yet taking advantage of social media for quality improvement purposes. This was an opportunity for us to explore whether social media could help organizations get information across a broad spectrum of patients that could help them redesign their care and whether there were any best practices around the world.”

Cathy Fooks, The Change Foundation

- Return-on-investment questions present another barrier. Should we devote scarce resources to explore this unmapped territory? What risks do we face if we embrace social media, and what if we don't? Will social media really help us reach the people we want to reach?
- Healthcare organizations are also concerned about practical questions. How ready are we to use social media? How should we use it most productively for our own goals, and what is the best way to start? What policies do we need to support this work and what level of the organization should approve them?

This guide and the eToolkit are designed to help organizations answer these questions.

ABOUT THE PROJECT'S PRODUCTS

The project had two phases, producing a two-part guide to current practice and future promise, and culminating in an online eToolkit that will be hosted by the Innovation Cell. The guide, provided for people who prefer to get information from a more traditional format, mirrors much of the content of the eToolkit, though there will be additional dynamic and interactive resources available in the online version. We encourage you to explore the eToolkit at innovationcell.com when it is released later in June.

PART 1

This is Part 1 of the guide, capturing the first phase of the project, in which the Innovation Cell undertook a series of systematic scans of the social media environment to understand how it intersects with healthcare, particularly in Canada. As a result of these scans, they are able to describe current leading practices, challenges, lessons, opportunities and limitations related to the use of social media in healthcare. Here they introduce the idea that healthcare organizations can use social media as a tool for quality improvement by tapping into the growing presence and power of online conversations. Through numerous examples from across North America – and by presenting the first open and user-editable Canadian directory of healthcare organizations using social media – Part 1 of the guide (like the forthcoming eToolkit) provides a snapshot of where we are now in this fast-changing world. It also explores important ethical issues, particularly around privacy and data control, that healthcare organizations must understand as they begin to navigate this new territory.

A FEW TECHNICAL NOTES

- **Social media is, by its nature, a dynamic environment. Information in this guide and in much of the soon-to-be released eToolkit is current as of December 2010 to June 2011, with the currency of different information marked accordingly. Some parts of the eToolkit are designed to be editable and are continually updated or can be updated by users.**
- **In our analyses, only data from open-access blogs were used, no personal identifiers were obtained, and no comments were actively solicited for the purposes of obtaining information about what clients thought about their experience of care at the two organizations that participated in our field explorations.**
- **We use the term “patients” throughout this guide and in the eToolkit, but we recognize that some healthcare organizations use “clients” to describe the people who receive their services. In our discussion of the field partnership with CAMH, we use “clients” as is the practice there.**
- **In this document, links without a reference number are definitional; if you are reading this online, you can explore the terms and background information provided through these links. Links with a reference number will take you directly to the source material (if you're reading online); for people reading this in hard copy, we've provided endnotes for these sources.**

PART 2

In the second phase, covered in Part 2 of the guide (“Two Case Examples and Imagining the Future”), the Innovation Cell undertook field explorations with two Toronto healthcare organizations to understand the frontline experience of providers, managers and executives as they begin to navigate these largely uncharted seas. Our field partners in this pioneering journey were Providence Healthcare and the Centre for Addiction and Mental Health (CAMH) – both teaching institutions affiliated with the University of Toronto – and they offer first-hand lessons that will be useful for all healthcare organizations grappling with similar issues as they explore how to harness the power of online dialogue and integrate social media within their own QI efforts.

Part 2 also imagines what the future might look like if and when healthcare organizations adopt social media to enrich their ongoing quality improvement processes. How will it change organizations themselves and how they interact with patients and caregivers? How will they measure the impact of these efforts? Finally, the Innovation Cell looks at the lessons of this project through the lens provided by Ross Baker’s book, *High-Performing Healthcare Systems: Delivering Quality by Design*, to offer advice on sustaining the value of social media as a tool for quality improvement.

ABOUT OUR FIELD PARTNERS

The Innovation Cell met with the field partners from February to November 2010. At the beginning of this project, CAMH was making moderate use of social media and the organization was interested in how these tools could inform quality improvement by focusing on improving bonds with its client community. At the same time, Providence Healthcare’s use of social media could be described as low and the organization was interested in how social media could inform its QI processes by becoming a tool to improve internal communications.

Please note that the field partners have not formally endorsed our reporting on this research or our recommendations to them on how they can advance their use of social media to meet their specific objectives. That being said, we are pleased to report that they have put their project learnings to good use. CAMH in particular has moved quickly to reflect and build on what they've gleaned during this timely experiment. They tell us that the project has augmented their understanding of the implications and opportunities that social media presents to healthcare organizations and that it has increased their capacity to make well-informed and strategic decisions about the uptake of social media.

ACKNOWLEDGEMENTS

The Change Foundation would like to acknowledge the Health Strategy Innovation Cell, in particular Neil Seeman and Carlos Rizo, for their knowledge, intelligent enthusiasm, and hard work in executing this dynamic project, for their engagement with our field partners, and for translating the language and lessons of a new terrain.

Those lessons were enriched by the participation of our field partners – Providence Healthcare and the Centre for Addiction and Mental Health. We would like to thank in particular former Providence Healthcare CEO Neil McEvoy and Director of Communications Beth Johnson and, from CAMH, Vice-President Susan Pigott, Robin Rowe, Director of Public Affairs, and Manuel Gittermann, Director of Operations, Policy, Education and Health Promotion. They and their teams embraced the project as probing and curious champions, using what they've learned to walk the talk and prudently pursue their commitment to use social media in new ways to advance patient-centred care.

And finally, we thank the members of the project's advisory board, the Ginger Council, who provided strategic advice based on their diverse expertise in healthcare, ethics, and social media. Their good guidance, expertise and engaging deliberations throughout the project stimulated our thinking and

helped us hone our project. Although we list them here with their affiliations at the time the Ginger Council was active, members participated as individuals and not as representatives of the organizations for which they work.

Melanie Barwick Associate Scientist and Director of Knowledge Translation in the Child Health Evaluative Sciences program of SickKids' Research Institute; Psychologist at The Hospital for Sick Children

Sonika Lal Policy Analyst, Health Care Access Strategy Unit, Health System Strategy Division, Ministry of Health and Long-Term Care (MOHLTC)

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Paula Blackstien-Hirsch Executive Director, Centre for Healthcare Quality Improvement at The Change Foundation

Marina Englesakis e-patient; Information Specialist, University Health Network

Rob Fraser Graduate nursing student, University of Toronto; founder, nursingideas.ca

John Sharp Manager of Research Informatics in Quantitative Health Sciences, The Cleveland Clinic

Tim Sturgill Director of Social Media and Staff Physician at Emergency Medicine Physicians (a U.S. medical services group)

Peter Szota Executive Director, Grand River Community Health Centre

Joe Peters Partner, Ascentum, Ottawa

Pat Campbell CEO, Echo: Improving Women's Health in Ontario

Joanna Zuk Senior Communications Officer, Association of Ontario Midwives

Quality improvement and social media: what's the link?

SUMMARY POINTS

- Research has documented the potential power of listening to patient and caregiver stories on open-access social media sites as an ethical way to complement the collection and reporting of information on patient and caregiver satisfaction.
- This is a new field of research without longitudinal studies; our working hypothesis is that using social media will support the quality improvement cycle at healthcare organizations.

LISTENING, IN OLD WAYS AND NEW

The importance of listening to the patient's story is a foundation of healthcare practice. For example, nurse practitioner programs have long emphasized the art of listening and the importance of patient narratives.¹ The medical profession has also long recognized the importance of listening to patient narratives to engender empathy, reflection, professionalism, and trust.^{2,3}

In [one study by National Research Corporation](#) in February 2011, 82.3% of U.S. residents surveyed who used social media trusted the information at a level

“ I think that social media is absolutely in the spirit of the Excellent Care for All legislation in Ontario and similar quality legislation emerging around the world. It can be very beneficial to take the pulse of what patients are saying about what they want and need at any given moment in time.”

Neil Seeman, Health Strategy Innovation Cell

of 3 or greater (on a scale of 1 to 5, with 5 being the highest), and 78.8% assigned a level of 3 or greater to the likelihood that social media would influence how they make their health care decisions.⁴ Given the rising influence of social media on individual healthcare decisions such as where to go for care and what services to seek out, social media is attracting the attention of researchers and policy-makers intrigued by its affordability, influence and reach. This real-time learning will potentially provide actionable insights into patients' and caregivers' needs and preferences across the continuum of care. Such stories may offer new knowledge to support health system integration and quality improvement for the delivery of care in home, community, acute and ambulatory care settings.

Online storytelling by patients and caregivers active on social media can complement traditional methods of capturing a range of perspectives on the quality of care (Figure 1). Healthcare organizations regularly seek to understand patient satisfaction in order to improve the quality of care. Increasingly sophisticated patient satisfaction surveys aim to engage the public and provide feedback to organizations about the quality of their care from the patient/caregiver perspective.⁵ It has been suggested that learning from patients by listening to their stories on social networking sites has the potential to lead to better understanding, among all stakeholders, about the richness and challenges of the patient experience.⁶

THE PROMISE OF QUALITY IMPROVEMENT (QI) THROUGH PATIENT-CENTRED CARE

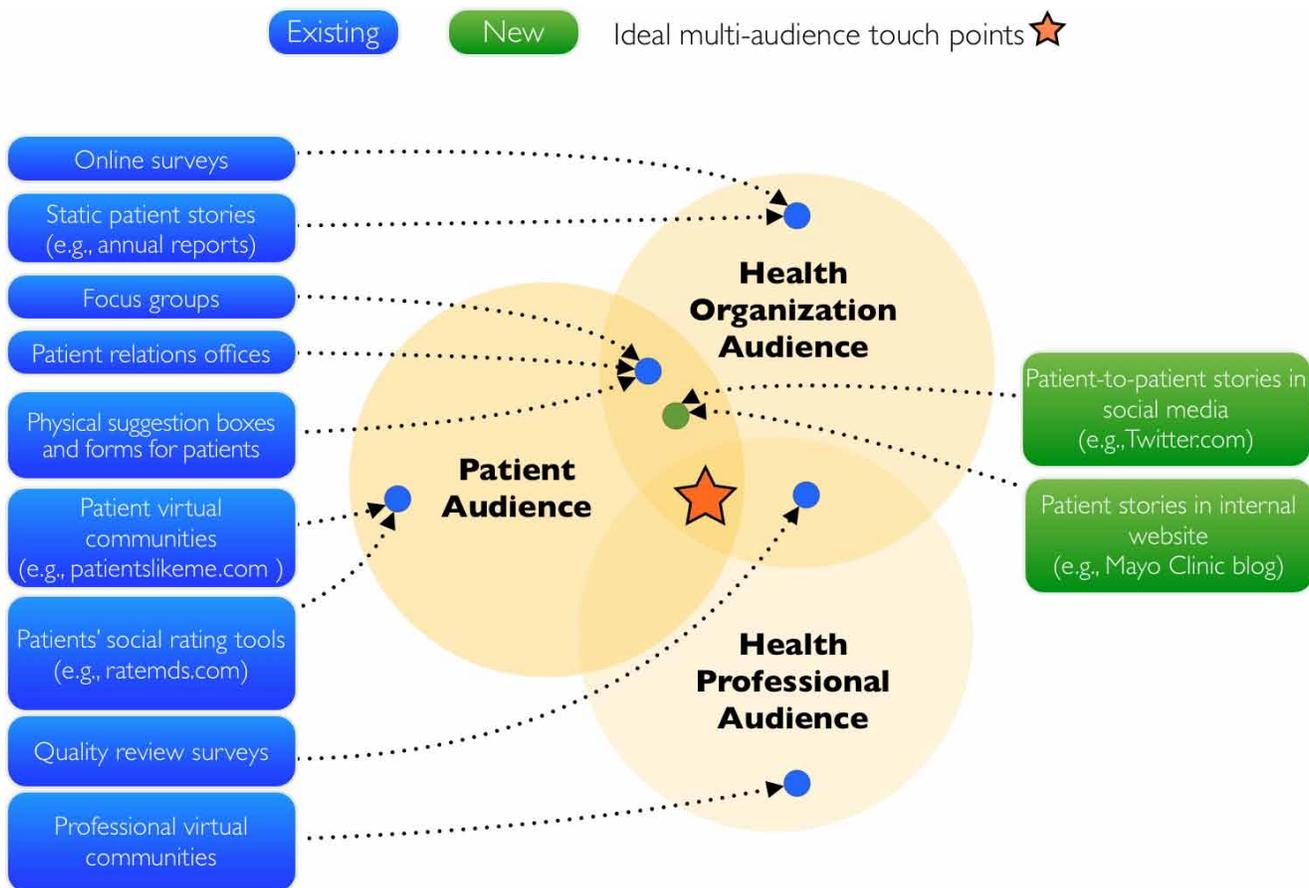
This guide starts from a belief in the importance of patient-centred care, which embraces two overarching principles: sharing power and connecting at an emotional level.⁷ Building from these principles, according to Moira Stewart and colleagues,⁸ are six core dimensions of patient-centred care: exploring disease and the patient's illness experience; understanding the whole person; finding common ground (problems, goals, roles) towards shared decision-making; incorporating prevention and health promotion; enhancing the patient-physician relationship; and being realistic. Quality improvement that results in more patient-centred care makes a demonstrably positive difference to the patient's health and experience of care and to the efficiency of care.

Given the extraordinarily rich and exponentially growing repositories of self-reported stories in social media from patients and caregivers describing their needs, wants, expectations and preferences, it is not difficult to conceive that learning from millions of these online conversations could support quality improvement in patient-centred care across its six dimensions. Scientific methods such as the plan-do-study-act (PDSA) methodology⁹ could be used to evaluate leading or emerging practices, just as these methods have been used to implement and test the effects of other new ideas to improve healthcare performance.

With the public reporting of healthcare performance data, performance information can affect the reputation of a healthcare provider or hospital. Positive performance results in professional pride and motivates quality improvement.¹⁰ Similarly, the public reporting of patient and caregiver stories using social media may provide even more immediate and sustained motivation for quality improvement, since social media offers opportunities for patients and caregivers to share their stories – and for healthcare organizations to respond – in real time.

The study of the human and motivational impact of social media is, like the rapid ascendance of social media itself, a very new field. Even newer is the thinking about how healthcare organizations can use social media to listen to and act on patients' experiences. It will be some time before long-term studies are available to confirm or refute our hypothesis that online conversations can enrich the quality improvement cycle. Meanwhile, we encourage you to explore this guide and consider how social media can become part of your QI toolbox.

FIGURE 1. ONLINE STORYTELLING CAN COMPLEMENT TRADITIONAL METHODS OF CAPTURING THE PATIENT/CAREGIVER EXPERIENCE



Source: Born, K., Rizo, C., Seeman, N. 2009. Participatory storytelling online: a complementary model of patient satisfaction. *Electronic Healthcare* 8(2): 71-75.

Emerging issues, activities and leading practices

SUMMARY POINTS

- **Social media is the topic of innumerable web-based resources. To make this guide useful, we developed and used Innovation Cell software that identifies trusted (i.e., most often shared) sources of information about using social media for quality improvement in healthcare.**
- **In the upcoming eToolkit, the What's Hot tab will dynamically update information from trusted sources, providing a "real-time literature review."**

SCANNING THE CURRENT LANDSCAPE

The Health Strategy Innovation Cell conducted a series of scans to outline emerging practices, current challenges, opportunities, and ethical, legal and privacy considerations in using information from online patient dialogue.

This section presents the results of five scans:

- 1) The general use of social media by healthcare organizations around the world
- 2) Open directory of Canadian healthcare organizations using social media
- 3) Patient engagement through social media: examining the Mayo Clinic
- 4) Reputation and social media
- 5) Privacy and ethical issues in social media

METHODOLOGY FOR THE WHAT'S HOT TAB IN THE ETOOLKIT

We launched a software tool to count and identify trends in how often references to social media use in healthcare were being shared on blogs and social media sites such as LinkedIn, YouTube, Facebook and Twitter. We wanted to identify which websites that talked about social media use in healthcare were the most viewed, read and shared online. We also wanted to track the most authoritative sources and the types of themes they contributed – themes such as fundraising, research, patient empowerment tools, news feeds, service advertisement, risk management, and quality improvement. This methodology has been [peer-reviewed](#).¹¹

We used standardized search strings to identify English-language websites that were discussing various uses of social media in the healthcare setting. Using a structured English-language algorithm, we were able to track, on a daily basis, which of these websites were rising in popularity (i.e., were being shared more frequently among Internet users).

1) The general use of social media by healthcare organizations around the world

SUMMARY POINTS

- **Healthcare organizations today use social media predominantly as a marketing and communications tool to improve their online image and visibility.**
- **Healthcare organizations are increasingly using social media for philanthropy, recruitment, customer service, patient support and knowledge translation.**

HOSPITALS ARE EARLY ADOPTERS AMONG HEALTHCARE ORGANIZATIONS

Compared to other types of healthcare institutions, hospitals are overwhelmingly early adopters of social media. Hospitals are at the front lines of patient care and therefore provide a hub for clinical services and the provision of information about healthcare quality.¹² Except for the notable exception of disease-related associations in the United States, non-hospital organizations taking up these new communication channels are, as of the time of writing, relatively few.

As in other sectors, those healthcare organizations that started using social media in their marketing and customer service activities did so to address the needs and concerns of their client populations. This has been particularly true in the United States, where private-sector facilities compete intensively for resources and positive media attention, but the non-profit and public sectors have also taken up the new communication channels. Some disease-related associations in the U.S. are heavy users of social media for the purposes of philanthropy campaigns and awareness building. As of March 2011, the American Cancer Society had more than 228,000 “likes” on its Facebook page, referring to the number of Facebook users who follow its updates. The Centers for Disease Control and Prevention had 82,000 likes on Facebook, and the American Diabetes Association had more than 72,000. Healthcare organizations in the U.S. have been quick to adopt social media and to find new and innovative uses for it.

Canadian healthcare organizations have lagged behind the U.S. in their uptake of social media. During our research phase, there appeared to be relatively few healthcare organizations outside the acute care setting that were using social media.

“Other organizations who have an interest in this area don’t need to reinvent the wheel, don’t need to start from scratch. They can learn from the experiences, processes, policies and procedures that other organizations have already taken into consideration.”

Melanie Barwick, The Hospital for Sick Children Research Institute

THE U.S. HOSPITAL SOCIAL NETWORK LIST

Ed Bennett, of the University of Maryland Medical System, tracks and reports on the use of social media by healthcare organizations in the U.S. [Hospitals and social media: a survey of best practices](#) is one of Bennett’s many slide [presentations](#) available on slideshare.net and provides a quick overview of the current landscape in the U.S.

Bennett’s [online tool, the Hospital Social Network List](#), is a reputable and trusted resource, documenting and regularly updating the thousands of social media channels being used in healthcare. (His website, at [ebennett.org](#), is titled “Found in Cache: Social media resource for health care professionals.”)

After identifying the trustworthiness and accuracy of Bennett’s list through our online aggregation tools described earlier, we secured his permission to supplement his table and to follow his template to compile the first open and editable directory of Canadian healthcare organizations using social media. (See Section 2, below.)

According to Bennett’s table, which we supplemented, there are (as of May 8, 2011) 965 health systems, healthcare organizations and centres in the United States responsible for 3,289 social media listings (486 YouTube channels, 777 Facebook pages, 714 Twitter accounts, 469 LinkedIn accounts, 723 foursquare accounts, and 120 blogs). These numbers, always in flux, represent official corporate-sponsored social networking sites. They do not include patient-generated or other externally created blogs or social media sites that may, for example, focus on a petition or complaint about a specific healthcare organization. There are other emerging web-based directories of healthcare organizations using social media for [Canada](#), [Europe](#), [Australia](#), and [Spain](#).

ONLINE COMMUNITIES FOR SOCIAL MEDIA IN HEALTHCARE

Conversations (so-called “tweet chats”) about social media in healthcare happen at scheduled times around the world on Twitter following the hashtags [#hcsmla](#) (USA), [#hcsmla](#) (Canada) [#hcsmla](#) (UK), [#hcsmla](#) (Latin America) and [#hcsmeu](#) (Europe). Tweet chats occur weekly – in Canada every Wednesday at 1 p.m. EST/EDT (three times/month) and the last Thursday of the month at 9 p.m. EST/EDT. An [open Google Docs](#) document serves as an archive of topics proposed by the community and all [transcripts of past chats are available](#) as well. Their six-month “[report card](#)” shows a vibrant community with more than 15,000 tweets with the [#hcsmla](#) hashtag and 1,005 unique Twitter users with at least one [#hcsmla](#) tweet.

SOCIAL MEDIA AS A MARKETING TOOL

In the U.S., healthcare organizations predominantly use social media as a marketing tool to increase their online visibility and to attract patients. A study of over 100 healthcare organizations by [Greystone.Net](#) found that only 12.5% of these organizations successfully attracted new patients by using social media.¹³ Cognizant of return-on-investment for their marketing and public relations efforts, private healthcare organizations are using social media to capture success stories for their annual reports and corporate websites. Organizations also report using social media to improve community relations (16.7%), customer service (8.7%), employee engagement (8.7%) and crisis management (4.5%). Notably, only 33% of organizations actively using social media have a formal social media policy, although the study did not report on whether such policies are board-approved or how the frequently they are updated.

NOT YET A BUDGET PRIORITY

The same study reports that in 70% of U.S. healthcare organizations using social media, the job of monitoring or “listening” to social media channels is handled on an ad hoc basis by a small number of staff – three or fewer people – typically in the organization’s website or marketing department. No information is provided on whether the data collected are used for QI purposes. [American Medical News](#) noted in March 2011 that many hospitals have abandoned their Facebook pages after initial enthusiasm.¹⁴ Summarizing a study by U.S. marketing company Verasoni which selected 120 hospitals at random, the newspaper reported that “fewer than 40% of hospitals posted content to their Facebook page on a daily basis, 25% posted twice a week and 25% posted once a month. Of the rest, three posted less than once a month and six had a presence but no activity. ... 83% of hospitals don’t solicit feedback from people who follow their Facebook feeds. And 97% don’t use Facebook’s discussion board.”

Budgeting for social media, including the hiring of dedicated employees to handle social media engagement, is relatively rare among U.S. healthcare organizations, the Greystone.Net survey shows. However, many respondents – as well as our own online colleagues, sources and contacts – have reported that this is likely to change in the near future.

According to dedicated “Health 2.0” discussion forums on [LinkedIn](#) (the professional networking site with more than 100 million registered users), healthcare organizations using social media frequently express interest in pooling marketing resources such as polling, identifying potential “influencers” online, and crafting coordinated marketing strategies for research and new products such as medical devices or mobile health applications.

CREATIVE USES FOR SOCIAL MEDIA IN HEALTHCARE:

EXAMPLES FROM THE U.S. AND CANADA

Fundraising: Fundraisers at healthcare organizations are charged with maintaining relationships with a wide array of stakeholders including patients, the public, government, donors and community organizations. Organizations around the world are already leveraging

social media to maintain these relationships and to create and sustain communities to support an organization’s growth. The many tools being used for fundraising include [mobile donating](#), where individuals can make donations via [SMS technology \(text messaging\)](#). For instance, the [Mobile Giving Foundation](#), which has been leading and enabling mobile giving in North America, reported in late February 2010 that [\\$41 million](#) had been raised through text messaging for Haiti following the [January 10, 2010, earthquake](#). In addition, blogs and broader social media campaigns provide new platforms for fundraising and community-building. Pediatric healthcare organizations and campaigns that have been early adopters of these tools include [BC Children’s Hospital Foundation](#), [BC Children’s Hospital Lottery](#), [Children’s Hospital Boston](#), [Wisconsin Children’s Hospital and Health System](#), and [SickKids Hospital Foundation](#) in Toronto.

Customer service and support: The [Sarasota Memorial Health Care System](#) is [using Twitter to answer patients’ questions](#) and to provide real-time customer service and support for patients and their families.¹⁵ This process could potentially feed directly into quality improvement activities.

News and information: News and information feeds are a long-time staple of social media. Social media allows for curated news feeds that elegantly group news items by client-filtered categories. For example, [All Children’s Hospital](#) in St. Petersburg, Florida, allows clients to keep up with hospital news including media references, new job positions, and key hospital events.

Patient education: Healthcare organizations are using social media to increase their capacity to reach patients and families with high-quality health information. At the [Henry Ford Healthcare System](#) in Detroit, physicians used Twitter to interact with more than 1,900 people and to [answer tweeted questions during actual brain surgery on a 47-year-old man](#). [Children’s Hospital Boston](#) launched “[Thrive](#),” the first health and science blog from a pediatric healthcare organization in the United States.

“ I hope these tools create the possibility for more dialogue between organizations, and I’d like to see healthcare providers and administrators start to use these tools the same way we’ve used medical devices – for patient education, for delivery of knowledge, for research, as a chance to engage, not just to do reputation management, fundraising and things like that.”

Rob Fraser, graduate nursing student

Advertise new services: Using YouTube, the [Nebraska Medical Center \(NMC\)](#) shared the experience of a patient who had surgery for a rare carcinoid cancer. This social media experiment generated many requests for the surgery, prompting NMC to open a monthly clinic for the condition.

Research and knowledge translation: Healthcare researchers want to see pioneering discoveries translated into bedside care – and to measure the impact of changes in practice. Hospital-based scientists and healthcare professionals are already [studying, and considering together](#), how social media can best be used to facilitate knowledge translation to improve patient care.¹⁶ For example, the U.S. [Agency for Healthcare Research and Quality](#) funds a number of [initiatives](#) that use social media tools for knowledge translation, dissemination and exchange.

Research is also underway to understand how social media could facilitate the dynamic processes of knowledge synthesis, dissemination and exchange. The Centre for Addiction and Mental Health (CAMH) in Toronto is testing new strategies for knowledge translation and practice change via Twitter, learning from existing strategies in other sectors. Other healthcare organizations are demonstrating how social media can provide researchers with real-time feedback, enabling rapid dissemination and discussion of research through blogs or Facebook. The story of Dave Meslin and his [“A note about suicide \(not a suicide note\)”](#) [blog post](#) generated real-time conversations and an open, collaborative space to share and disseminate information about mental health and suicide. Visitors simply linked, posted and responded to content.

The most-cited example of dynamic research using social media has been the so-called “ALS-lithium experiment” on [patientslikeme.com](#). Findings of a [May 2011 study published in the journal Nature Biotechnology](#) on the use of lithium in patients with the neurodegenerative disease ALS were generated from a trial conducted on the website.¹⁷ The findings, based on data contributed by over 500 members of this health information sharing website, contradicted an earlier study that suggested lithium could slow the progression of ALS.

Strategic hiring: There is a growing recognition among healthcare providers and marketing professionals that passionate fans or critics who rise to prominence through social media are strategic hires for the organizations they are applauding or critiquing. Such people can help nurture a good reputation (or rebuild a flailing one), becoming part of an internal team of social media communications professionals.

LINKING IN

Healthcare organizations with an active social media presence – such as those with organizationally sponsored, supported, or governed Facebook or Twitter accounts – are connecting with patients, clients and other stakeholders and sharing their experiences online and at speaking events and colloquia. Our structured scan reveals that healthcare organizations with a presence on LinkedIn are becoming more sophisticated in their social media usage; they are building a significant patient channel by leveraging one or more blogs, Twitter and Facebook.

2) Open directory of Canadian healthcare organizations using social media

SUMMARY POINTS

- We employed multiple scans and methodologies to identify Canadian healthcare organizations actively using social media.
- Cognizant that this information will change frequently as the number of organizations using social media grows, we compiled an open and editable directory.
- Readers are encouraged to help us keep the directory accurate and current by editing it online on behalf of their organizations.

PIONEERING EFFORTS

Following the example of Ed Bennett in the U.S., Ann Fuller, Director of Communications for the Children's Hospital of Eastern Ontario (CHEO), started a website called Social Media in Canadian Healthcare (SMiCH.ca) in November 2010 to curate a hospital social networking list for Canada. As of May 2011, 261 Canadian hospitals are represented in the SMiCH list, with 91 Facebook pages, 57 Twitter accounts, and 48 YouTube channels.

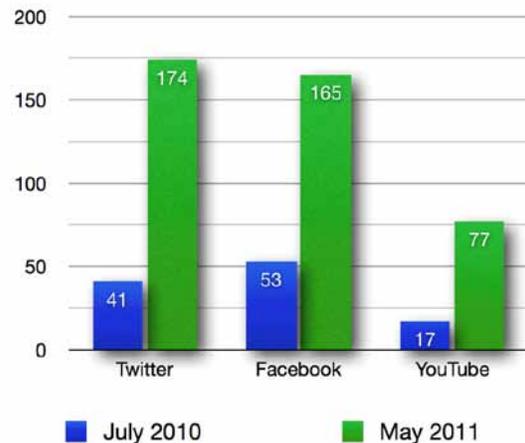
ABOUT THE OPEN DIRECTORY

We have witnessed the fast pace in which healthcare organizations have embraced social media and how quickly information can become out of date. With this in mind, we created the first open and editable directory of its kind in Canada, intended to complement existing efforts and dynamically capture all Canadian healthcare delivery organizations that are actively using social media. Like SMiCH, the list contains the name of the organization, province, website address, and Twitter, Facebook, YouTube and blog pages. Using a simple methodology and custom software (details below) we are also able to include statistics on the number of people following a Twitter account, the number of times a Twitter account is listed by other people on Twitter, the number of "likes" and "check-ins" received by a Facebook account.

When the directory was initially compiled in July 2010, it listed 111 social media accounts being used by Canadian healthcare organizations. Just 10 months later, the listing had already grown to 416 accounts (Figure 2), and we expect the numbers to keep growing.

FIGURE 2. GROWTH OF SOCIAL MEDIA IN CANADIAN HEALTHCARE

Number of Social Media Accounts in Canadian Healthcare



EDIT THE DIRECTORY

The directory is designed to be open and dynamic because the use of social media in healthcare is changing daily. We encourage readers to visit the [editable version](#) (accessible via Google Docs) and update or add information about your organization's social media presence. Editing the directory will be easy to do, like editing an Excel spreadsheet, and will not require that you have a Google Gmail account (Figure 3).

METHODOLOGY

To create the directory of Canadian healthcare organizations and their social media presence, we conducted three systematic searches (manual, semi-automated and fully automated) using consistent strings (keywords and language strings) and inclusion criteria.

1. MANUAL SCAN

- Using the search option available on social media sites (e.g., search.twitter.com), we used keywords such as “Canada” OR “Canadian” AND “hospital” OR “hospitals”. We also considered lists compiled by others on the Twitter website, and the Twitter followers of healthcare organizations already using social media.
- Using a list of Canadian academic health science centres found online (www.csci-scrs.org/english/teachinghosplist.htm), we manually searched for each organization on Facebook, Twitter and YouTube.

2. SEMI-AUTOMATED

- We obtained a list of Canadian healthcare organizations by province from the web (http://en.wikipedia.org/wiki/Category:Teaching_healthcare_organizations_in_Canada).
- All of these centres were cross-referenced with the word “Twitter”, “Facebook”, “YouTube” and the names of the social media sites of Canadian healthcare organizations identified in the manual scan.
- We plugged the healthcare organization names into an analytical software tool from Sysomos (a Toronto-based social media analytics company) that tracks active social

media use and combined the manual and semi-automated search strings. This resulted in a second, more comprehensive list.

3. FULLY AUTOMATED

- We obtained a list of all healthcare organizations in Canada from the website hospitalsworldwide.com and merged this information with previous lists to obtain a comprehensive list of organizations and their website home page addresses.
- Each organization’s home page URL was scanned by a software “robot” for visible display of social media use (e.g., a link to a Facebook page).
- To ensure accuracy, the results of the automated scan were reviewed manually and a final list was created. Organizations with a social media link were classified as one of the following: Agencies, Associations, Community Provider, Foundation, Government, Health Region, Healthcare Organization, Long-Term Care, Private Provider, Public Health, and Social Service Agency.

FIGURE 3. THE FIRST OPEN AND EDITABLE CANADIAN DIRECTORY OF SOCIAL MEDIA IN HEALTHCARE – AVAILABLE IN THE ETOOLKIT

	A	E	F	G	H	I	J
1	Organization	Website URL	Twitter URL	Twitter updates	Twitter followers	Twitter followers	Twitter lists
31	Sunnybrook Health Sciences Centre	http://www.sunnybrook.ca/	http://twitter.com	1484	3415	3860	239
32	Baycrest Centre for Geriatric Care	http://www.baycrest.org/	http://twitter.com	373	181	482	33
33	Toronto Rehab	http://www.torontorehab.com/	http://twitter.com	425	674	891	56
34	Toronto General Hospital	http://www.uhn.ca/applications/TGH/	http://www.twitter.com	555	211	922	50
35	Princess Margaret Hospital	http://www.uhn.ca/applications/PMH/	http://twitter.com	386	423	1077	98
36	Alberta Children's Hospital Foundation	http://www.childrenshospital.ab.ca/					
37	Centre for Addiction & Mental Health	http://www.camh.net/	http://twitter.com	718	1127	1762	157
38	Canadian Medical Association	http://www.cma.ca/	http://twitter.com	753	1359	1948	132
39	Credit Valley Hospital	http://www.cvh.on.ca/					
40	Dartmouth General Hospital	http://www.cdha.nshealth.ca/default.aspx	http://twitter.com	978	667	1061	67
41	L'Hopital Sainte-Justine (CHU mere-enfant)	http://www.chu-sainte-justine.org/Hon					
42	Grand River Hospital	http://www.grandriverhospital.on.ca/	http://twitter.com	34	14	108	4
43	Chedoke Hospital	http://www.hamiltonhealthsciences.ca/	http://twitter.com	205	169	483	29
44	Henderson General Hospital	http://www.hamiltonhealthsciences.ca/	http://twitter.com	205	169	483	29
45	Juravinski Cancer Centre	http://www.hamiltonhealthsciences.ca/	http://twitter.com	205	169	483	29
46	St. Peter's Hospital	http://www.hhsc.ca/body.cfm?id=157	http://twitter.com	205	169	483	29
47	Hamilton General Hospital	http://www.hamiltonhealthsciences.ca/	http://twitter.com	205	169	483	29
48	McMaster Children's Hospital	http://www.mcmasterchildrenshospital.ca/	http://twitter.com	205	169	483	29
49	Holy Family Hospital	http://www.providencehealthcare.org/					

3) Patient engagement through social media: examining the Mayo Clinic

SUMMARY POINTS

- The Mayo Clinic is a leader in experimenting with various social media tools to empower, educate and engage patients and staff.
- However, as of the time of writing, it is not evident that Mayo uses the online content provided by patients and caregivers to influence the organization's quality improvement cycle in a formal and sustained manner.

PATIENTS ARE ALREADY ONLINE

Patients are going online to seek information, select treatments and providers, share opinions and connect with other patients. In Canada, patients cluster in online communities such as [Patients Like Me \(patientslikeme.com\)](http://patientslikeme.com), a disease-community site where patients can share data in private forums; [Diabetes Mine \(diabetesmine.com\)](http://diabetesmine.com), a popular site for diabetes patients and caregivers; and [I'm Too Young For This! \(stupidcancer.com\)](http://stupidcancer.com), a forum for young adult cancer patients and survivors. Through other sites, Canadian patients are advocating better access to their health information ([Patient Destiny](http://PatientDestiny.com)) and a stronger voice in system reform ([the Patients' Association of Canada](http://thePatientsAssociationofCanada.com)) so that patients can be equal partners in their own care.

Clearly, patients, especially those suffering from chronic illness, want to share their ideas and experiences. How are healthcare organizations using social media to learn in real time what people are talking about online, and are they tying the learnings to quality improvement? This section looks at activities in a leading organization in the U.S.

THE MAYO CLINIC: A BREAK-OUT LEADER

Our structured scan indicated that a break-out leader in using social media for patient engagement and outreach is the Minnesota-based Mayo Clinic. Since it began [podcasting](#) in 2005, the Mayo Clinic has been proactive

in using social media tools to share in-depth medical information, interact with the public, and gather communities of employees, patients and their families.

We consider the Mayo Clinic's use of social media emblematic of current leading practice; it is regarded as such by e-patients (people who actively find, share and discuss information about their personal health conditions in online communities). However, based on our observation of Mayo's online presence and on our key informant interviews, it appears that even this groundbreaking organization has not explicitly linked social media to quality improvement efforts.

Below is a sample of the Mayo Clinic's pioneering efforts that other organizations may find worth considering:

- **Mayo Clinic Center for Social Media:** In July 2010, the Mayo Clinic announced the launch of the [Mayo Clinic Center for Social Media](#), a novel resource which aims to improve the adoption of social media tools by hospitals, medical professionals and patients. The site includes a blog, resources for people seeking to use social media in healthcare, consulting and coaching in social media, and training opportunities for individuals and organizations interested in adopting social media tools in healthcare.
- **Podcast:** Patients can visit the [Mayo Clinic Podcast Blog](#) to learn about [Mayo Clinic Medical Edge Video stories](#) and hear extended interviews with Mayo Clinic physicians. Patients can subscribe to have a particular category of podcasts sent to them automatically, or they can browse categories and search for specific topics. Usage patterns for services like this can help inform QI processes and priorities: by taking notice of which stories and podcasts are highly requested, healthcare organizations can gain insight into the specific kinds of information for which patients and caregivers are looking.

“A lot of the time, we want quality to be defined by the experts, but what we’re hearing from women across the province is that they have important perspectives on what quality means to them, and that’s a little different from how the experts define quality.”

Pat Campbell, Echo: Improving Women’s Health in Ontario

- **Mayo Clinic News blog:** Patients can visit the [Mayo Clinic News blog](#) for in-depth information on recent medical and scientific research and other breaking news about the organization. For example, patients can read about current [research](#) that may help predict future cardiac events, such as a heart attack, and can see an extended interview with the Mayo Clinic cardiologist who led an important study that has just been published. These interviews not only help patients and caregivers, but also assist health and science journalists (many with their own active social media profiles) to better understand the research underway at Mayo.
- **Sharing Mayo Clinic blog:** Mayo Clinic patients and their families, as well as Mayo employees, can access this blog ([sharing.mayoclinic.org](#)) to gather and share their stories. [Instructions on how to participate](#) and comment are freely available.
- **Facebook:** People can also [become a Mayo Clinic fan on Facebook](#).^{*} The Mayo Clinic’s Facebook page aggregates some of the items mentioned above and serves as another channel for people to share their Mayo stories. Again, these narratives can potentially feed into the QI process but are not currently used this way in a formalized manner.
- **YouTube:** At the [Mayo Clinic YouTube Channel](#), patients can see video of [patient stories](#), latest [research news](#), [Mayo Clinic Medical Edge stories](#), and other stories about the work of the organization.^{**}
- **Really Simple Syndication (RSS) Feeds:** Patients can also subscribe to a service that sends notice of the newest posts on Mayo Clinic’s various blogs and podcasts automatically to their email address.
- **Website:** [MayoClinic.com](#) hosts specialized blogs for discussions related to [Alzheimer’s disease](#), [diabetes](#), [depression](#), [food and nutrition](#), [quitting smoking](#), [pregnancy](#), [stress management](#) and several other topics.
- **Twitter:** Patients can follow the [Mayo Clinic on Twitter](#). To help people get started, Mayo has prepared an [effective Twitter introduction kit](#). Once patients have opted to follow the Mayo Clinic, they can reply (@mayoclinic) to one of the tweets and start a dynamic conversation with other Mayo followers. Twitter can be a source of online community for patients and a way to keep up with information from the Mayo Clinic.^{***}
- **CarePages:** Patients and family members can send and receive messages through their own password-protected pages on the Mayo Clinic’s [CarePages](#) website ([carepages.com/mayoclinic](#)) to efficiently keep in touch with family and friends during a patient hospitalization.

Each of these resources has a defined purpose and audience. The Mayo Clinic expects to support all of them and to continue to experiment with new technologies to engage with the public. At this stage, however, it is not evident that Mayo uses the content provided by patients and caregivers on these sites to influence the organization’s quality improvement cycle in a formal manner. For example, there is not a formal system by which patient stories can define a performance indicator (e.g. patient satisfaction) which then, in turn, could define a clear thematic priority for improvement (e.g. access to improved nutritional services for patients).

* Mayo Clinic had 48,760 Facebook fans as of May 18, 2011.

** Mayo Clinic’s YouTube channel had 3,260 subscribers and more than 4 million views as of May 18, 2011.

*** Mayo Clinic had 167,736 Twitter followers as of May 18, 2011.

4) Reputation and social media

SUMMARY POINTS

- **Monitoring social media for issues important to your patients and community is good practice not only for reputational risk management but, more importantly, as a potential source of ideas to improve services and an opportunity to measure public sentiment as part of a QI process.**
- **A QI culture that moves beyond simply monitoring social media – and actively listens, acts on patients' ideas and concerns, and communicates back to the public on actions taken – can build or reinforce a positive reputation.**

ACCOUNTABILITY 2.0

For large corporations, assessing the perceptions and concerns of stakeholders is a significant issue. It was the highest-ranked challenge for respondents in a [March 2009 study led by The Conference Board](#) in the U.S.¹⁸ The global report showed that 82% of companies surveyed are making efforts to manage reputational risk and, in so doing, they are investing more resources in online practices. The public wants to know what businesses and services are doing (in the for-profit and non-profit sectors alike), and the public expects to have a say.

Likewise in healthcare, where we heard from our conversations that reputation is an important asset that can either sustain or undermine efforts to improve quality of care. Healthcare organizations – frequently in the public eye through virally disseminated online media reports – are more exposed to reputational risk today than ever before.

Social media tools are strongly supporting and enabling this trend toward [“accountability 2.0.”](#)¹⁹ Tools such as Twitter, Facebook, Yelp and YouTube spread and mobilize information more rapidly and effectively than has ever been possible before. “Blogstorms” – where information gets passed online among existing and potential clients quickly and virally – can significantly

damage the public's trust in an organization. (Examples include recent product and service controversies around [Dell computers](#) and [Toyota recalls](#).) This observation prompted a prominent medical blogger, Dr. Kevin Pho, to observe that “it's important that medical institutions respond quickly and decisively to potential falsehoods spread on Facebook and Twitter. What used to take days to germinate, now spreads in a matter of hours.”

At the same time, there is evidence that being visible online can increase an organization's credibility and help to build public trust. More than half of patients 25–34 years old report being positively influenced if healthcare organizations have an active social media presence. According to a [Greystone.Net](#) report, this positive perception was particularly pronounced among young women selecting where they would go for maternity care.²⁰

BUILDING A “TRUST SENTIMENT” INDICATOR

“Sentiment analysis” is the monitoring of social media to determine whether an organization's online reputation is positive, neutral or negative. Many corporations across myriad sectors are starting to aggressively monitor social media for the purposes of sentiment analytics, although the number of healthcare organizations using this approach is still relatively low.

As patients and caregivers go online to share opinions about the quality of their healthcare experiences, their sentiments may affect the trust that others invest in a particular organization. In healthcare, monitoring social media for issues important to your patients and community is good practice not only for reputational risk management. More importantly, it can be an opportunity to measure public sentiment by building a “trust sentiment” indicator at the organizational or even unit level.

In this way, a QI culture that moves beyond simply monitoring social media – but rather actively listens, acts on patients' ideas and concerns about their healthcare experiences, and communicates back to the public on actions taken – can build or reinforce a positive reputation.

5) Privacy and ethical issues in social media

SUMMARY POINTS

- The spirit of current workplace legislation in many jurisdictions suggests that healthcare organizations may have an assumed legal responsibility to give employees reasonable, incidental access to social media sites while at work.
- As a practical matter, blocking access to social media sites means blocking access to the World Wide Web, which is increasingly “social” in all aspects.
- The risk of not having a social media presence is far greater than avoiding it and it is a duty of healthcare boards to mitigate reputational risk in a sustained and proactive manner.
- The widespread use of social media has upset traditional notions of privacy, but privacy principles still apply. For users of social media, privacy means the ability to control their data in a manner that respects the dignity and autonomy of the user.
- Prominent social media sites are increasingly working to ensure that their rules and policies prevent third-party access to people’s postings or web browsing history in any way that would violate protection of an individual’s identifying information.
- Healthcare organizations should consider it responsible practice to publicly advise patients, caregivers and staff how data posted on organizational and third-party social media sites may be used by the organization for quality improvement or other purposes.
- Any use of postings from social media sites for healthcare branding or quality improvement in healthcare should follow accepted practice for ethics in research and reporting. For example, online stories from patients, caregivers or staff should be anonymized unless the organization has obtained consent from the individual who has posted the material. The use of anonymized, aggregated data from patients’ social media postings should be handled like anonymized patient data from health records or surveys.

PRIVACY, CONFIDENTIALITY AND PATIENT AUTONOMY

With the inexorable growth of social networking in healthcare, questions arise about privacy, confidentiality and control of patients’ data, and related ethical concerns. These issues are closely linked to autonomy (the capacity of individuals to make informed, un-coerced decisions for themselves), a fundamental ethical principle in healthcare and a value consonant with the Canadian Charter of Rights and Freedoms.

The risk that healthcare workers might inadvertently disseminate sensitive proprietary patient data existed prior to social media. With social media, however, the potential for viral spread of private information following a breach poses much greater risk to patients. For example, a healthcare worker who saves patient data to his or her home computer, and then accesses social networks, can potentially leak private information to a peer-to-peer network, such as one used to share music online.

Without a clear understanding of privacy in the context of social media, healthcare organizations can put at risk both patient autonomy and the therapeutic relationship of trust, which depends on maintaining confidentiality. Patient autonomy and dignity depend on privacy, including the patient’s ability to control the collection, use and disclosure of personal information. People need to know: How will my information be used, and will those purposes violate my autonomy? Will my intimate choices and personal goals (e.g., wishing to pursue complementary alternative treatments, manage my weight more responsibly, adopt a child), relationships (e.g., with friends, family, employers, teachers), or existing commitments (e.g., retaining employment, education, housing, being a parent) be exposed to a third party?

These issues are already affecting organizational decisions, and not necessarily in ways that would support the use of social media for quality improvement. Privacy concerns and, more specifically, corporate *perceptions* over potential privacy concerns have led some organizations to block access from institutional networks to major social media sites including Facebook, Myspace, Yammer, LinkedIn, foursquare, Jumo, Ning, WordPress, Flickr, Meetup, YouTube, MapQuest, Qwiki, StumbleUpon and Twitter.

“ We have to recognize that people have data about themselves out on the Internet, and these data can be mined, and are being mined, by various organizations. The issue that people and organizations have to understand is how can we best ensure very rigid data control stipulations?”

Neil Seeman, Health Strategy Innovation Cell

STRATEGIES TO CONSIDER

What do healthcare organizations need to know to use social media responsibly and ethically? This section discusses the following issues and related strategies to consider:

- Do not block access to social media.
- Understand the “privacy payoff.”
- Keep current on legal developments and leading practices in privacy and data control.
- Learn from other sectors and resources.
- Develop a policy for employee use of social media, and take it to your board.
- Be aware of the ethics of “listening technology.”

As in our other scans, we employed structured, [peer-reviewed](#) aggregation techniques²¹ to identify the most current, trusted information on the topics of privacy and related regulatory issues in the context of social media. We used keyword strings and analyzed links shared among trusted users (“influencers”) in online discussions of these topics on LinkedIn and blogs. Like the links throughout this guide, hyperlinked content in this section represents the “wisdom of the informed crowd” – information that health-focused online communities consider most useful and relevant to Canadian healthcare.

Do not block access to social media SPIRIT OF EXISTING LAW DOES NOT SUPPORT POLICIES THAT SEEK TO KEEP EMPLOYEES FROM GOING ONLINE AT WORK

According to our review of the most trusted online literature, corporate decisions to block access to social media are often based on concerns that employees may use these sites to comment on hospital business,

which may violate the organization’s policies on electronic communications. Concerns are also raised that the use of social media in healthcare settings may contravene privacy regulations, such as the *Health Insurance Portability and Accountability Act (HIPAA)* in the United States or the *Personal Information Protection and Electronic Documents Act (PIPEDA)* in Canada.

In the hierarchy of information guiding organizational policy, sources should be considered in the following order: the Constitution, any governing statute, Canadian case law (judicial interpretations of governing statutes), high-level case law from similar jurisdictions, guidelines or pronouncements from privacy commissioners or regulatory authorities, organizational by-laws, and best evidence from scholarly articles and grey literature (i.e., reports and other non-peer-reviewed sources). In the absence of all of these sources, “emerging best practices” should define the reasonable standard of care for a healthcare board, whose policy on social media privacy should reflect a subjective standard of care – the diligence reasonably expected of directors based on their knowledge and experience.²² Since knowledge and experience on issues of social media vary widely on healthcare boards, it is therefore important to look for guidance where possible from the other sources listed above.

At the time of writing, no case law yet exists in Canada specifically dealing with these issues. However, under judicial interpretations of the [Charter of Rights and Freedoms](#), healthcare employees in publicly funded hospitals would have clear constitutional challenges available to fight the blocking of social media sites, as hospitals have been deemed subject to the Charter

by the Supreme Court of Canada in the landmark 1997 case of [Eldridge v. British Columbia \(Attorney General\)](#).²³ It is important to note that [provincial labour laws](#)²⁴ and standard bargaining unit rights give employees implied rights to communicate with virtual friends online during breaks, providing communication does not disrupt normal work routine.

BURDEN OF EVIDENCE FALLS ON THE BOARD

As a practical matter, blocking access to social media sites means blocking access to the World Wide Web, which is increasingly “social” in all aspects. For example, sites used every day for information retrieval such as MapQuest and Google are, in fact, social media. So are the free, highly secure, sharing applications such as Google Docs. Search engines, including Google and Yahoo, and the new generation of search engines (notably Qwiki) gather and organize information based on personal and filtered social preferences – i.e., based on the user’s previous searches and circle of online friends.

The burden of evidence for an organizational policy that blocks access to social media falls heavily on the board, and should be informed by the benefits of – and opportunities for – patient and caregiver outreach.

Understand the “privacy payoff”

HEALTHCARE ORGANIZATIONS CAN BALANCE INTERESTS AND MITIGATE RISKS TO ENABLE THE USE OF SOCIAL MEDIA

In considering ethical issues in the use of social media for quality improvement, healthcare organizations can be guided by what Ontario’s Information and Privacy Commissioner, Ann Cavoukian, and her co-author Tyler Hamilton have called the “privacy payoff.”²⁵ This perspective acknowledges that privacy should not be considered an “either-or” issue; instead, it should be viewed through the lens of corporate pragmatism, with a focus on how best to balance important interests.

A legal right to privacy in Canada is not codified in our Constitution, but criminal case law has confirmed that Section 8 of the *Charter of Rights and Freedoms* (which protects the right “to be secure against unreasonable search or seizure”) gives Canadians the reasonable

expectation of privacy. In addition – because the legal language around privacy predates the widespread uptake of social media – it is important that organizational policies explicitly extend privacy protections to the concept of “data control,” meaning that every user of social media has the right to control what happens with his or her personal information posted in online communities.

A BUSINESS CASE FOR PROTECTING PRIVACY

The business case for privacy, as Cavoukian describes it, is particularly apt in the context of social media.

As the Commissioner makes clear in her book, [Privacy by Design...Take the Challenge](#),²⁶ the business case for privacy depends on three principles:

- “Consumer trust drives successful [customer relationship management](#) (CRM) and lifetime value... in other words, revenues.”
- “Broken trust will result in a loss of market share, loss of revenue and lower stock value.”
- “Consumer trust hinges critically on the strength and credibility of an organization’s data privacy policies and practices.”

Despite their business-oriented language, these principles can serve as touchstones for healthcare organizations in designing data control and privacy policies related to social media use. For healthcare organizations, “consumer trust” affects much more than market share, as it encompasses ethical considerations involving patients and caregivers. A “lower stock value” in healthcare means a lower level of trust invested by key stakeholders that healthcare organizations need to work with beyond their staff (e.g., family physicians, community workers, researchers, nurses and volunteers). “Broken trust” can rupture the quality and continuity of care experienced by a patient.

As Cavoukian and Hamilton observe, a lack of attention to privacy (and, we would add, data control) can have negative consequences including:

- harm to clients or customers whose personal data are used or disclosed inappropriately;
- damage to an organization’s reputation or brand;

- financial losses due to a loss of business or delay in the implementation of a new product or service due to privacy concerns;
- loss of market share or a drop in stock prices following negative publicity;
- violations of privacy laws; and
- diminished confidence and trust in the industry.

A MATTER OF GOOD CORPORATE GOVERNANCE

Our scans suggest that a careful balancing of interests can allow healthcare organizations to benefit from engaging in social media, while mitigating these risks. Finding the right balance in the new world of social media is a board-level decision, as it is a matter of good corporate governance.

Consider, for example, whether a corporate policy that shuts down access to electronic communication may present more reputational and governance problems than a policy that enables an online presence for the organization. It may appear that a privacy or ethical breach (such as posting a patient's health data on Twitter, [or examining someone's Facebook page to determine appropriateness of sick-leave benefits](#))²⁷ may have much more serious consequences for patients and the organization than the loss of paper records. But consider that data from misused paper records can also be uploaded online, and that third-party hacking or inappropriate staff disclosure of confidential information can also compromise privacy.

Keep current on legal developments and leading practices in privacy and data control FOR USERS OF SOCIAL MEDIA, PRIVACY MEANS CONTROLLING THEIR DATA

The widespread use of social media has upset traditional notions of privacy – but privacy still matters. Several recent controversies show that privacy concerns in social media are more tangible than abstract. For users of social media, privacy is principally about data control – their ability to control the precise purposes for which information about them will be used.

[Google Buzz](#) experienced a firestorm over privacy when it launched in mid-February 2010. Buzz is a micro-blogging service for users of Gmail, Google's

email service. Buzz was designed to emerge organically from the user's email address book, creating a ready-made "circle of friends." Criticism quickly arose that users were not sufficiently informed about who they were communicating with. Google took action within 48 hours to change the automatic settings so that users have control over who they link with.

Canada's Privacy Commissioner and other privacy groups have had public exchanges with Facebook on a number of privacy issues. As part of a settlement of a large class-action lawsuit in California, Facebook shut down its "Beacon" feature. Beacon initially tracked subscribers' activities on external partner websites (such as movie fan sites) and published information such as users' online purchase of film tickets on news feeds that could be viewed by the subscriber's social network. This tracking continued even when users had logged off of Facebook and had declined to have their activities published on news feeds; the news feeds could be cached in perpetuity by Google or by other [search engine bots](#) crawling the web to expand their searchable index. Widespread criticism led Facebook to give users the choice to opt out of Beacon and then, in 2009, Facebook shut down the controversial service after it was the target of a class-action lawsuit.

DATA CONTROL: A GUIDING PRINCIPLE

In the absence of significant court rulings in Canada interpreting privacy or health law statutes in the context of social media, healthcare organizations would be wise to adopt the principle of data control in any activities related to social media. The concept that individuals should have control over their personal information in social media is consonant with the Canada's *Personal Information Protection and Electronic Documents Act* (PIPEDA) and the principle of informed consent, which is statutorily embedded across Canada and the Western world. Just as patients have the right to reasonable access and control over their health records, protection of patient autonomy dictates that individuals retain control over their postings on social media sites, including the history over which websites have been visited.

“ I think the mechanisms available through web 2.0 really tie patient input back into the quality agenda. We do see this technology as helpful to reach some of the harder-to-reach or more marginalized groups in our community.”

Pat Campbell, Echo: Improving Women's Health in Ontario

The concept of data control can serve as a guiding principle for Canadian healthcare organizations intending to use postings from social media for the purposes of quality improvement. The principle suggests that organizations should advise the public before any such data are used. Such notice might explain the organization's intention to use the social media data; the manner in which this process is to be undertaken; the ways in which publicly posted material will be fed into the quality improvement cycle and considered by the board and/or board committees; the patient-centred and quality improvement rationale for doing this; and the healthcare organization's sensitivity to the principles of privacy and data control.

The use of anonymized patient data gathered from social media sites is analogous to the use of anonymized, aggregated patient-level data taken from physician billing records or surveys. Both can protect the patient's right to privacy and control over their personal information, while contributing to an organization's quality improvement activities. As with all research, any process for collecting and using data for the purposes of quality improvement research should meet the requirements of the [Tri-Council Policy Statement: Integrity in Research and Scholarship](#) issued by Canada's Natural Sciences and Engineering Research Council, the Social Sciences and Humanities Research Council, and the Canadian Institutes of Health Research.

Learn from other sectors and resources IN DEVELOPING POLICIES ON SOCIAL MEDIA USE, HEALTHCARE ORGANIZATIONS CAN FIND GUIDANCE FROM A DIVERSE RANGE OF INITIATIVES

Prior to embarking on quality improvement initiatives that use social media, one option for healthcare organizations is to set up internal workshops to explore issues of privacy and data control. Also, by joining forces in facilitated workshop sessions with organizations facing similar challenges and journeys toward implementation, healthcare organizations can learn collaboratively about how others are developing and using social media responsibly.

Social media policies govern how employees and individuals share sensitive corporate information. Two sources of information on social media policies from diverse sectors around the world are [SocialMediaGovernance.com](#) and [HLWiki Canada](#), an online resource created by health librarians. From banks to libraries to government agencies, many sectors have developed policies, toolkits, handbooks, and other resources as they move forward on the same issues that healthcare organizations are now exploring.

The social media journey of the [U.S. Department of Defense](#) is particularly relevant. The organization moved from a culture that was resistant to change to one that embraced social media and, in 2010, issued a [policy](#) that permits general use while prohibiting specific activities such as gambling and pornography.²⁸ This development is instructive given that the military sector must be hyper-sensitive to the vulnerabilities of its troops and the disclosure of its strategic operations.

KEEP CURRENT ABOUT TERMS AND CONDITIONS OF USE OF SPECIFIC SOCIAL MEDIA CHANNELS

The Beacon and Buzz controversies, described in the previous section, highlight the need for organizations to encourage all social media users to stay informed about the terms and conditions and consent forms on social media sites. Our review of popular social media sites reveals considerable variability in the location, size, clarity of information, ease of translation (into multiple languages), and forms to opt in or out of various privacy controls.

Terms and conditions may change frequently, and, although users must legally accept substantive changes in such terms, evidence from our conversations suggests that few people give much thought to the potential consequences inherent in making these changes. Users should carefully monitor the privacy settings of sites they access, by visiting the site's "settings" or "privacy" page to make sure personal information remains private (if desired) and to find out who has access to their information.

Healthcare organizations should also consider pointing users to important educational initiatives, notably those of Ontario's [Information and Privacy Commissioner \(IPC\)](#)²⁹ and the 2008 "[Rome Memorandum](#)," a report from the International Working Group on Data Protection and Telecommunications.

These initiatives aim to raise awareness about key privacy issues, such as the fact that postings to sites such as Twitter can, in some instances, remain accessible to technicians (through the software's [application programming interface](#)) even after the user has retracted the posting. The Rome Memorandum includes a comprehensive list of potential privacy risks associated with the use of social media and provides guidance on privacy protection measures for regulators, website providers and users. It has been identified by the IPC as an "important resource for the public and stakeholders on best practices for safeguarding personal information on social networking sites."

Develop a policy for employee use of social media, and take it to your board

THE BOARD NEEDS TO APPROVE THE ORGANIZATION'S SOCIAL MEDIA POLICY

Healthcare organizations do not appear to take lightly the decisions they face over whether to block or mediate social media sites. Many are acting proactively by setting up committees to review policies already in place and to advise on modifying them to articulate the appropriate use of social networking sites by employees while on duty.

Healthcare organizations are also taking action by educating employees about expectations and potential disciplinary actions associated with violating social media policies, just as they do for rules relating to the wrongful disclosure of confidential information. Based on our reading of the current [Ontario Public Hospitals Act \(Reg. 965\)](#), we recommend that social media policies be formally approved at the board level. However, we have found wide variation in the level at which hospitals currently ensure such policies are approved.

COMMON ISSUES WITH EMPLOYEE USE OF SOCIAL MEDIA

Like corporations generally, healthcare organizations in Canada allow incidental personal use of electronic and telephone communications systems when it does not consume more than a trivial amount of time or interfere with staff productivity. Services like personal email or access to the Internet are generally allowed for employees during break periods, and such use is often written into employment contracts.

In the health sector, personal use does not include engaging with patients via social media. However, some employees and contractors, including physicians, have engaged with patients online, [even "friending" patients on Facebook](#),³⁰ a topic of much recent ethical debate within the research and clinical community,

with no consensus. Seven percent of U.S. physicians use online video conferencing to communicate with their patients, according to the 2011 “Taking the Pulse” study of trends in physicians’ digital adoption by Manhattan Research, a pharmaceutical and healthcare market research company. Increasingly, caregivers and patients are texting, emailing, and using Skype to try to reach their healthcare providers. Some providers report that these technologies help strengthen their communication. Yet many doctors remain reluctant to use such tools despite increasing patient demand.

For physicians, communicating with patients via social media may raise ethical concerns. [American Medical Association policy](#) discourages physicians from socially interacting with patients on social media, though professional sites are encouraged. The Association has a long-standing policy, adopted before social media was on the radar, that physicians should not practice medicine online with patients (e.g., through email) when there has been no prior face-to-face relationship.

Most healthcare organizations reserve the right to monitor, review and inspect all uses of their electronic communication systems including email, Internet usage, voicemail, fax and other vehicles. Information technology departments in hospitals use a variety of tools to monitor employees’ use of social media. Lack of attention, for example, to an employee’s distribution of offensive material on social media could expose the organization to claims of negligence or discrimination for failing to maintain a safe, comfortable workplace. Despite these measures, employees can still carry their personal mobile phones, many capable of accessing social networking sites directly, without having to go through the organization’s server.

Be aware of the ethics of “listening technology”

USERS OF SOCIAL MEDIA HAVE A RIGHT TO KNOW HOW THEIR DATA AND CONVERSATIONS WILL BE USED, AND WHY

The outright copying of messages from private, secured online discussion forums for commercial purposes is a clear violation of users’ rights to control their personal data, in healthcare or other sectors. “Listening technology” refers to software that can

mine online conversations for information about users. Does listening technology violate privacy? Is it being used to take advantage of people’s personal data for unethical purposes? The answer to this question – one widely discussed in the for-profit sector – is evolving.

The use of listening technology in the commercial context has been the focus of media scrutiny, for example in the *Wall Street Journal’s* [“What They Know” series](#) in 2010.³¹ Listening technology raises two interconnected ethical issues:

- “mashing up”: listening technology can capture personal identifiers and connect these data with other personal information, such as social insurance numbers and health insurance information.
- “tracking”: using “cookies” that monitor which websites people visit, listening technology can document people’s interests – such as which political parties they support. This information can be sold to third-party vendors, who could identify users and target them for advertising.

PROTECTING USERS

In social media, these risks may surface if the social media site can transmit users’ identifying data to companies when users click on ads. This practice is concerning in the context of a site like Facebook, where the user ID is linked to a person’s real name which could be mashed up with other personal data and then sold. Myspace pledged to discontinue this practice as of May 2010, as has Facebook, which also announced in October 2010 that it would block the transmission of user IDs.

For users to be further protected, all developers of applications available on social media sites should be blocked from sharing user data with any party. (Applications, or “apps,” are pieces of software that enable social media users to play games or share common interests.)

INCREASING CONSUMER ATTENTION LEADS TO GREATER PROTECTION

Increasing consumer attention to this issue is protecting social media users, with regulatory and industry-initiated changes trending toward greater and greater personal control over one's online data. Following an investigation by the Privacy Commissioner of Canada, Facebook took action in June 2010 to limit apps to accessing only the public parts of a user's profile, unless the user grants formal permission for more private access. Facebook then created a control panel that allows users to see which apps are accessing the various categories of their personal information. These practices support the principles of user autonomy and data control. Going further, Facebook has obtained a software patent for establishing and maintaining user-controlled anonymous communications. This development demonstrates that there is consumer demand for increased data control, and this trend can be expected to escalate.

Meanwhile, a growing number of Internet tracking companies (e.g., BlueKai Inc., Lotame Solutions Inc. and eXelate Inc.) are joining the [Open Data Partnership](#).³² This initiative – designed to allow consumers to edit personal information collected about them from online sources – builds upon the [Self-Regulatory Principles for Online Behavioral Advertising](#) announced by the Digital Advertising Alliance in July 2009.

A proposed [“Do Not Track” law](#) in the United States would, if passed, go beyond current U.S. federal law, which requires websites aimed at children under 13 to obtain parental permission prior to collecting personal information such as children's names or email addresses.³³ The proposed law would institute an outright ban on tracking to protect children and teenagers, requiring parental agreement for third parties to collect personal information. We expect many similar laws will be debated around the world in the near future.

Civil case law is also emerging to protect Internet users. [In December 2010, a lawsuit was filed in the U.S. \(the first of its kind in that country\) for alleged use of “history sniffing,”](#) a surreptitious method of detecting which websites someone has visited.³⁴ This is the latest approach to take aim at technologies that harvest – and potentially sell – Internet users' personal data without their permission.

CONCLUSION

Patients are searching for information, speaking out online and want to be heard. According to the May 2011 Pew Research Center report, The Social Life of Health Information, of the 74% of U.S. adults who use the Internet, 80% of users have looked online for health information. (The survey asked respondents about 15 health topics, including information about a specific disease or treatment.)³⁵ This is equivalent to 59% of all U.S. adults, and we estimate the proportion to be similar in Canada. Social media in healthcare holds substantial promise, including the construction of valuable information sprung from collaboration, patient-to-patient social supports, and more sustained and collaborative patient-provider relationships across the continuum of care.

“Patients themselves will have a much richer set of possibilities to talk amongst themselves, to communicate with caregivers, and to enlist a broader range of caregivers because the technology empowers them in new and different ways.”

Tom Sommerville, Ontario Ministry of Health and Long-Term Care

Despite this great promise, it is important to be guided by the emerging evidence rather than the hype and to evaluate soberly how social media benefits healthcare. Through this investigation, we learned that, in healthcare, social media is being used in myriad ways: community engagement, peer support, research outreach, education and advocacy, sentiment (or brand) tracking, philanthropy, and citizen feedback. Looking at the evidence gathered thus far, we can conclude:

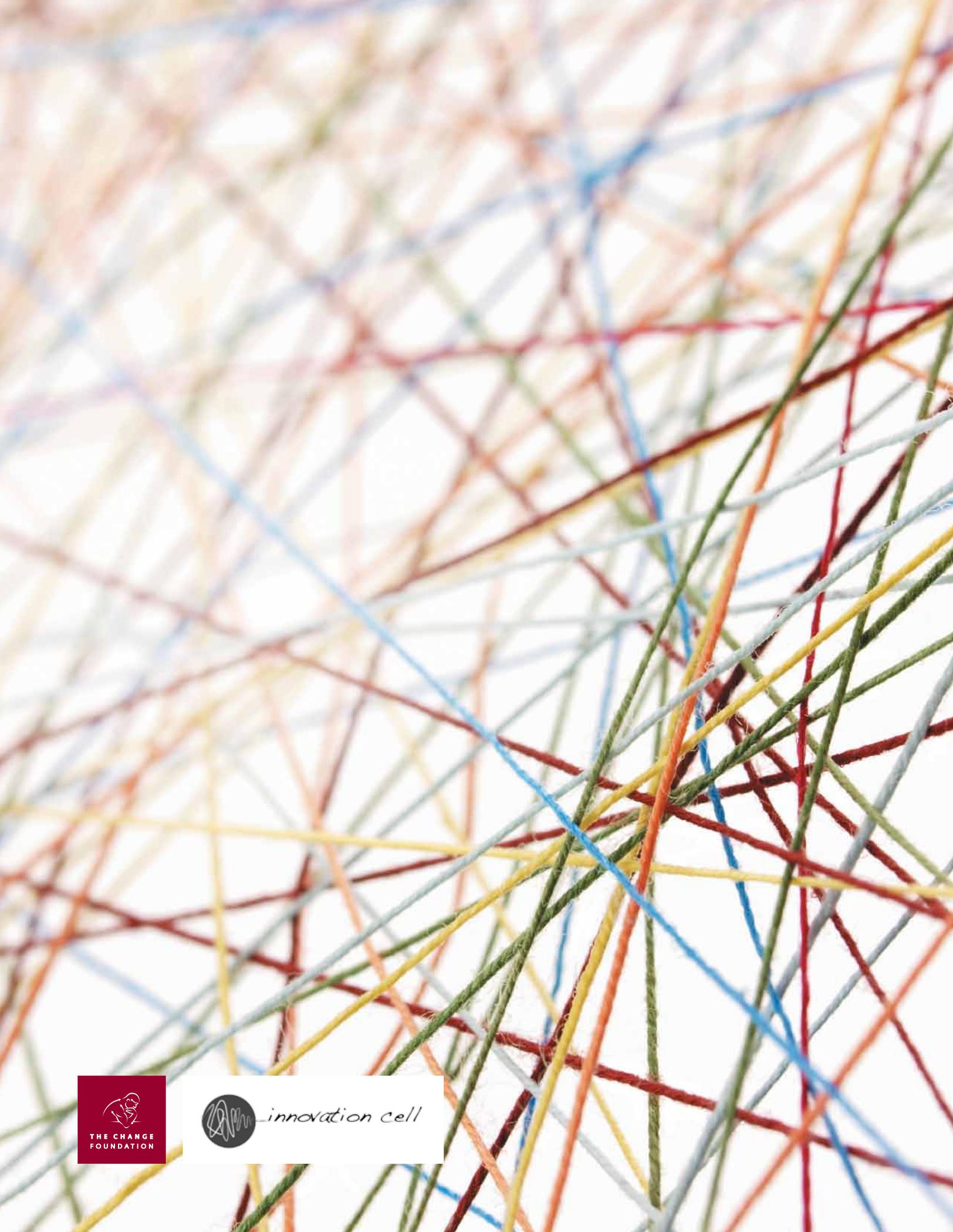
- There are demonstrable benefits for patient outreach using social media.
- There are clear fundraising benefits to using social media.
- There are clear benefits that it can provide emotional support for patients and caregivers.
- There is no systematic evidence thus far of clinical benefits.
- There is no clear evidence thus far of formal integration of social media into quality improvement cycles for those organizations that have used social media.

A growing number of healthcare organizations are developing social media policies, although usually in response to crises (e.g., a negative blog about a treatment denied at an organization). Many issue-specific social media initiatives (e.g., patient groups) are organically created by members of the public. The main stumbling block to adoption of formalized social media policies is the lack of best practices to enable organizations to become less risk averse and, thereby, more accepting of this new media.

We hope this suite of materials released by The Change Foundation and the Health Strategy Innovation Cell will enable a dialogue within and across healthcare organizations, as occurred during our field partner explorations with the Centre for Addiction and Mental Health and with Providence Healthcare. We suspect that, in short order, the dialogue over the appropriate use of social media in healthcare organizations will itself be conducted more and more using social channels online. Social media will become so ubiquitous that ignoring it in healthcare will be akin to ignoring the importance of basic communication tools, like the telephone or the doorbell. The more we listen, the more our collaborations are meaningful, and the more they can move us toward fulfilling the promise of continuous quality improvement.

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