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ORIGINAL ARTICLE

Bipolar disorder research 2.0: Web technologies for research capacity and knowledge translation

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Abstract

Rationale, aims and objectives: Current Web technologies offer bipolar disorder (BD) researchers many untapped opportunities for conducting research and for promoting knowledge exchange. In the present paper, we document our experiences with a variety of Web 2.0 technologies in the context of an international BD research network: The Collaborative RESearch Team to Study psychosocial issues in BD (CREST.BD).

Methods: Three technologies were used as tools for enabling research within CREST.BD and for encouraging the dissemination of the results of our research: (1) the crestbd.ca website, (2) social networking tools (ie, Facebook, Twitter), and (3) several sorts of file sharing (ie YouTube, FileShare). For each Web technology, we collected quantitative assessments of their effectiveness (in reach, exposure, and engagement) over a 6-year timeframe (2010-2016).

Results: In general, many of our strategies were deemed successful for promoting knowledge exchange and other network goals. We discuss how we applied our Web analytics to inform adaptations and refinements of our Web 2.0 platforms to maximise knowledge exchange with people with BD, their supporters, and health care providers.

Conclusions: We conclude with some general recommendations for other mental health researchers and research networks interested in pursuing Web 2.0 strategies.

KEYWORDS

bipolar disorder, community-based participatory research, knowledge translation, social media, Web 2.0

1 | INTRODUCTION

In a world filled with new research and information, complementary problems exist for knowledge "creators" and knowledge "users." In health research, investigators often struggle to make findings heard and to affect change in health behaviours and clinical care. Likewise, health consumers often have difficulty identifying credible and comprehensible information, and increasingly rely on the Internet for solutions (see Turner et al¹). For example, individuals living with mental illness frequently turn to the Internet for information related to their condition (eg, LaValley, Kiviniemi, & Gage-Bouchard²). Clearly, researchers should be using the Internet as a central venue for disseminating research findings, and, in so doing, may expedite and encourage use of those results.

But how should researchers use the Internet to disseminate information? Which online tools serve a researcher best? Moreover, could researchers use Web-based strategies to improve the quality of research? This article addresses these questions by reviewing several online tools and presenting the outcomes of their use for a specific health condition, bipolar disorder (BD); results may hold to similar pursuits in other health conditions. As background to our review and analysis, we provide explanations of the meaning of the terms knowledge translation (KT) and Web 2.0.

1.1 Web technology reach

The scope of the Internet is vast: While the monthly audience for the New York Times approaches 100 million, the potential monthly audience for a blog or Facebook post is approximately 350 million and 600 million, respectively (see Bik & Goldstein³). Social media forms have seen the most dramatic levels of adoption: As of 2013, 1 in 7 people actively used Facebook and 340 million tweets were posted to Twitter each day.⁴ Although many scientific organizations already make use of these technologies (see Van Eperen & Marincola⁵), and most public health organizations use at least one of these technologies for KT purposes (see Thackeray, Neiger, Smith, & Van Wagenen⁶), researchers are not on the whole active in this medium. The unfortunate adverse effect of the scientific community largely ignoring the growth and reach of the Internet and social media (see Eagleman⁷) is that there is a plethora of misinformation on the Internet (eg, Gallagher & Doherty⁸).

1.2 Using Web technologies for research

In addition to being a KT platform, the Internet holds the potential to increase research effectiveness and capacity (see Bik & Goldstein⁹). Web-based outreach could enhance recruitment of research participants (see other studies^{9,10}), particularly from difficult-to-access populations; internet tools could foster collaboration between geographically separated research groups (eg, Van Eperen & Marincola¹¹). Web technologies also offer new ways of studying phenomena: One study illustrated, for example, how Twitter could be used as a means of measuring the "Geography of Happiness" 12; another used Twitter to confirm the growing use of psychostimulants as study aids amongst university students.¹³ Of course, all new research possibilities carry their own ethical concerns. 14,15

Academic institutions are also beginning to use Web-based metrics to measure faculty productivity and impact. For example, there is good evidence that Twitter activity immediately following the publication of a scientific article (Tweetations) can predict citations of that article over the long-term. 15-17 This tweetation-citation correlation allows universities to guickly evaluate the impact of their researchers (to the extent that there are tweets about their research), without waiting several years for journal citations to appear; indeed, alternate metrics (Altmetrics) have been developed for this purpose and are being used by academic institutions (see other studies 18,19).

1.3 | What is knowledge translation?

According to the Canadian Institutes of Health Research, KT is an "iterative process that includes the synthesis, dissemination, exchange and ... application of knowledge to improve health, provide more effective health services and products, and strengthen the health care system". 20 An integrated KT model focuses on the practices of knowledge exchange; that is, the sharing of knowledge between and across researchers and knowledge users. This approach emphasizes collaboration with those who have personal knowledge and experiences of health conditions, under the assumption that this will maximize the likelihood of delivering relevant, pragmatic, and effective interventions.

1.4 | What is Web 2.0?

The term "Web 2.0" refers to "the technical, aesthetic, and functional criteria established to enable collaboration and sharing of information between users on the Internet" (see Shapiro & Ossorio²¹)—a second generation of the Web that permits users to produce, contribute, and debate online (see Brossard, D. & Scheufele⁴). A key strength of Web 2.0 is its social component. Indeed, the rapid adoption of tools that enable social networking, such as Twitter and Facebook, illustrates how compelling an experience social media can be for users.

Web 2.0 applications, such as social networking tools, have also been developed for defined populations of users. For example, there exist tools for health care and health KT purposes, ushering in what has been called either "Health 2.0" or "Medicine 2.0" (see Stump, Zilch, & Coustasse²²). Patientslikeme.com is a high-profile example: This tool allows users with comparable medical conditions to share healthrelated information, such as treatment experiences; it has led to several high-impact patient run clinical trials (eg. Thelwall, Haustein, Larivière, & Sugimoto²³). Such tools, therefore, offer improved access to and engagement with evidence-based research outputs, empower populations of end users, and have direct implications for research on specific conditions such as BD. 15,24 Still, although there is good reason to be optimistic about the utility of Web 2.0 tools, it is important to realize that their utility in health care settings requires validation (see other studies^{22,24}). Further, it must be acknowledged that the corporate models—and their use of personal information for Web tracking and targeted advertising-upon which many free Web 2.0 platforms

are based, have serious potential privacy consequences for users in health care settings.

1.5 | CREST.BD and Web 2.0

The Collaborative RESearch Team to study psychosocial Issues in Bipolar Disorder (CREST.BD) is a multidisciplinary network of researchers, health care providers, people living with BD and their allies. The network is dedicated to collaborative research and KT about psychosocial factors in BD, specializing in "community-based participatory research" (CBPR), wherein stakeholders are actively engaged in the full cycle of research and KT. 20,25 Because of this emphasis. CREST.BD has developed a comprehensive and participatory Web 2.0 KT strategy that engages diverse end users, including people with BD and their supports, health care providers, researchers, community and government agencies, and mental health educators. Specifically, CREST.BD seeks to leverage Web 2.0 to (1) address BD stigma; (2) support self-management; (3) engage in knowledge sharing and consultation; (4) encourage active end-user engagement in health research; and (5) monitor and address misinformation on the Internet and attend to common barriers to health literacy. 11,22 The aim of this paper is to describe the implementation and evaluation of CREST.BD's Web 2.0 strategies.

2 | METHODS

Our CREST.BD network members disseminate research findings via traditional peer-reviewed publications, and, in tandem, develop research outputs for accessible online platforms. Content is generated collaboratively, and in an interdisciplinary context, in pursuit of a Web presence that is current, accurate, and of high quality. The online environment created by CREST.BD comprises 3 categories of technologies: (1) the crestbd.ca website, (2) social networking tools, and (3) file sharing. We have approached the implementation of each of these technologies with a recursive and iterative design approach (see Figure 1). For example, and as outlined in the following 4 subsections, we have involved the end users of the technologies in each stage of the design and implementation.

2.1 | Crestbd.ca website

The first version of the CREST.BD website, crestbd.ca (http://www.crestbd.ca), launched in 2007, was a static site developed to support study recruitment and basic unidirectional KT. The crestbd.ca website was first redeveloped (in-house) in Spring 2013 into a more dynamic site capable of supporting multidirectional KT, education, and online engagement using: (1) the free-to-use WordPress content management system (http://www.wordpress.org), (2) a custom modification of a proprietary WordPress theme, and (3) freely available WordPress plugins (eg, to enable the live Twitter feed). The site was redeveloped again (using a contracted website development company) in Spring 2016.

At each stage of development, CREST.BD's Community Advisory Group, a 12-member knowledge-user advisory, provided feedback on the site's navigation, content, language and style. The Community

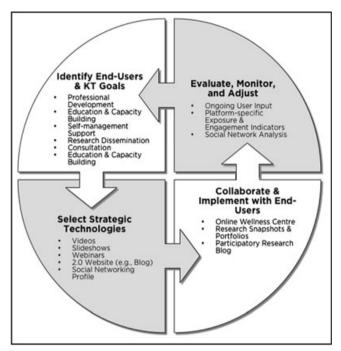


FIGURE 1 CREST.BD design approach

Advisory Group shaped key aspects of the site's Web 2.0 features (eg, blog), and identified and helped mitigate audience-specific barriers. The second (2013) iteration of crestbd.ca focused on incorporating 3 features to increase online engagement and support KT:

2.1.1 | Research portfolios

Project-specific online portfolios, utilizing text and multimedia. These provide an overview of research methods, progress, and findings of an ongoing BD-specific network study. Multimedia tools include slideshows and videos exploring research methods and findings.

2.1.2 | Research snapshots

Concise plain-language summaries of peer-reviewed publications by network members, cowritten by end users (eg, a health care professional and a person with BD) in collaboration with an academic researcher.

2.1.3 | Bipolar research blog

The original version of the blog (launched Spring 2013) published new content on a monthly basis. A revisioned version (eg, weekly instead of monthly) was launched in Spring 2016. Posts feature contributions from academics, peer researchers (people with lived experience of BD participating in research) and health care providers, who provide content related to larger BD research projects, current individual research studies, or peer-reviewed articles. For example, our "study-specific series" involved 4-5 blog posts by several contributors that described research progress (eg, strengths and challenges of CBPR) and findings (qualitative and quantitative) from an interdisciplinary perspective and within a CBPR context. The blog serves multiple purposes, including: (1) acting as a platform for engagement and dialogue around BD research, (2) fostering accountability and increasing transparency of the network's research activities (see Kouper²⁶),

and (3) situating the CREST.BD network as a credible source of interdisciplinary expertise in the field of BD.

2.2 | Social networking tools

Facebook (www.facebook.com) and Twitter (www.twitter.com) were the primary social networking tools leveraged. These platforms enable rapid and targeted sharing of research findings to a large number of potential end users. In addition, these channels were used to engage in dialogue and develop linkages with academics, decision makers, health care associations, and community-based organizations. These channels were also used to strengthen CREST.BD's role as a leader in BD research by disseminating content from, and directing traffic to, the evidence-based materials on the CREST.BD website (see Austvoll-Dahlgren, Bjørndal, Odgaard-Jensen, & Helseth²⁷).

2.3 File sharing

YouTube (http://www.youtube.com) and SlideShare (http://www. slideshare.net) comprise the 2 file-sharing tools used to promote dissemination of multimedia content developed to promote network activities and research outcomes. The content developed for file sharing was used to support learning following workshops and webinars, to explain complex psychosocial concepts (eg, multiple levels of stigma, http://www.youtube.com/watch?v=B9427JvlaPc), and to demonstrate research approaches. Conference presentations were also recorded and archived for future use using these channels.

Metrics for monitoring and evaluating impact

To monitor the success of our Web 2.0 activities and inform future initiatives, investments and the 2016 redesign of the website, we used application/platform-specific metrics, which, in turn, allowed us to evaluate the key performance indicators of reach, exposure, and engagement (see other studies²⁷⁻²⁹). That is, the metrics sought to measure (1) degree of reach (ie, number of individuals who had contact with the specific platform); (2) amount of exposure (ie, number of times content was viewed; and (3) level of engagement (ie, degree to which individuals acknowledged (eg, Facebook page likes), shared, and created content (eg, comments) to influence other users (see Neiger, Thackeray, Van Wagenen, et al²⁹). Our metrics also sought to capture relationships between the various Web-based activities.

Monthly analytics data were compared for November between 2010 and 2016.

2.4.1 | Crestbd.ca website

Each month we collected analytics reports for crestbd.ca via Google Analytics (www.google.com/analytics). Reach was assessed by examining the number of new and unique visitors, as well as audience characteristics (eg, demographics, location, and device use). Exposure was assessed by examining the overall number of website visits and total page views. Engagement was evaluated by comparing the number of new vs return visits, time spent on the website per visit, and the number of pages viewed per visit (see Turner²⁸). Monthly analytics data for crestbd.ca were compared for the month of November for each year from 2010 through to 2016.

2.5 | Social networking tools

Facebook and Twitter offer their own free, application-specific analytics tools. In addition, 2 supplementary social media management tools were leveraged: Hootsuite (www.hootsuite.com) and Twitonomy (www.twitonomv.com).

Measures for documenting the results of our Twitter activities included measures of reach (eg, number of followers), exposure (eg, number of mental health lists the @CREST_BD Twitter account is linked to) and engagement (eg, number of mentions, retweets). Twitonomy provides detailed feedback on the influence and activity of @CREST_BD followers and the users we follow. This, in turn, helps target Twitter conversations and content to reach influencers in a specific topic.

Facebook posts were created to engage users in dialogue through commentary between individual, influential users, and larger organizations. We monitored Facebook activities daily and responded to user comments, where appropriate. The Facebook analytics tool, Facebook Insights, provided us with audience demographics (eg, gender and age) and engagement as assessed via several metrics (eg, page likes and shares). Facebook Insights also provided us with the total weekly reach of CREST.BD activities. However, due to numerous changes in Facebook Insights metrics over the past 5 years, in the present paper, we chose to only compare the consistent metric of page "Likes" for the month of November in 2011 through to 2016.

2.6 ∣ File sharing

YouTube and SlideShare both provide built-in analytics capabilities that collate data from several metrics. These include number of: views (exposure), channel subscribers, and shares (engagement). In addition, for each video, YouTube captures the average view duration, the percentage of views that were completed views, and engagement indicators.

3 | RESULTS

Our Web analytics demonstrated the importance of daily outreach and activity on social networking sites, accessible content for multiple Web 2.0 channels, collaborative creation of Web 2.0 content, and participation from end users. All CREST.BD channels demonstrated increased traffic with our target audiences. While engagement from online users was less consistent (ie, on crestbd.ca), we found high-end user engagement by inviting participation in content creation. Specific analytics are detailed in the following subsections.

3.1 | Crestbd.ca website

In general, our website development work was accompanied by a growth in reach and exposure. Monthly analytics data for the number of website visits, number of unique visitors, percentage of new visitors, number of page views, and time spent per visit were captured for the month of November across the years 2010 to 2016.

Reach and exposure indicators demonstrate increases in levels of activity on the crestbd.ca website.²⁸ Specifically, website visits, number of unique visitors, unique page views, and the proportion of new vs returning visitors tended to increase over time (Figures 2–4). However, analysis of number of pages viewed per visit (Figure 5) and average time spent on the website per visit (Figure 6), both common

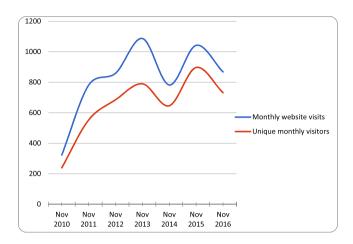


FIGURE 2 Monthly website visits and unique monthly website visitors—Google Analytics results for crestbd.ca for the month of November in years 2010-2016

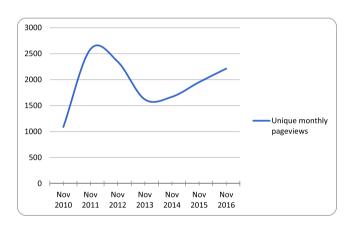


FIGURE 3 Monthly unique page views—Google Analytics results for www.crestbd.ca for the month of November in years 2010-2016

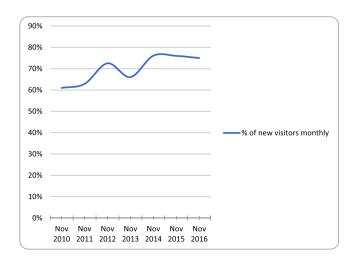


FIGURE 4 Percentage of new visitors monthly—Google Analytics results for www.crestbd.ca for the month of November in years 2010-2016

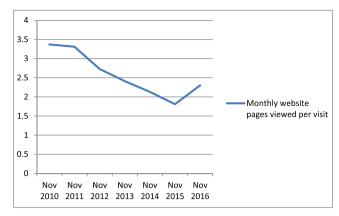


FIGURE 5 Monthly website pages viewed per visit—Google Analytics for www.crestbd.ca for the month of November for years 2010-2016

means for measuring website engagement,²⁸ suggest a decreasing level of engagement with the crestbd.ca website over time (see discussion).

Google Analytics data that detailed the flow of traffic to the website (eg, Google search, social media, and organic search), indicated that 2 of our social media channels are heavy contributors to our website traffic: In November 2016, of 897 total website views, 27.2% of total site visitors were referred to crestbd.ca from other sites (ie, as opposed to those who manually typed the site address into their search bar). Of these, Twitter and Facebook were responsible for 17% of total monthly unique visits to crestbd.ca; Facebook was responsible for directing 9.7% and Twitter was responsible for directing 7.4%. To provide a more in depth analysis of traffic to the various subsections of the website and to inform our 2016 website redesign, we examined page-level Google Analytics data for the final 6 months of 2015 (July 1, 2015-December 31, 2015). During this period, 4887 sessions occurred by 3674 unique visitors (73% first-time visitors) with the bulk of this traffic coming from Canada (45%) or the United States (18%). The top most visited pages were the homepage (2616 page views), the page providing BD assessment scales (927 page views), pages describing CREST.BD (team description: 522 page views, about us: 307 page views), followed by research portfolio pages (eg, self-management portfolio) and pages providing concrete tools (ie, linking to bdwellness.com and bdqol.com). The monthly Bipolar Research Blog (2013-2016) saw less traffic (the top 10 blogs received in the range

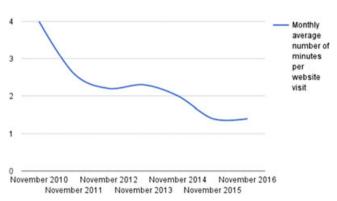


FIGURE 6 Monthly average number of minutes per website visit—Google Analytics for www.crestbd.ca for the month of November in years 2010-2016

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of 769-174 page views over a 2-year period) with the most visited blogs being on topics of wide interest (eg, mindfulness approaches) or study-specific blogs.

During July 1, 2016 to December 31, 2016, there were 5142 sessions by 3904 unique visitors, 74% of these first-time visitors to the site. The bulk of the visitors, again, were located in Canada (55% of total visitors), or the United States (14% of total visitors). During this period, the most-visited pages were the homepage (2158 page views), the "about us" page (741 page views), BD tools pages (709 page views), and research portfolio pages (693 page views), followed by the Bipolar Research Blog page (440 blog homepage page views). Increased traffic to the new weekly version of the Bipolar Blog was encouraging to see.

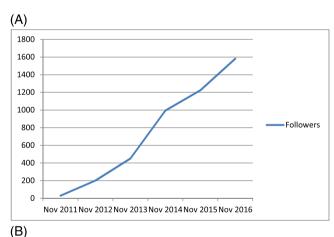
3.2 | Social networking tools

In general, our social networking activities were accompanied by a strong growth in reach, exposure, and engagement.²⁹

3.2.1 | Twitter

Monthly Twitter analytics data for the number of followers, retweets, mentions, and URL clicks were captured for the month of November in 2011 to 2016 (Figure 7).

The number of followers metric indicates increased reach via our @CREST_BD Twitter handle, and the metrics of number of retweets, number of mentions, and number of URL clicks indicate increased levels of interaction.



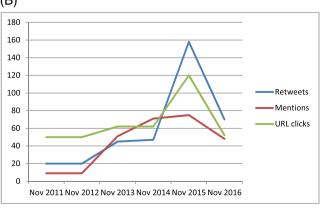


FIGURE 7 A and B: Monthly Twitter analytics—Followers and retweets, mentions, and URL clicks

In November 2016, our tweets earned 20,300 impressions (total number of Twitter streams @CREST_BD tweets were delivered to). By comparison, in November of 2014, @CREST_BD tweets earned 16,500 impressions. Moreover, as of February 2016, the @CREST_BD Twitter handle had been included on 69 lists of mental health research experts and was mentioned daily by researchers, community organizations, mental health advocates, and health leaders in Canada.

3.2.2 | Facebook

Monthly Facebook analytics data for the number of page likes of the CREST.BD Facebook page was captured for the month of November 2011 to 2016 (Figure 8). The number of page likes metric indicates increased reach and interaction via our CREST_BD Facebook page.

3.2.3 ∣ File sharing

As of November 2016, CREST.BD's YouTube channel; YouTube viewership continues to increase consistently. In general, CREST.BD's most-viewed videos and slides involved content that was cocreated by community members living with BD.

3.2.4 | YouTube

Reach and exposure for YouTube was assessed by number of views at channel and video-specific levels. Engagement indicators included "estimated number of minutes watched." Monthly CREST.BD YouTube video views increased from 324 in November 2012, to 492 in November 2013, to 516 in November 2014, to 819 in November 2015, and 585 in November 2016. Estimated minutes viewed for the months of November 2011 (5 minutes), November 2012 (1031 minutes), November 2013 (1527 minutes), November 2014 (2526 minutes), November 2015 (3933 minutes) and November 2016 (2561 minutes) illustrate the growth of our YouTube channel since its creation in 2011. YouTube videos with the highest level of engagement were under 5-minutes and were characterized by (1) relaying brief research findings; (2) illustrating a lived-experience narrative; or (3) facilitating clinical education. This is clear from both the number of individual views and estimated minutes viewed, respectively, for videos within these categories.

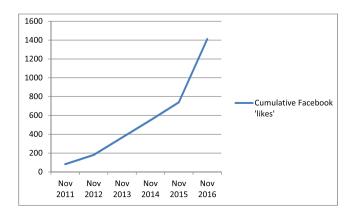


FIGURE 8 Monthly Facebook insights

3.2.5 | SlideShare

As of November 2016, we had a total of 71 SlideShare files—these presentations received over 31 000 views since this channel's creation in November 2011. Total annual SlideShare views have nearly doubled year to year, with 4229 annual views between November 2012 and November 2013, 8461 views between November 2014 and November 2015, and 15 307 views from November 2015 to November 2016. Interestingly, we found that when we promoted new slideshows, either by social media or by embedding them on the crestbd.ca website, this resulted in 30 to 60-day spikes in viewership. The most popular SlideShare content were presentations that captured specific research studies and explored their methods, results, and findings.

4 | DISCUSSION

4.1 | Website

Reach and exposure metrics for the CREST.BD website improved over the 6-year assessment period, yet metrics (Figures 5 and 6) indicate decreasing engagement with the website over time. This was curious given our focus on creating tailored content and the overall increase in website traffic (Figures 3 and 4) and social media. Possible explanatory factors include a potential inability to compete with the volume of bipolar-focused content fast becoming available online. A more likely explanation is that higher engagement was occurring between the main CREST.BD website and the 2 new websites the network launched to support self-management of BD in Spring 2015: the Bipolar Wellness Centre (www.bdwellness.com) and Quality of Life Tool (www.bdqol.com). These websites were energetically promoted through in-person events across Canada and on our social media platforms, with both launching on World Bipolar Day in Spring 2015. That the CREST.BD website is the main driver of traffic to these 2 new websites supports this hypothesis. In short, we may have been a victim of our own success.

Page-level engagement metrics showed that, as expected, the website landing page saw the most traffic, followed by pages that provided concrete tools and resources (eg, BD assessment scales and self-management tools), those describing the network itself or describing specific research portfolios. These website metrics provided us with useful insights moving forward. The knowledge gained about the type and style of content that engages visitors, and the avenues through which visitors navigate the site was thoughtfully applied as we developed an overhauled version of the website in 2016.

4.2 | Social media

Our social media indicators demonstrated the importance of active (ie, daily) maintenance of social media channels, including monitoring and responding to engagement cues, sharing our own and others' content, and identifying and engaging potential followers.^{29,30} Twitter has proven to be one of our most important communication channels; it has allowed for rapid dissemination of CREST.BD research and helped us keep abreast of community dialogue, as well as scientific discussions

and research external to our network. The continuous growth of our Twitter profile is responsible for creating linkages with stakeholders across Canada and internationally and for driving traffic to the content on the CREST.BD website.

While the growth in Facebook followers is more modest than our Twitter profile, engagement in respect to comments, shares, and page posts are consistent with followers and provide an opportunity for CREST.BD to capture and respond to feedback from our followers on the content promoted via Facebook.

4.3 | YouTube and SlideShare

Short YouTube videos that shared research findings, lived-experience narratives, or supported clinical education had the highest levels of engagement. The most popular Slideshare content described findings and methodological approaches from specific research studies. Slideshare illustrates the cost-effective nature of file-sharing applications. The presentations are iterations of conference or educational presentations, require minimal modification and are easily embedded in external websites. In turn, they receive substantial exposure, and provide rapid dissemination of and access to CREST.BD studies. To adequately leverage the capabilities of SlideShare, we continue to focus our energies on featuring new presentation content frequently and consistently.

4.4 | Relationships between channels

Links to YouTube videos, SlideShare content, publications, and portfolios were embedded in website posts as often as possible. In this scenario, for example, the publication of a blog post on the website, that was subsequently promoted via social media, has the potential to lead to increases in social media followers, mentions on social media channels, increases in views of file-sharing content, and increases in landing on crestbd.ca pages. Monitoring traffic sources to website landing pages is important for understanding where website traffic originates for specific types of content.

The degree of energy CREST.BD directs towards building future Web 2.0 strategies will be informed by the continued monitoring of indicators, and also by the strategic priorities of the network and of the network researchers.

4.5 | General discussion

For both knowledge "creators" and knowledge "users," we have identified the challenge of information management in a world deluged with data and dialogue. Challenges for health researchers include disseminating findings and impacting clinical change; challenges for people with mental health conditions include identifying credible health advice and finding it in a timely and accessible format. We have summarized the potential scope of internet tools such as blogs, tweets, websites, while clarifying the meaning of the terms Web 2.0 and KT. Finally, we have demonstrated the preliminary outcomes of the use of these tools for a specific health condition, BD, which serves as a useful model for other chronic health conditions. Individuals with BD and their families are vigorous users of websites and social media

channels to obtain health guidance^{31,32}; in turn, the use of these channels offers researchers faster clinical implementation of new findings.

As described previously, CREST.BD seeks to leverage Web 2.0 to address BD stigma, to support self-management, to engage in knowledge exchange, to encourage engagement in health research, to monitor and address misinformation on the Internet³³ and, importantly, to attend to common barriers to health literacy faced by members of the general public, including difficulty understanding and appraising information; frustration with large amounts of research results; and lack of familiarity with principles related to health concepts. 11,22

First, the problem of stigma for all people who live with mental health conditions is an enormous one. Research indicates that individuals with BD consistently report stigma as one of the greatest challenges of living with the condition. 34,35 Stigma can be shaming and can prevent those who need help from accessing it. Web 2.0 has the potential to reduce the effect of stigma in several ways. Second, individuals may seek information about conditions confidentially, repeatedly, and at their own pace. Third, information is presented in various modalities (eg, graphic, written, spoken, etc.), which are easily tailored to individual learning needs and styles. Fourth, Web 2.0 channels may decrease isolation by allowing individuals with BD to connect with one another. Finally, societal stigma may be eroded as a result of increased exposure and accessibility to diverse sources of information, media, perspectives, and communication technologies facilitated by Web 2.0. Our qualitative research in youth living with BD has pointed to the importance of future research to create stigma-free online spaces for BD education, knowledge sharing, and social connection.³⁶ Web 2.0 approaches also hold the potential to support self-management, which in turn has the potential to improve health and quality of life in people with BD. These activities are setting the foundation for implementing large-scale Web 2.0 self-management interventions.

Importantly, Web 2.0 KT initiatives encourage active end-user engagement in CREST.BD's research foci. By using channels that support users to engage with research processes and outcomes, CREST. BD is strengthening its role as a credible source of evidence, while encouraging engagement in BD research. The CREST.BD's collaborative research model yields dividends in the Web 2.0 arena, allowing end users to be involved in conceptualisation, design, and evaluation of tailored resources. More research on both the efficacy of Web 2.0 for these goals and the barriers to engagement, however, is required to inform future related interventions. 22,27,30

We have presented our experiences using a variety of Web 2.0 technologies in the context of an international BD research network: CREST.BD. Web analytics demonstrated the importance of daily activity on social media sites; accessible content on multiple Web 2.0 channels; collaborative creation of Web 2.0 content; and inviting participation from end users. In general, all CREST.BD Web 2.0 channels demonstrated increased traffic with target audiences. Thoughtful attention to what was—and was not—working effectively in terms of, exposure and engagement, and incorporating those findings into redesigns and refinements on our digital platforms allowed us to maximize the impact of our research.

We have demonstrated encouraging preliminary outcomes of the use of Web 2.0 tools for a specific health condition, BD-which we believe serves as a useful model for other chronic health conditions. Moreover, it seems that the Internet offers an efficacious method of engaging in collaborative, participatory research-a primary aim of our CREST BD network

REFERENCES

- 1. Turner A, Kabahi A, Guthrie H, Burket R, Turner P. Use and value of information sources by parents of child psychiatric patients. Health Info Libr J. 2011;28(2):101-109. https://doi.org/10.1111/ j.1471-1842.2011.00935.x
- 2. LaValley SA, Kiviniemi MT, Gage-Bouchard EA. Where people look for online health information. Health Info Libr J, in press. 2016. https://doi. org/10.1111/hir.12143
- 3. Bik HM. Goldstein MC. An introduction to social media for scientists. PLoS Biol. 2013;11(4):e1001535. https://doi.org/10.1371/journal. pbio.1001535
- 4. Brossard D, Scheufele DA. Science, new media, and the public. Science. 2013;339(6115):40-41. https://doi.org/10.1126/science.1232329
- 5. Van Eperen L, Marincola FM. How scientists use social media to communicate their research. J Transl Med. 2011;9:199. https://doi.org/ 10.1186/1479-5876-9-199
- 6. Thackeray R, Neiger BL, Smith AK, Van Wagenen SB. Adoption and use of social media among public health departments. BMC Public Health. 2012;12:242. https://doi.org/10.1186/1471-2458-12-242
- 7. Eagleman DM. Why public dissemination of science matters: a manifesto. J Neurosci. 2013:33(30):12147-12149. https://doi.org/ 10.1523/JNEUROSCI.2556-13.2013
- 8. Gallagher S, Doherty DT. Searching for health information online: characteristics of online health seekers. J Evid Based Med. 2009;2(2):99-106. https://doi.org/10.1111/j.1756-5391.2009.01021.x
- 9. Bik HM, Goldstein MC. An introduction to social media for scientists. PLoS Biol. 2013;11(4):e1001535. https://doi.org/10.1371/journal. pbio.1001535
- 10. Brossard D, Scheufele DA. Science, new media, and the public. Science. 2013;339(6115):40-41. https://doi.org/10.1126/science.1232329
- 11. Van Eperen L, Marincola FM. How scientists use social media to communicate their research. J Transl Med. 2011;9:199. https://doi.org/ 10.1186/1479-5876-9-199
- 12. Mitchell L, Frank MR, Harris KD, Dodds PS, Danforth CM. The geography of happiness: connecting twitter, sentiment and expression, demographics, and objective characteristics of place. PLoS One. 2013;8(5):e64417. https://doi.org/10.1371/journal.pone.0064417
- 13. Hanson CL, Burton SH, Giraud-Carrier C, et al. Tweaking and tweeting: exploring twitter for nonmedical use of a psychostimulant drug (Adderall) among college students. J Med Internet Res. 2013;15(4):e62. doi: 10.2196/jmir.2503
- 14. Syed-Abdul S, Fernandez-Luque L, Jian W, et al. Misleading healthrelated information promoted through video-based social media: anorexia on YouTube. J Med Internet Res. 2013;15(2):e30. https://doi. org/10.2196/imir.2237
- 15. Stafford T, Bell V. Brain network: social media and the cognitive scientist. Trends Cogn Sci Sciences. 2012;16(10):489-490. https://doi.org/ 10.1016/j.tics.2012.08.001
- 16. Balfe M, Doyle F, Conroy R. Using Facebook to recruit young adults for qualitative research projects; how difficult is it? Comput Nurs. 2012;30(10):511-515. https://doi.org/10.1097/ Inform NXN.0b013e31826e4fca
- 17. Eyesenbach G. Can tweets predict citations? Metrics of social impact based on Twitter and correlation with traditional metrics of scientific impact. J Med Internet Res. 2011;13(4):e123. https://doi.org/10.2196/ jmir.2012

- Allen HG, Stanton TR, Di Pietro F, Moseley GL. Social media release increases dissemination of original articles in the clinical pain sciences. PLoS One. 2013;8(7):e68914. https://doi.org/10.1371/journal. pone.0068914
- Priem J, Groh P, Taraborelli D. The altmetrics collection. PLoS One. 2012;7(11):e48753. https://doi.org/10.1371/journal.pone.0048753
- Canadian Institutes of Health Research. (2011) Knowledge Translation at CIHR [Internet]. [cited 16 April 2013]. Available from: http://www.cihr-irsc.gc.ca/e/39033.html
- Shapiro RB, Ossorio PN. Regulation of online social network studies. Science. 2013;339(6116):144-145. https://doi.org/10.1126/ science.1219025
- Stump T, Zilch S, Coustasse A. The emergence and potential impact of medicine 2.0 in the healthcare industry. *Hosp Top.* 2012;90(2):33-38. https://doi.org/10.1080/00185868.2012.679909
- Thelwall M, Haustein S, Larivière V, Sugimoto CR. Do almetrics work? Twitter and ten other social web services. *PLoS One*. 2013;8(5): e64841. https://doi.org/10.1371/journal.pone.0064841
- Stellefson M, Chaney B, Barry AE, et al. Web 2.0 chronic disease selfmanagement for older adults: a systematic review. J Med Internet Res. 2013;15(2):e35. https://doi.org/10.2196/jmir.2439
- D'Alonzo KT. Getting started in CBPR: Lessons in building community partnerships for new researchers. Nurs Inq. 2010;17(4):282-288. https://doi.org/10.1111/j.1440-1800.2010.00510.x
- Kouper I. Science blogs and public engagement with science: practices, challenges and opportunities. J Sci Commun. 2010;9(1).
- Austvoll-Dahlgren A, Bjørndal A, Odgaard-Jensen J, Helseth S. Evaluation of a web portal for improving public access to evidence-based health information and health literacy skills: a pragmatic trial. PLoS One. 2012;7(5):e37715. https://doi.org/10.1371/journal.pone.0037715
- 28. Turner S. Website statistics 2.0: using Google analytics to measure library website effectiveness. *Tech Serv Q.* 2010;7(3):261-278. https://doi.org/10.1080/07317131003765910

- Neiger B, Thackeray R, Van Wagenen SA, et al. Use of social media in health promotion: purposes, key performance indicators, and evaluation metrics. *Health Promot Pract*. 2012;13(2):159-164. https://doi. org/10.1177/1524839911433467
- Chou WY, Prestin A, Lyons C, Kuang-yi W. Web 2.0 for health promotion: reviewing the current evidence. Am J Public Health. 2013;103(1): 9-18. https://doi.org/10.2105/AJPH.2012.301071
- 31. Michalak EE, Hole R, Livingston JD, et al. Improving care and wellness in bipolar disorder: origins, evolution and future directions of a collaborative knowledge exchange network. *Int J Ment Heal Syst.* 2012;6(1): 16. https://doi.org/10.1186/1752-4458-6-16
- 32. Michalak EE, Lane K, Hole R, et al. Towards a better future for Canadians with bipolar disorder: principles and implementation of a community-based participatory research model. *Engaged Scholar*. 2015;1(1):132-147. https://doi.org/10.15402/esj.v1i1.41
- Krause C, Puri A. Crash Course In Twitter and Social Media for Healthcare Improvement. Vancouver, BC: British Columbia Patient Safety and Quality Association's International Forum on Quality and Safety; 2013.
- 34. Suto M, Livingston JD, Hole R, et al. Stigma shrinks my bubble: a qualitative study of understandings and experiences of stigma and bipolar disorder. Stigma Res Action. 2012;2(2):85-92. https://doi.org/10.5463/SRA.v1i1.14
- 35. Hawke LD, Parikh SV, Michalak EE. Stigma and bipolar disorder: a review of the literature. *J Affect Disord*. 2013;150(2):181-191. https://doi.org/10.1016/j.jad.2013.05.030
- Noack K, Balram Elliott N, Canas E, et al. Credible, centralized, safe, and stigma-free: what youth with bipolar disorder want when seeking health information online. UBC MJ. 2016;8(1):27-31.

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