

What does Twitter's unravelling mean for medical advocacy?

■ Cite as: *CMAJ* 2022 December 19;194:E1697-8. doi: 10.1503/cmaj.1096030

Posted on cmajnews.com on December 02, 2022

If any moment showcased Twitter's influence as a hub for health information and advocacy, it was the first months of the COVID-19 pandemic.

As the world scrambled to piece together a picture of the novel coronavirus, physicians, scientists, and public health experts stepped up to share personal stories, data, and analyses on the platform under medical and pandemic-related hashtags.

#MedTwitter, a tag previously used by health professionals to network, organize, and share the daily joys and struggles of the profession, became a window to the front lines of the crisis at a time when official information was tightly controlled and sometimes out of step with the situation on the ground.

Posts under the viral hashtags #Masks4Canada and #CovidIsAirborne raised awareness about the efficacy of masks and the potential for airborne transmission of SARS-CoV-2 long before many health authorities acknowledged their importance publicly.

And when SARS-CoV-2 vaccines became available, volunteer vaccine hunters quickly filled a void in official communications to provide real-time data on available vaccination appointments across Canada.

Twitter also facilitated the recognition of long COVID as patients around the world swapped stories of complex and unfolding symptoms that were not initially recognized in health care and policy circles.

"Twitter has been a surprisingly effective communication tool to disseminate information globally and exchange ideas during the pandemic when time is critical and knowledge is frequently updating," said Jennifer Kwan, a family physician in Burlington, Ont.

Kwan built a following during the pandemic posting daily summaries of COVID hospitalizations and deaths — information that was buried in complicated spreadsheets and lengthy reports issued by various public health units.

But the future of Twitter as the defacto hub for health information and professionals has been thrown into question since Elon Musk acquired the platform in April, promising to relax content moderation and reinstate suspended accounts.

Hitting reset

Since the sale became final in October, Twitter has seen a rise in hate speech. The platform's coveted blue verification checkmark, previously reserved for vetted public figures, briefly became available for anyone to buy for \$8 a month, leading to a wave of imposter accounts. One imposter, posing as the drug-maker Eli Lilly, claimed the pharmaceutical giant would make insulin free, driving the company's share price down 4%. Advertisers jumped ship, and massive layoffs at Twitter slashed through key moderation staff, executives, and engineering teams, raising doubt about the sustainability of the platform and sparking an exodus to alternatives.

In a sample of 566 physicians who were previously active on Twitter, 75% were still posting on the platform as of mid-November, according to a social media monitoring report from health care consultants at ZoomRx.

Some high-profile users like Kwan, who stepped back from regular posting in May, were already reconsidering their use after two years of constant pandemic updates and amid rising harassment of health advocates online.

A few have welcomed Twitter's decline as an opportunity to shutter their public

profiles in favour of private chat groups with colleagues.

These groups are more difficult to find and join, and thus more local and insular, Kwan said. "Public forums allow patients to understand the medical world while contributing their own perspectives, and a part of this dialogue may be lost."

However, many health professionals and organizations are sticking with the platform — some because there's no obvious alternative, some because they don't want to lose their existing networks, and others, like cardiologist Eric Topol, as a way to "counter and stand up to misinformation."

"There's still block and mute," Topol tweeted. "Don't give up hope for improvement."

United States Food and Drug Administration Commissioner Robert Califf said that he would not leave Twitter, noting that the FDA "continues to use Twitter for good and do everything in our power to protect the public from potential harm."

The controversy surrounding Twitter has underscored how dependent public health and medical circles have become on the tool for getting their message out.

"We are talking about a [private] social network's loss impacting on the delivery of public health in Ontario," said Yoni Freedhoff, an associate professor of family medicine at the University of Ottawa.

Freedhoff said he is "very quick to mute and block," and as a result, his timeline "hasn't changed all that much." However, he has noticed fewer of the voices he used to see regularly, "because they are either gone or pulling back from the platform."

"It really should not have been that Twitter was necessary, required, or beneficial

for the metering out of public health during a pandemic. Yet I think it was — and that’s a statement not about the value of Twitter as much as it is about the failure of public health in Canada.”

Health professionals, scientists and the public increasingly rely on social media pressure to get the attention of media and policymakers “in a way they can’t ignore,” Freedhoff said. “Without a tree to be shaken as far as trying to move the leaves, I think if Twitter disappeared altogether, there would be far less influence on public policy during emergent times.”

Freedhoff has also made connections through the platform that have led to real-world collaborations on research, knowledge translation, and advocacy.

“The ability to not just collaborate but simply ask questions of some of the world’s foremost experts is a very useful thing for people in a whole host of fields,” he said.

That’s especially true for people who otherwise lack access or influence, including those experiencing poverty and homelessness, said Naheed Dosani, a palliative care physician and assistant professor in the department of family community medicine at the University of Toronto.

“It’s been a great way to also bring about public awareness of topics that sometimes are not covered by traditional mainstream media,” Dosani said. “In some cases, it was only covered by traditional mainstream media because you were able to raise awareness through Twitter.”

Diversifying online footprints

Hive, Mastodon, and CounterSocial have all seen surges in sign-ups since #RIPTwitter and #GoodbyeTwitter started trending online. Audio-based chatrooms like Clubhouse and Discord have also been touted as alternatives. Many clinicians already use TikTok and Instagram to share information, while Facebook’s private groups and Reddit’s many subgroups dedicated to medicine provide forums for connecting with colleagues.

Fragmentation of audiences and information to other platforms will require different approaches to health information and advocacy, said Shana MacDonald, an associate professor in communication arts at the University of Waterloo who studies the impact of social media. “It’s just going

to take probably a little bit of time for everybody to acclimatize themselves to the differences between the platforms.”

Facebook and LinkedIn sit at greater extremes of personal and professional life than Twitter, while Reddit and Mastodon are more decentralized in their structure, with subgroups and servers focused on specific topics and communities, and varying rules for access and posting.

It’s still “up in the air” what Mastodon will become because there needs to be a larger number of users to play around with the platform and see what emerges, MacDonald said.

For example, “hashtags only emerged [as a key feature of Twitter] because Black feminist activists understood it was a way of really quickly gathering a community through a searchable function — that was an invention of users,” she said. “Mastodon may end up having functions that people explore and turn into really useful practices, but we just don’t know.”

For physicians who want to reach a general audience and are comfortable being the star as well as the creator of their content, Instagram and TikTok are the best Twitter alternatives, MacDonald said. However, these platforms favour video content, requiring a different set of skills and more time for content production.

It’s not yet clear what could replace the role Twitter has served as a tool for medical newsgathering and dissemination, MacDonald added. “We’re losing a centralized place for expert voices. If Twitter actually goes bankrupt and it doesn’t exist anymore as a platform, we’ve lost a massive archive of knowledge. We have a cultural history and a medical history embedded in that site that may not stand the test of time.”

As the the host of CBC Radio’s *White Coat, Black Art*, emergency physician Brian Goldman said he uses Twitter to track “what important ideas are entering the zeitgeist.” The platform also serves as a workaround for many clinicians to call public attention to issues without running afoul of their institution’s media relations departments.

“People realize that when they stuck their neck out [on our show] that their hospital administrator or local health region were listening. They would contact them and talk to them about whether

they wanted to be so candid on a national radio show. Social media bypasses that,” said Goldman. “I have found that it’s easier to be braver and more honest on social media than it is on a national radio show.”

Others argue that disentangling the media’s codependence with Twitter as both a source and a competitor isn’t necessarily a bad thing.

“Gone would be real-time feedback, criticism, and perspectives on stories. Gone would be a universal venue for breaking news. Gone would be screenshots of the best bits from stories. Gone would be the easy access to sources and experts and interviews conducted by DM,” Jack Shafer wrote in *Politico*. “All true! But where is the catastrophe? Might journalists be forced to use their phones again?”

For all Twitter is touted as a public forum, Shafer noted, it remains “a very elitist institution.”

According to a Pew Research Centre study, only one in five Americans use Twitter, and the top 25% of users by volume write 97% of all tweets. Meanwhile, research into the followerships of local health departments suggests they’re more likely to be followed by other health and governmental organizations than by individuals.

Dosani said the crisis at Twitter has prompted some of his colleagues to start “diversifying their contributions to their online footprint.”

“Regardless of the platform, there will always be a need for physicians and other health workers to be active on this platform,” he said. “It’s part of our accountability to society to be there to present scientific and evidence-based information, to address health policy issues and to support, at a macro level, the improved care of people in this country. I think we have a responsibility and duty to be online, regardless of which platform it is.”

Diana Duong, CMAJ

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