

saving face?



Facebook's reputation as a responsible steward of personal data took a major hit with the Cambridge Analytica scandal. But contributors to its vibrant patient communities don't appear to have taken their (very personal) business elsewhere.

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SINCE ITS 2004 FOUNDING in Mark Zuckerberg's Harvard dorm room, Facebook has traversed a gilded path to success. In June, more than 2.5 billion people used one of the company's apps, which includes Facebook, Instagram, WhatsApp, and Messenger. The company is, by any reasonable definition, a juggernaut.

Facebook, with its 2.2 billion monthly users, seemed unstoppable — until the Cambridge An-

alytica scandal. The contretemps accompanying the discovery of the British consulting firm's clandestine collection and peddling of data harvested from Facebook dovetailed with fear over the spread of "fake news" and inappropriate meddling in our digital spaces.

In turn, this brought to the surface generalized anxieties about data privacy and personal privacy online. After all, if the product is free, the user is



the product — so we have been paying for Facebook with our data. In late July, seemingly as a result of anxiety and a weaker-than-expected Q2 report, Facebook stock plunged more than 20%, erasing more than \$120 billion in market value in one day.

General privacy-related agita notwithstanding, it was unclear how the Facebook-Cambridge Analytica scandal might affect one of the biggest growth areas for the platform: online health communities. These communities, many of which are hosted on

Facebook pages, have become increasingly popular over the years, providing a platform for patients and loved ones to learn about an illness, seek resources and support, and connect with others.

But there was concern within the health and pharma world that outwardly vocal patients would cut back on their online community activities and there would be a dampening effect on patients' willingness to participate in internet disease forums. Four months after Zuckerberg testified before Congress about the Cambridge Analytica affair, where does Facebook stand with patients and caregivers?

NO NEWS EQUALS GOOD NEWS?

Early returns on Facebook engagement suggest that, for many online health community operators, the Cambridge scandal didn't significantly impact the way they go about their business. "I was expecting to get more questions, but it has been business as usual," says Amrita Bhowmick, chief community officer for Health Union, which operates 18 condition-specific online communities, each with its own public Facebook page. According to the company's data, the weekly organic reach of those pages has increased 61% on average in 2018 compared to 2017, with the volume of engaged users increasing 5%.

Sue Simon, president of the Hepatitis C Association and a patient advocate in Health Union's Hepatitis C community, still sees Facebook as an invaluable resource. "Facebook provides an already built forum for HepatitisC.net," she explains. "It brings in multiple patients who are looking for information and support about hepatitis C. Other patients who have joined can benefit from the public discussions in a safe environment."

For Simon, the concern about personal privacy is "overblown," though she's quick to recognize that others may feel very differently. It's one thing to share compromising data about oneself online, it's another thing entirely to share personal experiences.

She points out anonymity is of far greater concern where stigma stubbornly persists, such as in the LGBTQ or substance-abuse forums. But, as Bhowmick suggests, there may be some ancillary benefit to a public page where all issues can be discussed openly. "We publish a lot of content about the realities of living with a condition to normalize those issues," she says. "Having the public page gives you the benefit of being completely transparent."

Jack Barrette, CEO and founder of the Wego Health network, also anticipated a Facebook mass exodus that never quite occurred. In late March, Barrette published a blog post entitled "For health communities, Facebook is too important to delete," a bit of prevent defense that argued the majority

Given the benefits and risks of Facebook from a privacy standpoint, what advice would you give other patients?



Melissa Adams VanHouten Nothing functions quite like Facebook groups. I have found no other community site which equals the flexibility and options Facebook offers.

of people in health communities “would not have found each other if not for Facebook.” In the post, he concluded “deleting Facebook isn’t just impractical, it’s undesirable.”

But since then, Barrette thinks the concern over privacy on Facebook has been a non-event, at least in the health space. Traffic to Wego’s private Facebook pages has not declined and patient-led communities have not migrated to a new platform. Which begs the question: Is Facebook irreplaceable?

DAMAGE IS DONE

In May, Andrea Downing, a moderator for a private Facebook group for women who carry a gene mutation associated with a higher-risk breast cancer called BRCA, discovered a Google Chrome extension that allowed anyone to download names, employers, locations, email addresses, and other details of all 9,000 people in the group. Downing contacted the security researcher Fred Trotter, who found closed Facebook groups had a privacy loophole that made it possible for third parties to discover the names of people in them, and that third-party marketers were using applications and browser extensions to harvest the information en masse.

After being alerted to the problem, Facebook closed the loophole in June. But the damage had been done. The BRCA group elected to change from a closed group to a secret one, and discussion on the page is “very quiet right now,” according to member Casey Quinlan, a writer and policy consultant on open science, open data, and patient-driven health-care system transformation. “There are much more active conversations on Twitter of late. Facebook feels like a ghost town,” she says.

Facebook’s responses to other privacy-related concerns have been wanting. In July, the @BraveBosom Twitter account, which is run by Downing and Jill Holdren, another BRCA member and community data organizer, posted screenshots depicting cyber bullying from hackers who had gained access to a

closed Facebook group of sexual assault survivors that had 15,000 members.

“Instead of dealing with the hackers,” the account wrote, “Facebook chose to delete the entire group.”

After Facebook’s stock tumbled in late July, Dave deBronkart, a leading advocate for patient engagement and data ownership who is better known as “e-Patient Dave,” noted the company may have good reason to be worried. “Its only advantage is that everyone is already there,” he says, “which is perhaps its great vulnerability, especially if they’re really not competent at security.”

Asked if she would start a group on Facebook now, Quinlan was blunt. “Absolutely not. Facebook has always been creepy in their use and sale of user data, encouraging users to share all of the things so it could better sell those users like warehouses full of widgets on the open market. It’s their business model: Selling user data to whoever hands over money.”

DeBronkart adds, “If the company is not competent at keeping bad actors out, and word gets out, why would anyone want to discuss anything private there if alternatives exist?”

The problem, at least from the perspective of the data privacy hawks, may be that alternatives to Facebook are hard to come by. It’s true that, in terms of growth, Facebook may have hit a ceiling. The company’s Q2 report showed monthly users were up just 1.5% and daily users 1.4%, down from Q1’s 3.1% monthly and 3.4% daily growth. User growth, especially in the most-profitable North American region, has effectively plateaued.

But that’s because there aren’t any more people. About 65% of the total population of the U.S. and Canada uses Facebook at least monthly, so the fact the company isn’t losing users is a clear sign of health. Buttressing this outlook is that the lower revenues Facebook projected in its Q2 report may have an alternate explanation: While total revenue growth rate decelerated 7%, Facebook CFO Dave Wehner stated on an earnings call that total expenses for 2018



are expected to grow 50% to 60% over last year as the company spends more to combat disinformation campaigns and other bad actors on the platform.

Viewed in sequence, this series of actions looks more like the doings of a company with titanic strength and self-assurance. Facebook still has by far the biggest slice of the social media pie and patient leaders report little change in how they use the platform. As Stratechery's Ben Thompson has written, "At the end of the day, Facebook took a massive hit by choice. The company is not maximizing the short-term, it is spending the money and suppressing its revenue potential in favor of becoming more impenetrable than ever."

'BUILDING GLOBAL COMMUNITY'

And Facebook's growth may be evolving in a direction that makes it more amenable to online patient groups. Zuckerberg is famously — maybe even naively — optimistic about Facebook's mission to connect the entire world. In a 2017 earnings call, the CEO sketched out a road map to enable "more meaningful groups to get formed," each with an "engaged leader," to meet Facebook's five-year goal of helping 1 billion people join meaningful communities on its platform.

Zuckerberg also posted a manifesto titled "Building Global Community," in which he wrote, "We recently found that more than 100 million people on Facebook are members of what we call 'very meaningful' groups. These are groups that upon joining, quickly become the most important part of our social network experience and an important part of our physical support structure. There is a real opportunity to connect more of us with groups that will be meaningful social infrastructure in our lives."

That sounds a lot like the utility patient advocates and community leaders found in the platform. Melissa Adams VanHouten, an advocate for patients with gastroparesis, manages a private Facebook group with more than 21,000 members. After the Cambridge



Analytica scandal, VanHouten reported there were some people who suggested reforming the group on another site, but that idea was quickly dismissed by the majority of members. (Her comments came in response to a survey posted by Wego Health.)



"I think it caused our members to think about the value of Facebook," she wrote. In another comment, she added, "I've found no other community site that equals the flexibility and options Facebook offers."

Maria Thomas, a patient leader with hyperhidrosis, added, "The use of Facebook to bring awareness and support to those who need a voice can't be understated. If all these platforms were to disappear tomorrow, where would that leave us with our advocacy efforts?"

And for some community leaders, change is just hard — especially if you are already accustomed to sharing private details with a wide public. "I'd like to say I've gotten more cautious, but I haven't — I already put my life out there for the world to see," says MarlaJan Wexler, who writes about living with lupus and other issues at the Luck Fupus blog. "If you put something on the internet, it's not private, no matter how private you think it is. I was freaked out when I first read the privacy breaches, but it didn't really change how I operate my blog and business."

Wexler shares her posts on her social media pages and notes Facebook drives the most traffic. She started blogging in 2012 as an outlet for the anger and confusion she felt after her diagnosis. For a while, it was just "free therapy," until a reader reached out to say Wexler's writing had helped her through something, too. That flipped a switch for Wexler: She realized chronicling her personal journey could be a conduit to a greater community, and even a reason for her illness to exist in her life.

"As it's continued to grow, I realized I have a much further reach with Facebook than blogging alone," she adds. "I'm not saying it's right to sell our data, but if you're going to be part of the online community, you have to go in with your eyes open." ■

If Facebook was to become less popular, which alternatives would you use to communicate?



Maria Thomas Social media is a powerful tool, but if all these platforms were to disappear tomorrow or the algorithms change for the millionth time, where would that leave us with our advocacy efforts?