Grindr faces fury for sharing HIV data (Update)

3 April 2018, by Maggy Donaldson

Experts had greeted with enthusiasm efforts from the self-proclaimed world's largest gay dating app to promote regular HIV testing and status disclosure—but the effort backfired badly with the revelation that Grindr was sharing the data, prompting calls for a boycott.

The West Hollywood, California-based dating app, which claims 3.6 million daily active users globally, confirmed Monday it had been sharing users' personal data—including HIV status—with third party software vendors.

The revelation dovetails with a furor over lax personal data protection at Facebook.

The social media giant has come under withering scrutiny since it became known that a British consulting firm, Cambridge Analytica, harvested tens of millions of its users' personal data to create voter profiles for Donald Trump's presidential campaign.

Grindr chief technology officer Scott Chen sought to distance the dating app's public relations mishap from the Facebook scandal, calling the sharing no more than "industry standard practice."

He said Apptimize and Localytics, the companies that used Grindr's data, were simply tasked with software optimization and "under strict contractual terms that provide for the highest level of confidentiality, data security, and user privacy."

But a wave of advocacy organizations and users say the revelations are a serious violation of trust and privacy—with some worrying the news could undercut recommendations from HIV prevention experts to regularly get tested and disclose HIV status with potential sexual partners.

One Grindr user who identified himself as Danny said he originally thought the dating app's option to disclose HIV status was "great," also lauding frequent reminders on the app to get tested.

"As an HIV negative man, I still had lingering anti-HIV sentiments, but with these blatant disclosures, I was forced to learn," he told AFP. "I really thought that Grindr cared about the gay community, and was forcing us to have an important dialogue about our health and safety."

He called Grindr's sharing of the data "a slap in the face."

"It's sad, because I think that it did drive important conversations within our community."

The AIDS Healthcare Foundation (AHF) echoed that sentiment, calling Grindr's data-sharing "an egregious breach of confidentiality laws," demanding it "immediately cease and desist the reckless practice."

"It is extremely unfortunate that those men who have been courageous enough to share their HIV
status, be it positive or negative, on their Grindr profiles, may have now had that most personal data indiscriminately shared by Grindr," said Michael Weinstein, the AHF president.

'Key role' of apps

Approximately 1.1 million people in the United States live with HIV, according to the US Centers for Disease Control and Prevention—among them an estimated 166,000 people unaware of their status.

The CDC recommends that everyone ages 13 to 64 get routine annual HIV testing, adding that sexually active gay and bisexual men could benefit from more frequent tests.

In 24 US states people aware that they are HIV positive are legally mandated to tell partners, according to the health agency.

AIDES, a French HIV-advocacy organization, called for boycotting Grindr in light of the news—but emphasized that sharing HIV status on a dating app before meeting can "allow HIV-positive people to avoid a possible rejection when they announce it verbally," helping to "normalize the perception and image of HIV-positive people."

Dan Wohlfeiler, a public health expert who directs the organization Building Healthy Online Communities, said open conversations about HIV are vital—and "apps play a key role in helping those conversations happen."

"We also hope that apps help users make informed decisions as to how their data are being kept safe."

Natasha Babazadeh, a law fellow at the Electronic Privacy Information Center, emphasized that Grindr must be transparent about how it is using the data or risk losing consumer trust.

"Just as users have begun deleting their Facebook accounts after the Cambridge Analytica controversy, dating app users will similarly delete or extensively restrict their use of such apps," she said in a statement to AFP. "If corporations fail to protect their users' data they will face the ramifications."

For his part, Danny said he "will think twice before using Grindr again."

"There are plenty of ones that gay men can use that aren't sharing our HIV status," he said. "These are the ones I'd turn to first."

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