Patient Influencer Perspectives
on Social Media

WEGO Health Landscape Survey
Q1 2019
Introduction

In 2017, we published a comprehensive Behavioral Intent Study which revealed that 87% of patients will ask their physician about a medication if they learned about it from a trusted patient influencer. The study revealed that patient influencers – recognized leaders on social media – are playing a critical role in the choices patients make in relation to their own health journey.

This year, we decided to take a closer look at how patient influencers themselves are engaging with social media. We wanted to learn what influencers say about the importance of social media in the patient journey, how they are dividing their time between various social channels, and which organizations in the healthcare industry they are choosing to follow. We were also particularly interested in understanding how usage patterns are changing in view of privacy concerns and overall perceptions of trust among the leading platforms.

We surveyed 412 patient influencers across dozens of chronic, complex and rare health conditions in the U.S. Among the most notable findings, the majority continue to turn to Facebook on a daily basis, despite concerns over the company’s business practices. The vast majority say their motivation is to connect with their peers in patient communities – both publicly and privately.

In addition, we found that nearly half of those on Facebook have modified their privacy settings or now use the platform less than in the past. They are also more discerning when it comes to choosing how they share certain types of information on Facebook, electing to use private groups or direct messaging more frequently.

While patient influencers rely heavily on social channels to navigate various aspects of their health journey, they engage less with pharma companies on social media than they do with other entities in the health care industry. For example, 29% of patient influencers follow a pharma brand if they are on that brand’s therapy. By contrast, 92% follow one or more health advocacy organizations. Nearly 50% follow a health care provider, such as a physician, clinic or hospital.

Our findings suggest that life sciences companies face a unique challenge when looking to engage with patients online. A key takeaway is the need to work through social media channels outside their own. As we learned in 2017 with our Behavioral Intent Study, their best hope, at least for now, may be in working in close collaboration with patient influencers – the leaders in patient communities who have earned the trust of their peers, and have the followers to prove it.
Key Findings

Patient influencers rely on social media to make health decisions

- Nine out of ten patient influencers say that online communities play an important role in their health decisions
- Nearly half say online communities play a "very" or "extremely important" role
- 87% say social media is critical to the future of the patient communities
- 88% of patient influencers have shared a medication experience on social media; nearly seven in ten have shared both a positive and negative experience

Pharma continues to lag behind when it comes to social media engagement

- Only three out of ten (29%) of patient influencers follow a pharma brand on social media for a medication or therapy they take
- 19% follow a pharma brand for a medication or therapy they do not take
- By contrast, 92% of patient influencers follow a health-related advocacy organization
- Nearly 50% follow a health care provider such as a doctor, clinic or hospital
- 66% of patient influencers subscribe to one or more channels on YouTube, but fewer than 10% subscribe to a channel sponsored by a pharma brand
Key Findings

Despite privacy concerns, Facebook remains social network of choice for patient influencers

- 98% of patient influencers use Facebook and 90% say they use it daily
- 94% are members of a health-related Facebook group
- 89% use Facebook posts to share health information publicly, and 84% use Facebook groups
- 37% have changed their profile settings due to privacy concerns
- 3% of patient influencers have either stopped using Facebook or deleted their account due to privacy concerns

When it comes to trusting social media platforms with personal data, Twitter ranks highest

- Patient influencers trust Twitter and Instagram most when it comes to personal data, but Facebook and Pinterest outrank YouTube and Snapchat
- Out of the six most commonly-used social media platforms, Snapchat ranked lowest when it comes to trust
- If Facebook went away tomorrow, 34% of patient influencers say Instagram would be their next choice for connecting with peers in their condition community; Twitter was next in line, with 26%
Key Learnings

This summary of our first Quarterly Landscape Survey for 2019 includes some key learnings for life sciences companies that are looking to more effectively engage with patients through social media. We’ve called out some of these learnings in the pages that follow with a icon. They include:

* Nearly half of those surveyed (48%) are sharing health information privately in closed groups. While traditional social media marketing is unlikely to reach patients who use those channels, UGC-style content created by patient influencers may be one way to break through to a broader captive audience.

* The online sources patients most frequently turn to for health-related information are not necessarily the sources they trust the most. The findings suggest that many patients start their research journey in social groups in order to gather insights from their peers or to seek support. But they turn to other sources to learn more, such as a health care provider or a website such as Mayo Clinic or WebMD.

* Nine in ten patients state that online communities play an important role in their health decisions. Yet pharma websites are among their least-trusted resources. By contrast, online patient communities are among the most trusted. This suggests that patient influencers are one way to connect authentically with patients online and build a brand’s sentiment and trustworthiness.
Patient Influencers Rely Heavily on Social Media to Collaborate

95% of patient influencers use social media to advocate on a specific health condition or topic.

52% of patient influencers contribute content to the online health community at least daily.
THE INFLUENCE OF SOCIAL: CONSUMPTION

Sources for Health-Related Topics

Social media sites are a primary go-to resource for staying on top of health-related topics for patient influencers. Only 3 in 100 influencers turn to pharma sites.

**TOP CONDITIONS OF FOCUS FOR PATIENT INFLUENCERS**

1. Chronic Pain
2. Autoimmune Diseases
3. Mental Health
4. Anxiety
5. Fibromyalgia
6. Cancer
7. Multiple Sclerosis
8. Rare Disease
9. Rheumatoid Arthritis
10. Depression
Most Trusted Sources for Health-Related Topics

Patient advocacy organization, HCP websites and health portals top patient trust rankings. Pharma websites and YouTube rank the lowest.

Social media sites are the primary go-to resource for staying on top of health-related topics, but they rank third when it comes to being the “most trusted” source.
When it comes to overall usage of social media by patient influencers, Facebook, YouTube and Instagram are the top three destinations.

When it comes to daily usage of social media, Facebook is by far the dominant channel, with 9 out of 10 influencers using it at least daily.

Despite privacy concerns, Facebook remains the dominant social media channel for patient influencers.
The influence of social consumption

When it comes to connecting with other patients who share a condition, Facebook, Twitter and Instagram are the top channels for patient influencers. Snapchat is the least used channel for condition communities.

More than 80% of patient influencers turn to social media to connect with peers and access support.

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<th>Platform</th>
<th>Access to Support</th>
<th>Access to Health-Related Information</th>
<th>A Therapeutic Place to Vent</th>
<th>A Place to Escape</th>
<th>A Place to Connect</th>
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Connections and support are primary motivators.
94% of patient influencers say that online communities play at least a "somewhat important" role in their health decisions.

48% say that online communities play a "very important" or "extremely important" role.
Who’s Winning the Race for Followers?

- 9 in 10 patient influencers follow an advocacy organization
- Nearly 50% follow a health care provider
- 20% to 30% follow a pharma company, with more following a brand if they are on that specific therapy
THE INFLUENCE OF SOCIAL: SHARING

Top Social Channels for Sharing Health-Related Information

Facebook and Twitter are the top social media channels for sharing health-related information, but blogs and Instagram are close behind.
Sharing a Medication Experience on Social Media

• While nearly 7 in 10 patient influencers have shared a medication experience on social media, 13% were exclusively positive, compared to 5% that were exclusively negative.
The Trust Factor

Public vs. Private Information Sharing

When it comes to sharing health information, 4 in 10 messages are shared privately, through groups or direct messaging.

For patient influencers, the decision to share information publicly or privately depends largely on the type of content being shared.
THE TRUST FACTOR

Which Social Media Channels are Trusted Most

Among patient influencers, Twitter and Instagram are the most trusted platforms when it comes to protecting personal data.

Although Facebook and Instagram are both owned and operated by Facebook, Inc., patient influencers trust Instagram over Facebook when it comes to their data.
Privacy Concerns and Facebook

55% of patient influencers say that privacy concerns have not changed their use of Facebook.

37% have changed their privacy settings.

3% have either stopped using Facebook or deleted their account.

- No change
- Changed my privacy settings
- Use it less
- Spend more time on other social channels
- Other
- Stopped using it
- Deleted my account
THE TRUST FACTOR

Which Social Platform Would Replace Facebook

- **34%** of patient influencers say Instagram would be their top choice if Facebook was no longer an option.
- **26%** would opt for Twitter.
- **23%** would choose websites that host patient discussion groups or forums.

Nearly a quarter of patient influencers will choose patient forums, should Facebook no longer be an option – many of which may be private.
Engaging with patients where they are on social media makes sense for life sciences companies, but it’s a formidable challenge. Patients spend little time on pharma social channels and rely on numerous other trusted sources for information and support.

WEGO Health helps life sciences companies by collaborating with patient influencers to conceptualize, create and share content that can drive high-value actions on social media. We combine the power of consumer insights and patient-driven content with the science of influencer marketing to deliver scalable engagement across patient communities.

Drawing upon human-centered design principles, WEGO Health’s end-to-end services enable biopharma companies to seamlessly collaborate with vetted patient influencers on the development and execution of digital marketing and communications campaigns, specifically those intended to drive awareness and adoption of new therapies, treatment options, and patient support programs.

Want to discover how? Visit wegohealth.com to request a consultation with a member of our team.