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SOCIAL MEDIA AND HEALTHCARE

The social media influencers your patients are turning to before they get to your clinic

Instagram and TikTok accounts of patients with lived experience of their conditions are the new "Dr Google." **Stephanie Santos Paulo** speaks to four "patient influencers" about misinformation, medical gaslighting, and paid-for promotions

Stephanie Santos Paulo *editorial registrar*

Tilly Rose was "a medical mystery for over 20 years," discharged from hospital several times with no clear diagnosis to explain the symptoms that had plagued her since age 10. "I began sharing little snippets of my life behind the hospital curtain on my Instagram," she tells *The BMJ*. That was in 2020; Rose's Instagram account @thattillyrose now has more than 106 000 followers.

"At my most desperate, I posted on Instagram and asked the world for ideas," she says. Replies from medical professionals, researchers, and patients all over the world flooded into her inbox. After looking into every suggestion she received, she was led to a doctor in Germany and has since had three surgeries after diagnosis of multiple vascular compressions, a condition in which blood vessels are compressed by surrounding structures, compromising normal blood flow.[1]

"Instagram saved my life," she says.

Rose is one of many "patient influencers" who have amassed large followings on social media by sharing personal stories of their conditions and care that foster a sense of authenticity and emotional connection with followers.[2] Patients and doctors alike have been consulting search engines for answers to unexplained medical problems for years, but social media platforms such as TikTok and Instagram are now superseding "Dr Google." In a 2022 survey of 2000 adults commissioned by the US pharmacy discount company CharityRx, one in five Americans said that they consulted TikTok before their doctor when seeking treatment for a health condition.[3]

Influencers form online communities that act as a support network for patients who believe that they can't get sufficient access to doctors or feel dismissed by them. But there is concern that some influencers may propagate harmful health related behaviours and decisions by spreading misinformation, promoting products that may have no evidence base, and being influenced themselves by conflicts of interest around paid commercial partnerships.

Access and advice

Unlike many of his Instagram followers, Liam Robertson had never heard the words "ulcerative colitis" when he had it diagnosed. "I was going to my doctor saying, I'm bleeding from my bum. And he was saying, there's nothing wrong with you. I did that for three years."

Robertson, whose page @livingwithulcerativecolitis has 9300 followers, has since received as many as 100 direct messages in a single day, many from people who suspect that they too have ulcerative colitis. Drawing on his own experience of the condition, he has advised patients on preparing for medical appointments, highlighting the importance of recording specific symptoms such as number of stools passed per day, presence of mucus or blood in the stool, and dietary triggers.

"It's almost like a strategy to help them," Robertson tells *The BMJ*. "I don't feel like they should need that, but we do."

Lily Mae, whose Instagram account @chronicallylil details her life with diagnoses of Ehlers-Danlos syndrome, endometriosis, and vascular compression syndrome, says that several of her diagnoses came about because of her online community, now with more than 11 500 followers. "Other patients shared their experiences, symptoms, and advice, and it gave me the knowledge to advocate for myself and bring up certain conditions to my doctors," she says.

Robertson adds, "I think partly that people are finding social media better for answers because it's not easy to get hold of a medical professional." He's not wrong: patients hoping to see a specialist NHS doctor in secondary care can expect to join a waiting list of 7.4 million people.[4] The government's 18 week treatment target, which aims for 92% of patients to start non-urgent treatment within 18 weeks of referral, hasn't been met since 2016.[4]

Misinformation and commercial partnerships

But influencers have come under fire for promoting diagnostic tests that lack evidence of benefit in healthy populations, carrying risks of overdiagnosis and overuse.[5] Doctors have expressed concern about patients who have opted for alternative treatments in place of conventional evidence based medicines for conditions such as diabetes, on the basis of misinformation found online.[6]

Robertson has seen a "big movement" of influencers on social media encouraging people to come off their medicines for conditions such as ulcerative colitis—suggesting, for instance, that it can be "fixed by stopping eating rubbish foods."

Some influencers may face consequences for spreading inaccurate health information, while others go unchecked. In June 2025 the UK Advertising Standards Authority declared the social media influencer Chantelle Knight to be in breach of UK advertising rules after she shared a TikTok and paid-for Facebook post promoting SaffPro, a supplement containing saffron, as an alternative to medicine for attention deficit/hyperactivity disorder.[7, 8]

The effectiveness of such advertising regulations on tackling health misinformation is dubious, however. "Existing breaches of advertising rules often result in little more than warning letters or content removal, with limited deterrent effect," write Raffael Heiss and colleagues in a *BMJ* analysis.[9]

Social media influence may also be leveraged to promote products for commercial gain, such as paid partnerships between influencers and drug companies.[2, 10] "Patient influencers act as a form of interactive direct-to-consumer advertising," said Erin Willis in 2023, commenting on a study she coauthored on how influencers communicate about medicines on their social media.[2] Willis, an associate professor of advertising, public relations, and media design at the University of Colorado Boulder,[11] is also a coauthor of the related new analysis in *The BMJ*.[9]

Curative bed sheets and mushroom tea

Robertson points to one company that sells "grounding sheets"—bed sheets that purport to reduce inflammation in the body. "A guy said that he cured his ulcerative colitis with this bed sheet," says Robertson. "The scary thing is, they're selling a lot of them."

Another influencer promoted a mushroom tea that he says cured his Crohn's disease. "He's all over the internet now," says Robertson. "Almost a million pounds in sales he's made from this Crohn's disease 'cure.'"

Robertson also warns that the word "influencer" can be problematic, as it emphasises "influencing someone's decision to buy something as opposed to influencing someone to make the right decision about their health." He adds, "I don't think I've ever promoted a product purely for direct monetary gain, aside from my own books and the nutrient support product I developed. Whenever I post content that I've monetised as an influencer, I always disclose it, either verbally within the post or by using 'Ad' in the caption."

Jen Moore, who posts about endometriosis and adenomyosis on her Instagram account @jen.dometriosis, says that she's "extremely selective in the partnerships I do accept, which are always disclosed in the manner set out by the Advertising Standards Authority." She adds, "Branded content is always put forward as my personal experience or as a potential option to look into—never as medical advice or promises of results.

"I've built the trust of thousands of patients, and that's something that I don't take for granted or ever want to misuse."

Lack of nuance—and growing need for regulation

Robertson says that even when influencers try to share evidence based information, it can be hard to capture important nuances when making short form content. He explains, "If you're wanting to snap your attention on a five second clip, you can't put much information in that. It's a responsibility. I think you need to be really careful."

Some countries are introducing regulations to moderate health related content on social media. *The BMJ*'s new analysis[9] argues that measures such as the EU's Digital Services Act can hold large online platforms accountable for user content that poses health risks,[12] whereas France and Italy take a different approach by targeting influencers directly, such as issuing fines for posting content that breaches rules.[13, 14]

In China there are reports of a new law introduced in October 2025 that requires online influencers to show relevant credentials, such as a degree or professional certification, before posting about regulated topics such as health, finance, or education.[15]

Heiss and colleagues write, "All of these measures face obstacles . . . There is no one-size-fits-all-solution." They argue that effective moderation of health misinformation will require "collaboration between multiple stakeholders, particularly governments and social media platforms."[9]

Younger people may be particularly receptive to health advice from influencers who have no medical qualifications. In a 2025 survey of 16 000 respondents across 16 countries conducted by the communications company Edelman, a third (33%) of Gen Z and early Millennial participants (aged 18-34) said that content creators with no medical training had influenced their health decisions, which compared with only 9% of those aged over 55.[16]

"Medical gaslighting" and the patient-doctor divide

Even when patients receive health advice from a real life doctor they may come away feeling dissatisfied with what they receive, and they may turn to social media to air their grievances.

"Medical gaslighting" has become a popular term on social media (search for "#medicalgaslighting" and you'll find over 46 000 Instagram posts, as well as many hours' worth of TikTok videos), and it has even been recognised in academic literature.[17] Moore explains, "It's when a medical professional of any kind diminishes, questions, invalidates, or makes you feel like what you're experiencing isn't correct or that you're not a reliable narrator of your own experience." She lists the term on her Instagram biography.

On the other hand, doctors may be unconvinced by the value of online patient communities. "['Influencer'] is a bit of a dirty word in certain circles, including clinical ones," says Moore, who prefers to emphasise her roles as an educator, author, and campaigner when speaking to medical professionals. "Doctors are very sceptical of what's happening on social media; patients are very sceptical of what's happening in a doctor's office."

She explains, "The mistrust is understandable—but it's something that we have to embrace and repair. [Using social media] opens a dialogue that you just can't have in a 10 minute appointment. It's a huge, huge opportunity to start rebuilding that trust between patients and clinicians."

This is why she facilitates sessions with medical students at Cambridge University, teaching them about the patient experience of endometriosis and adenomyosis. "The work I try to do, through social media and offline, is to bridge that gap and almost be a relationship therapist between the two," says Moore. "Unless we involve clinicians in what we're trying to do, nothing's going to change."

She emphasises the role of patient influencers in signposting followers towards medical professionals. "I'm just laying out the information from experts and saying, take this to your medical team and talk to them about these options," she says. "I'm not actually trying to diagnose anybody or tell them which treatment path to take. That's a doctor's realm, not mine."

Lily Mae concludes that doctors also need to engage with patients who share their stories online. “I wish healthcare professionals would listen and engage more with patient communities online,” she says. “There’s such a wealth of firsthand knowledge being shared—real stories, symptoms, and lived experiences that could help improve care if more providers took the time to understand them.”

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