TuSalud

New AI Tools Are Helping Some People Manage Long COVID

RTHM and TurnTo recently debuted long COVID intelligence platforms. Some have found them helpful, but others are concerned about AI.

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Key points you should know:

- Some people with long COVID are using artificial intelligence (AI) tools like ChatGPT, as well as new long COVID-specific AI products from RTHM and TurnTo, to make sense of confusing symptoms, follow the latest studies, and inform care teams who don't have long COVID expertise.
- Navigating an expensive healthcare system with a complex and stigmatized disease, some users say these tools are their only option for parsing dense and rapidly evolving scientific research quickly and keeping track of their own complex symptoms.
- Medical experts say the technology can be helpful if used with caution, but advise users to be aware of common pitfalls, like bias or hallucination, which could mislead people into pursuing experimental treatments that could be risky for them.
- Some users say they're conflicted about AI's ethical and environmental impact and wish they weren't forced to use technology that compromises their values.

For about two years, 26-year-old Taylor H. has been bed- and housebound, facing confusing and ever-evolving long COVID symptoms. Her initial cognitive dysfunction has worsened, giving rise to new issues like dizziness, eye strain, and sound sensitivity. Doctors and tens of thousands of dollars in lab tests — which typically come back normal — have done little to guide her.

But recently, she's used a new tool she says finally paints a clearer picture of what's going on in her body. Instead of calling her doctors' offices, she types detailed questions about her symptoms and treatment options into an artificial intelligence (AI) app on her smartphone browser that scans

her medical records and evaluates the latest research.

One day, it reassured her that her runny nose might not be a new viral infection — which could significantly set back her recovery — but instead the result of poor sleep. On another, it explained she might be a good candidate for a clinical trial exploring tirzepatide for long COVID. Lately, she's been asking about fibrin amyloid microclots, and whether her symptoms and lab test results suggest she might have them.

Taylor is among a small but growing group of people with long COVID looking to technology to manage their own care. It's not exactly a new approach — people with complex chronic conditions have turned to online forums and chatbots like ChatGPT for answers for years. But in recent months, two companies have begun beta testing and publicly debuted AI assistants specifically tuned to long COVID and related conditions.

Without AI, "I'm unable to conduct my own 'smell test' to determine if a certain treatment seems like a good fit for my case," due to debilitating symptoms that prevent her from extensively browsing the internet or trying out new drugs or therapies, Taylor wrote to The Sick Times in an email. But AI has meant "I CAN conduct my own research without having to spend hours scanning research articles and interpreting data and drawing conclusions."

Taylor uses a tool called the "intelligence platform," developed by RTHM, a telehealth company focused on long COVID and complex chronic illness. RTHM's free service — which the team calls a "copilot for health" — interprets patients' own descriptions of their health along with uploaded medical records and suggests potential new treatments based on the latest research.

Another health tech company, TurnTo, recently launched "Turny," marketed as a "sidekick" that draws on medical research and patients' and experts' perspectives to answer questions, like whether certain experimental therapies could be effective for long COVID. It also delivers personalized weekly updates on the latest research, new clinical trials, and online and local events.

Some people with long COVID whom The Sick Times interviewed also said they've used OpenAI's ChatGPT to summarize long COVID research. (The company updated its consumer usage policy in October to clarify that it shouldn't be used for medical advice "without appropriate involvement by a licensed professional." OpenAI did not respond to The Sick Times' request for comment on any long COVID-specific usage policy.)

AI has been used in the long COVID space in other ways: Some clinicians and researchers are experimenting with AI embedded in electronic medical records to help flag long COVID cases from a vast list of symptoms, while others have identified potential treatments to study in clinical trials. These forms of AI are designed for use by medical research institutions, instead of by consumers and patients.

These tools are coming online as AI's entry into healthcare sparks heated controversy. Major health insurers, like UnitedHealthcare, have used the technology to justify denying insurance

claims despite medical need. Researchers have warned that AI can reinforce systemic bias against certain patient groups during clinical care, especially if primarily trained on historical data. And despite improvements, the technology is still prone to hallucination, meaning it can convincingly present false medical information as fact. That's in addition to artificial intelligence's massive environmental toll, from processing queries to cooling data centers.

Still, there's an acute shortage of clinicians well-versed in long COVID, and even fewer who have time to stay up-to-date on the latest research, which comes out almost daily, said Nisha Viswanathan, director of the University of California, Los Angeles's long COVID program. Waitlists for long COVID clinics can also be months or years long — and many are closing, increasing pressure on remaining clinics.

If used responsibly, AI tools that reference medical literature could help people with long COVID advocate for themselves if clinicians dismiss their symptoms or suggestions, Viswanathan said. "Just knowing the treatments are out there" can be helpful for people.

How these tools work

Both RTHM's and TurnTo's tools are designed to be conversational, meaning they ask and answer questions in plain language instead of medical jargon. Depending on the tool, users might type or use voice-to-text to ask questions like, "Would hyperbaric oxygen therapy be an effective treatment based on my symptoms?" Or, "Should I ask my doctor about low-dose naltrexone?" Both companies emphasize that their content should be viewed as suggestions and educational information, and not diagnoses or prescriptions.

"Folks really need access to expertise, to the knowledge base," said Jennifer Curtin, RTHM's co-founder and chief medical officer. AI, she added, could potentially help "scale expertise and scale care, at a price point that works for more people."

Clinicians and scientists don't fully understand long COVID's biological roots, so Curtin said RTHM is experimenting with integrating other outside data sources, including thoroughly vetted social media posts, into its knowledge pool. (Posts drawn from Reddit, X, and other sites, Curtin said, would be presented to users in a separate, clearly labeled tab, and could include people's testimonials on certain drugs or therapies.)

The team hopes to "get as much data as we can and put it together." The company's eventual goal, she said, is creating a detailed personalized care plan that users can bring to their clinicians, and predicting which treatments could work for a particular patient.

Curtin said some RTHM AI users—there are currently a few thousand—find the tool helpful in explaining long COVID to doctors who don't have experience with the disease, or who dismiss their symptoms as anxiety. At a recent informational webinar, RTHM users said they asked the tool to interpret complicated test results and suggest further imaging that could clarify treatment options, among other uses. (RTHM's online pharmacy service offers telehealth consultations and prescriptions for $50 to $60 per assessment, depending on the medication. That's less expensive

than its $1,000-a-month clinic, which has a $1,500 one-time onboarding fee and a 3-month minimum commitment.)

TurnTo, a start-up based in Australia, currently offers free three week trials of its AI products, some of which are beta versions; after that memberships are $2 a week. RTHM's intelligence platform is currently free; founders told The Sick Times they'll likely continue to offer a free tier, with a restricted number of queries, and later roll out paid subscriptions for greater or unlimited usage.

TurnTo began as an app where patients could discuss certain complex conditions, beginning with cerebral palsy. At the time of publication, TurnTo did not connect The Sick Times to any long COVID users for interviews.

Taylor, who heard about RTHM on TikTok, beta tested the AI tool and uses it almost daily to research trials and treatments. And while she currently struggles to pay for her current medications, treatments, and doctors' visits, she said she would likely pay for the service if she had to.

"It would be disappointing, but the benefit I've received from using RTHM AI is too great to lose," she said. "Long COVID is all about risk-benefit consideration. I'd have to say that the benefit I receive from the platform would outweigh a monetary risk."

The downsides of AI

Though both sites emphasize that users' sensitive, identifiable data won't be shared outside the platform, experts warn that AI tools accessible on the internet can inadvertently expose medical information due to poor security or patchy privacy policies, especially if they work with third-party advertisers or marketing firms.

Since it doesn't directly offer medical care and isn't based in the United States, TurnTo is not legally bound to HIPAA, the privacy law that typically prohibits providers, insurers, and their business associates from sharing medical records without permission. Founder Jessica Dove London said the company still "upholds" HIPAA and European data privacy standards, aiming to "meet and exceed user expectations as to how we deal with sensitive health information."

RTHM's telehealth service, in which clinicians evaluate patients virtually, is separate from its intelligence platform; Curtin maintained that its AI tool is still HIPAA compliant even though it does not directly offer medical care.

TurnTo disclosed on its site that personal information may be shared with commercial partners if users opt in to communication from those partners, but London clarified to The Sick Times that it does not allow third-party advertisers to access user chats. TurnTo's site disclosed that some personal and sensitive data may also be used in research datasets.

Some users told The Sick Times they're also careful to weigh the environmental impact of AI against its benefits. Climate scientists warn that generative AI tools use five to ten times the amount of energy of a single internet browser search. Training AI models requires significant data center usage, and individual queries are processed at data centers, which need an extensive water supply to be cooled.

"I know a lot of people, especially in the chronic illness community, who are very attuned to intersectional justice issues, are rightly concerned about AI," said Maya Lindemann, a person with long COVID who also voluntarily beta tested RTHM's tool. "I think it's important and worthwhile to be thoughtful about when and how we use it."

For example, the environmental impact of AI queries might be less than the carbon footprint of traveling to specialists across the country, especially if many of these visits are unhelpful, Lindemann added. RTHM and TurnTo both echoed this argument to The Sick Times.

Difficult trade-offs

Ezra Spier, founder of Long COVID Studies and a technology consultant who has long COVID, warned against placing the environmental burden on long COVID patients instead of holding tech companies accountable for industry practices. "It's really unfair to ask individuals to make this horrible trade-off, this choice between the environment and healing themselves."

And while these tools can certainly help people parse dense scientific literature, it's not clear how well they identify bias, he added. For instance, several peer-reviewed papers indexed on PubMed, which these tools could draw from, conclude that exercise could potentially treat long COVID and ME — a belief that subsequent studies, as well as widespread experiences of people with these diseases, have challenged.

"I'm concerned that patients who don't have access to robust healthcare, or who don't have a high level of scientific literacy, or who maybe are just in a very difficult situation looking for help…might act on info or guidance from the models that could be potentially harmful," Spier said.

Unchecked, these tools could also push very sick patients with limited financial resources toward expensive, unproven therapies, Viswanathan warned.

Curtin acknowledged that RTHM's intelligence platform is built on top of general AI models, which were trained on a massive amount of data that could include small or flawed medical research studies. But RTHM's team of human experts curates which studies the tool prioritizes as references in conversation with users, she said. The tool has specific instructions not to recommend graded exercise therapy to users with suspected post-exertional malaise, despite many flawed studies supporting its use, Curtain said. And it recommends that users get screened for PEM before trying any exercise-based therapies.

Viswanathan urged users to be especially aware of potentially harmful drug interactions, and to carefully weigh the amount of evidence supporting an experimental treatment against its out-of-

pocket costs.

“If you read [about a treatment] on one of these AI portals, will you then aggressively pursue something or take money out of your savings thinking you’re going to get an answer, and then be out thousands of dollars and still not better?” she asked.

“It is a great tool to start the conversation, but I think ultimately it needs to be used as an adjunct to your healthcare providers.”

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