

White Paper

The Evolution of Health Literacy: Challenges and Opportunities for Clinical Trial Recruitment in the Digital Age



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Executive summary

Health literacy has made progress over the past decades, especially with the advent of the internet and social media. However, there is still room for growth in this crucial area. In a time where many people get their health knowledge from social media, misinformation and disinformation can spread like wildfire, making it difficult for users to know who and what to trust.

Sponsors looking to recruit patients for clinical trials need to take these factors into account or risk missing out on patients who fit their protocols. Meeting the right patients where they are in terms of health literacy as well as background and location could make a big difference in convincing them to participate.

The status of health literacy

In 2020, the Centers for Disease Control and Prevention updated its definitions of personal and organizational health literacy to fit with the US government's Healthy People 2030 initiative. Health literacy is central to one of the initiative's overarching goals to "eliminate health disparities, achieve improved health for all, and attain health literacy to improve the health and well-being of all."¹ The CDC definitions are as follows:



Personal health literacy is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.²



Organizational health literacy is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.²

How health literate are we in this digital age where information is at our fingertips? If we are to assess this,

we first need to look at how literate we are in general as a society.

According to 2024-25 statistics from the National Literacy Institute, about 21% of US adults are illiterate, and 54% of US adults have a literacy below sixth-grade level.³ Earlier data from 2022-23 suggest 50% of Americans read so poorly they are unable to perform simple tasks such as reading prescription drug labels.⁴ Also, a 2018 study estimates that approximately 80 million US adults have limited health literacy and observes that this can adversely affect the quality of their healthcare and lead to poor health outcomes.⁵

These statistics set an uphill battle for the cause of health literacy. However, the American Speech-Language-Hearing Association makes the point that health literacy encompasses more than the written word; it includes understanding health information that patients see or hear, whether from their physician or from videos on social media. Besides format, other elements that play a role in health literacy include experience with the healthcare system, cultural and linguistic factors, and how information is communicated.⁶

Social media: blessing and curse

To that end, online social media platforms appear to have great potential for improving health literacy. They connect billions of people, and user involvement and retention on the platforms are typically high compared with traditional websites. Plus, because social media users take an active role by creating their own content, social media can be more impactful than conventional web-based solutions. Studies show social media's potential as a tool for health interventions through activities like supportive discussions with friends and family, healthy behavioral change and counseling, and health research.⁷

The flip side is that social media can quickly distribute and amplify health misinformation and disinformation (information deliberately intended to mislead from the facts). Even if the health information as initially distributed is clear, accurate, and easily accessible, some users' responses to it may be emotional, expressing skepticism or distrust and even twisting the facts into myth.

According to one study analyzing data from the 2022 Health Information National Trends Survey (HINTS), over one-third of social media users (35.61%) perceived high levels of health misinformation, and roughly two-thirds (66.56%) reported high perceived discernment difficulty, meaning it was very difficult for them to distinguish between true and false information. Interestingly, those with lower subjective health literacy were less likely to report a high amount of perceived misinformation, while those with lower subjective digital literacy were more likely to report a high perceived misinformation amount.⁸

Those who perceived high levels of health misinformation were less likely to share general health information on social media, use social media information to make health decisions, and use social media information in discussions with their healthcare providers. Those who perceived high levels of discernment difficulty were more likely to use social media in health decisions and healthcare provider discussions.⁸

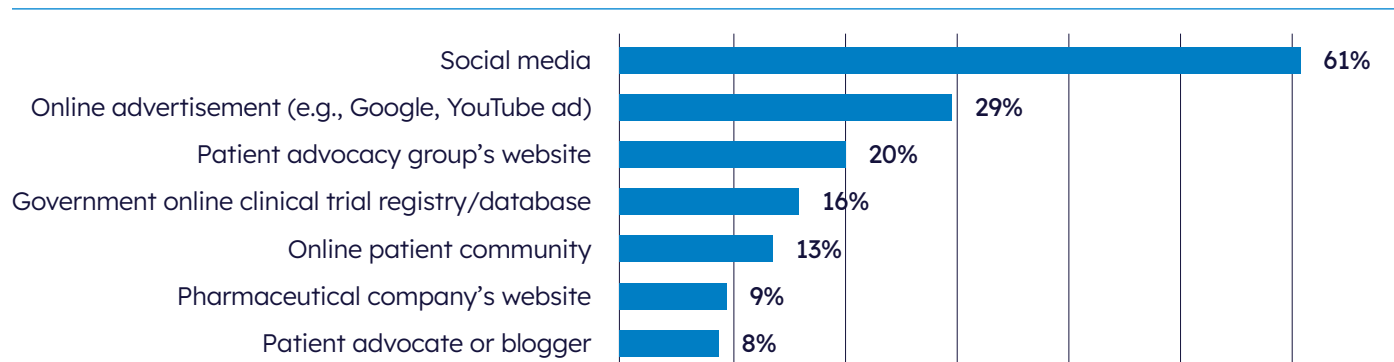
Behtash Bahador is Director, Health Literacy at the Center for Information and Study on Clinical Research Participation (CISCRP), a nonprofit organization that provides resources designed to educate and empower patients and the public to participate as partners in clinical research. Bahador says he thinks far more people are health literate today "due to the availability of information online and through social media channels." However, he adds, "many others are led astray, and many others are not able to utilize the improvements that we've seen online and in social media quite yet." He notes that dubious sources of information and the rise of misinformation have made the ability to use information for decision-making "far more difficult.... It has become more staticky, let's say."

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Bahador cites CISCRP's 2023 Perceptions & Insights study, which found that roughly two-thirds of respondents who had never participated in a clinical research study and who had heard about a study in the past six months obtained information about such studies online. Breaking it down further, 61% of those who obtained the information online received it from social media (see Figure 1).⁹

Figure 1. Online sources of clinical trial information

Where online did you see or hear about a clinical research study?

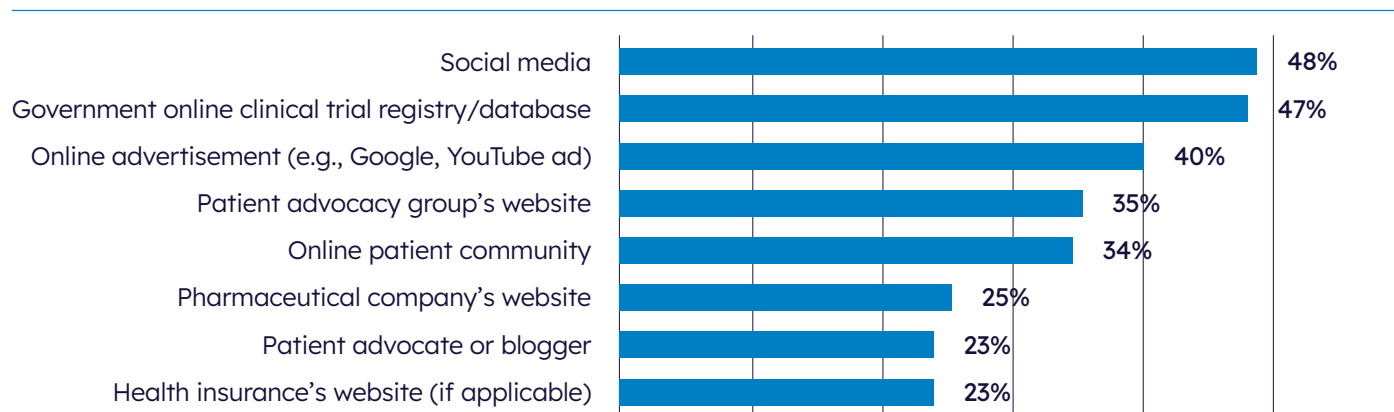


Source: CISCRP 2023 Perceptions & Insights Study

Interestingly, when those who never participated in a clinical study were asked where they would prefer to learn about such studies, 58% said from their doctor, as opposed to 46% who said they would prefer to learn about them online. Of those, 48% said they would rather hear about them on social media. (see Figure 2).⁹

Figure 2. Online clinical research awareness preferences

Where online would you most prefer to learn about a clinical research study?



Source: CISCRP 2023 Perceptions & Insights Study

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‘TikTok made me do it’

Dezbee McDaniel is Co-founder and CEO of CliniSpan Health, a platform that leverages and builds influencer technology for clinical research equity.

McDaniel says he believes people are more health literate now than they were in the pre-internet era. “I think of it as a ‘meet people where they are,’” he says. “Pre-internet, obviously people were at different places and you can meet them there. But I think that it’s easier to meet people where they are online from an organization standpoint.... There are so many more options and there are so many more ways to access them.”

He adds that social media statistics indicate people are being educated by online content. “‘TikTok made me do it’ is something I’ve heard so many people say, and it’s very real. I do believe that things like TikTok have offered a chance for people to get health education in a way that they never had before.”

McDaniel says TikTok is one of the most popular social media channels for obtaining health information — everything ranging from recipes to more academic learnings. He says TikTok is one of the platforms CliniSpan influencers use to educate people. “I would say TikTok and Instagram would be the top two social media platforms,” he says, adding that social media in general is where he sees more people obtaining health information due to its communal, peer-to-peer nature.

As far as more traditional online channels like websites and offline channels like in-person events, McDaniel says they are still useful, but that pairing them with social media is the best strategy. “As much as we’re digitally inclined to educate people and reach people, we would never suggest to only do that. ... I think the more that you can be present, the more you give yourself the ability to relate to the community and actually get them activated on their health.”

Decision-making also part of health literacy

Bahador says online tools have improved the ability to instantly access and understand information on conditions, symptoms, and treatments. However, he notes, health literacy goes beyond simple understanding of health information: It also encompasses the ability to access and use that information to make health-related decisions.

“Using the information to make health-related decisions is I’d say a little bit more of the challenge,” he says. To that end, Bahador says he believes patients have become more self-empowered, and organizations are responding to that while “also understanding their equal and complementary role in health literacy, which is organizational health literacy. They, too, are looking to support patients,” he says.

“I would say the environment for shared decision-making between patients and providers or professionals is far more equitable. Again, that’s partially because patients are now empowered with more information, and they’re more empowered to know what it means to advocate for oneself. It’s not just having the information, it’s knowing what you are entitled to in terms of time and appropriate communication, et cetera. And I think many organizations have responded to that.”

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Pros and cons of AI

As is the case throughout the health landscape, artificial intelligence (AI) has made its presence felt in terms of health literacy. The good news is that AI has expanded access to health information and made it easier for people to obtain answers to their health questions in natural, accessible language.

However, there are limitations to the technology. Depending on what sources are used to train it, AI is capable of producing inaccurate information and amplifying misinformation. Plus, consumers vary considerably in their access to AI, their abilities to determine the accuracy and reliability of AI-generated information, and their trust in and responsiveness to the information provided by AI.¹⁰

From the consumer side, McDaniel says, AI is “raising potential for more distrust. ... I think AI is making it harder for someone who is already wondering about how to improve their health literacy.

“You have to wonder now if this chatbot I’m talking to is AI, or if it’s a human. And you have to wonder ... whether you can trust that thing you’re engaging with. ... I think

AI from the consumer side maybe makes the ability to create trust a little bit more difficult potentially.”

“In terms of patient agency, AI-powered search tools are certainly helpful, but that comes along with a sort of AI literacy of its own,” Bahador says. “Understanding the limitations that the AI has, but also its functionality and capabilities. So, how to use it effectively and then not sort of necessarily treating it as end all, be all sorts of information. They still need to check, particularly when it comes to making health-related decisions.”

Even with that, Bahador says he believes AI-enabled search is better than the traditional “Doctor Google” sort of search. “Having an interaction with an AI-powered tool is definitely far more effective. And I think the tools are consistently being refined and they have their disclaimers and they do try to provide appropriate context. But again, there are of course limitations, and I worry that people think of it as sort of an easy button when in certain situations it should not be treated as that.”

McDaniel sees more upside with using AI on the organization side, as it can provide advantages like

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streamlining operations. “Then again, the main concern from my perspective is ... if you engage with patients, how does the AI make the patients feel? How do they perceive AI in your business? If it makes them more comfortable, I would say keep using it. If it makes them less comfortable, I would urge people to think about whether or not it’s something that they actually work into their strategy, or to test how they could make people more comfortable with that.”

McDaniel says he finds the distrust level to be high with AI “because it makes it harder to know if something is real. And I think that was already a problem on social media. ... This is something we have to worry about, that we make sure our influencers are sharing only trusted info.”

Those involved in improving health literacy should work to strengthen people’s skills and abilities to locate and use trustworthy health information. They can also look for opportunities to more actively contribute to AI training and algorithms to ensure availability of accurate, trustworthy health information and reduce the risks of misinformation.¹⁰

“I think it’s a matter of educating and truly empowering individuals to be able to critically evaluate and ascertain

for themselves the level of trust that they should put into any output coming from AI,” Bahador says. “What we know about AI is that at any time it can start to hallucinate or just not provide consistent information.... That’s just a result of the way that these tools work. So, for making a personal health decision, something that is consequential ... you can’t be only using an AI tool for that. However, you can certainly accelerate the process of seeking resources, seeking information and then better preparing yourself to have interactions with a medical professional.

“So, I would say it’s trustworthy as a tool. It cannot be trusted as a decision-maker for you.”

McDaniel says if the industry is going to continue to invest in AI integration, it needs to figure out how to create trust. “I think the challenge ... is to figure out how to make people comfortable with that because we don’t want people engaging with our health systems, with AI, where they’re even more uncomfortable than they already were because then we’ll see even less participation in the health system. I think if we focus on that, we can still increase the participation and the trust while also increasing the AI integration at the same time — if industry makes it a point to really pay attention to how is the patient responding to AI ... and not just how do we as industry feel about AI.”



Reflect the patient's situation

According to McDaniel, there are two specific ways clinical trial recruitment materials and communications can accommodate diverse health literacy levels among target populations. “Number one is reflection, making sure that they reflect the people that they’re trying to reach,” he says. “I think it may be a little harder on the former side, but if you have multiple groups — like by race or by age or any other demographic — that you’re trying to reach, I think the materials should reflect that specific group as closely as possible.”



This includes taking native language into account for materials and communications. When interviewing participants for a study on how language and health literacy impact health information seeking experiences, 82% reported at least one negative experience when searching for health information. The participants were divided between 487 English speakers, 256 Chinese-language speakers, and 257 Spanish speakers. Chinese-language speakers were more likely to express frustration during search, while Spanish speakers were more likely to report having difficulty understanding the information. Those with limited health literacy reported more effort, frustration, concern about quality, and difficulty understanding information. These findings reinforce the importance of communicating in the languages native to the population being recruited for the trial.¹¹

McDaniel acknowledges that these actions are harder for marketing teams, as it requires more time and

investment to develop materials and obtain insights. “But in our experience, what we found is that it does sometimes take a little more investment upfront, but that in the long term the ROI, the value is there for the consumer and for the organization.”

He adds that sponsors should “create niche communities and create content that speaks to just that community. Don’t try to have one study ad that reaches five different communities,” he cautions. “That makes it much harder to resonate with them.”

The second way to accommodate diverse health literacy levels, says McDaniel, is through patient involvement. “I think that a lot of times former companies involve patients in the process too late,” McDaniel says. “They’re getting feedback on something that they’ve already developed versus they really should be getting feedback in the development process.”

McDaniel suggests having a committee of three to five patients working with trial teams to give direct feedback on what works and what doesn’t work for them. “That’s something that we have done that has warranted great outcomes for us that I would suggest the industry do.”

Bahador says one thing that has really improved in recent years with materials and communications is the use of plain language. In addition to that, he says it is important to incorporate multi-channeled, multi-layered communication formats because different people respond to different channels. “You need to have probably some video as well because people will respond to that best. You need to have some information written out [because] that’s going to be what some segments of the population respond to, because that’s what they’re used to.”

McDaniel says the social media influencers used by CliniSpan have helped improve recruitment rates among populations with lower health literacy because patients are more likely to follow and relate to them. “You can imagine that their health literacy might be similar,” he says. “So they’re getting information from someone that’s at the same level as them, and so their ability to intake and use that information is much higher. ... If a doctor is trying to speak to these same people, they might not actually adopt the information and use it as efficiently as someone on their same level.”

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According to McDaniel, patients tend to see doctors as in a class above them, which brings up feelings of inadequacy and fears of being judged. “They’re not the average person,” he says. “And the influencer feels like the average person. So, the average person wants to listen to the average person, not necessarily what they consider ‘high society,’ in our experience.”

It’s also important to speak to patients in layman’s terms, McDaniel says, suggesting the fifth-grade education level as a good benchmark. “I think once the education level comes down, there are a lot of feelings that go away. People aren’t feeling like, ‘Oh, they used a word that’s too big for me to understand. They think they’re smarter than me.’ ... You combat that by being at the same level as them. Now their guard is down and they’re ready to actually hear what you have to say and to act on it.”

Having people from patients’ communities communicate with them is also key, McDaniel says. “If someone on your team is from that community, and they have the culture and background to relate, tap into that. Have them go out and leverage that culture and background to relate to the community.”

Bahador says getting to know and understand these different groups is key to meeting their health literacy needs. “There needs to be foundational research done together with those populations, and then there needs to be continued engagement with the patient population to test materials to refine approaches,” he says. “That’s the two-pronged strategy that needs to be employed — patient community insights and involvement as well as multichannel, multilayered, multi-deliverable approaches to delivering information.”



Literacy improves health equity

Bahador says health literacy is “incredibly important” to ensuring equitable access to clinical trials — and not just for patients.

“Ensuring that everybody has a chance to access information, to understand information and to make good decisions for themselves is obviously sort of a baseline that we should already be at,” he says. “And yet we’re not. And part of that is ... the organizational health literacy. I think organizations have a continued responsibility to do everything that they possibly can to not only ensure that there are tools and information available, but that they are prioritizing the populations that are and have historically been more marginalized with regard to health inequity. That is what equity means. It’s putting resources towards those who need them most.”

“Having said that, pragmatically, I think understandably more organizations probably are approaching it as, ‘Let’s get a good baseline first so that everybody has access to good information that can help them make decisions,’ and then you put the strategies in place to then better support those populations who have been marginalized in many ways.”

Bahador observes that a digital divide still exists with regard to online and social media — particularly on the global stage. “Not all populations benefit equally ... and that’s not necessarily entirely due to access. Part of that is also ... making sure that folks are technology literate, that they are critical consumers of information.”

Bahador reiterates his view that health literacy goes beyond information — it incorporates health-related actions, particularly with regard to clinical trial participation. “Health literacy really does extend with regard to the wraparound experience of being in clinical research. And it’s the same with an individual’s health,” he says. All the questions a patient has with regard to travel, compensation, child or pet care, and trial burden need to be answered in a way they can understand.

“That’s where it ties back to the more traditional view that people have with respect to health literacy, which is ... are there clear instructions for this mobile application that you have for the clinical study, are people able to use that? Do they know how to use the concierge service? Is the information around that in plain language? ... Health literacy extends to nearly every aspect of an individual’s experience with regard to their health.”

Monitor changes in the market

According to McDaniel, when recruiting for clinical trials, it's important to operate at the same level as the patients you seek. "Are you willing to invest the time, money, effort to meet patients where they are?" he asks. "From an organization perspective, it may not in the short term feel like it's worth the investment or ROI. I would say give yourself time to see the value actualized. It's marketing. It takes time to communicate and to receive and to then act on a message."

"Related to that, take the time, energy, effort to understand where they are. There's no reason to guess in today's landscape. There's so much data available on so many things, and you can analyze it and make well-informed decisions. From my experience, I feel like pharma hasn't made the most well-informed decisions when it comes to patient communication, and I think that people are very presumptive about what a patient's wants and needs are without actually fact checking that."

McDaniel says those needs can change quickly in today's environment. "We live in a world where technology is developing so quickly, and patients' needs can change so quickly. ... It's almost like you need to keep a constant pulse on patient changes and patient needs. ... Right now, how I'm seeing it, the insights are few and far between in general. We're taking insights from two or three decades ago in the industry and still trying to assume that that is what patients need today. ... We aren't updating our knowledge and insights on what patients need and changing our strategies and infrastructure accordingly."

"Something that we've done is try to keep a constant pulse on what patients are seeing. [There's] something we do called social listening where people on social media, they post hashtags and content and we're able to feed information from that. So, if there are patients or people talking about health things on Instagram, Twitter, we're able to actually draw insights from that and then make changes and suggest that to ... companies like, 'Hey, this is what we're seeing on social media in this quarter. This is something that's super important for health right now, you might want to address that.'"

"That's something we've tried to do through influencers is keep that constant pulse on what's happening as it relates to people's health, how are they understanding their health literacy and accessing health services and things of that nature. And then how can we take that, understand it, and package it in a way that provider can make sense of it and use that knowledge and insight accordingly. So, we're trying to be that player that is keeping that constant pulse on patients, where we don't feel like that is something that we've done too well industry-wide."

McDaniel notes that when sponsors monitor the patient environment consistently, they are better able to respond to shifts. "As something changes with a patient group, if you have constant insights coming to you, then at the moment that change happens, you'll understand it" vs. not seeing it coming. "And then you're building your infrastructure, and then five years goes by and you miss that huge insight. And you're now wondering, 'Why can't we get patients in trials like we used to? Why can't we get them to act on our materials like we used to?' It's because you didn't update your insights."



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A Guide for Debunking Misinformation

According to The Debunking Handbook 2020, simply correcting misinformation online is unlikely to “fully unstick” that information. It recommends following these steps to fully and successfully debunk the false or misleading information:

- **FACT**

Lead with the factual information — make it simple, concrete, and plausible. The fact should not be more complex and should have the same explanatory relevance as the original misinformation.

- **MYTH**

Warn about the misinformation before you cite it, and then cite it only once. Repeating the myth once is beneficial to updating belief.

- **EXPLAIN FALLACY**

Explain why the misinformation is wrong as follows:

- Say why the misinformation was thought to be correct in the first place
- Say why it is now clear it is wrong
- Say why the alternative is correct

It is important to clearly convey the inconsistency to readers so they can resolve it.

- **FACT**

To finish, reinforce the factual information — multiple times if you can. Make sure this reinforcement provides an alternative causal explanation.

Source: Lewandowsky S, Cook J, Ecker U, et al. (2020) The Debunking Handbook 2020. 12–13. Available from <https://skepticalscience.com/docs/DebunkingHandbook2020.pdf> [Accessed July 15, 2025]

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