

# Impact of Mis/Disinformation on Health Care Information Literacy

[June 3, 2019 Rebecca Hill Information Literacy](#)

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In recent months, you need only look at the newspaper or watch online to see the consequences of disinformation about vaccinations. According to the [CDC](#), 555 individual cases have been confirmed for 2019. Globally, the [World Health Organization](#) declared that measles cases had gone up 300%. Because the crisis has ballooned, some states like New York have declared an emergency and mandated vaccination for those who chose not to vaccinate. Other cities or counties like in [Waukesha, Wisconsin](#) have imposed quarantine restrictions on those with measles. Many of these failures to vaccinate cases originated from disinformation disseminated by online groups about vaccinations and autism. As a result, people didn't vaccinate their kids, adding not only risk to themselves and others but also creating a public health risk too. So why did people rely on information that has been scientifically disproven and incorrect?

Currently, nearly nine out of ten adults lack the skills to understand their health care, something the U.S. Department of Health and Human Services calls, "health literacy." In the early 2000s, this concept of health literacy was defined by the National Library of Medicine as "the degree to which individuals can obtain process and understand basic health information and services needed to make appropriate health decisions." Implicit in the definition was a person's ability to understand and evaluate health care information.

Currently, [only 77% have basic or below basic health literacy](#), creating what health care experts are calling a public health issue. Why is health literacy so low? One reason is the U.S. health care system. It is a system that is "deeply and perhaps fatally flawed," said Elizabeth Rosenbaum in her book, *An American Sickness: How Healthcare Became a Big Business and How You Can Take It Back*. It's a system so dysfunctional that it takes an expert to understand it. But for ordinary folks like you and me, it can be like navigating uncharted and rough waters.

Think about it. How many times have you left the doctor's office feeling confused, unable to recall what the doctor told you or wishing that you had asked that one question you forgot to ask? The system design itself contributes to poor health literacy.

Plus having a low health literacy can complicate an individual's health care. Understanding health conditions, treatment options, or medications is hard. As a result, poor outcomes like wrong medication dosages or delayed or even failure to get treatment may result. In turn, health care costs can increase because a sicker patient costs more to treat.

When disinformation and misinformation are mixed in, health literacy further declines because not only are folks getting incomplete information; now they are getting false and often misleading information. A [2018 study](#) found that dissemination of misleading drug information through social media could harm the public. The study found that potentially misleading claims were the most frequent offenders. All these things together form a major roadblock to long term health issues too like health care delivery, policy, services, and research.

So, poor health literacy like poor education has a trickle-down impact that, if we continue in this direction, it never really improves. With complications of dis/misinformation, as we've experienced with the current measles epidemic, it only gets worse.

So, what do patients do when they can't get the information that they need? Well, they look elsewhere. The place they look? The library. [One study](#) reported that 60% of survey participants stated that libraries were among their preferred sources of health information.

For librarians, health *information* literacy is their endgame. A form of information literacy and a component of health literacy, [health information literacy](#) is "the ability to find and assess the relevance, validity, and utility of information for a participate purpose." In plain language it means librarians respond to health care questions by using the resources available in the public library or online. The problem is that for many public librarians not trained in health information literacy so supplying this help can be tricky.

How many times has a patron ask about medication, but couldn't spell the drug name? Or a patron who did not fully understand the conditions and side effects they want to explore? Some patrons get too personal, say too much about their health. So it's awkward.

Then there are the times when a librarian or patron may have differing personal conflicts over health care issues, for instance, say vaccinations. All these situations can be uncomfortable and threaten the type of information they get. Unfortunately, however, few librarians ever get the training to navigate these situations even though questions about specific diseases, drugs, alternative therapies, disease prevention or treatment options continually arise.

Still, patrons seek out libraries and librarians to answer their questions. Why?

Because health care is so personal, complicated, and maybe even controversial, asking these about health information means that patrons must have a high level of trust to ask the librarian in the first place.

[Recent Pew Research Center studies](#) show that most Americans believe that public libraries are reliable and trustworthy when meeting their information needs. In fact, 78% of adults feel that public libraries help them find information that's trustworthy and reliable. For millennials, that number is even higher- 87%. So, trust figures heavily when it comes to health information literacy. But what does that trust mean?

Matthew Sullivan, author of the study, "[Leveraging library trust to combat misinformation on social media](#)," says it remains to be seen what "trust" in libraries actually means. "In the health context, do they trust libraries in the sense of trusting themselves to find information when using a library, or trust that good information might be found there? Or would they also trust libraries if libraries took a stand on an issue or made a more concerted effort to combat mis/disinformation," said Sullivan. The question is what kind of role does the library play especially with mis/disinformation and what exactly does that role look like for health care literacy?

Dictionary.com's 2018 Word of the Year, [misinformation](#), is defined as "false information that is spread, regardless of whether there is intent to mislead." On the other hand, [disinformation](#) means "deliberately misleading or biased information; manipulated narrative or facts; propaganda." Where we have seen it the most, is online especially with the 2016 election cycle. Mostly when you look at the two concepts, their difference is the intent by the speaker or disseminator of that information.

Right now, [two-thirds of all Americans](#) access the news through their social media accounts, and approximately [46% of Facebook users](#) see news about healthcare and medicine in their Facebook feeds. According to Emily Vraga, author of several studies on health misinformation on social media, misinformation in health care is "especially problematic because it can interfere with our ability to make good health decisions," most famously displayed in terms of vaccinations where misperceptions of vaccines have stopped people from getting their children or themselves vaccinated.

In the health care, mis/disinformation in healthcare is problematic for [three reasons](#): 1) prevents individuals from engaging in behaviors that mitigate risk; 2) contributes to public health risks, and 3) prevents the public from weighing policy choices addressing these issues. Remember the 2014 Ebola epidemic when social media messages created hostility towards aid health care workers? Those messages ultimately caused trouble with controlling the outbreak. The question then: Can you solve a problem like mis/disinformation?

[A 2017 Pew Research study](#) questioned whether misinformation was an issue that could be easily solved. One expert likened it to a "social condition like crime." So, if it's not solvable, maybe mitigation is how you combat it. One method that is proven is to correct with-immediate, authenticated corrections of the mis/disinformation.

According to Vraga, corrections to misinformation on social media can have a beneficial impact on those that see it online. In fact, we've found evidence of success,

she says, on Facebook and Twitter across several health care topics. How do these corrections work?

According to Vraga, users and organizations should immediately speak up when his/disinformation is identified on social media by using authoritative sources to counter the false claims. But, the type for the correction definitely matters, says Vraga.

“Our work has so far found that expert organizations appear better able to correct misinformation than ordinary users,” said Vraga. “While we haven’t focused on librarians specifically, if they are seen as experts in a particular field or topic, I would suspect that their corrections would also carry more weight especially if combined with references to expert materials that counter the misinformation.” So, if you see someone sharing something false, says Vraga, “I recommend the “see something, say something approach to misinformation.”

What does this all mean for health information literacy? For librarians, it means updated, and current health care resources including print resources that are necessary. Also, libraries who already offer extensive computer training should train on health care information database access like Medline so patrons have access to timely medical information and can ease their print-minded reliance.

Libraries too can actively train their librarians on health information literacy techniques and practices, so staff is more at ease in answering health-related questions. Since approximately 70% of studies on healthcare show that healthcare website quality is often incomplete or inaccurate, libraries can develop programming that helps patrons tell the difference between good and bad information. Or programming that promotes functional health literacy among patrons.

Libraries, too, should create a “corrections” strategy as part of their health information literacy program on monitoring and countering mis/disinformation in health care then respond accordingly by providing authenticated and accurate information.

Most importantly, the library field needs to better understand the problem of mis/disinformation before designing solutions, says Sullivan. “We need to begin examining and testing our claims that libraries are trusted and that libraries have a role to play in fighting misinformation.”