

Health Literacy

A Research Report by the W2O Center for Social Commerce at Syracuse University's S.I. Newhouse School of Public Communications

The Approach To This Study:

Definitions, Research Questions, Methodology

Defining Digital Health Literacy

- *What it IS (*Sub-topics within digital health to explore):*
 - Understanding of insurance coverage, premiums, and networks
 - Basic disease understanding post-diagnosis
 - Medication adherence (most relevant to our pharmaceutical clients)
 - Navigating coordinated care networks (e.g. which doctor do I see for what?)
 - Preventative care management (e.g. what is needed and why to prevent disease?)

- *What it's Not:*
 - *Expert knowledge of disease states and managing health from a condition-based standpoint*
 - *Knowing every doctor or nurse in one's network/location*
 - *Having opinions on the quality of hospitals*
 - *Being an expert on searching WebMD*

Methodology

The topic of digital health literacy hasn't yet been analyzed to scale. We used social media and online news as a look into the digital zeitgeist of our time, using AI and Machine Learning to analyze text and pull out key themes that emerged from the conversation.

- *Quantitative:*
 - Social listening
 - Twitter, Reddit, Forums
 - Text AI / Topic Modelling / Theme Clustering / Language Gap Analysis / for observed 'behavior' via social discussion and engagement
 - Search Cluster Analysis

- *Qualitative:*
 - Social listening
 - Twitter, Reddit, Forums (?)
 - Reading samples
 - Verbatim / quote extraction
 - Coding

- Within qualitative social listening, reading samples, and verbatim / quote extraction, the following questions are aimed to be addressed:
 - What are online audiences engaging with, talking about?
 - Wants, needs, points of passion, pain, hopes, concerns.

- Do we see signs of awareness, understanding gaps?
- Are there gaps between the questions asked by online audiences vs. the content found?

Top Line Findings:

The democratization of information is accelerating. Healthcare consumers are actively seeking out an ever-wider range of information from an expanding range of resources, influencers, and voices to proactively manage their health.

Companies are not THE go-to source but they can play a role in to play role of creator and convenor in elevating the voices and sources that are by creating and space for their stakeholders to hear from who they want to, who they value and trust.

Key Findings

1. The democratization of information is speeding up – patients turn to a wide variety of sources in their moment of need.
Patients turn to authoritative and reputable sources for well-defined healthcare topics. (Tell me logically)
On less-defined or less-understood topics, they crowdsource information via social media. (Talk with me emotionally)
2. There is a need and desire for additional diverse voices in health literacy, who can authentically speak to historically underserved populations
Consumers are looking for companies to:
 - Recognize that sometimes you are not always the best spokesperson: their stakeholders are
 - To play role of creator and convenor: create and space for their stakeholders to hear from who they want to, who they value and trust
 - Elevate those voices and sources
3. They see search and earned media as a “tell me” interaction, whereas social media is a “talk with me” interaction. They crave engagement and conversation on social media, rather than having information pushed
4. Patients turn to earned and social media for different topics, reflecting patient desire for information vs. conversation
 - Earned media leads on managing health, mental health, understanding diagnoses
 - Social media leads on understanding insurance, navigating care networks

What does this mean?

Patients see themselves as their own best health advocates and stewards of their health. Those who do not respect or work with that perspective are destined to be irrelevant in the eyes of patients.

Digital Health Literacy in 2020:

2020 Changed Everything...

...and COVID-19 and DE&I dominated and converged healthcare conversation topics

The Macro Issues of 2020 Saw a Normally Diverse Set of Healthcare Topics Converge; Inter-Related Topics Dominated in 2020

*This is the **media landscape** that companies operated within and needed to break through:*

- **2018:**
 1. Opioid Crisis
 2. Pricing
 3. Recalls
 4. Trump & Politics
 5. FDA
 6. Pharma Mergers & Acquisitions
 7. PBM/Payer Mergers & Acquisitions
- **2019:**
 1. Politics
 2. Women's Health
 3. Research/Trials
 4. Health Care System / Plans
 5. Opioid Crisis
 6. Vaccination/Anti-Vax
 7. Marijuana
 8. Mental Health
 9. Vaping / Tobacco
 10. Pricing
- **2020:**
 1. COVID-19
 2. 2020 Election
 3. Healthcare Policy
 4. Racial Divides
 5. Equity and Access

(These topics became more inter-related than ever before)

Within News/Earned Media, New Topics Driven by the Pandemic Propagated

Spikes in Earned Media Topics Were Driven Largely by the Pandemic, Reflecting Pressing Needs of the Time

- These emerging topics include:
 1. Preventative Care
 2. Vaccine Education
 3. Understanding Health Insurance
 4. Healthcare Tech & Access
 5. Serving the Underserved
 6. Understanding Diagnoses
 7. Mental Health
 8. Managing Personal Health

Coverage Came From a Wide Variety of Sources

In particular, “Crowd Sourced Learning” and “Social Messaging”-driven sources resonated during the onset of the pandemic, and re-emerged as conversations around vaccines and reopening resonated

- Notable spikes in conversation occurred in:
 1. April, 2020 from Crowd-Sourced Learning sources
 2. November, 2020 from Research and Traditional Education sources
 3. December, 2020 from Crowd-Sourced Learning sources

Information Sources Have Become Fragmented and Diverse...

...Audiences Are Looking for Authentic & Trusted Voices and Sources Who Speak To Them and Who are Like Them

We Have Moved From a Coverage To Influence Model

- The broadcast/coverage communications model of the past was typically unidirectional, opaque, one-to-few, and centered on concentrated media. A company would communicate its message through a medium communicating to many individual consumers.
- We have now moved to an influence and information model that is typically democratized, transparent, 1-9-90, and centered on hyper-fragmented media. A corporative narrative is developed consisting of engaging content and experiences, influencer relationships, and a communications strategy. Moreover, this communications strategy is aimed at creating targeted engagement from key stakeholders including patients, advocates, and HCPs.

Earned Media Highlights the Need for Voices From Diverse Audiences To Educate Patients

From targeted COVID-19 briefings/outreach to minority communities and children, to local advocacy, there is opportunity for organizations to partner with and elevate people in their communities to share important messages

In terms of health literacy conversation volume from January 1st, 2020 – December 31st 2021, total mentions in news coverage reached 29,391. Notable spikes in conversation occurred during the following months:

- a) *March*: Article about misinformation around the COVID-19 outbreak causing difficulties for patients get syndicated widely; the article quotes Dr. Ruth Parker, a health literacy expert
- b) *June*: Companies begin getting recognized for efforts in addressing health and racial inequalities, articles about improving health literacy for urban and minority communities published. Some advocates begin highlighting the impotence of funding universal childcare, highlighting concerns around future low health literacy
- c) *September*: Article suggesting kids-only COVID-19 briefings to improve health literacy goes syndicated widely. A lack of diversity in COVID-19 briefings causing lower health literacy among minorities is also mentioned

- d) *October*: An article highlighting women uplifting their communities during the pandemic gets shared widely; highlights a woman in India who goes door-to-door to improve health literacy. Company efforts to boost health literacy also get highlighted
- e) *November*: An effort by medical students to write a new Hippocratic oath that emphasizes allyship and the improvement of health literacy goes viral. Articles about health benefit open enrollment also get syndicated widely, citing a UnitedHealth Group study suggesting that improving health literacy could save over \$25B per year

Patients Took To Social Media To Share Personal Experiences, Receive Advice and Learn About Conditions That Are Either Not Well-Defined or Have Large Support Networks Already Established

77,356 tweets were compiled from January 1st, 2020 – December 31st, 2021 across Twitter and Forums to pull out the following key themes in conversation within the overarching topic of understanding diagnoses:

1. ***Sharing Experiences (34% of conversation)***: Patients used social media to share their health journeys and challenges with others, primarily on treatment area-specific forums. Discussions involved seeking out others with similar diagnoses, asking about their history with those diagnoses and seeking advice that might help manage their conditions, as well as their spirits
2. ***Cancer (22% of conversation)***: Cancer appeared as a frequent topic in understanding diagnoses. In particular, breast cancer patients tended to share information with each other most broadly, discussing test results, consultations with physicians and potential care/treatment regimens for their cancers. There was also discussion around tests and events leading up to diagnosis, such as evaluation of lymph nodes and when to seek further care and testing.
3. ***Soliciting Advice (21% of conversation)***: Patients turned to social media, including Twitter and forums, to solicit advice from those who have been in similar situations or have dealt with their diagnoses. They seek information on how to navigate uncommon diagnoses, as well as less-understood treatment areas like mental health. Beyond questions and advice about navigating the health system, they also seek emotional support and relevant anecdotes to their questions.
4. ***Dietary (17% of conversation)***: Conversations around dietary conditions and diagnoses emerged within the broader conversation, with patients asking about conditions like celiac disease and gluten intolerance, and how best to manage those diagnoses. There were also discussions around how to best manage diabetes symptoms, and how patients can find resources and information to navigate their condition.
5. ***Financial (6% of conversation)***: Some turned to social media to seek understanding on the potential future financial impact of their diagnoses, asking about costs of treatments, how to work with their insurance providers and what they should be expecting in terms of longer-term impact.

And They Use Different Channels To Seek Different Types of Information

Understanding Insurance Was the Top Topic for Search and Social, But Other Topics Showed Significant Differences

Patients overwhelmingly turned to search for questions around Understanding Diagnoses, while they took to social media to discuss Medication Adherence and Preventative Care

Search behavior was broken down into the following categories by most frequently referenced topics:

1. Understanding Diagnosis (48%)
2. Understanding Insurance (36%)
3. Preventative Care (8%)
4. Medication Adherence (6%)
5. Navigating Care Networks (2%)

They're No Longer Passively Learning...

...They're Advocating For Themselves and Actively Seeking What They Want To Find (Even if Some of That Information is Inaccurate)

COVID-19 Drove Conversation Within All Categories, With New Voices and Greater Desire for Two-Way Communication Appearing During the Pandemic

77,356 tweets were compiled from January 1st, 2020 – December 31st, 2021 across Twitter and Forums to pull out the following key themes in conversation within the overarching topic of digital health:

1. ***Understanding Insurance (34% of conversation)***: Understanding health insurance was the largest topic that emerged on social media, which saw notable spikes throughout the year caused by discussions around the accessibility/cost of health insurance, driven by political conversation as well as the COVID-19 pandemic. These conversations have since declined with a small bump from conversations around 2020 elections.
2. ***Navigating Care Networks (22% of conversation)***: The second biggest topic in the conversation, discussion around navigating care networks spiked during the onset of the COVID-19 pandemic, driven by questions and uncertainty around insurance coverage for treatments, hospital stays and testing. Patients discussed a lack of trust and open two-way communications with HCPs, as well as the desire to better understand the decisions they make with their care before committing to them. Discussions on being patients turned away from care during the height of the pandemic also made an impact.
3. ***Medication Adherence (21% of conversation)***: Conversation was steady through the year, primarily focusing on the importance of ensuring the patients (particularly mental health patients) continue to take their medication. However, most voices being elevated or engaged with were influencers outside of the healthcare realm, indicating the importance of reaching non-traditional audiences with targeted messaging.
4. ***Preventative Care (17% of conversation)***: Discussions around preventative care saw the largest growth of any topic in the second half of 2020, focusing primarily on vaccines and their subsequent efficacy, rollout and potential mandates to be vaccinated. In the first half of the year, mentions of managing health (E.g. blood pressure, weight) to potentially reduce COVID-19 symptoms also made an impact.

5. **Understanding Diagnoses (6% of conversation):** Conversations around understanding diagnoses primarily fall within treatment areas that are still being explored such as mental health and dietary conditions. Other than breast cancer, conditions with defined treatments and diagnoses did not make a significant impact, indicating those discussions still primarily sit with physicians.

Including Discussions About Healthcare Cost and Coverage, and Potential Solutions

Healthcare Cost and the Perceived Lack of Value for Cost Was a Significant Issue, Leading Some To Tout Ideas Like Medicare for All

77,356 tweets were compiled from January 1st, 2020 – December 31st, 2021 across Twitter and Forums to pull out the following key themes in conversation within the overarching topic of understanding health insurance and premiums:

1. **Cost and Debt (34% of conversation):** Discussions around the cost of healthcare, especially as a result of care needed due to COVID-19, was the most prevalent conversation within the health insurance conversation. Mentions focused on the cost of care putting wide swaths of patients into medical debt with little forgiveness, particularly during a time of declining incomes and employment.
2. **Insufficient Care (22% of conversation):** The second largest topic of conversation focused primarily on the healthcare industry's lack of preparation to deal with the COVID-19 pandemic, resulting in deaths of friends and family members. Patients wondered why they were paying so much for health insurance when they were not receiving a perceived level of satisfactory care, buffeted by a tweet from Senator Bernie Sanders that went viral.
3. **Medicare For All (21% of conversation):** Some patients used the hardships caused by the global pandemic to advocate for Medicare for All, highlighting beliefs that with public healthcare, patients' insurance wouldn't be tied to their employment status nor would payments be as high. They advocated for a "Medicare Crisis" program to be instated that would extend those benefits to a larger swath of citizens due to the pandemic.
4. **Unemployment (17% of conversation):** Mentions of unemployment primarily focused on the majority of Americans' healthcare being tied to their employment status, with patients seeking out how to continue receiving their medical care during the mass unemployment caused by the pandemic and subsequent shutdowns.
5. **Payers (6% of conversation):** Patients expressed frustration and confusion towards insurers/payers for an initial lack of clarity on coverage around COVID-19, as well as difficulties in getting their care covered and paid for, with some broadly blaming the private health insurance industry for issues they faced in receiving reimbursements for care.

And They Are Influenced Not By Industry, But By Politicians and Celebrity Activists

Influential Sources for Patients in the Conversation

Patients in the digital health literacy conversation are not largely tapped into the healthcare industry or healthcare policy influencers; they instead heavily follow public figures and celebrities discussing health. Within this set, the most influential health policy influencer was Bill Gates (ranked #36)

The following influencers represents a list of notable sources patients turn to within health literacy conversation:

1. [Barrack Obama](#): 130,146,859 followers
2. [Hillary Clinton](#): 30,965,542 followers
3. [Ellen DeGeneres](#): 79,127,563 followers
4. [Michelle Obama](#): 20,545,718 followers
5. [Stephen Colbert](#): 19,400,672 followers
6. [Rachel Maddow](#): 10,630,700 followers
7. [Elizabeth Warren](#): 6,950,623 followers
8. [Neil deGrasse Tyson](#): 14,554,984 followers
9. [Chris Hayes](#): 2,417,836 followers
10. [Emma Watson](#): 29,219,106 followers
11. [Nate Silver](#): 3,637,324 followers
12. [Jimmy Fallon](#): 51,869,039 followers

So What?

Guidance to Communications Practitioners:

Understand Your Role & Mind the Language You Use

- *Understand Your Role:*
 - Foreground your organization's role and responsibility
 - Recognize that sometimes you are not always the best spokesperson: your stakeholders are
 - Play the role of creator and convenor: create and space for your stakeholders to hear from who they want to, who they value and trust (elevate those voices and sources)
 - Recognize that relevance is co-created
 - Recognize people need to want to believe you before they will
- *Mind the Language You Use:*
 - Make it authentic, plausible – show more than tell
 - Make it a community dialogue more than corporate monologue
 - Use the language of common ground shared experience: “us” “we”
 - Dial up the science, but be plainspoken
 - More emotional than technical – human not clinical
 - Be the voice of reason
 - Make it easy to digest, difficult to refute
 - Turn facts into narratives

- Make it relevant, tangible

Respond To Stakeholders' Expectations

Stakeholder-relevant companies are...

- *...taking a stand not just making a statement:*
 - Serve the **interest of all stakeholders** not just shareholders.
 - Stakeholders want companies and CEOs to **take a stand** and speak out on cultural, societal, economic, employment, political, climate bi-partisan **issues**
 - aligned with their **values and principles**.
 - they'll **reward it** and they want to **help**.
- *...focused on action & accountability:*
 - **Action and accountability**
 - *Businesses to be a **catalyst** for real, sustainable **change** (as trust in government falls) provided it's **aligned with the company's expertise and mission***
 - *Deliver on **vision, mission, values, behaviors***
 - *Deliver on **purpose and promises** in a genuine, honest, fair, transparent way.*
 - **Focused more on Environmental, Social, Governance (ESG) more than strictly Corporate Social Responsibility (CSR)**

