Health Equity Through Health Fact-Checking: A Primer
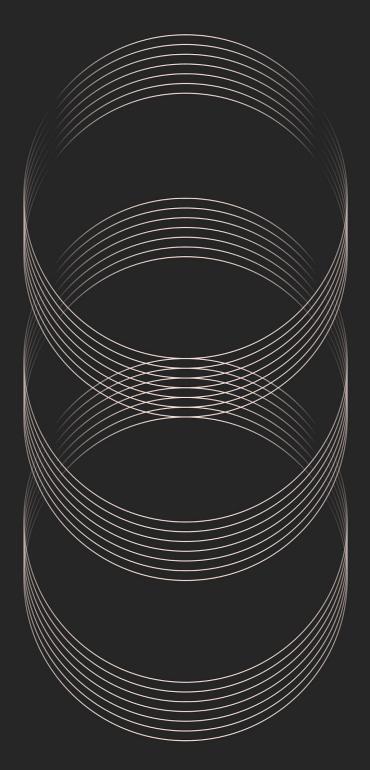
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Health & Information Equity

"Equity is the absence of avoidable, unfair, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically or geographically or by other means of stratification. 'Health equity' or 'equity in health' implies that ideally everyone should have a fair opportunity to attain their full health potential and that no one should be disadvantaged from achieving this potential."

— World Health Organization

Addressing health misinformation from the lens of health equity requires acknowledging the barriers and facilitators to accessing, evaluating and engaging with health information, and addressing the consequences that social-structural factors—including legal, political, cultural, economic systems, the availability of social supports, and factors including language, race, gender, class, income, education and access—have on the relationship between inputs (including health information inputs) and health outcomes.

Contents

The world today has more internet users than people with access to essential health services. This means that increasingly, people are seeking out critical health information online—over 80 percent of people that use the internet say they use it to search for health-related topics.

Health misinformation that users are consulting online is influencing vaccination rates and herd immunity, rates of antibiotic use, the adoption of response efforts in epidemics, and care-seeking for serious illnesses. The sharing of low-credibility content also leads to distrust—not only between health providers and their patients, but between communities and the health systems meant to serve them. Research shows that this disproportionately affects populations in low socioeconomic environments, queer communities and communities of color.

Viral misinformation that facilitates the spread of a particular health outcome or disease is known as a **"misinfodemic"**. Misinfodemics are a growing public health issue. They have recently contributed to outbreaks of measles, preventable tooth decay, and Ebola. The virality and reach in today's digital information ecosystem widens and amplifies fears and misunderstandings around health topics like vaccinations, diagnostic processes, treatments, and interventions, requiring public-health practitioners to simultaneously battle the spread of misinformation alongside the spread of disease.

As various interdisciplinary groups of academics, health practitioners, journalists and others attempt to address challenges surrounding the credibility, amplification and accessibility of high-quality health information, an increasingly central part of the conversation is fact-checking— a well-known and popular method of correcting misinformation.

Strengthening the infrastructure and resources that fact-checkers need to adequately address high risk, low-quality health content must be a priority. The impact that misinfodemics have on population health suggests it is critical and urgent to re-think and innovate around responses to health misinformation.

This report highlights four key takeaways

01

Verifying health content requires the creation and implementation of "standards of care," similar to standards that can be found in other fields in which human risks and liabilities are involved.

Health practitioners working in national and intergovernmental health organizations have regulatory bodies that ensure quality of care, protocols for responses to health queries, and guidelines for compliance to a specific standard of care. The risks associated with communicating and correcting health-specific content online may be significant enough to require an additional set of principles that align with long-standing public health standards of care.

When communicating health information, research highlights the importance of consulting experts with specialized knowledge of a specific topic. Fact-checking organizations largely do not have health experts in-house, so the time, effort and commitment offered from external sources often determines what content gets fact-checked and at what rate. Delineating the health topics that specific expertise is essential for can make content prioritization, and expert-seeking, less demanding for fact-checking organizations.

02

Standards of care for health fact-checking need to address the inequities that vulnerable communities already face. Those communities stand at greatest risk of further marginalization and compromised safety.

Health misinformation that is largely incorrect or factually inaccurate for a certain segment of the population might actually be useful or factually accurate for another segment of the population. When encountering simplified or binary fact-checking outputs, readers must have health literacy skills—which are dependent on linguistic, cultural, demographic and structural factors—to determine what information within a fact-check is applicable to their personal health circumstances, and what may be harmful.

An infrastructure for accountability is needed for the potential health outcomes of incorrect information (and information debunks), for data security violations and how they impact vulnerable populations, and for information outputs that normalize health myths through repeated exposure—an issue that disproportionately affects communities with linguistic and/or literacy barriers.

03 Health fact-checking workflows require a uniquely tailored approach that prioritizes audience safety and privacy.

Search queries for health content can be uniquely personal. Some fact-checking initiatives allow users to submit their health questions or claims in public or semi-public spaces, such as Facebook groups, WhatsApp groups or via text or instant message. This can result in the unintentional collection of contributors' personally identifying information (PII). Considering the pathways that audiences use to request fact-checks is especially important within the context of vulnerable or potentially criminalized identities, such as queer communities, or when considering the stigma that may be associated with seeking information about politicized and criminalized health topics, such as abortion or birth control.

04 Insights from the fields of behavior science and health communications can inform more efficacious health fact-checking outputs.

Much of the existing body of empirical research that focuses on fact-checking is specific to political content. Bringing together insights from public health communications and health behavior science research, though studies do not explicitly focus on fact-checking interventions, can inform more effective corrections outputs in misinfodemic contexts.

Fact-checkers stand in a unique position of practice and authority when it comes to addressing misinformation on the internet. They are ideal stewards for caution and care when it comes to addressing harmful online health content. With this role in mind, and given the increase in requests for verifications of health-related content online, the fact-checking community is an optimal group for early adoption of a health information and communications standard of care.

In this primer we look to the history of fact-checking, and traditional success metrics of fact-checking initiatives, which largely respond to the attention economy. We contrast these metrics—which may be misaligned with achieving health outcomes—with metrics from public health communications and behavior change models. We then examine the unique elements of health-specific fact-checking and the challenges faced by fact-checking organizations responding to health misinformation. We highlight the importance of a standardized set of principles that translate into improved health literacy and positive health outcomes, and don't exacerbate mistrust, inequalities or risks. In doing so, we uncover reasons for why addressing health misinformation should involve a stronger integration of public health communications and behavior science research, and may require an entirely new set of supplemental fact-checking standards.

Acknowledgements & Important Notes

Part 1

HEALTH FACT-CHECKING IN DIGITAL CONTEXTS

Today's velocity and democratization of information online is forcing historic structural change in our interactions with digital content, and in the strategies used by communications practitioners, advocacy organizations and fact-checkers to evaluate, assess, and deliver corrections for misinformation.

Processes for, and distribution of, corrections through fact-checking is relatively new; the practice did not begin in newsrooms until the turn of the 20th century, when journalism was becoming more official, standardized and objective in format (Fabry, 2017). It was developed in response to increased propaganda and a growing presence of "yellow journalism", a term used to describe newspapers that contained poorly-researched content and an emphasis on eye-catching—albeit heavily misleading—headlines (Fabry, 2017; Samuel, 2016). As a result, news desks like the "Bureau of Accuracy and Fair Play," started in 1913 at *New York World*, were implemented to formalize newspapers' relatively new commitment to fact-based reporting, and "'to correct carelessness and to stamp out fakes and fakers. They would keep track of who was making errors [and...] catch repeat offenders"(Fabry, 2017). These methods were developed in response to a moment in history punctuated by a changing media environment. New landscapes required new techniques for communicating impartiality and rigor on the part of the journalism community. These strategies were accompanied by the development of formalized codes of ethics and professional organizations.

We are experiencing a similar historical moment today. The world now has more internet users than people with access to essential health services such as primary care, dental care, or surgery.

Eighty percent of internet users currently search for health information online, and, as the ease of online connectivity increases, we expect more and more individuals to use online content as a primary source of sometimes critical health information. Amidst this surge in searches for online health information, misrepresentations and misinterpretations of scientific research, and mal-intended creation of fake health content, pollutes our online ecosystem. Medical 'quackery', or the dishonest practice of claiming special knowledge or skill in disease prevention and treatment, is as old as the medical profession itself, and, though regulated in offline contexts, is still "as popular as ever" online (Boyle, 2013[$]). Further, digital health content covering scientific research often contains overhyped, misleading headlines, accompanied by inaccurate or incomplete coverage with research limitations or conflicts of interest buried deep into the body of articles, if present at all.

Some work has been done to combat this issue. In one misinformation intervention on its platform, Facebook collaborates with different third-party fact-checking organizations to identify and examine potentially false claims. Similar collaborations are also used in decision-making about content moderation policies at Facebook and other social media platforms. (Facebook, n.d.; Koerner, 2019). Nonetheless, the Daily Beast recently reported that problematic health content is still slipping through Facebook's efforts to curb misinformation (Montgomery, 2019). Many of these initiatives also narrowly focus on addressing vaccine hesitancy, when in reality the issue of misinfodemics is much broader than vaccines alone. Health misinformation touches on a wide range of health issues from abortion to cancer, and contributes to a wide variety of real-life harm, such as an increase in tooth extractions among children as a result of preventable decay, and negative responses to healthcare measures during lethal epidemics like Ebola (Arora & Wendell Evans, 2010; Allgaier & Svalastog, 2015).

On a more foundational level, research is needed to examine how fact-checking, a process of information correction that pre-dates the internet, can be successful in addressing health misinformation in its current form—especially given the expansive and complex digital contexts through which health misinformation spreads today: via images and memes, through private messaging channels, and at rates faster than ever before (Amazeen, 2013; Africa Check, Chequeado & Full Fact, 2019).

Looking to public health strategies might be a useful path forward. Before the idea of health misinformation caught widespread public attention, health leaders were already busy addressing the challenge (Bubela & Caulfield, 2004; Diaz et al., 2002; Larson et al., 2013[$]; Seymour et al., 2015). For decades, researchers and practitioners have been responding to pharmaceutical and wellness industry-propagated health claims, as well as misinformation brought into doctors' offices by patients (Ashley & Jarvis, 1995[$]; Seale, 2003; Caulfield, 2011; Caulfield, 2012[$]; Caulfield, 2016[$]). Still today, academics and researchers seek to counter misleading claims in retracted academic papers, on social media platforms, and in private messaging spaces (Larson, 2018; Gyenes & Mina, 2018). Responses to misinfodemics should lean on these established areas of research and practice in the field of public health, whenever possible.

As symptom searches outpace expert consultations, and primary care providers are no longer the primary providers of care, the industries of health and information science will become increasingly intertwined, and their thought-sharing increasingly critical to our health and well-being.

Given today's attention economy, where clicks drive revenue models and headlines inform strongly-held beliefs, the way we communicate and correct health news requires an innovative update. Research at the intersection of information access, behavior science, and communications can help direct health fact-checking interventions towards efficacy and decreased adverse health outcomes. These insights can highlight new, engaging strategies for communicating corrections, and ways of doing so at scales that match the large volume of health misinformation traversing the web.

Next

Measuring success in the attention economy

MEASURING SUCCESS IN THE ATTENTION ECONOMY

In the field of public health, metrics for success in health promotion and communication are based on changes in attitudes, beliefs, and perceptions of social norms. Compared to corrected knowledge alone, these metrics can be used to inform stronger interventions that impact knowledge and awareness, and ultimately improve health behaviors in the longer-term (Paluck & Ball, 2010; Macpherson, 2018; Chan et al., 2017).

Today's success metrics for fact-checking are in line with traditional journalistic scales, such as engagement rates of articles, social media reach, and awards dedicated specifically to fact-checking. Measures for engagement and reach are necessary in an attention economy; knowledge transfer by public visibility is a critical method during a time of tremendous change in our information environments. However, most outputs for fact-checked information seem to meet the goals of journalists and researchers better than they do the needs of patients, patient advocates, or their communities.

Key indicators for success that fact-checking organizations have identified to improve the information environment include:

positive overall public perceptions of fact-checking organizations and the outputs they produce

journalists picking up fact-checks and integrating the findings into their reporting

reduced views of false information on social media platforms once a third-party fact-checking collaborator has identified that piece of content as misinformation

official corrections made to the public record

retracted false statements made by public figures

a concern among public figures that their language is "being watched"

(Amobi, 2018; Wangui, 2019; Mantzarlis, 2015; Facebook, 2018).

These indicators are incredibly important, especially for topics without a scientific ground truth to inform the public record. In the case of health misinformation, existing metrics for impact may need redefinition, and additional metrics that specifically examine behavior and perspective change. Could the way a fact-check is presented encourage the sharing of a particular piece of truthful content about exercise on social media? How might fact-checks change the way readers think about the prevalence of vaccine hesitancy?

Members of the fact-checking community have called for the development of more creative impact metrics, informing how and whether fact-checking outputs need to be modified in response to changing patterns around the world (Mantzarlis, 2015; Stencel, 2015). Of course, assessing the impact of fact-checking initiatives with respect to 'changed thinking', 'increased knowledge', or 'improved awareness' of a given topic is challenging, especially when trying to determine longer-term behavioral, normative or societal changes that result from verifications, fact-checking, or corrections (M&E Lab, 2019). These require strong qualitative and mixed-methods research components. Looking to existing literature reviews and aggregations of successful knowledge, perception, and awareness interventions can assist fact-checking organizations in determining which behavioral factors could lead to the impact that best aligns with their target audiences (Behavior Change Framework, 2018). This closer examination of relevant impact research and program successes can strengthen fact-checking efforts and pave the way for a greatly improved digital health information ecosystem.

Next

Applying Public Health Research & Tools

APPLYING PUBLIC HEALTH RESEARCH & TOOLS

1 / Health Belief Model

Our willingness to change our behavior corresponds with the beliefs we hold about the risks, relevance, benefits and barriers related to that change. Innovative fact-checking that addresses these perceptions can help reduce the impact of misinformation on health outcomes.

2 / Social Norms Theory

What we *think* is happening in society is a better predictor of our behaviors than what is actually happening. How fact-checks are designed can prevent the exacerbation of false perceptions and reduce unintended health outcomes.

3 / Stages of Change/ Transtheoretical Model

If a person is not ready to change their beliefs, correcting them might have unintended health consequences. Different levels of readiness may require different framings for health corrections, ideally that align with a target audience's readiness stage.

4 / Re-Evaluating Mental Models

Debunking might be most effective when a user is encouraged to update the background knowledge they used to develop their understanding of a false piece of information.

With much of the current literature focused on political fact-checking, it is necessary to better identify how cognitive biases play out when readers encounter health information. Many factors may contribute to how fact-checking may impact decisions or behaviors.

We know that presenting end-users with corrective information (fact-checks) can yield adverse effects. This can happen because of "motivated reasoning", a concept that explains how we are motivated by emotions to "protect our preexisting belief systems [...] from social and identity threats" (Young, Jamieson et al., 2017). With motivated reasoning at play, a person's likelihood of "correctly" processing a particular piece of information is related to both their ability and their motivation to do so. In addition, experts have found that belief in misinformation can strengthen if a correction triggers confirmation bias, potentially leading to backfire effects in which an individual becomes even more entrenched in their beliefs when presented with conflicting information (Nyhan & Reifler, 2010; Young, Jamieson et al., 2017; Amazeen, 2013). This pattern was recently examined with respect to political hashtags. Findings demonstrated that using hashtags for partisan or controversial issues as a communication tool can result in audiences "perceiv[ing] the news as less socially important, and are less motivated to know more about the social issues related to the [social media] post" (Ha Rim Rho & Mazmanian, 2019).

One study has offered some contrary evidence to the construct, demonstrating that the backfire effect may be *less* widespread than previously thought, particularly with regard to political topics. Study participants reviewing political statements and corrections, including some replicated from previous research studies, experienced no backfire effects through their study design (Wood & Porter, 2017). However, the authors caveat these findings, and reference the possibility that, for certain topics, when end-users are "asked at moments when ideology or partisanship, or both, are particularly salient—[it] might plausibly trigger factual backfire" (Wood & Porter, 2017).

Health may be one of these topics. Research tells us that communicating corrective information may be challenging for triggering topics with strong identity markers or deep-seated controversial beliefs (Kalichman et al., 2012; Tsai et al., 2012; Bode & Vraga, 2015[$]). One example of this is the interest in, and use of, vitamin supplements.

Safety considerations surrounding how vitamin supplement fact-checks are communicated is of particular concern, as certain vitamins may be accompanied by contraindications in treatments for conditions such as HIV or cancer. It is important for fact-checkers to be aware of such health conditions that may require extra caution in reducing confirmation bias effects (Kalichman et al., 2012; Tsai et al., 2012).

The findings of another study emphasized that providing audiences with corrections for myths such as "the flu vaccine causes the flu", using language adapted from vaccination guidelines developed by the Centers for Disease Control and Prevention (CDC), "significantly *reduced* intent to vaccinate among respondents with high levels of concern about vaccine side effects" (Nyhan & Reifler, 2015).

Further research on the impact of motivated reasoning and confirmation bias in the health context is needed to determine whether presenting fact-checks in a way that clearly visualizes a piece of empirical information as corrective is the most effective strategy. Findings from recent misinfodemic response research does reference that including a source to substantiate fact-checked information can make corrections on social media more effective, that corrections produced by health information authorities on social media are more effective than those produced by an individual, and that displaying correct information before displaying misinformation can improve perceptions or behaviors (Reichel, 2019; Vraga & Bode, 2018[$]; Bode & Vraga, 2018[$]; Vraga & Bode, 2017[$]). However, it is important to note that empirical research to date largely focuses on case studies specific to vaccine sentiment and hesitancy, and epidemic/crisis communications, with study sample populations that make findings difficult to generalize.

Though not directly tested in fact-checking contexts, there is a large body of existing public health research centered around health communications and behavior change that can help inform effective corrections in both crisis and prolonged misinfodemics.

1 / Health Belief Model

Our willingness to change our behavior corresponds with our perceptions about the risks, relevance, benefits and barriers related to that change. Innovative fact-checking that addresses these perceptions can help reduce the impact of misinformation on health outcomes.

An important public health behavioral model to consider is the Health Belief Model, which was developed by social scientists in the 1950s to explain low rates of participation in preventive medicine and disease treatment (Glanz, 2001$^{\$}$; LaMorte, 2019). The Health Belief Model takes into account the impact that a person's perceptions and beliefs have on their health decisions and outcomes. This includes perceptions and beliefs such as:

a person's perceived susceptibility of contracting an illness

the perceived benefits of particular health actions or behaviors

the knowledge that health treatments or preventative measures don't necessarily guarantee a lack of illness, or adherence to public health recommendations

(Becker & Janz, 1985; LaMorte, 2019).

the perceived severity of consequences of engaging or not engaging in a health behavior

Research demonstrates that perceived barriers are a significant predictor of health behaviors, suggesting a greater emphasis that fact-checking organizations can take on identifying, developing and testing output structures that can effectively counter such perceived barriers (Jones et al., 2015).

For fact-checkers, corrective health messages informed by the health belief model can involve, for example, messaging that addresses the perceived barriers target audiences might have that prevent them from aligning their health behaviors with a corrected piece of misinformation. Fact-checks can also highlight what the perceived benefits of a specific piece of corrected information might be for the target reader or for their communities.

Providing audiences with cues for action, and including prompts that encourage confidence in a reader's' ability to succeed, can help situate fact-checks as an a contributor to changing target audience perceptions or behaviors.

2 / Social Norms Theory

What we *think* is happening in society is a better predictor of our behaviors than what is actually happening. How fact-checks are designed can prevent the exacerbation of false perceptions and reduce unintended health outcomes.

Health behavior science research also tells us that the misperceptions we have about how our peers think or behave can impact our own behavior (LaMorte, 2019). Our behaviors may be predicated more on our *perceptions* of what dominant social norms are rather than what they *actually* are. One of the challenges with fact-checked misinformation is that, depending on how a correction is presented, it may reinforce a perception that the misinformation is related to a dominant social norm among readers. Such a misperception that a given social norm, such as vaccination refusal for infants, is a dominant norm, can influence behavior whether or not the perceived prevalence of that norm is actually true. These misperceptions can result from what are called *descriptive norms,* or norms based on what seems to represent prevalent patterns in the community. They can be established when members of the community who do have that norm stand out because of a particularly strong action they take, or the frequent discussion of their actions or beliefs (Paluck & Ball, 2010). *Injunctive norms*, another type of norm, is based on the perception of what behaviors are predominantly approved-of or disapproved-of in a given community, such as "in our community, refusing to vaccinate against measles, mumps and rubella is not acceptable". These norms can also impact our behaviors and decisions (Croy et al., 2010[$]).

So how can fact-checking organizations ensure that outputs don't exacerbate misperceptions about social norms, or make them seem more prevalent than they actually are, while providing the necessary corrected health information to target communities? Research about communications efforts to reduce gender-based violence, conducted by researchers from Princeton University's Woodrow Wilson School of Public and International Affairs and the Department of Psychology, highlights additional pathways forward that may be useful for sharing corrective information, particularly through the lens of social norms marketing. This research emphasizes the importance of addressing injunctive norms rather than descriptive norms, specifically because messages that incorporate injunctive norms are more difficult to disconfirm through observation, and injunctive norm messaging can discourage behaviors (Paluck & Ball, 2010). Referencing the approval or disapproval of particular norms (injunctive norms) is preferable to communicating the prevalence of a norm in a community (injunctive norms), which inadvertently communicates a baseline to audiences that may strengthen or impact their perceptions and behaviors in an unwanted way (Paluck & Ball, 2010).

For the fact-checking community, this can involve structuring outputs in a way that doesn't centralize the false piece of information, and crafting messages in a way that emphasizes the approval or disapproval of the statement meant to change audience behavior. The National Social Norms Center at Michigan State University provides a series of case studies in which effective social norms interventions have been used to address problematic perceptions and behaviors.

3 / Stages of Change/ Transtheoretical Model

If a person is not ready to change their beliefs, correcting them might have unintended health consequences. Different levels of readiness may require different framings of health corrections that align with a target audience's readiness stage.

Framing a health message in a way that is misaligned with the target audience's current stage, or degree of readiness to change a behavior, can result in unintended outcomes, according to one key component of the Stages of Change/Transtheoretical Model (Westley et al., 2004). This model, applied frequently in health communications intervention design, involves an examination of the different phases that a person takes in their efforts to change behavior.

These stages, as defined by the Rural Health Information Hub include:

Pre-contemplation: There is no intention of taking action.

Contemplation: There are intentions to take action and a plan to do so in the near future.

Preparation: There is intention to take action and some steps have been taken.

Action: Behavior has been changed for a short period of time.

Maintenance: Behavior has been changed and continues to be maintained for the long-term.

Termination: There is no desire to return to prior negative behaviors.

The stages of change/transtheoretical model looks towards identifying the phase that a target audience member is in when designing health communications outputs (Westley et al., 2004). Research suggests that tailoring how corrections are presented to research surrounding target audience's current stage can be an effective strategy for fact-checkers in mitigating unintended health consequences. This strategy is particularly important for addressing information tied to the perception of a dominant social norm, targeting how corrective information is framed to meet readers where they are and ensure that "'well-intended messages do not produce undesirable behaviors" (Slater, 1999; Prentice-Dunn et al., 2009).

4 / Re-Evaluating Mental Models

Debunking might be most effective when a user is encouraged to update the background knowledge they used to develop an understanding of a false piece of information.

When readers encounter a piece of information, they form a narrative explanation for how this new content fits into the rest of their world, a "mental model" or cognitive map to formulate an understanding of a topic. These models are continuously updated in the presence of new information, at varying rates and degrees of effectiveness depending on the size of the change needed to a mental model to accommodate for new information (Hamby et al., 2019; Swire & Ecker, 2018). Fact-checking largely updates existing mental models by replacing inaccurate information with factual information. In the case of health fact-checking, however, this can be a difficult cognitive task, as often the only thing that can be said about a piece of misinformation is that it *isn't true*, without the ability to offer an alternative explanation.

Researchers from the University of Illinois at Urbana-Champaign Social Action Lab and the University of Pennsylvania's Annenberg Public Policy Center collaborated on a cumulative review of 20 different experiments that involved forms of debunking social and political news content.

The results from their analysis highlight an important hypothesis for what contributes to successful fact-checks—that debunking can work more successfully when the information presented to target audiences inspires them to update the existing mental models they used to justify the original piece of misinformation to themselves (Chan, Man-pui Sally, et al, 2017). Combining interest and awe in fact-checks to encourage a "global update" of a reader's mental model can help strengthen the belief in corrected health information (Kurby & Zacks, 2012; Swire & Ecker, 2018).

As health misinformation continues to receive increased attention in the digital communications and technology sectors, new intervention designs are being implemented. The variety of fact-checking initiatives, approaches, outputs and priorities translate into a health communications field that has recently expanded well beyond the inputs of health care providers and health institutions, once responsible for broadcast diffusion of health messages. Programs designed in collaboration with researchers, or interventions that build upon existing behavioral research, can help contribute to a corpus of literature that can render better and more informed solutions.

Of course, addressing health misinformation is becoming increasingly challenging, as health myths spread in new, and sometimes unpredictable ways, through social media and private messaging apps in forwarded messages, memes, and doctored images, among other modes. And the health impacts can be significant. This complex web of health misinformation flows is influencing vaccination rates and herd immunity, appropriate use of antibiotics and treatment regimens, the adoption of response efforts in epidemics, and access to care for serious illnesses. The consequential impacts that health information online are having on health outcomes offline makes for a unique opportunity to set standards of excellence and responsibility for health content creators and correctors, and a critical time for building the necessary infrastructure for fact-checkers to contribute effectively in ways that prioritize equity, accessibility, and do-no-harm public health principles.

Next

Challenges in Misinfodemic Response Efforts

CHALLENGES IN MISINFODEMIC RESPONSE EFFORTS

As nearly half of the world's population is unable to access health services, and efforts to increase access to the internet continue to expand, digital sources are increasingly becoming an important vessel for health information (WHO, 2017; Pew Research Center, 2013; Chen et al., 2018).

The growing ubiquitousness of the digital realm in the pursuit of health and well-being makes the role of fact-checkers increasingly important. As a direct response to increased requests for addressing health misinformation, fact-checking organizations are working to adapt their existing methodologies to better accommodate health-specific content. In doing so, fact-checkers have identified a number of challenges with existing workflows, especially when trying to address health misinformation at scale (Full Fact, 2019; Furlan, 2017; personal communication, Africa Check, 2019).

Challenges in misinfodemic response efforts include:

limited access to the right subject experts

difficulty determining items of high priority

challenges in accessing primary sources for review

deciphering nuanced biostatistics, epidemiology or medical language

allocating the additional time necessary for accommodating for the above challenges while juggling a number of fact-checking priorities

Infrastructure needs to be available for more effective and efficient verification, and to strengthen the ability for fact-checking organizations to respond to a diverse range of health topics. There remain significant barriers to overcome.

1 / Trust

Research has identified decreased levels of trust in physicians and health institutions, disproportionately affecting low-income communities, and younger populations (Born et al., 2009; Cammett et al., 2015; O'Malley et al., 2004; Sheppard et al., 2004). The commodification of health services—through private insurance markets, fee-for-service models, and other health systems that offer unequal opportunities to accessing care according to the ability to pay —has been hypothesized as one key mechanism related to decreased trust in and use of health services (Huang et al., 2018; Sheppard et al., 2004).

Both decreased trust in health systems and decreased use of health services are determinants of how optimal one's health outcomes might be, and whether an individual adheres to recommended services or treatments Ward, 2017; Bonds et al., 2004; Jones et al., 2013; O'Malley et al., 2004). And decreased trust in health institutions, as well as lessened compliance with treatments, is exacerbated by health misinformation, resulting in a perpetuating cycle (Sheppard et al., 2004; Vinck et al., 2019).

2 / Public Health Wins are 'Non-Events'

One of the biggest challenges that public health communicators have faced for decades when producing health content, especially targeting audiences outside of patient or patient advocate communities, is the fact that a public health success or "win" exists when *nothing* happens. When diseases *don't* turn into epidemics, when big cities maintain their sanitation infrastructure and there *isn't* an E. coli outbreak, when children receive their required vaccines at the appropriate times and as a result *do not* incur the corresponding illnesses—those are public health successes. In the media, non-events framed as 'promising results' or 'potentially game-changing' can mislead the public into misinterpreting the correct scientific public record (Victory, 2018).

Identifying flaws in clearly over-hyped or misleading health news headlines requires deciphering the epidemiology or biostatistics language prevalent in research articles on which the content online is based. Distinguishing between correlation and causality is challenging, and in attempts to avoid scientific jargon, journalists or health content creators may end up using language that leads to exaggeration: "For example, writers might try to avoid dry scientific jargon, like 'correlates with', and instead use everyday expressions like, 'increases.' So, 'Being breastfed correlates with good behaviour" becomes, 'Being breast fed increases good behaviour'" (Adams et al., 2017). These distinctions are crucial, and for fact-checking organizations, when conducting corrections of this nature, it becomes increasingly important to have easily accessible topic or methods experts to assist with interpretation.

3 / Availability of Information

Much of public health research exists behind paywalls. Scientific abstracts and press releases can, at times, be the only readily available content for fact-checkers. Further, this scientific research is often written in specific and complex language that can be unfamiliar to non-subject matter area experts.

The availability of public health information online overshadows the *accessibility* of that information. This is largely a legacy challenge: health and science journals were never intended to be sources of information for general audiences. The original intent was for these journals to serve as an outlet for scientists to discuss and debate one anothers' findings, and build upon existing bodies of knowledge. While general audiences "are entitled to eavesdrop on those conversations [… they] shouldn't do it if [they] don't know the limits and caveats" (Gary Schwitzer, interviewed by Brooks, 2016). In such contexts, especially in deciphering complex epidemiological research caveats, fact-checking organizations have flagged that correcting health content goes beyond in-house expertise (FullFact, 2019). As a result, organizations rely on external experts, which requires building strong networks of accessible topic specialists in order to regularly produce health-focused content.

If fact-checking organizations largely do not have health experts in-house, time, effort and level of commitment of external sources determines what content gets fact-checked and at what rate. These resource constraints can result in lacking or ineffective health misinformation response.

Organizations can begin to address this challenge with a combination of resources: a) a pool of topic area experts, which can be developed through close collaboration with public health institutions or universities and b) a specific set of guidelines that can help fact-checking organizations easily identify the nature of verification requests that should be reviewed by a health practitioner. This can both ensure accuracy, and serve to confirm that a fact-check contains the necessary caveats to make it a safe piece of information shared with a potentially larger audience than it directly relates to.

4 / Audience Safety

Fact-checking efforts to address false claims online are an incredibly important component of reducing the impact of misinformation on health outcomes. The belief in false health claims can result in adverse health outcomes, but there may be also adverse health outcomes that result from limited or caveat-free health fact-checks that are not generalizable to wider audiences (Larson, 2018; Gyenes & Mina, 2018; Tsai et al., 2012). This is especially true for fact-checking topics where caveats surrounding exceptions to harmless interventions or early-stage research are essential for preventing harms, such as verifications or corrections that review vitamin supplement research, without referencing potential interactions with HIV medications (Kalichman et al., 2012; Tsai et al., 2012).

It is also important for fact-checking organizations to correct information that is frequently referenced in news stories with conflicting messages, such as cures for chronic illness, in a way that doesn't exacerbate treatment whiplash -- the back-and-forth, contradictory reporting that repeatedly references cures and causes for a given condition.

Audio podcasts produced by Health News Review share the experiences of individuals adversely affected by harmful health content in the media:

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A man with a brain tumour was misled by a company news release that made claims about a breakthrough drug that were not properly filtered by the news media. His hopes for treatment were raised, only to be crushed when his doctor told him the drug was not ready for human use. Two women with breast cancer told us how difficult it is to make treatment decisions when there are conflicting news stories, or when celebrities make news about their own treatment decisions that may have no relevance to other women. (Schwitzer, 2017).

Considering the ways that communities might be affected differently by the spread of health misinformation online is fundamental. In places where access to health services like abortion care are restricted or inaccessible due to laws or limited resources, for instance, the internet becomes a primary means of obtaining relevant information (Reis & Brownstein, 2010). Important factors including literacy levels, language abilities, gender, citizenship status and age impact information-seeking needs and patterns online, and the ability to verify content or seek input from a health professional offline (Cohall et al., 2001; Hunt et al., 2016; Berkman et al., 2011; Parker et al., 2003; Berkman et al., 2015[$]). These factors may also impact the access to—and efficacy of—particular forms of fact-checks. For example, less positive views of fact-checking outputs are experienced by individuals with lower levels of education (Nyhan & Reifler, 2016).

To ensure principles of equity and fairness in the fact-checking prioritization process, safety considerations must be made by fact-checking organizations in their process of selecting claims for verification. This includes understanding the potential risks faced by patients who may make decisions based on the information that matches their queries online, and re-thinking processes that inform the which misinformation claims are prioritized for review. Some organizations fact-check health content that emerges on social media, in online forums or in private messaging channels. But for initiatives that allow users to submit claims or questions that they would like verified via text message or instant message, or in public or semi-public spaces such as Facebook or WhatsApp groups, it can result in the unintentional identification or collection of contributors' personally identifying information.

This is especially important for individuals with vulnerable or potentially criminalized identities, such as queer communities and migrant populations, or when considering the stigma that may be associated with information-seeking about certain health topics, such as birth control or abortion care (Melpolder, 2019). Without guarantees of safety or security, individuals or communities most in need may not feel comfortable requesting fact-checks, resulting in the questions they need answered most being overlooked. By taking the impact of these submission strategies into consideration, and developing new pathways for inquiry that prioritize the safety of contributors, and the risks associated with different health topics, the communications field can move closer towards a public health value-informed, equity-centered fact-checking approach.

These safety considerations continue through the information-seeking process, as a target audience member searches for health answers online. For vulnerable groups, simply querying particular topics, such as contraception or abortion, can put them at risk (Melpolder, 2019). For fact-checking organizations addressing misinformation involving such topics, one possible mitigation strategy can emerge through coordination with public health and human rights organizations that specifically work on access to care for vulnerable groups, deciding together upon key terms for search engine optimization that do not put populations at risk.

5 / Repeated Exposure

Research also demonstrates risks faced through increased normalization of health myths through repeated exposure—even in efforts to debunk those myths. Experimental evidence tells us that simply labelling a piece of existing information as false or incorrect can leave audiences uncertain when forced to remember what exactly the false piece of information was, and the misinformation itself is repeated and made more familiar (Wilkes & Leatherbarrow, 1988$^\$$; Johnson & Seifert, 1994; Walter & Murphy, 2017$^\$$; Chan, Man-pui Sally, et al, 2017; Lewandowsky et al.,, 2012; Swire et al., 2017).

  The impact of this repetition, and of health misinformation more broadly, may disproportionately affect populations with language or literacy barriers, or those with limited internet access (McKee & Paasche-Orlow, 2012; Echevarria & Vogt, 2010). Part of this may have to do with fewer health literacy tools, trainings, research and staff being accessible to smaller, less health-literate subsets of the population, as the majority of health communications interventions are designed for people not in those subsets, with higher literacy and language skills (McKee & Paasche-Orlow, 2012).

6 / Accountability

To date, there is no infrastructure for responsibility or accountability for potential adverse or harmful health behaviors and outcomes that can be tied to incorrect or edited debunk reports, or information presented in debunks that are not generalizable to all. This is a wider challenge for the health communications field, as there are no standardized codes of responsibility when it comes to improving health information online, and there is also little consensus on whether there is one lead authority when it comes to that information. Full Fact identified health fact-checking as a "major area of public interest in which no body has primary responsibility for providing accurate and useful information", and gave one case example where their attempts to "fact check a claim about the safety of a bathroom product for pregnant women saw [them] bounced repeatedly between the press offices of 13 different public bodies, all of whom believed that providing such information was somebody else's job" (Full Fact, 2019).

As the role of fact-checking organizations expands towards filling gaps in health information translation and providing corrections to misrepresentations of health topics, it is increasingly important to build a relevant infrastructure for standards of quality, accountability and responsibility for the unique risks specific to health misinformation response.

7 / The Importance of Context

When responding to forms of health misinformation that involve misrepresentations of research through fact-checking, especially through binary (true/false) or trinary (such as true/misleading/false) conclusions, it is important to consider that health misinformation that is largely incorrect or factually inaccurate for a certain segment of the population, might actually be useful or factually accurate for another segment of the population. Much of health information requires re-contextualizing for different individuals' experiences and health backgrounds. Gary Schwitzer, founder of the health information site Health News Review, articulated in a 2019 article about fact-checking that, "when communicating about biomedical research, you can be 100 percent factually correct while being 100 percent unhelpful to your audience…Fact-checking alone often fails to capture questions of nuance and context that arise—or should arise—whenever evaluating medical evidence," (Schwitzer 2019).

This means that in the current context and frameworks of fact-checking, even if the health information shared in a fact-check is technically correct, it may remain completely irrelevant or even dangerously misleading for information-seeking audiences (Schwitzer 2019). One example of this paradox that scientists and intergovernmental organizations who develop health communications materials are struggling with is Celiac disease, an autoimmune disorder in which eating gluten, a protein found in different species of wheat, barley and rye, triggers an immune response in the small intestine that, over time, damages the lining of the small intestine, leading to malabsorption of nutrients in the long term (Health Canada, 2018). It has a current estimated global prevalence rate of 1.4%, and a prevalence of 0.5% in North America (Singh et al., 2018).

Fact-checking an extreme claim circulating that might include phrasing like 'eating too much bread can kill you" would likely be labelled as false, as, for most of the population, this is probably the case. But for someone with celiac disorder, the disease can in some, cases ultimately be fatal (NIH Genetic and Rare Diseases Information Center, 2015).

Another example is referenced by the UK's National Health Service on a study linking sugary drinks and cancer, emphasizing the importance of contextualizing fact-checks into the broader body of research rather than fact-checking claims in isolation:
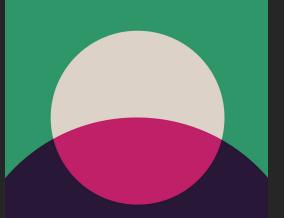
"

This was a good–quality study, but it's difficult to pinpoint the impact of 1 part of a person's diet on their health. Ideally, more studies are needed to assess this link. But we already know that consuming too much sugar is not good for us. This story has had extensive coverage in the UK media. While the reporting was broadly accurate, many headlines were alarmist, such as the Mail Online's claim that "Just ONE drink of fruit juice or sugary tea a day can dramatically increase the risk of cancer". Focusing on an increase in relative risk without putting it into the context of actual risk (absolute risk) is not particularly helpful for readers. Also, many headlines did not make it clear that we cannot be sure that sugary drinks are directly causing the increase in risk (Bazian, 2019).
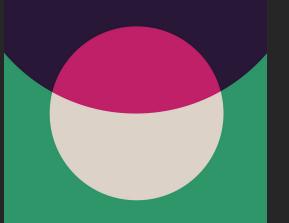
Delineating the types of caveats needed in a health fact-check, and whether the requirements may differ across health topics, can mitigate against some of the risks associated with misrepresented generalizability of corrections.

Next

Looking Forward: A Standard of Care for Health Fact-Checking

LOOKING FORWARD:

A STANDARD OF CARE FOR HEALTH FACT-CHECKING

To address the unique challenges facing professionals in situations where recommendations can lead to life or death outcomes, different fields employ corresponding standards of care: accountability measures for degrees of thoughtfulness, thoroughness, care and caution in a specific practice. These accountability measures are especially important for industries such as public health and medicine, as well as other fields in which lives and livelihoods are at high risk. In medicine, standards of care are closely affiliated and applied to legal accountability for medical malpractice, as are duties of care in fields like engineering and architecture (Moffet & Moore, 2011; Dal Pino, 2014; Morris, 2017; Miller, 2012). In these fields, trust in a standard of care is upheld through professional bodies, board certifications and the legal system.

In many important ways, systemic checks and balances like those employed in public health already exist within the fact-checking and journalism communities; the idea of enhancing existing information care measures is not a novel one. The International Fact-Checking Network (IFCN) code of principles commit to transparency, fairness and open and honest corrections (IFCN, 2019). Codes of ethics and principles also exist in newsrooms, journalism schools and professional societies (Society of Professional Journalists, 2014). Ombudspersons and public editors, members of newsrooms responsible for upholding the operating principles of journalism, are still relevant but declining in American journalism contexts (Starc, 2010; Spinner, 2017; Spayd, 2017; Farhi, 2013). Efforts to develop standards for online content in a technical setting have also emerged, with groups such as the Trust Project, the Journalism Trust Initiative and the Credibility Coalition (the latter is a Meedan initiative with Hacks/Hackers).

One of the intentions behind the construction of the IFCN was to establish a more robust mechanism for the public to differentiate robust fact-checks from their lower quality counterparts. Given the unique challenges specific to the online health information context, the knowledge of misinfodemics, and the real-world harms of health misinformation, we are presented with a moment of opportunity for health-specific additions to existing journalistic and fact-checking standards.

At present, no specific code of conduct or duty of care applies to health fact-checking. In contrast, health practitioners working in national and intergovernmental health organizations have regulatory bodies that ensure quality of care, specific protocols for responses to health queries, and guidelines for compliance to a specific standard of care. In the fact-checking world, organizations such as the IFCN develop codes of principles that fact-checkers can be signatories of, demonstrating the importance of a commitment to high standards of content production (IFCN, 2019). One of the purposes of setting up these principles was to have guidelines that would allow readers and organizations to "help distinguish reliable fact-checking" (IFCN, 2019).

Knight Science Journalism published a recent report on fact-checking, recommending that "outlets provide more robust guidelines for fact-checking, as well as processes for tracking corrections after publication" (KSJ, 2018). However, for health fact-checking, building upon existing guidelines rather than creating a framework specific to health misinformation response may not be the correct approach. The unique set of challenges associated with producing, prioritizing and being responsible for the verification outputs of health-specific content may be significant enough to require an additional set of principles that align with long-standing public health standards of care.

Of course, the creation of standards can not *solve* health misinformation. Nutrition labels have created standards around informing people of the sugar content in their food, but diabetes continues to increase in the United States. HIPAA standards aim to ensure patient privacy in medical settings, but data leaks and breaches continue to happen. Standards for vehicle safety and traffic laws certainly limit the damage of accidents, but millions nonetheless are injured or die each year. However, we do have frameworks that help identify the nature of specific violations, and a process through which complaints and concerns can be raised. Whether or not this can be useful in addressing digital health misinformation will depend on a larger system of practices and ethical codes. To get to that point, however, we can begin with an informed standard of care around fact-checking.

As accessing online health information has long overtaken human interaction with trained medical providers, and as doctors' offices are replaced by search bars, patients seek out answers to health questions online. (Tonsaker et. al., 2014). Perhaps a standard of care for fact-checking organizations engaging in the dissemination of health information, tasked with the role of verifying and correcting content online, may provide the public with a guiding standard through which to discern high-quality content from low. In a professional medical setting, a patient's experience of a low standard of care might prompt filing a complaint, a lawsuit, or taking behavioral actions like leaving the doctor's office or choosing not returning to a specific clinic. A standard of care in an online health information context can empower parallel decision making in users' consumption of content, or at least provide fact-checking organizations with the guidelines needed to make sure that communication outputs don't yield unintentional and adverse health behaviors, decisions or outcomes.

Some ideas about applying public health models to the spread of misinformation have already been proposed. A 2019 Center for Strategic & International Studies report articulates:

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The many parallels between misinformation and disease offer policymakers an opportunity to look to the field of global health for lessons in how to battle the spread of infectious agents…This principle of building a resilient system to prevent outbreaks provides a useful model for combating misinformation. Rather than engaging in censorship to counter actors or ideas individually, policymakers and industry should focus on building a resilient information system that is ready to mitigate the effectiveness of misinformation without restricting the free marketplace of ideas. (Felten & Nelson, 2019)

A standard of care for today's digital-first health era could inform prioritizations in search indices and media literacy tools, and could be used in research on indicators of low quality health content. Such a standard could also incorporate vital consensus-building elements such as a set of ethical guidelines through which health messaging strategies are beta-tested, and could be achieved through close collaboration with public health institutions or universities. Features might include a specific set of guidelines for health-specific verification requests, identifying which of those requests should be reviewed by particular health experts to ensure validity, accuracy and inclusion of necessary caveats.

The development of new standards, similar to public health "standards of care", would encourage reporters, fact-checkers and platforms to treat health content as a special category of information with specific and serious associated risks.

The internet continues to change global health in fundamental ways. With intergovernmental organizations and national governments reconciling movements to pursue universal health coverage for all with limited availability of in-person health providers, resources and services, the internet plays a crucial role in mediating access to health through access to information. Setting standards for the communication and correction of health content online is an essential component of addressing unmet needs, strengthening the internet as a valuable and viable source of health information. The benefit of online health communities may be of particular importance to vulnerable populations, including populations with stigmatizing conditions where privacy and anonymity are essential for safety. Today's fragile digital ecosystem of health information, and the amplification of misinformation, makes for a critical responsibility in the hands of publishers and verifiers of digital health information.

The fact-checking community is central to misinfodemic response efforts as groups around the world attempt to address the challenges of accessibility, equity, and credibility of health information. These response efforts must involve processes and approaches that acknowledge the distinct and significant risks associated with misleading, misrepresentative and misinformed health content. Correcting, responding to, and mitigating the impacts of health misinformation requires new and innovative strategies, adaptive for an online health context in which viral misinformation is contributing to real-world disease.

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