

FOREWORD

Professor Kang is a physician scientist working on vaccines and public health, particularly focused on children and enteric infectious disease in India. She is an elected Fellow of all the Indian science academies, is the first Indian woman to be elected to Fellowship of the American Academy of Microbiology and to the Royal Society, and the only physician-scientist to receive the Infosys Award in Life Sciences.



In the past 21 months, we have dealt with a deluge of information about viruses, infection, treatments, vaccines, and the people who make, use, or evaluate them. While the pandemic was a fire hose of information, some true and reliable, some inaccurate and some completely false, the spectrum of information, misinformation and disinformation is no different for any aspect of public health. It is important to recognise that while accurate information matters for all of society, information asymmetry, and exposure to misinformation disproportionately affects the populations that have traditionally been marginalised.

Factly, which aims to change the public information landscape by providing to the public both access and explainers about important and relevant information across a range of topics, has undertaken a critically important exercise in the past year. In partnership with Facebook, Factly has trained a Health Fellow and deployed her to explore the misinformation landscape in India. Through detailed analysis of available sources of data, checks with experts and interviews with key leaders, Factly has developed a Health Misinformation Report covering myths and misconceptions in 10 sectors including immunisation, nutrition, maternal health, menstrual health, sexual reproductive health, cancer, COVID-19, public health concerns, mental health, and non-communicable diseases.

From the known myths around menstruation to the beliefs and practices of those who believe that cancer can be addressed by diet alone, the Factly-Facebook Health Fellow has undertaken a listing of common misinformation in India, identified the correct information and discussed current practices and potential communication strategies with experts from multiple disciplines. The areas chosen by the Fellow are critical to public health, where an understanding of the range and scale of misinformation is immense, and the potential for damage and impairment is large. It is clear from many of the myths that she describes that there is a particular focus on the deliberate disempowerment of women, couched in the language and practice of a specific culture or tradition. The laying out of the construct and countering of this misinformation is essential if we are to use an understanding of human physiology and pathology to address health and medical needs with the best available data and tools.

The value of this effort to create a landscape, provide accurate information and obtain inputs from experts cannot be overstated. With the flood of information that fills every media channel to the information networks within families and communities, it is important to understand not only what information is reliable, where to check on its accuracy and how to counter misinformation, but also to think about what this means for our society as a whole. India has had many people's science movements that have sought to counter the 'escape into magical beliefs and instant solutions' and Factly uses new communication channels to scan and counter the burgeoning of belief in unproven associations and treatments.

Trust is hard to establish and easy to lose. For science, and particularly health related science, this report is a key building block in an approach to establish society's trust based on a solid foundation of carefully evaluated information. The processes followed by the Fellow in each of the 10 areas describe a careful approach undertaken for the benefit of Indian society.

Factly has recognised and addressed a critical need and should be congratulated and recognised. Look forward to more efforts to further build science in our society.

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EXECUTIVE SUMMARY

‘Post-truth’ was declared as Oxford Dictionary’s word of the year for 2016. Since then, the concerns of debunking fake news and containing the spread of misinformation have only been increasing dramatically across the globe. Amidst the overwhelm of social information in the digital world, user traffic, clickbait content, sentimental analysis, and rumours set out by confusion (misinformation) or on purpose (disinformation) have taken the centre stage. One of the largest, daunting, and unseen effects of the widespread use of technology (social media) has been the incessant and persistent bombardment of misinformation on varied topics. In the wake of the ongoing pandemic, the rampant spread of health misinformation has translated into real-time consequences where people have either resorted to attempting unscientific cures and delaying treatment or refusing to take the vaccine, among other things.

While COVID-19 is not the first pandemic the world has known, it is the first to exist in the age of technological and information explosion. Owing to the over-sharing and over-abundance of opinions available both online and offline, we are now dealing with the dual burden of both the pandemic and the infodemic. While this phenomenon of health misinformation is not novel, this form of fake news directly affects the health of millions of Indians who desperately depend on social media as the main source of information. If unchecked, this will snowball and severely impact the overall wellbeing and access to the right healthcare services. “In this social media absorbed ecosystem we dispense with depth and discussion at the expense of brevity, but in that brevity, we dispense with rationality”, writes Amitabh Kant, Chief Executive Officer of the NITI Aayog. Case in point being that during the COVID-19 breakout, in the chasm of uncertainty, people were particularly susceptible to misinformation due to an intricate combination of cognitive, social, and algorithmic biases, i.e., information overload and limited attention spans. Social media had become a medium of hope to people information of any and every kind was overshared in the hope that something out there will prove to be useful. Instead, misinformation was amplified to such an extent that it has become a threat to public health. The subsequent lockdowns only added to the uncertainty.

People often laud social media for its democratised content. In the age of information, as Joan Donovan, Research Director of the Shorenstein Center on Media, Politics and Public Policy says, “where information is extremely cheap, knowledge is expensive.” While it is imperative to stay informed, one should not fall prey to misinformation that includes falsification of certain facts in order to propagate a certain individualistic or collective interest. The Centers for Disease Control and Prevention (CDC) has rightly pointed that “one of the global problems we deal with today is the viral spread of medical myths”, which is in no way less scarier than a viral epidemic. Widespread medical misinformation goes beyond the prospect of personal beliefs and, in fact, affects people at the psychological and physical levels. This is because it

quickly catches public attention and leads to panic and confusion. Some of the most relevant instances include the MMR vaccine being linked to autism, promotion of e-cigarettes as a safe alternative to tobacco, the propaganda of anti-vaccination (influenza, pneumonia and HPV vaccines), widespread misinformation and stigma surrounding bad menstrual practices that leads to school dropouts, reinforcing gender discrimination and many others that incur severe social, economic, physical and environmental costs. Similarly, while the conversation around mental health has just started to get the required attention, the rampant misinformation has only added misery to the existing layers of social stigma.

The Health Misinformation Report is, therefore, authored in a hope to become a seed or **starting point**, and not the end, for health-related misinformation in the Indian context. As the foundation to solidify and enhance the misinformation knowledge in the health domain, the exercise undertaken is to essentially understand the myths, misconceptions, stigma, superstitions, and taboos in the chosen 10 priority health sectors. The overall goal is to map the entire health misinformation landscape to shape public knowledge, attitudes, and concerns in the health sector.

“Misinformation is not like a plumbing problem you fix. It is a social condition, like crime, that you must constantly monitor and adjust to”, says Tom Rosenstiel, Author, Director of the American Press Institute and Senior Fellow at Brookings. While social media has been a catalyst in the spread of misinformation, it is, however, also important to note that merely expecting social media platforms to fix the crisis is a deeply flawed approach because most of the disinformation is shared in a decentralised manner through messaging. The real challenge is to ensure the teasing out of misinformation and help consumers decipher the facts. In this context, the role of fact-checkers, especially in the field of medical news owing to the ongoing pandemic, cannot be over-emphasised.

As part of their fact-checking programme, social media giant Facebook has launched a Global Fellowship to combat health misinformation. Factly Media & Research has been shortlisted among the 10 fact-checking organisations across the globe to be offered this fellowship. The fellowship announcement was made at a time when the world was reeling under the repercussions of misinformation owing to the ongoing COVID-19 pandemic. On account of being their credible fact-checking partner, the aim of this report is to map the misinformation landscape in India and accordingly develop methodologies and strategies to combat health-related misinformation in the country.

The plan/methodology to combat health misinformation followed in this report is a three-fold strategy:

1 *Literature Review:* Through a literature review of research papers, credible articles, consequential data, and insights, we have prioritised the 10 areas/sectors under the health domain where misinformation is prevalent and affects a larger population.

2 *Personal Interviews:* For the report analysis, we have undertaken thorough primary research to interview sectoral experts including academicians, professors, doctors, and social media influencers for first-hand and ground-level relevant insights; this, combined with the secondary research, has provided authentication and holistic understanding of the misinformation in each of the sectors.

3 *Social Media Analysis:* For the report, we have used CrowdTangle, a public-insights tool which essentially identified the prevalence of health misinformation and outlined strategies to be adopted to effectively contain misinformation through deep-rooted stakeholder partnerships.

The report covers basic misinformation (myths and misconceptions) in the following sectors: immunisation, nutrition, menstrual health, maternal health, sexual reproductive health, cancer, public health concerns, non-communicable diseases, mental health, and COVID-19. Each chapter has five parts including an introduction/literature review, common myths and misconceptions, a case study, excerpts of the interviews done with the sectoral experts, and a conclusion.

The idea was to provide a fundamental understanding of the core subject of each of the chapters and through secondary research, identify and map the kind of existing misinformation in that area. The secondary research coupled with the interviews of the relevant sectoral experts and organisations have been invaluable to triangulate and validate the research so far. In this regard, we reached out to stakeholders who are experts and organisations that work in each of these sectors for their insights. We conducted 21 expert interviews, reached out to 64 stakeholders (experts/organisations) and created a repository of over 500 myths and misconceptions panning across these 10 health sectors.

The overarching understanding of this report is that misinformation is not a homogenous entity but, in fact, manifests over time, generations, geographies, and communities. Therefore, there exists no ‘one-size-fits-all’ approach and solutions must be tailor-made for each of the

problem statements. The complexity of the problem is further compounded by the fact that medical misinformation is particularly layered, i.e., the myths and misconceptions are often couched in ambiguous medical terms and traditional practices. For instance, bad menstrual practices continue to be followed till date owing to the stigma and the lack of awareness of a natural physiological process. Therefore, to begin with, it is pertinent to address the root cause of the problem of misinformation and the entire research points towards education and awareness being the antidote to misinformation. However, owing to the grey areas and the intricacy of the layered problem, the solution is not so straightforward. Amidst the disparate information overload, the prerequisite is to contextualise and simplify the correct information. In the same breath, given the layers of the problem, the challenge is also not to oversimplify or misrepresent it. In this regard, the participation of the local stakeholders/actors who understand the behavioural, social, linguistic, and practical norms of the region coupled with effective messaging from the state is *one* of the most efficient and suggested pragmatic solutions.

However, the onus to weed out the extent and the depth of misinformation does not lie with one stakeholder like the state or fact-checkers, but is a collective effort that includes educating oneself, trusting science as an evolving and self-correcting mechanism, to rely on credible sources for consumption, separating fact from emotion, approaching fact-checkers when in doubt and questioning the authenticity of information, among others. Please do take cognisance of the fact that while fact-checkers might not hold all the answers, the public can be rest assured that they will be guided with credible sources and methodology, and be provided with a clarification, if not a conclusion. Therefore, a starting point to weed out misinformation is the added layer of responsibility to fact-check before consuming, and especially sharing, any information.

Limitations

The Health Misinformation Report strives to serve only as a starting point and is not an exhaustive literature in understanding and combating health-related misinformation. Given that misinformation is heterogeneous and affects the psychology of people sharing and consuming it, the report does not undertake a quantitative investigation of the extent and depth of misinformation in the health sectors. Taking into account the complexity of the issue and the time constraint, the qualitative aspect of the research is subjective and the criteria for the selection of experts hung on their prior work in their respective sectors and the closest association to understanding misinformation. Owing to the uncertainties of the pandemic, timelines and the subsequent lockdowns, the primary research is limited to the interviews with the experts. We hope that future research will continue to investigate evidence-based data to gain insights into especially pressing topics such as medical misinformation in the developing world.