



# Medical Misinformation



The Rise of Medical Misinformation: Why this needs to be addressed urgently

October 2021

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Nebula Research is a Community Interest Company formed to provide high-quality research to improve outcomes for all. As a Community Interest Company, any funds received are utilised to improve the business and to provide a wider array of services – especially to public sector, charity sector and voluntary sector organisations.

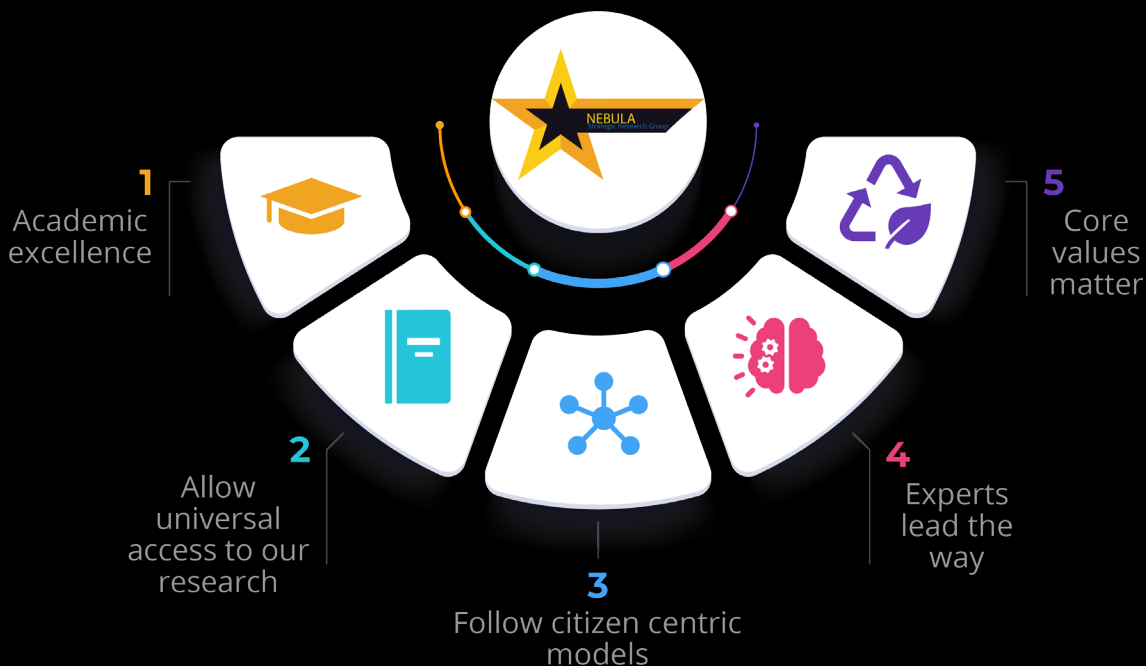
Our mission is to enhance the opportunities available to the public sector and to ensure the best citizen outcomes through research and the application of academic theory in practice.

We seek to develop high-quality research by fostering ideas into realisation to increase the total sum of knowledge for all.

Nebula Research has a simple vision – to be pioneers in research practice. By incorporating real-world practice into our research, we will continue to lead organisations and individuals towards discoveries that enable real change to be implemented for the overall good of citizens right across the globe.

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1. To be academically excellent.
2. To ensure research is published as widely as possible and is easily accessible.
3. To ensure that, where required, all research follows citizen-centric models.
4. To ensure all research is led by only the most suitable expert in the field.
5. To only work with organisations which share our values.



## About the Authors

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Sanjeev Gupta is a Professor of Healthcare Informatics and Technology at Apsley Business School and a part-time lecturer at Kingston Business School. He is also the owner of Nebula Research CIC and Strategic Discourse Ltd.

Sanjeev is a public sector specialist and regularly teaches a number of disciplines linked to public sector service delivery. He is a champion for ensuring services place the citizen at the heart of any delivery model and works to ensure new research is developed which benefits citizens globally.

Having worked in the public sector for many years, Sanjeev has a unique insight into the issues faced with the strategy and management of citizen-facing services. He has a particular interest in ensuring all citizen-facing services are responsive and responsibly delivered.

### Co-Author – Toby Flannigan BSc

Toby Flannigan is a researcher at Nebula Research who specialises in the public sector. With several years of experience in UK healthcare, especially the NHS, and a wider set of skills regarding the whole UK public sector, Toby conducts market research and data analysis for multiple programmes.

Toby graduated with a degree in Marketing Communications & Advertising and has since transitioned his career into the wider Strategic Consulting domain. Toby has led a number of University Research Group programmes.



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## Research Summary

This paper seeks to understand the phenomenon of fake news and its' particular application in the areas of medical misinformation. A review of the literature shows that there is an increase in the amount of fake news and medical misinformation available, especially through social media channels.

The paper examines the rise of fake news and how a particular section of this – medical misinformation – has increased over the past several years. The research shows that the increase in medical misinformation has led to an increase in patient harm and has even led to death.

By completing a comprehensive review of the literature on medical misinformation, the authors are able to show that such misinformation is spread quickly and with little cost to the producer/disseminator. The motivations behind the production and dissemination of medical misinformation are examined as they are not based on financial factors alone.

The authors also examine how medical misinformation has changed public perception in a number of cases, leading to large scale outbreaks of infectious disease, poisonings, and other harmful outcomes.

At a time when massive vaccination attempts are being made due to the current COVID-19 pandemic, the dissemination of medical misinformation could hamper public health efforts. Although, at the current time (2021), a large amount of the reporting and research on medical misinformation is based around COVID-19, the authors have attempted to make this paper more generally based around all medical misinformation.

The impact of social media on the spread of medical misinformation is also examined. The authors show that social media is one of the main channels for the dissemination of medical misinformation, in no small part due to the very low cost and the speed that information can be shared with millions.

Finally, the paper suggests that policymakers, social media leaders, journalists, researchers, scientists, and medical providers must all work quickly to challenge this and to put in place robust solutions to reduce the rise of medical information.

## Introduction

In today's society, we are surrounded by information sources. With citizens across the globe gaining greater access to the internet, the amount of information available at no or little cost to everyone has massively increased.

Previously to the high availability of broadband and mobile broadband internet services, the availability of information sources was limited for many. Most people received their information from study, news sources, or by making efforts to visit information stores (e.g. libraries) to find the information required.

In order to publish information, one needed to be able to find a publisher who was able to print the paper/book/etc., and to convince publishers that the work was worthy of publication. In many cases, this presented many challenges, including the requirement from the large majority of publishers that claims made were substantiated with evidence – this is especially true of claims made in the health and care arenas.

However, the rise of the internet and services such as WordPress, which allow simple publication of websites at very low cost, has resulted in the ability for all people to publish information without the usual checks provided by more traditional publishers. This has led to varying quality of information availability.

Furthermore, the rise of services such as WhatsApp, Twitter, Facebook, Instagram, Pinterest and other social media and messaging applications has allowed anyone with an internet connection to spread information unchecked.

The rise of such untrusted information dissemination is not new but has become much more prevalent in recent times. The increase in this misinformation at best confuses people, and, at worst, leads to negative healthcare outcomes, including death.

## The Rise of 'Fake News'

'Fake news' is a fairly recent term – a neologism. It is applied to that information, which is presented as fact, but actually has no basis in fact. It has been defined by Higdon as “false or misleading content presented as news and communicated in formats spanning spoken, written, printed, electronic and digital communication” (Higdon, 2020).

However, it should be noted that this definition would also apply to satire – especially where the satire was not obvious from the context. Across the globe, comedians and satirists use 'fake news' style stories as the mainstay of their entertainment (e.g. Spitting Image, Last Week Tonight with John Oliver, Saturday Night Live, The Onion). In fact, comedians have often stated that any ban on 'fake news' must be carefully managed to ensure that entertainment is not curtailed. In a paper published in 2012, Reilly suggests that satirical fake news “significantly reframed public discourse surrounding two dominant issues: the Iraq War and the 2008 American presidential election.” (Reilly, 2012, p. 273).

Certainly, comedians and entertainers have long used 'fake news' to highlight absurdities and help audiences engage with difficult political and scientific areas. However, the use of 'fake news' to entertain must not be confused with the use of 'fake news' to reframe public opinion – as was found to be the case in the above example.

In their paper from 2020, Allen et al. found that there was an exponential increase in the availability of 'fake news'. The authors stated, “we note that according to Google Scholar at the time of final submission, 2210 English language publications with 'fake news' in the title had appeared since January 2017, compared with just 73 in all the years leading up to and including 2016.” (Allen, et al., 2020).

A study from Poland (Waszak, et al., 2018) showed how this issue exists in multiple languages and for communities across the globe. The authors found that by analysing the top shared news stories on social media platforms, leading medical misinformation actors could be identified.

Due to this meteoric rise of 'fake news', Gelfert (2018) suggested that the term 'fake news' should be “reserved for cases of deliberate presentation of (typically) false or misleading claims as news, where these are misleading by design.” (Gelfert, 2018, p. 84).

Comments by senior politicians, and their support staff, may increase the reliance on fake news. In 2016, Michael Gove – then Justice Secretary for the UK – stated that “people in this country have had enough of experts” (Mance, 2016). In a televised interview on NBC in 2017, then President Trump's counsellor, Kellyanne Conway, suggested that incorrect information given by the then Press Secretary – Sean Spicer – were “alternative facts” (Conway, 2017). Events such as Brexit and the 2016 US Elections saw an outpouring of 'fake news' to attempt to support various political ambitions. This phenomenon has been seen in various political and social battles across the globe.

This rise of the 'fake news' phenomenon is potentially harmful – and becomes much more potentially harmful where this is applied to medical issues such as vaccines, therapies, and treatments.

## The Dangers of Medical Misinformation

Medical Misinformation is a term applied by the authors to any factually incorrect medical-based information which is published by any channel to change peoples' views to any medical situation.

Although recent medical misinformation has been growing in the areas of COVID-19 and the COVID-19 vaccines, there is must other misinformation shared on a daily basis.

Medical misinformation is not always pushed in order to meet specific social or political agendas. In many cases, misinformation is shared by people who mean well but lack the expertise to challenge the information they are forwarding. Flannigan & Gupta, when discussing fake news related to the COVID-19 epidemic, found that "misinformation can be believable because it seems plausible, often the most influential aspect of a fake news story is that of the person disseminating it. If the disseminator is charismatic or famous, their uninformed opinion tends to carry greater pertinence" (Flannigan & Gupta, 2021, p. 8).

Vilification of all medical misinformation sharers does little to help the situation. It is less useful to vilify those who have – often innocently – shared misinformation. It is, however, imperative that policymakers and providers of communication platforms work together to counter this rising threat.

Medical Misinformation takes many forms. From "calls to arms" on social media – e.g. COVID-19 is a government conspiracy, 5G is being used to spread a virus, etc. – to more structured misinformation offering cures for diseases such as cancer, misinformation harms those who are unable to understand the lack of science behind the claims.

Misinformation tends to play on emotions and can often include numbers and other metrics to make the information seem accurate. There are attempts made to justify the information as valid – without any academic, business or scientific referencing – using techniques which play on the psychology of the reader (Berger & Milkman, 2012).

Scientists have also used misinformation to further their careers or their research. For example, in 1998, a study by Andrew Wakefield and twelve colleagues suggested a link between the MMR vaccine and autism (Wakefield, et al., 1998). Although subsequently revoked, this paper affected the trust parents placed in the safety of the vaccine. As reported by the Indian Journal of Psychiatry in 2011, "appallingly, parents across the world did not vaccinate their children out of fear of the risk of autism, thereby exposing their children to the risks of disease and the well-documented complications" (Rao & Andrade, 2011, p. 96), and "outbreaks in the UK in 2008 and 2009 as well as pockets of measles in the USA and Canada were attributed to the nonvaccination of children" (Rao & Andrade, 2011, p. 96). Such harm led to complications for the children involved, including long term harm and death.

In the above case, Wakefield and his colleagues were found guilty of falsifying facts, and of deliberate fraud. The *British Medical Journal* found that Wakefield had financial incentives for the fraud (Deer,



2011). Such scientific medical misinformation is the most dangerous of all medical misinformation as it breaks down trust in science and scientific research.

But dissemination of medical misinformation is not usually perpetrated by scientists. Most ‘fake news’ available seems to originate from, and be shared by, non-scientific sources (Hopp, et al., 2020; Elliott, 2019; Cision PR Newswire, 2019; Cision PR Newswire, 2021; Center for Information Technology and Society (CITS) at UC Santa Barbara, n.d.; PolitiFact, 2017). Medical fake news seems to have a much greater reliance on social media (Waszak, et al., 2018; Merchant & Asch, 2018; O’Connor & Murphy, 2020; Poulouse, 2021).

Such non-scientific sources often use scientific-looking claims to encourage readers to accept the information given (Health Feedback, 2021; Spencer, 2020; Health Feedback, 2021b). The articles rely on emotive language and a natural tendency of the audience to believe information from sources outside of the mainstream to convince audiences (Garrett & Weeks, 2017; O’Brien, et al., 2018; Sindermann, et al., 2020).

Reliance on ‘fake news’, especially medical misinformation, has the potential for seriously harmful outcomes. Reports of citizens refusing vaccines, seeking ineffectual alternative treatments, attacking health and care providers, and various other harmful effects are constantly reported. In a review of ‘fake news’ in India, the authors of the report found 67.2% of ‘fake news’ is health-related, and most ‘fake news’ is negative (63.2%), having a real threat to public health (Al-Zaman, 2021). Others have found that ‘fake news’ exacerbates outbreaks of infectious disease (Brainard & Hunter, 2020).

The motivations behind the creators and disseminators of medical misinformation have been found to be very varied. Financial gain is a main motivation for those who provide alternative or complementary therapies (Lavorgna & Horsburgh, 2020). Financial gain is not only made through the selling of alternative therapies but can also be through monetisation of interactions, engagements, pay-per-click, etc. But other motivations exist.

For example, Apuke & Omar (2020) carried out an extensive review of ‘fake news’ in Nigeria in which they found many people were motivated to share such information due to their civil obligation to inform others and provide advice or warning (Apuke & Omar, 2020).

Talwar et al. (2019) found that various other reasons for sharing ‘fake news’ exist, including online trust, self-disclosure, fear of missing out, and social media fatigue (Talwar, et al., 2019). Lavorgna & Horsburgh (2020) also found other motivations, including the desire to be credited, a genuine belief that the creator/disseminator is helping patients, or a sexual motivation – where the authors found cases of alternative practitioners sexually assaulting patients under the guise of medical treatment. There were also cases of people wishing to support their own internal beliefs and opinions (especially holistic or conspiratorial beliefs), and finally, some cases where there were possible mental health disorders prevalent.

Research has also shown that medical misinformation has led to changes in the behaviour of patients, leading to increased instances of harm (Islam, et al., 2020; Chary, et al., 2020; Waszak, et al., 2018). Sunstrom et al. (2018) conducted focus groups with women about decision making around contraception. They found that misinformation released by healthcare providers negatively affected the decision-making process (Sunstrom & Dempsey, 2017).

It is clear from the research that medical misinformation can, and often does, lead to patient harm. The impact of dissemination of this misinformation needs to be understood, and policymakers and platforms need to do more to help counter this.

### **The Impact of Social Media on ‘Fake News’ and Medical Misinformation**

Social media technologies have allowed massive dissemination of information to a global audience in a matter of seconds, at very low cost (Berthon, et al., 2012; Deb, 2014; Bak-Coleman, et al., 2021). The increasing availability of broadband internet and cheaper devices (computers and mobile devices) to access this information has also increased its’ spread.

In 2014, ‘fake news’ was linked to the key threats to society by the World Economic Forum (World Economic Forum, 2014). In the report, the WEF suggested that the use of Twitter was to blame for the rapid spreading of misinformation online in specific cases. The report acknowledged that over 1 billion messages were sent on Twitter every two-and-a-half days (at that time) and that the issue to managing these is a big data problem.

Studies have shown that the number of people consuming news on social media channels continues to increase (Gottfried & Shearer, 2016). Research has shown that the majority of people (64%) only get news on one site (Gottfried & Shearer, 2016), which suggests that these people have little ability to cross-check the information received for accuracy.

In a speech at the Munich Security Conference in 2020, the Director-General of the WHO stated that “epidemics have the potential to cause severe political, economic and social instability and insecurity.” (World Health Organization, 2020). The Director-General went on to state that the latest pandemic (COVID-19) had brought with it an ‘infodemic’ which spreads more easily than any virus, and is as dangerous. Calls were made for all governments, companies and news organisations to work with the WHO to help manage this appropriately.

Research has further highlighted the negative social media has had on spreading misinformation – especially medical misinformation (McKee, et al., 2019; Krishna & Thompson, 2019). Other research suggests that such medical misinformation has led to behavioural changes in the general population and that this is now a serious threat to public health (Forster, 2017; Schwitzer, 2017). In her article in the Independent, Forster (2017) noted that “Of the 20 most-shared articles on Facebook in 2016 with the word ‘cancer’ in the headline, more than half report claims discredited by doctors and health authorities or – in the case of the year’s top story – directly by the source cited in the article.” Schwitzer

(2017) went further in stating, “Health news that is fake, sloppy, inaccurate, imbalanced, or incomplete threatens public health, public policy, and individual decision making.”

Research by the Centres of Disease Control and Prevention (2013) showed that there is a need to tackle the poor use (overuse, mismanagement of prescribing, storage issues, etc.) of antibiotics to tackle increased microbial resistance (Centres for Disease Control and Prevention, 2013). Other research has shown an increase in misinformation on antibiotics, which has led to a change in behaviour of citizens and an increase in the risk of microbial resistance (Smith, et al., 2015; Andersen, et al., 2019).

The increased use of social media channels to disseminate healthcare and policy information increases the confusion for end users of these channels. Valid healthcare messages sent by organisations can get confused with medical misinformation messages sent alongside these. Furthermore, with citizens understanding that social media has become a legitimate channel for sharing healthcare information, it becomes harder to spot those articles which contain ‘fake’ information.

When such medical misinformation changes perceptions and alters treatments sought, the public health impact can be severe. Cases such as the measles outbreak in the United States in 2019, or the reduction in children receiving the MMR vaccine in the United Kingdom in the early 21<sup>st</sup> century, all show how medical misinformation can lead to severe consequences.

Overall, it is clear that social media has had an impact on the availability and dissemination of medical misinformation, and, in many cases, this has led directly or indirectly to patient harm.

### **Limitations of the Research**

This research is based on secondary sources only. There is no primary research conducted, and, as such, further primary research is recommended to ensure that the information provided is timely.

Furthermore, the research has attempted to deal with the issues of medical misinformation. It is understood that the whole phenomenon of ‘fake news’ is wider than this, and so may require a more comprehensive and joined-up approach.

### Conclusion

'Fake news' and, especially, medical misinformation are both harmful and can lead to changes in public perception of health services and treatments. The massive rise in social media has led to a situation where misinformation can be shared quickly and at no cost – further increasing its' availability.

With citizens less able to cross-check information to ensure it is accurate – lack of skills, times, inclination, etc. – changes in behaviour linked to misinformation continue to increase. Such changes can have massive negative public health effects, and there is a requirement on policymakers, social media leaders, journalists, researchers, scientists, and medical providers to tackle this issue urgently.

The authors of this report suggest that the phenomenon of Medical Misinformation needs to be challenged openly and with vigour. Policymakers and providers of all media need to put in place robust solutions which can help resist the growing amounts of medical misinformation available.

Without a constructive approach to combating medical misinformation, citizens will make poorer choices around their own health management and will, ultimately, have potentially serious health outcomes.

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