

## **The impact of disinformation on the right of access to health care services in South Africa**

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Access to truthful, factual and accessible information is both a human right and a prerequisite for enabling individuals and communities to secure all other rights, including the right to health (Marais et al., 2017; McDonagh, 2013; The People's Health Movement South Africa, 2011). As Michael Thiede explains, "Health information plays a key role in increasing health services access in the sense that it creates health knowledge. ... In general, information stimulates access by making the objective choice set transparent to the individual and granting her the autonomous choice." Furthermore, "health information needs to be comprehensible for the average health care user, adequate and trust-worthy" (Thiede, 2005). Misinformation and disinformation, that is, the communication, advice, guidance, counsel, knowledge, facts, data and statistics that are not trust-worthy and spread falsehoods, directly interfere with the public's entitlement to the "highest attainable standard of health".

Unfortunately, South African history is replete with the negative impact of health disinformation on access to health care services. One notorious example was when Dr Matthias Rath encouraged AIDS patients in Khayelitsha to discontinue anti-retroviral (ARV) treatment in favour of vitamins (Treatment Action Campaign, 2005). AIDS denialism, the outright denial that HIV causes AIDS (or that the virus even exists) dissuades people from testing for HIV. This can expose their partners to risk of infection or to ignore positive test results, acting as a barrier between people living with HIV and much-needed medical care (Kalichman, 2009) Beyond its individual impact, health misinformation and disinformation can influence government policy. This was seen during the Mbeki presidency, where government policy, heavily influenced by AIDS denialists, contributed to the deaths of hundreds of thousands of South Africans (Geffen, 2009).

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More recently, misinformation and disinformation on social media has targeted the Human Papillomavirus (HPV) vaccination (Delany-Moretlwe et al., 2018). HPV is a sexually transmitted virus responsible for almost all cases of cervical cancer, the second most common cancer diagnosed among South African women (Williams et al., 2023). In 2014, the process of raising awareness about HPV vaccination and seeking parental consent in advance of the rollout of a national school-based HPV vaccination campaign led to concerted push-back by anti-vaccine activists, who spread alarmist disinformation via SMS and on social media (Wiyeh et al., 2019). In some health districts, this disinformation campaign affected uptake of the vaccine in both public (Khosa et al., 2022) and private (Milondzo et al., 2022) schools, exposing girls to preventable disease and possibly death in later life.

The public health goal of the HPV vaccination campaign was to reach at least 80% of school-going girls, thereby eliminating the opportunity for the virus to spread in the population through achieving “herd immunity”. Therefore, the right to health for all depends on the effectiveness of vaccination rates at the population and not just individual level. A similar principle applies to other infectious diseases where an effective vaccine is available, notably measles. Measles is a highly infectious, potentially disabling or deadly disease where 95% of the population must be immunised to prevent outbreaks (Bester, 2016).

Unfortunately, anti-vaccine activists in South Africa have long encouraged refusal of measles vaccination, for example through the Facebook group “Vaccine Awareness South Africa” (VASA). This group has doubled in membership in the past decade (from 5400 members in 2015 to over 11000 members in 2025) and was also a significant amplifier of dis- and misinformation during the COVID-19 pandemic (BBC Trending, 2021). Although difficulties of access, rather than anti-vaccination campaigns, are thought to be the major contributor to lower-than-ideal measles vaccine coverage in South Africa, the contribution of dis- and misinformation has not been specifically studied (Burnett, 2015).

During the COVID-19 pandemic, purveyors of mis- and disinformation mobilised rapidly, even in the early months of the pandemic (Kalichman et al., 2022). While highly visible global vaccine inequities and the delay in accessing COVID-19 vaccinations in South Africa arguably contributed to increased vaccine hesitancy (Cooper et al., 2021), the role of anti-vaccine disinformation should not be discounted. South Africans were exposed to mis- and disinformation produced globally, including from the state-sponsored Russian RT news service (Jemielniak and Krempovych, 2021) and the “Disinformation Dozen” of notable

USA-based anti-vaccine activists (Nogara et al., 2022). Activity in one South African-based anti-vaccination group, which included both online and offline messaging and coordination of protests, peaked in July 2021, just as the government was rolling out opportunities for COVID-19 vaccination to the general population (Peter van Heusden and Rebecca Pointer, forthcoming). Anti-vaccine activists went so far as to launch court challenges to the COVID-19 vaccination and, while these were not successful, they were further used on social media to foster skepticism and advocate against vaccination (Broughton, 2024).

In addition to the dis- and misinformation spread by anti-vaccine activists against routine childhood and adult immunisation, other life-saving health interventions like cancer therapy have also been targeted. Research in South Korea, for example, tracked disinformation advocating for the use of the canine (dog) anthelmintic medication Fenbendazole to treat cancer (Jeong et al., 2024; Yoon et al., 2022). Anecdotal evidence suggests that this “infodemic” has spread to South Africa via social media and contributed to people with cancer postponing or avoiding therapy altogether.

Often anti-vaccination positions are paired with advocacy for “alternative remedies”, such as is the case with Christine Hewlett who both sells naturopathic “immune boosters” via her online store, The Health Nut, and is the administration of the aforementioned Facebook anti-vaccine advocacy group VASA. Links between the “wellness industry” and the promotion of anti-vaccine beliefs and other forms of health mis- and disinformation have been identified internationally (Burt-D’Agnillo, 2022; Moran et al., 2024). Unfortunately, in South Africa certain doctors have been responsible for spreading anti-vaccine and other health misinformation (“HPCSA warns that anti-vax doctors may face misconduct inquiries,” 2021; Peralta, 2021). Given doctors’ perceived expertise, this is a particularly dangerous development (Jalbert et al., 2025).

South Africans are increasingly relying on social media for news, with the use of social media as a news source growing from 48% in 2018 (Chingwete et al., 2018) to 75% in 2022 (Hofmeyr, 2022). Meanwhile, major social media companies, including Twitter (now X) and Meta (formerly Facebook) have abandoned fact checking (Arya and Kanozia, 2025). The media landscape in South Africa has also seen a proliferation of “online news” sites including ones accused of spreading mis- and disinformation, alongside a wider erosion of editorial integrity (Grebe, 2021; Wasserman, 2020). Orentlicher has argued that “governments’

obligation to disseminate and ensure public access to timely and accurate information about pandemics, including vaccines” should become a duty under international law, perhaps in the currently negotiated WHO Pandemic Accord (Orentlicher, 2020). Yet, we live in a reality where world powers and their leaders are actively promoting mis- and disinformation (Froehlich, 2020) and, for a variety of reasons, are complicit in interrupting the right of access to accurate information regarding health. In 2021, the US Surgeon General published an advisory on building a healthy information environment (Murthy, 2021), and recommended that media organisations, technology platforms and governments have roles to play in combating what he called “the pollution of the information environment”. In a bizarre turn of events, the newly appointed head of the US Department of Health and Human Services, noted anti-vaccine activist Robert F. Kennedy Jr, was forced in March 2025 to instruct Children’s Health Defence, the organisation that he founded, to take down a misinformation-filled website that falsely re-used branding from the USA Centers for Disease Control and Prevention (US CDC), the public health agency of his own government (Stolberg et al., 2025)<sup>3</sup>.

With its multilingual, multicultural and pluralistic population, South African society is riven with fault lines that enable the creation of sub-populations within which dis- and misinformation thrive (Davies-Laubscher, 2024; Katoto et al., 2022). In this context, phenomena like vaccine hesitancy are not simply the result of a “knowledge deficit” but have at their root, socio-economic and political determinants (Cooper et al., 2022). As has been shown during the COVID-19 pandemic, those most disaffected with government, notably poor communities, are particularly susceptible to dis- and misinformation campaigns, leading to a perverse “double-abandonment” where those least able to access the right to health are further alienated from accessing this right through distortion of the information environment and its associated harmful effects on their capabilities to maintain physical, emotional, mental and spiritual health (Cerovac and Drmić, 2023).

Misleading or false information undermines trust and jeopardises decision-making based on reliable information. Those holding misinformed beliefs consider truthful information as

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<sup>3</sup> Spoofing of official health communication resources is not new: during measles outbreaks in the USA in 2017 to 2019 anti-vaccine activists altered and redistributed official health department documents so as to spread disinformation (Martin et al., 2021) and South African anti-vaccine activists have used official sounding names like “SA VAERS” (invoking the name of the US CDC run Vaccine Adverse Events Reporting System - VAERS) (Real411, 2021).

anathema. Moreover, as Thiede argues, we must recognise that trust is not a given but rather emerges in the context of people's understanding of social systems as fair and ethical. Trust - and thus trust in information - arises in a relational, reflective context. Interventions in the information sphere to support South Africans' ability to access their rights to health will thus require an all-of-society approach that includes health in all policies, especially information policies together with an equity-focus. This requires interventions to support the rights of the most vulnerable members and segments of our society.

With this in mind, community-focused interventions to provide accurate health information are key. On the social media sphere, Sarah Downs and colleagues have, for some years, tracked and responded to the activity of anti-vaccine activists in South African Facebook communities (including those targeted at new mothers). In addition, during the COVID-19 pandemic, health journalist Pontsho Pilane was a regular guest on Motswedding FM answering COVID-19 questions in Setswana (Benjamin, 2021). Community health workers (CHWs) can also play key roles in addressing health concerns and (re)building trust in the health system and health interventions (including vaccines) (Astuti et al., 2024).

In marginalised communities, however, structural and health system issues, including the judgemental and unempathetic behaviours of some front line health care workers, undermine effectiveness and trust (Watkins et al., 2021). A potential approach to tackling the health dis- and misinformation "infodemics" would thus involve preventative interventions to address risk factors for susceptibility to those messages (socio-economic, cultural and political) together with activities focused on tracking and diverting emerging infodemics themselves (Enria et al., 2024; Ishizumi et al., 2024). The right to accurate health information cannot stand alone, but rather is embedded in activities of care, compassion and social solidarity that make up the right to health in its complex entirety.

Much is, unfortunately, still not known about how dis- and misinformation specifically impact help-seeking behaviour among all South Africans; and, the activities of malicious actors in the dis- and misinformation sphere have largely gone unmonitored. While the South African Department of Health conducts regular health promotion campaigns that provide truthful information on topics such as vaccination, more needs to be done, in partnership with the media industry, the health professions and health regulatory bodies such as SAHPRA.

Finally, support for research in this area (perhaps coordinated by the Medical Research Council) must be prioritised as a matter of urgency (Cooper et al., 2024; Zollo et al., 2024).

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