

**Written evidence submitted by**

**Dr Ozge Ozduzen (Lecturer in Digital Media & Society at University of Sheffield);  
Dr Billur Aslan Ozgul (Lecturer in Political Communication at Brunel University London);  
Dr Nelli Ferenczi (Senior Lecturer in Psychology at Brunel University London)**

This submission focuses on misinformation and trusted voices. Our answers below are based on a research project on community mistrust and vaccine hesitancy, funded by the British Academy, the Social Science Research Council (SSRC) and the Science and Innovation Network in the USA (SIN USA) between 2021 and 2022. The project investigates the impact of historical marginalisation, social exclusion, official communication, and community mistrust on the discursive and social production of vaccine hesitancy on both social media platforms and in physical spaces in the United Kingdom and United States of America (see Ozduzen et al. 2022). We conducted in-depth interviews, focus groups, and systematic social media data analysis to uncover the experiences, beliefs and opinions of our research participants. Although our focus was on vaccine engagement of minoritised communities, we also investigated the ways that vaccine hesitant individuals in the UK consume information and misinformation content and engage with their respective sources. We finally analysed their reaction to official governmental information on vaccines and other health information, scientific advice, and health initiatives.

**1. Which organisations are the most trusted sources of information in the UK?**

Our findings show that communities with previous hesitancy towards vaccines and health procedures do not perceive official health and government-related organisations as trusted sources of information and do not prefer to follow mainstream media outlets for health-related information, data, and news. In their perception, exclusive official communication do not take into account non-white bodies (e.g., in the reporting of clinical trials) and experiences. They instead discussed a heterogeneous, yet communal vaccine identity rooted in their close social networks online or in their “safer” physical spaces, such as their church community. This identity contrasts with a homogenous anti-vaxx identity, which many participants explicitly distinguished themselves from. This distinction reflected concerns about the vaccine and the multiple reasons why they mistrusted official sources of information due to historical legacies and contemporary communal narratives of medical racism. Our interviewees also criticised mainstream media for labelling vaccine hesitant communities as “anti-vaxx”. The divisive mainstream media coverage had politicised vaccine choice through aligning the vaccine choices with particular political ideologies (e.g. far-right).

Although recent research showed that people use the Internet to engage with both homogeneous and heterogeneous people and views (see Martin et al. 2021; Ross Arguedas et al. 2022; Vaccari and Valeriani 2021), there is also substantial research on online echo-chambers, examining how users tend to form homogeneous networks online and a segregation of networks into communities of like-minded individuals (see Eslen-Ziya et al.

2019; Rusche 2022). In the lack of trust for official institutions and organisations, a predominant section of these communities used social media platforms to obtain information and data on the COVID-19 vaccine and other health procedures, and to socialise with like-minded users/groups, which segregated these communities from other networks of users. Even those participants, who reported that “they are not really big on social media”, highlighted that they obtained their trusted health information through YouTube videos, Facebook groups, TikToks, Reddit subreddits, Telegram channels, BitChute, and Twitter.

More specifically, our participants followed doctors and scientists on visual social media platforms such as YouTube and TikTok. They also got their information from independent (anti-establishment) journalists on alternative social media platforms such as Telegram and from online influencers such as Rashid Buttar, Gareth Icke, Joe Rogan, Mike Yeadon and Sherri Tenpenny. Our interviewees also identified websites such as Infowars, podcasts such as Dark Horse and WhatsApp groups on topical issues to be their trusted sources of health information. Recent research conducted by the Centre for Countering Digital Hate (2021) showed that almost two-thirds (about 65%) of all online anti-vaccine content was shared by twelve leading anti-vaccine influencers, some of which were also identified by our research participants as trusted sources for health and pandemic related information, such as Sherri Tenpenny and Rashid Buttar. Thus, our participants relied on multiple sources for (mis)information, and, in general, took a decentralised approach in obtaining information.

Social media use did not decrease their trust towards information obtained face-to-face. Our research participants also relied on face-to-face communication to obtain information on health and other matters of national debate. They particularly trusted religious authorities in their own close social networks, such as trusted figures in their church or mosque communities. They also preferred their GP to be a member of a minoritised community. Our informants also valued their face-to-face communication with their GP and specialist medical doctors (whom they knew from before) in their attempt to reach trusted information on health. Trusted information is thus viewed to originate from already trusted people in each community.

## **2. Where do you seek authoritative information to make up your mind about matters of national debate (such as vaccines and climate change)?**

Our findings show that vaccine hesitant communities did not seek authoritative information from official platforms, scientific outlets, and mainstream media channels due to their lack of trust in these sources. Official public health messaging narratives put forward by the UK government during the COVID-19 pandemic linked vaccine uptake with a return to the social and economic norms of the pre-pandemic world. Our findings revealed that this intention did not fully resonate with those who had no stake in the pre-pandemic world, showing that the personal lived experience of exclusion and marginalisation as a community can result in a

lack of trust in the healthcare system, procedures, and providers, which thus feeds citizens' mistrust towards official information related to matters of national debate (e.g., vaccines).

In the face of their mistrust towards official and mainstream information sources, our research participants reported that they primarily sought information on social media platforms, with content shared by their trusted sources on these platforms representing trusted information in lieu of official health and government channels. YouTube, a visually appealing social media platform, was a popular tool for obtaining news by watching videos and short documentaries made by amateur or semi-amateur users.

Amongst these platforms, we also identified newer platforms such as Telegram to be the most popular platforms where vaccine hesitant users looked for alternative authoritative information on health. Recent research shows that Telegram has become “a trusted news source” not only amongst youth (Lou et al. 2021), but also amongst activists, as the app offers encrypted messaging opportunities (see Herasimenka et al. 2020; Ameli and Molaei 2020). Telegram has also recently been identified as a platform where anti-establishment actors, who are deplatformed from legacy social media platforms, such as Twitter or Instagram, have migrated to (Rogers 2020). Telegram provides these actors with the ability to speak their mind due to less strict content moderation policies in place and the availability of end-to-end encrypted voice and video calls. For example, our research participants mentioned their effective use of the Telegram channel entitled “COVID VACCINE VICTIMS” to receive information about the side effects of the COVID-19 vaccine. This shows that despite the abundance of authoritative information on matters of national debate, users tend to “do their own research” to make up their mind using visual and new social media platforms.

### 3. Are you able to “do your own research” on matters of national debate?

Our findings reveal that people who are already excluded from and/or do not feel a sense of belonging to the mainstream generally avoided mainstream media sources and official governmental sources related to matters of national debate (e.g., vaccines or social distancing measures). They perceived that there was a lack of sufficient, comprehensive, and inclusive official health messaging and an absence of multi-sided and thorough public debate. The perceived lack of confrontation and interaction between medical doctors, virologists and other scientific experts with opposing views also prompted our participants to independently “do their own research” online as lay scientists. Indeed, most of our participants reported that they “did their own research” online to obtain health information, and that this was an integral process in them a) moving away from relying on formal and mainstream sources of information and b) the formation of their vaccine hesitance.

Furthermore, our interviewees discussed that due to the deluge of information available online, they could form robust and objective opinions about the vaccine; some interviewees employed terminology used in empirical research such as ‘reviewing evidence’ and

'evaluation' when describing the ways that they obtained their information online. They sought out the views and recommendations of medical doctors or scientists online, who held views alternative to the official information presented by the government and mainstream media and similar to their own.

While vaccine communities largely avoided mainstream media to do their own research, they reported that they were inevitably exposed to health information through mainstream media outlets, such as the BBC. In such circumstances, our participants felt that they needed to fact-check these contents with their own trusted sources on social media platforms and in their close social networks. For example, our interviewees highlighted that when they saw official information on mainstream media about the COVID-19 vaccine, to cross-check information about the short-term and long-term effects of the vaccine, they did their own research online to learn more about the mRNA technology and its possible side effects. They were able to find a variety of sources online that confirmed their pre-existing concerns about the trustworthiness of the COVID-19 vaccine. To seek a remedy for the spread and reach of misinformation and users' tendency to "do one's own research", however, should not mean to shut down public debate or the contestation of ideas (Cover 2022). In fact, open discussions in online and/or physical spaces about citizens' concerns and reservations on matters of national debate (e.g. vaccines) would bring communities together, tackle polarisation and in the long run mend democracy.

#### **4. What role should the National Academies have in being a source of authoritative, trustworthy information?**

The National Academies can do outreach activities in online and physical spaces to bolster their role in the dissemination of trustworthy and authoritative information. We recommend that the priority of the National Academies should be to build trust and disrupt unequal relationships that many of our participants described as characterising their everyday interactions with governmental and healthcare institutions, scientific and medical institutions, and mainstream media outlets. To do so, the National Academies can design outreach initiatives in physical and online spaces such as open forums, which take place *within* communities. Where possible, these community outreach projects should include trusted members of communities in question, such as religious leaders. Medical experts, academics who are experts in the area and other relevant members of the public should also be included in these outreach events to facilitate further trust and rapport. We recommend that these regular (rather than contingent) outreach initiatives should function as spaces where individuals, who may have suspicions towards scientific information on vaccines or climate change, feel that they can have open dialogues to discuss their concerns, beliefs, and experiences and receive responses from relevant individuals or stakeholders without judgement.

This would address the concerns raised by our participants that they obtained much of the knowledge about health information through personal research (e.g., online), because they

felt that they could not hold these conversations with healthcare practitioners or other relevant experts due to their fear of potential marginalisation and/or stigmatisation. Previous research on digital diplomacy showed that online audiences like to engage with activities that invite their participation in ways that reflect their knowledge of the topic (Ozgul et al. 2021). The public can be sceptical if they think they are being manipulated by the state (Manor 2018). Instead of acting as a network of information distribution, the online platforms of National Academies should also foster horizontally arranged online networks of exchange.

In disseminating information and organising outreach activities, authoritative health information created and shared by the National Academies, government bodies and healthcare institutions should acknowledge communities' lived experience of medical racism and contemporary experiences of racism within healthcare, their agency, and moral concerns around issues such as the side effects of vaccines or other concerns related to healthcare. These activities and strategies should also recognise the varied life experiences of different communities and avoid polarising discourse: public institutions need to adopt language that does not stigmatise individuals with suspicions towards scientific information.

## 5. Are National Academies prominent enough voices in engaging with the variety of debates on the internet?

Our findings revealed that members of various vaccine-hesitant communities connect with like-minded people and find trusted members of their own community more trustworthy. To have a prominent voice and engage with vaccine hesitant communities and other similar communities that might have mistrust towards scientific information, we propose that the National Academies first need to connect with trusted information sources such as religious or community leaders or medical experts that the vaccine hesitant communities trust.

Second, to share the findings from academic research on matters of national debate, we suggest that the National Academies and/or the government improve their online communication with the public. To communicate complex information, the National Academies and/or the government should partner with communications and information visualisation experts on a permanent basis to timely develop effective, bite-size, simple, and useful resources and visual materials. Recent research highlighted the importance and necessity of more and clearer resources on the risks and benefits of vaccines as the relationship of trust is established through sustained informed choice discussions (see Pringle et al. 2022). To make research more accessible and clearer, we recommend that important information on matters of national debate should be shared as bite-size audio-visual content on the Academies' websites. These audio-visual bite-size information should then be promoted on popular social media platforms using social media affordances, especially targeted ads and hashtags. We also recommend the National Academies to have a presence and create content on newer social media platforms such as TikTok to appeal to wider audiences and keep up-to-date with new media formats of sharing information.

## 6. Is the provision of authoritative information responsive enough to meet the challenge of misinformation that is spread on social media?

Providing the public with authoritative information is crucial but not enough to meet the challenge of online misinformation. Our findings suggest that disseminators of public information can play an important role in preventing vaccine hesitant communities to turn predominantly to social media platforms for information. Yet, for this, cultural sensitivity, social and political awareness, and care should be at the core of the training of these disseminators such as medical practitioners, journalists, academics and other professionals (i.e. members of relevant civil societies), who might be at the forefront of face-to-face information dissemination. National academies can play a major role in collaborating with universities to organise public trainings, open forums and workshops for those who engage in public information dissemination.

In addition to information dissemination, we show that content moderation plays a major role in users' understanding of and engagement with information sources. Although deplatforming users and removing content proved effective to tackle the spread of misinformation and disinformation on social media platforms, more recent research shows that deplatforming makes users feel that they are "censored" and ultimately isolated (see Ozduzen et al. 2022). In being deplatformed, users migrate to new platforms with more welcoming and 'oxygen-giving' extreme public (see Rogers 2020). We suggest the national academies partner with tech companies to develop better policy for moderating content on social media platforms. National academies could also partner with academics and civil societies to highlight good practice guidance for the moderation of viral misinformation sources in matters of national debate.

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