

## Commentary



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# "No disease for the others": How COVID-19 data can enact new and old alterities

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## Abstract

The COVID-19 pandemic invites a question about how long-standing narratives of alterity and current narratives of disease are entwined and re-enacted in the diagnosis of COVID-19. In this commentary, we discuss two related phenomena that, we argue, should be taken into account in answering this question. First, we address the diffusion of pseudoscientific accounts of minorities' immunity to COVID-19. While apparently praising minorities' biological resistance, such accounts rhetorically introduce a distinction between "Us" and "Them," and in so doing produce new and re-enact old narratives of alterity. Second, these unsubstantiated narratives thrive on fake news and scarcity of data. The second part of this commentary thus surveys the methods through which the COVID-19 test is administered in various countries. We argue that techniques used for data collection have a major role in producing COVID-19 data that render contagion rates among migrants and other minorities invisible. In the conclusion, we provide two recommendations about how COVID-19 data can instead potentially work towards inclusion.

## **Keywords**

Data collection, COVID-19, migrant, minorities, race, immunity

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The Johns Hopkins University COVID-19 counter glooms from a black webpage. Today 30 May 2020, the global count has reached 5,707,163 cases (Johns Hopkins University Coronavirus Resource Center, 2020a). Since the beginning of the year, the counter daily tells stories of countries and of their leaders: those who were suddenly overwhelmed by the virus, those who saw the tsunami at a distance and took measures, and those who did not. However, this is not the only story that data about the COVID-19 pandemic can tell. The same Coronavirus Resource Center at Johns Hopkins has recently mapped the U.S. states that have released breakdowns of COVID-19 data by race (Johns Hopkins University Coronavirus Resource Center, 2020b). These data tell a different story, a narrative of "others" severely hit by the pandemic:

Black Americans and other historically disadvantaged groups are experiencing infection and death rates that

are disproportionately high for their share of the total population. For example, while Black Americans represent only about 13% of the population in the states reporting racial/ethnic information, they account for about 34% of total Covid-19 deaths in those states. Asian Americans and Latinx Americans also show elevated impacts in some regions. (Cooper, 2020)

The fact that different techniques of data collection and analysis allow different narratives is not a novel insight in critical data studies (e.g. Gitelman and Jackson, 2013; Stanley, 2013). Yet the COVID-19 pandemic

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2 Big Data & Society

seems to work as a litmus test revealing associations between data-based narratives of disease and narratives of alterity. In the United States, the so-called "race data" (United States (US) Census Bureau, 2017)—historically vectors of medical racism (Savitt, 1982; Willoughby, 2019)—are now revealing a worrisome correlation between COVID-19 contagion and race. Similar associations suggest a key question: How are long-standing narratives of alterity and current narratives of disease entwined and re-enacted in the diagnosis of COVID-19?

In what follows we briefly discuss two related phenomena that, we argue, should be taken into account in answering this question. First, we address the diffusion of pseudoscientific accounts of minorities' immunity to COVID-19. While apparently praising minorities' biological resistance, such accounts rhetorically introduce a distinction between "Us" and "Them," and in so doing produce new and re-enact old narratives of alterity. Second, these unsubstantiated narratives thrive on fake news and scarcity of data. The second part of this commentary surveys the ways in which the COVID-19 diagnostic test is administered in various countries. We argue that techniques used for data collection have a major role in producing COVID-19 data that render contagion rates among migrants and other minorities invisible. In the conclusion, we advance two recommendations about how COVID-19 data can potentially work towards inclusion.

## The immunity of the Other

As the pandemic and the related panic spread worldwide (Depoux et al., 2020), pseudoscientific accounts of minorities being allegedly immune to COVID-19 went viral (Ross, 2020). Between March and May 2020, fake news circulated on alt sites, local televisions, social media, or instant message apps, insinuating that "people of color may be immune to the coronavirus because of melanin" (Williams, 2020), or of "blood genetics composition of subsaharan Africans" (Teresa, 2020). According to widely diffused Whatsapp threads, immigrants allegedly "do not get sick of Covid-19 thanks to their anti-tuberculosis vaccine" (Meli, 2020). Or, "it looks like none of the approximately two million Asian or African thirdcountry nationals residing in [Italy] is hospitalized" (Pennarola, 2020). As most fake news, these narratives were circulated through channels that did not claim any political belonging nor identity, were further spread by users genuinely convinced, and were deleted a few days after they are issued (Autorità per le Garanzie nelle Comunicazioni (AGCOM), 2018).

Such narratives find their *raison d'être* in introducing a rhetorical distinction between "Us"—i.e. the majority

of the population suffering from (the risk of) contagion—and "Them"—i.e. an indefinite alterity that is defined by its ability not to share the burden of pain, risk, and contagion. Apparently, immunity puts these minorities in a privileged position. However, in so doing they are enacted as "Them," an irreducible alterity. These pseudo-medical narratives of disease eventually become rhetorical strategies producing alterity.

Most notably, alterity by immunity works as a signpost, pliable enough to acquire different figurations in different contexts. The "Them" can be from time to time "the black," "the African," "the immigrant," "the Muslim," "the worker." In the United States, this distinction rests on previous race classifications, alterity is identified along racial variables. Discourses of race have indeed resurfaced in the myth of black immunity (Carter and Sanford, 2020), spread by white and black communities alike. The twitter message "So NONE of these Corona Virus cases have been people?! LEMME FOUND OUT IMMUNE. It's the least God can do after slavery" (Williamss, 2020) was retweeted almost 57,000 times and received 385,000 likes. All this while data show that African American communities are disproportionately affected by COVID-19 (Eligon et al., 2020).

Yet, race is not the only classification associated immunity. As the International alleged Organization for Migration (IOM) has pointed out, conspiracy theories spread against the Jews, Muslims, and people of Asian or European descent (United Nations Department of Global Communications (UN DGC), 2020). Often, migrants, the displaced, and people on the move come to populate the signpost of alterity (IOM, 2020). In India, where tens of thousands of inter-state migrants had to return home after having lost their jobs and became infected on return trains, Uttar Pradesh chief minister Yogi Adityanath claimed that migrant workers are strong men used to "sweat" and as such recover much faster from COVID-19 than "normal persons" (Khandekar, 2020a). In Italy, social media and alt sites rumors claimed that non-European migrants are immune to the coronavirus because they are regularly vaccinated against tuberculosis (Meli, 2020). Such narrative was supported by the alleged argument that people of color and migrants are absent in COVID-19 wards mainly populated by white, native patients (Huffington Post Italy, 2020; Pennarola, 2020). Such fake news was so popular as to push the head of the Italian national health organization to publicly declare that the contagion curve was similar for Italian and foreign citizens (Stranieri in Italia, 2020).

Dismissing such narratives of disease as mere fake news circulated by extremist groups would mean underestimating their potential to poison COVID-19 Pelizza 3

policies. First, immunity theories have been more or less naively circulated also by medical staff (Huffington Post Italy, 2020), professionals (Shenoy, 2020), and politicians (Khandekar, 2020b). This is not uncommon with fake news: once they enter the public debate, they can appeal to the most diverse users (Autorità per le Garanzie nelle Comunicazioni (AGCOM), 2018). Second, such narratives of disease are not just racist and xenophobic: they are also dangerous. On the one hand, minorities might adopt less cautious behaviors in the belief that they are immune (Mock, 2020). On the other hand, such theories postpone policy actions that would instead be urgent. These theories are limited to picture the status quo (e.g. the absence of migrants in hospital wards and medical facilities), instead of questioning socio-economic and security reasons of such absence (e.g. fear of exposure prevents migrants and minorities from being hospitalized and tested, see McFarling, 2020). By so doing, they obscure the structural obstructions to equal diagnosis and treatment.

Third, unsubstantiated claims about resilience to COVID-19 may have serious consequences for democratic coexistence. Already stigmatized and vulnerable populations might feel the need to show their allegiance to the community, or even be openly asked so. As Rana Hogarth has pointed out in her history of racialized medicine in the United States, during the 1793 yellow fever outbreak in Philadelphia, people of color were deemed immune and co-opted to care for the whites. As a result, they were infected *en masse*. Furthermore, the narrative of alterity was strengthened, and not weakened, by their care effort:

the idea of innate black immunity placed an undue burden on the city's black inhabitants. For those black people who did stay behind to help, it meant buying into a belief that at its core defined their bodies as being distinctive and unequal to whites. (2017: 30)

The yellow fever case constitutes a textbook example of how narratives of disease can eventually enact narratives of alterity.

Finally, as Carter and Sanford (2020) have recalled, claims of immunity constitute the other side of the same coin that sees the demonization of minorities as vectors of disease. Labeling COVID-19 as "the Chinese flu" is only the last in centuries-old tropes that associate disease to their supposed region of provenance (e.g. the "Spanish flu"). Not only do both claims of immunity and provenance erase the suffering of marginalized people, but they also actively reproduce their marginalization by enacting them as alterities.

# Segregated data collection

Narratives of disease can enact narratives of alterity, but they do not do so in a vacuum. They require data, or a lack thereof. Immunity theories thrive as fake news, plausible but deceiving. Deceiving, because they are purposefully crafted to induce false beliefs (ISD, 2020). Unsubstantiated immunity theories are circulated with the goal of provoking predetermined reactions that can directly or indirectly benefit the initiators. They are however plausible because they somehow echo verified events. The narrative of black immunity due to the "blood genetics composition of subsaharan Africans" (Teresa, 2020) was built on the confirmed news that a Cameroonian student in China promptly recovered from COVID-19 (Vincent, 2020). The theory of migrants' immunity due to the anti-tuberculosis vaccine referred to the news of novel trials aimed to test the potential of the live, weakened strain of a microbe similar to that which causes tuberculosis to strengthen the innate immune system (De Vrieze, 2020).

However, plausibility is not enough. To thrive, pseudo-medical narratives of disease also need the absence of robust data about the actual spread of contagion among minority populations. Acknowledging this, some United States senators and members of Congress have called for the collection of race and ethnicity data on coronavirus infections (Warren et al., 2020). We argue that techniques used for data collection have a major role in producing COVID-19 data that render contagion rates invisible among migrants and other minorities, and thus allow unsubstantiated narratives of disease to spread. An overview of how coronavirus testing for data collection is conducted in diverse countries exemplifies different causes of the underrepresentation of minorities in COVID-19 data.<sup>2</sup>

Analyzing the eligibility criteria to testing adopted by the countries which have published them, we have found both structural and implicit bottlenecks that may explain why minorities are underrepresented in COVID-19 data. First, access to health care and testing in most countries requires public or private health insurance. Populations on the move are structurally excluded (Narea, 2020), and minorities can experience lower health insurance coverage rates than the rest of the population (Hargraves, 2002). Low coverage structurally reduces possibilities of being tested. On top of that, there are also implicit reasons, associated with the social status of patients. In the United States, for example, there is evidence that physicians are less likely to refer African Americans for testing when they visit a clinic with symptoms of COVID-19 (Farmer, 2020, for a similar argument about pregnant black women's complaints going downplayed, see Hogarth, 2017. See also Carter, 2019; Wenneker and Epstein, 1989).

4 Big Data & Society

Second, testing strategies tend to prioritize dwellers who have regular access to health care, such as longterm residents of nursing homes and front-line workers. The UK testing strategy, for example, is organized around four "pillars," or principles, which prioritize test administration to people in need at Public Health England (PHE) labs and National Health Service (NHS) hospitals, and health, social and care workers and their families (UK Government, 2020). In Italy, by regulation the test is administered to the hospitalized and nursing home residents with breathing conditions, exposed medical and care staff, symptomatic civil servants providing essential services, symptomatic residents of assisted communities, and vulnerable people with chronic illnesses (Bocci, 2020). In Ecuador, a country heavily hit by the pandemic, testing requires identity cards (Ministerio de Salud Pública de Ecuador, 2020). In Finland, tests are administered primarily to patients with severe symptoms of respiratory infection and to health and social care staff. Attention has also been paid to groups of patients with chronic diseases and to those over 70 years of age. In Sweden, initially COVID-19 testing was conducted by area of residence. Since mid-March, testing was administered to symptomatic patients in need of hospitalization and health and nursing care personnel.<sup>3</sup> By definition, people on the move do not make up such populations. The only country which seems to collect data independently from a regular, established resident status is South Korea, where individuals are eligible for testing due to their symptoms, travel history or contact history.

Third, COVID-19 testing privileges administration at hospitals and health care facilities. However, stigmatized, irregular, or simply scared minority populations are less prone to seek testing and treatment at formal facilities (McFarling, 2020). Migrants may be too afraid to travel to these sites because of fears of being reported to the authorities (Bulman, 2020). On the one hand, reluctance to show up at health care facilities significantly affects COVID-19 data collection. And indefinite number of people are dealing with the disease in the solitude of their homes of shelters, and data will never be collected about them. On the other hand, as the IOM's Director General António Vitorino has recalled, thousands of stranded migrants worldwide do not have access to even minimal treatment nor health screening (United Nations (UN), 2020). Refugees in cramped settlements experience daily shortages of water, soap, and other basic facilities, not to mention the impossibility of complying with social distancing (Kelly, 2020). Furthermore, in the last months many have undergone forced lockdown inside camps like Moria and Vial in Greece, a measure thought to prevent the diffusion of the virus (Milan et al., 2020).

In such circumstances, the only possibility to collect data about COVID-19 and administer tests is public or NGO medical staff reaching the camps. However, there are resistances in this regard, as the case of Singapore demonstrates. Since April, Singapore—previously lauded for its efficient approach to tracing coronavirus cases—is facing a second wave linked to its cramped migrant workers' dormitories. Despite many reported symptoms, migrants have been the last ones to be tested and recorded, and only after the second wave's surge in cases. Medical teams reached dormitories on the outskirts of the city-state only when new infections increased to several thousands (Ratcliffe, 2020). In the United States, people detained by the US Immigration and Customs Enforcement in immigration detention facilities throughout the South of the country have been isolated after they were possibly exposed to coronavirus. Despite the exposure, it has been reported that detainees were not provided with personal protection supplies, nor were they given proper COVID-19 information or tests (Levin, 2020).

We suggest that these severe limitations to data collection contribute to rendering invisible or at minimum underrepresenting racial minorities, people on the move and migrants in COVID-19 data. Such underrepresentation then combines with the plausibility in allowing unsubstantiated narratives of disease flourish undisturbed.

## **Conclusions**

In this brief intervention, we have demonstrated how narratives of disease can create new and re-enact old narratives of alterity. The scarcity of COVID-19 data about select populations that are rhetorically identified as "Other" allows such narratives to spread on social media, instant message apps, and alt websites. To conclude, we would like to provide two recommendations to show how COVID-19 data can instead potentially work towards inclusion.

First, as we have suggested, narratives of disease introduce a distinction between "Us" and "Them." As alterity works as a signpost, ensuring that robust data about people at risk of becoming targeted as 'Other' are produced and circulated would cut the ground from underneath fake news initiators' feet. In other words, data should be used to impede the rapid, unscientific, and xenophobic definition of "immune" populations.

Second, any such effort will be as robust as the techniques for data collection that it deploys. Given the above-mentioned reasons why minorities are currently underrepresented, improving the techniques of data collection requires expanding their scope. Such expansion should take place by questioning the

Pelizza 5

standard assumptions that characterize medical data collection about resident populations in non-epidemic times. One of these assumptions is that infected people benefit from established resident status. Other assumptions posit that everyone can access health insurance, or that people with symptoms usually show up at medical facilities. Data collection needs instead to test people who are not insured, who lack resident status, who are not working or living in medical facilities, and who are unlikely to show up at medical facilities. In order to detect those assumptions, we suggest that involving ethnographic methods in survey design would be helpful. Ethnographic investigation could, for example, better identify the circumstances under which people avoid medical facilities, or the urban and rural locations where tracking and testing people on the move is more feasible. Adopting ethnographic methods could unpack assumptions that work in normal times, but not in times of pandemic, and thus contribute to designing a more just and inclusive methodology for COVID-19 counting.

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#### **Notes**

- 1. With "alterity" we refer to the outcome of sociotechnical processes that exert "cuts" in a continuum and so define identities by difference (Barad, 2007; Pelizza, 2019). Therefore, narratives of alterity are those performative acts which *enact* someone as different, and do not limit themselves to *represent* difference.
- 2. The main source for this survey was the web aggregator Our World in Data and its GitHub repository, both available at https://ourworldindata.org/coronavirus-testing (Roser et al., 2020). Claims without quotation refer to the official sources aggregated on this site. When supplementary sources are used, they are clearly indicated.
- 3. It is important to specify that the reported countries are the only ones who have issued official notes about their techniques for data collection. Apparently, the vast majority of countries have not disclosed their testing strategy.

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6 Big Data & Society

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Pelizza 7

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