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Making the COVID-19 Pandemic Visible: The Power of Grassroots Mapping Initiatives

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Since March 2020, digital maps have been used around the world to spatially display COVID-19 cases and deaths. Some of these maps aggregate official government data, and others are built with user-generated content. Particularly in low-income communities, where residents do not have proper access to tests, user-generated maps help people understand the scope of the pandemic. Two examples of grassroots initiatives that use maps to make the pandemic visible are *Conexão Saúde* (Health Connection) and *Painel Unificador COVID-19 nas Favelas* (Unified COVID-19 Slums Dashboard). Both were developed in Rio de Janeiro, Brazil, one of the countries with the highest number of COVID-19 deaths per capita in the world. This study describes the implementation of these initiatives, considering how networked grassroots approaches can be effective in locally mapping and managing a pandemic. The findings reveal that the interconnection among mobile platforms, community leaders, and nongovernmental organizations (NGOs) are critical sociotechnical assemblages that help manage a public health crisis that would otherwise remain invisible to the world.

Keywords: mapping, smartphones, networks, grassroots initiatives, COVID-19, pandemic

Maps allow us to visualize information that would otherwise remain hidden and unknown—such as the actual number of COVID-19 cases and deaths in a low-income community. Maps do not simply represent territories—by spatializing information about communities and drawing interconnections among people, they have the potential to shape social connections, help us understand how diseases move through spaces and help to identify resources. Kitchin and Dodge (2007) have importantly noted that maps are not mere static representations of space. As they point out, maps are never fully formed; they are constantly evolving, in a permanent state of becoming, because they are also products of always-changing social practices. In this process, mapping—a verb, not a noun—also produces space and reveals power imbalances. As such, maps can highlight socioeconomic differences in specific territories, but they can also be used by communities to help solve local problems, as I demonstrate in this study. Since March 2020, mapping practices have been used around the world to spatially display COVID-19 cases and deaths, helping communities manage the pandemic. Accessed mostly via mobile devices, these maps functioned as aggregators of user-generated data, as people shared their personal locations and

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symptoms information. However, this process also highlighted existing power struggles between communities and governments.

Right after the World Health Organization (WHO) declared COVID-19 a pandemic in March 2020, a myriad of technological solutions intended to map and track cases and monitor the mobility of people were developed with the intent to help stop the spread of SARS-COV-2, the virus that causes the COVID-19 disease (Collado-Borrell, Escudero-Vilaplana, Villanueva-Bueno, Herranz-Alonso, & Sanjurio-Saez, 2020; Goggin, 2020; Kitchin, 2020; Rose-Redwood et al., 2020). These solutions included heat sensors and temperature checks in public transportation, geolocation sensors to track the mobility of people, and apps that asked people to report symptoms and tracked and mapped cases. While some of these initiatives were applauded, others were met with fear and skepticism. Because these technologies were primarily focused on surveillance and tracking, much of the literature about them focused on the privacy and surveillance concerns of using these apps, their threats for civil liberties, and contributions for surveillance capitalism (Kitchin, 2020). Contact-tracing apps, in particular, received an overwhelming amount of attention in 2020 (Ahmed et al., 2020; Andrejevic, Davies, DeSouza, Hjorth, & Richardson, 2021; Goggin, 2020).

Collado-Borell and colleagues' (2020) survey of COVID-19 apps found that most of these apps were designed by governments—a finding in contrast with other types of health apps, which are normally developed by scientific foundations or hospitals. While the proliferation of these mobile apps happened all over the world, they were particularly important in middle- and low-income countries. Verhagen and colleagues (2020) point out how health-related data collection via mobile phones has been effective in rural areas where people have limited access to information and communication technologies. In the past, mobile messaging has been used for community epidemic surveillance during the Sierra Leone Ebola epidemic and for rabies surveillance in Tanzania (Verhagen et al., 2020). In these cases, mapping and tracing initiatives have aided not only how to control the spread of a virus but also helped populations understand the severity of a disease and how they could get access to scarce resources, such as tests and healthcare providers. They also signaled to people about which areas to avoid and how mobile they could be.

Among middle-income countries,[1] Brazil is a significant case because it has had, throughout the pandemic, one of the highest numbers of COVID-19 deaths and cases per million people (Ritchie et al., 2020). However, these numbers are subnotified because of the lack of widespread testing in the country (Thornton, 2020). And yet, not only did Brazil's federal government not take measures to mitigate the spread of the virus; it often contributed to its dissemination. As Campos (2020) and de Matos (2021) show, Brazil's far-right president, Jair Bolsonaro, refused to impose any type of lockdown, openly spoke against the efficacy of masks, and defended the use of highly controversial medications, such as ivermectin and hydroxychloroquine, to treat COVID-19. Bolsonaro was elected in 2018 and has often been called the "Trump of the tropics" (Phillips, 2018) because of his strong ideological alignment with former U.S. president Donald Trump's neoliberal political agenda, misogynistic and racist remarks, and science denialism. As a result, the pandemic has brought into wide evidence the absence of government support and leadership in implementing effective public health policies in Brazil, particularly in low-income areas.

[1] Brazil is considered an upper middle-income economy, according to the World Bank.

One of the outcomes of this lack of federal leadership and response to the pandemic was the emergence of grassroots projects and coordination among low-income community leaders, nongovernmental organizations (NGOs), foundations, and private institutes. It is true that some state and municipal governments in the country do maintain portals and dashboards. But actual positive change in managing the pandemic emerged from some of these initiatives in mapping the virus's spread. These localized, bottom-up responses to tracking the virus are important because they give visibility to a tragic situation that includes a lack of public health policies, government oversight, and widespread infection and death that would otherwise remain unnoticed. User-generated maps, in Brazil, helped to visualize an otherwise invisible situation.

To understand the relationships between pandemic management, mapping initiatives, and low-income communities, I first situate the development of COVID-19 mapping apps in the context of a longer history of mapping epidemics. Then, I describe my research on decentralized and local initiatives of mapping the pandemic in Brazil, highlighting the process by which I gathered data, and how the data were analyzed. Finally, I present two specific case studies of pandemic-mapping initiatives: *Painel Unificador COVID-19 nas Favelas* and *Conexão Saúde*. My goal is to show how these initiatives came to reinforce existing perceptions of grassroots and community power in low-income communities. As I show below, the evidence suggests that they have made a difference in the course of the pandemic in Rio de Janeiro's favelas. For example, case-fatality rate dropped almost 90% in affected areas after *Conexão Saúde* got off the ground. This study contributes to the ongoing studies at the intersection of social geography, mobile communication, and mobilities that focus on pandemic response, particularly to the interdisciplinary fashion that investigates sociotechnical solutions to understand and manage public health crisis. This study can also help us understand how to report information that often evades official data-collection efforts, which can be useful to reveal socioeconomic disparities, help localized prevention strategies, and manage future pandemics, especially in the developing world.

Pandemic Mapping

Mapping health information to understand public health crises is not new (Mocnik, Raposo, Feringa, Kraak, & Köbben, 2020). One of the first uses of spatial visualization to map health information happened during the London cholera outbreak in 1854. As it has been widely described (Gordon & de Souza e Silva, 2011; Johnson, 2006), British physician and epidemiologist John Snow deduced that the cholera outbreak was originating from the drinking water on a Broad Street well after plotting the location of cases on a map of London. Based on the visualization, he found out that cases were more prevalent in households that used that specific well. A few years earlier, Edwin Chadwick plotted on a map of Leeds (United Kingdom) deaths from a cholera outbreak in the 1830s, and color-coded the city streets according to upper- and lower-income households (Koch, 2011). By layering the information, he was able to infer that the outbreak was disproportionally affecting lower-income people and deducted that disease mortality was primarily related to social inequality, instead of personal hygiene or "bad luck," as it was normally believed. Those early initiatives are significant not only because they represent some of the earliest attempts to add epidemics location information to representations of space but also because they highlight how mapping can reveal previously hidden socioeconomic disparities and prompt public health experts to act upon that information.

The United Kingdom's cholera maps set the pace for the visualization of disease outbreaks and epidemics that only accelerated in subsequent decades. With the development of computers and visualization software in the 1980s, Geographical Information Systems (GIS) could be digitized and the amount of information being plotted on digital maps increased substantially. In the late 1990s and early 2000s, with the popularity of the World Wide Web, these epidemic maps could be built with publicly available online data and widely shared with the public. During the SARS epidemic in 2002–2003, a mapping team in Hong Kong, one of the hardest-hit areas during that epidemic, used the Hong Kong's Department of Health data to geocode cases on city streets (Geraghty, 2020). In addition, for the last 20 years, major health organizations—including the WHO and the U.S. Center for Disease Control (CDC)—have used Web-GIS to manage infectious disease outbreaks by helping public health authorities send resources to susceptible areas and predict outbreaks. During the Zika outbreak in 2015, for example, "the WHO and CDC used GIS to analyze data about mosquito habitat and demographics to predict likely locations of Zika and thus reveal populations vulnerable to infection" (Geraghty, 2020, para. 17).

Following the trend with past pandemics, in 2020, several governments, public health agencies, and tech companies launched Web-GIS and dashboards that tracked the spread of SARS-COV-2. Some notable examples are the Johns Hopkins University Coronavirus Resource Center (Center, 2022) and Our World in Data (Ritchie et al., 2020). Most of these public dashboards were created by governments and were national in scope, but state and municipal governments' public health agencies often created their own Web-based dashboards as well (Ivanković et al., 2021). These dashboards showed trends in cases, deaths and, later on, vaccinations (Fareed et al., 2021). However, as Pietz, McCoy, and Wilck (2020) note, most did not correlate public health interventions (e.g., stay-at-home orders, closing of businesses, contact tracing) to viral spread. As a result, they all lacked clarity on how mapping could help public health interventions, and thus, affect infection rates. Using mapping to help public health interventions is exactly what makes both *Conexão Saúde* and the *Painel Unificador COVID-19 nas Favelas* so relevant, as I will show later on.

Another common characteristic of government dashboards is that they are generated by official data (Pietz et al., 2020), which is a problem in countries with a severe lack of testing, as is the case with many Global South countries, like Brazil. While Brazil has one of the highest numbers of COVID-19 cases and deaths, it has one of the lowest number of tests per capita (Worldometers.info, 2022). Tests in the country are expensive and scarce (Dantas et al., 2021; de Oliveira & Araújo, 2020), leading to intense case subnotification. In January 2022, for example, when the Omicron variant raged the country, people were instructed not to test, unless they were experiencing severe symptoms (G1, 2022). Consequently, official government dashboards displayed a misleading picture of how the pandemic was actually evolving in the country.

In addition to lacking accurate data, government dashboards are mostly designed for the Web, and so are hardly accessible for the population who does not have access to desktop computers and laptops, as is the case with most people in developing countries. Primarily in low-income communities, access to the Internet happens via mobile phones (Evans, 2018; Ling & Horst, 2011; Marler, 2018). During the pandemic, mobile phones have also been used in low-income communities as channels for telehealth, scheduling tests, reporting symptoms, and cases (Verhagen et al., 2020). Not surprisingly, government-generated Web-

based dashboards are not intended to serve minoritized populations. This is where mobile apps come to fill the gap.

With the popularity of smartphones in the late-2000s, mobile apps like Waze and Yelp became famous for collecting user-generated data and displaying maps where users could access real-time information about their environment, such as the location of the most recent car crash, or the newest review of a local restaurant. Crowdsourced information, however, is older than smartphones. Around the mid-2000s, the so-called Web 2.0 allowed users not only to pull geographic information about the environment around them but also to push information to maps (Goggin, 2015; Haklay, Singleton, & Parker, 2006). As Gordon and de Souza e Silva (2011) put it, "mapping has changed from something that can spatialize social information to something that can socialize spatial information" (p. 28). The most obvious examples of these types of collaborative maps were Google maps mash-ups, which could aggregate user-generated data about virtually anything, such as the locations of municipal reported crimes or Associated Press headlines. Crowdsourced information, when plotted on a map, becomes part of the local informational landscape and reveals hidden aspects of the social geography of locations. Although Web-based GIS have been relevant in collecting and displaying crowdsourced aggregated data, smartphones made it incredibly easier to contribute to these maps because people normally carry their smartphones wherever to go, and so can contribute location-based information to mobile maps in real time. While crowdsourced smartphone apps have been popular for a decade, it was not until the COVID-19 pandemic that smartphones were systematically used to plot user-generated pandemic information on interactive maps.

Mapping the Virus in Brazil

Interested about the worldwide trend in using smartphones and mapping to track the pandemic, in April 2020, I started my quest to find such initiatives in Brazil. As a Brazilian-U.S. citizen, I am fluent in both Portuguese and English. I have lived half of my life in Brazil and half in the United States, and I visit Brazil at least once every year. This experience puts me in a unique position to understand the Brazilian socioeconomic, cultural, and political context, and to translate and interpret the data I have collected for this research.

To survey pandemic-mapping initiatives in Brazil, during April and May 2021, I have widely searched online for COVID-19 mobile and mapping apps developed in the country between March 2020 and March 2021. Seeking to understand who developed them, for what purpose, and in service to whom, I analyzed their websites, read popular press articles and press releases published about them, and watched lectures and videos available online about these projects. My goal was to understand their development process and impact. In a second phase, in June and July 2021, I conducted in-depth interviews with the main developers, organizers, and volunteers of these projects and initiatives. Each interview lasted about one hour and was conducted online via Google Meets. I also interviewed project leaders and organizers asynchronously via WhatsApp voice messages. I took detailed notes about each app/initiative creation date, the actors involved in the development of the projects, the duration of the projects, the pros and cons of each project, the community impact, and the technology requirements. In sum, I analyzed the network created by the relationships between mapping, mobile devices, developers, users, and organizations,

focusing on how these networks were constituted in each case, and how they made a difference in the lives of populations during the pandemic.

In this process, I identified three primary categories of COVID-19 mapping initiatives in the country: those developed by individual citizens, those developed by private startups, and those developed or supported by grassroots initiatives and NGOs. An example of the first category is *COVID por CEP* (COVID by ZIP CODE), developed by Thales Mesentier, an architect and programmer resident in Rio de Janeiro. In his free time, he developed a Web-based app that retrieves public raw data from the Rio municipal government database and plots COVID-19 cases and deaths on a map of the city. The data are geolocalized by zip code, and the representation is so precise that cases can be identified at the scale of a single street block. Although *COVID por CEP* received up to 43,000 daily accesses right after its release in July 2020, it could not expand beyond the city of Rio because of the lack of reliable data at the state level. *Brasil Sem Corona* (Brazil Without Corona) is an example of the second category. The mobile app was developed by Colab, an existing mobile platform used country-wide. Colab's app allows people to report problems in urban areas, such as potholes or broken trash cans, and sends the complaints directly to city governments. Colab took advantage of their existing civic engagement platform to ask users to report their COVID-19 symptoms via the app. This way, they did not have to rely on official government data, which are often incomplete. These data were then geolocalized and displayed on a map, and, similar to the citizen's complaints, also shared with municipal governments.

Colab engages citizens in civic participation in what they call "participatory surveillance," that is, users provide data about the city or themselves hoping to make governments accountable and respond with appropriate public policies. While *COVID por CEP* could not expand because of the lack of official government data, apps like *Brasil Sem Corona* fulfilled a gap created by a lack of testing data in the country. *Brasil Sem Corona* partnered with several local municipal governments across the country that could use the collected data to help tackle local viral outbursts. By forecasting where cases could increase, local governments could direct scarce resources, such as tests, to specific areas in the city. But this app also depended on public participation, and with the decrease in the number of cases around September 2020, people stopped contributing, and they deactivated the portal.

Like *Brasil Sem Corona*, the *Painel Unificador COVID-19 nas Favelas* and *Conexão Saúde* also relied on crowdsourced self-reported data for mapping the pandemic. In addition, they used other strategies to collect data and serve the low-income populations who did not have access to mobile or smartphone phones, such as the work of volunteer community leaders to collect these data and deliver information to the population. Both projects were developed and supported by a network of grassroots initiatives that includes NGOs, community leaders, public and private research foundations, and individuals willing to volunteer their time to help these communities. In Rio de Janeiro, they came to fulfill a gap created by the lack of official data and government support. The strength and relevance of these projects stem from their ability to connect several low-income communities horizontally and from the bottom-up. These initiatives did not come from the governments and are not part of any coordinated nation or state-wide public health initiative, as often occurred in Global North countries. They are grassroots networks aiming at solving a public health problem in locations where government intervention is often absent. They did not solve the pandemic, but their implementation actually made a difference in the lives of people living in these communities, by helping

them have access to tests, meals, and self-isolate. They also helped people understand viral spread by visualizing cases and deaths in their communities.

Grassroots Initiatives to Manage the Pandemic

Painel Unificador COVID-19 Nas Favelas

Early in 2020, a group led by the Catalytic Communities (CatComm) NGO realized that the favelas in Rio de Janeiro were disproportionately affected by the pandemic, and if the communities themselves did not step up, the virus would rage without control. Like in many other countries in the world, the pandemic hit the most vulnerable hardest (McCoy & Traiano, 2020). Living in crowded multigenerational households, having a job that does not allow for remote work, and the lack of resources in the public health system all contributed to a disproportionate number of deaths among the metropolitan poor population (Rocha et al., 2021). As Ribeiro, Ribeiro, Veras, and de Castro (2021) showed, areas with less education, more household crowding, and lower income were associated with more deaths. For example, in 2020, COVID-19–related deaths in public hospitals were almost double those in private hospitals (Werneck, Bahia, de Lima Moreira, & Scheffer, 2021). According to Peres and colleagues (2021), Black and Brown patients also showed higher in-hospital mortality than White patients, and White patients were admitted less frequently to ICUs. In urban areas, most of the non-White poor population lives in favelas, which are extremely low-income neighborhoods embedded in some of the wealthiest areas of big cities like Rio de Janeiro and São Paulo. It is estimated that in Rio de Janeiro, the second-largest city in Brazil, about 1.5 million people live in favelas, which corresponds to 25% of the city's population. The COVID-19 death rate in Rio's favelas was one of the largest in Brazil. By July 2021, more than 6,000 people had died of COVID-19 in Rio de Janeiro favelas, which is more than the number of cumulative COVID-19 deaths in many countries up to that point (Thuswohl, 2021).

Favelas are historically invisible to public policies, and (purposely) forgotten by governments, lacking proper connection to city utilities, like cable and electricity. According to a recent World Bank report, 35% of the Brazilian population has no access to proper sanitation, such as running water and a sewage system (Ibarra, 2020). It is well known that favela dwellers often create clandestine connections with the city utilities, such as electricity and cable TV (called "gatos") to acquire basic services that normally do not reach them (de Souza e Silva, Sutko, Salis, & de Souza e Silva, 2011). The systemic lack of basic services and infrastructure in favelas was exacerbated during the pandemic. According to Theresa Williamson, CatComm's founder and director, one of the main issues they were facing was the lack of available tests, so people would get sick and die, and these cases would not become part of the official government tracking dashboards (Catalytic_Communities, 2020b). In addition, even if they did get tested, official positive results were often plotted on COVID-19 dashboards outside of the favelas.

Many favela residents do not have official addresses. Their system of street names and numbers also does not belong to the official maps of the city. Early Google maps represented favelas as green areas, and until 2017, the Rio municipal government left favelas out of the city's official maps distributed to tourists ("Prefeitura do Rio," 2017). Although many of these favelas are part of official maps now, more than 50% of favela residential addresses still do not have a zip code. When requested for a home address, favela

residents frequently give the location of a nearby store or community center, which are often outside the geographic area of the favela (Galdo, 2021). As a result, when they test positive for COVID-19, the case is associated with a "formal" nearby neighborhood, leading to a skewed picture of the pandemic situation in the favelas (Gracie & Scofano, 2020). As Gracie and Scofano (2020) show, many governments' COVID-19 dashboards represent the favelas' geographic areas as empty spots, as if there were no cases in those locations. This situation makes the deployment of public policies, especially in a large public health crisis with the scope of COVID-19, even more difficult because these communities are, literally, invisible.

Aware of this problem, as early as March 2020, each favela started to count their COVID-19 cases on their own (Catalytic_Communities, 2020b). To collect the data, volunteer residents went from door to door, asking for information about cases and deaths. They also collected this information via WhatsApp—the most popular mobile app in Brazil (Mari, 2020). CatComm had been working with several favela community leaders since the year 2000, so they could reach a wide network of favelas, and as soon as the pandemic began, they started to organize biweekly Zoom meetings to discuss the pandemic situation in the favelas (T. Williamson, personal communication, June/July 2021). One of their first activities was to organize and consolidate all the scattered information about COVID-19 cases and deaths from all the favelas on an Excel spreadsheet. In May 2020, they had a meeting with Esri, an international supplier of Web-GIS maps. Esri has a volunteer program to provide free GIS services to underprivileged communities and helped CatCom transfer all the data from the spreadsheets to an online dashboard that resembled the Johns Hopkins University COVID Dashboard (T. Williamson, personal communication, June/July 2021; Figure 1).

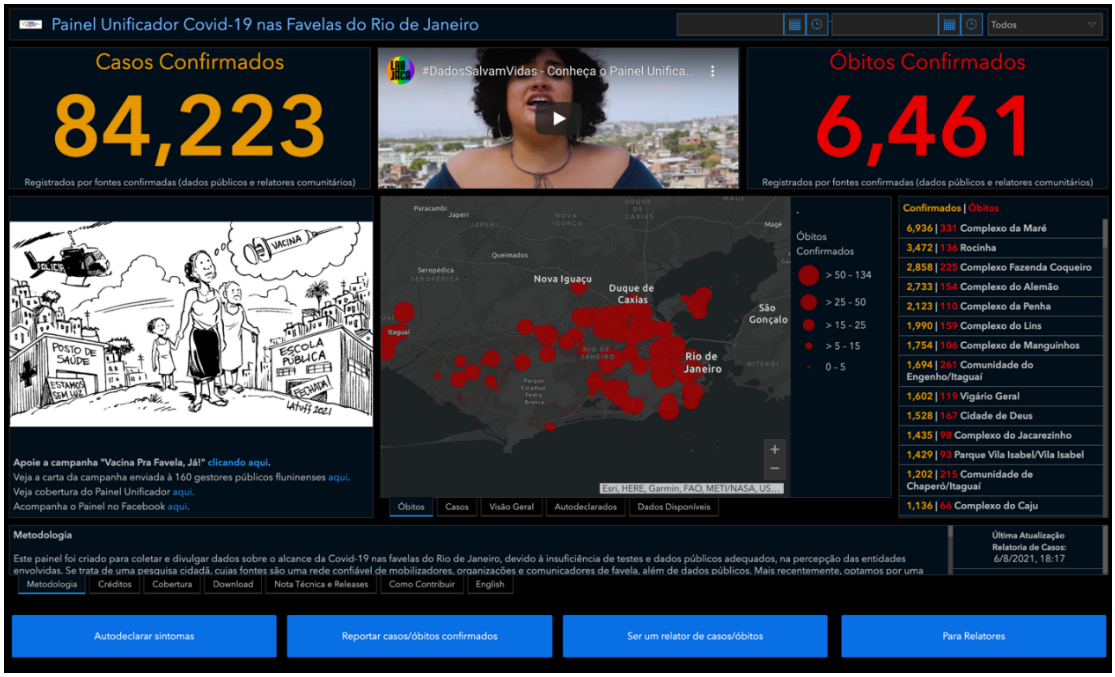

Figure 1. Painel Unificador COVID-19 nas Favelas do Rio de Janeiro (Catalytic_Communities, 2020a).

The points on the map indicating COVID-19 cases and deaths come from four main sources. First, a small few cases (about 1.5%) originate from official municipal government dashboards. Second, about 5% come from data reported by volunteers. As explained above, volunteer workers collect this information in their communities, either in person, going from door to door, or via WhatsApp. These volunteers are either community leaders who already worked with CatCom in the past, or recently recruited by the *Painel's* initiative. The *Painel* has a link to a Google form for recruiting volunteer workers in the communities. Third, about 15% originate from a Google form where people can report their own symptoms or report a COVID-19 case or death in their community. Individuals with access to an Internet connection can thus directly submit information via this form on the *Painel's* website. Finally, most data (about 80%) come from a manual process of matching existing zip codes with actual favela's geographic areas.

The GIS map used to represent the favelas on the *Painel* come from the municipal government database, where each favela is represented as a polygon. However, their most recent data were from 2010, and as such, the *Painel's* team of volunteers worked with community leaders to (1) redesign the polygons to match the actual geographic limits of the favelas as of 2020, and (2) add new polygons where new favelas emerged during the past decade (Gracie & Scofano, 2020). In addition, they collected zip code data associated with COVID-19 cases and deaths from municipal government databases. However, as explained earlier, these data are misleading because some of the zip codes associated with neighborhoods actually belong to favelas, and some are unassigned to any particular neighborhood. The volunteer team, then, gets these zip codes that do not belong to any specific neighborhood and match them with existing favelas geographic areas (polygons) on the map. In addition, they look at zip codes that are associated with official neighborhoods, but that often cross into the favelas. They look at the four-digit zip codes to find out which of these cases should actually belong to the favelas—not the official neighborhood. According to Renata Gracie (personal communication, February 18, 2022), project volunteer and FioCruz researcher, this is a very laborious process that needs to be done partly by hand. As of this writing, the *Painel's* dashboard is updated every two weeks and aggregates data from more than 400 favelas in Rio de Janeiro, representing more than 70% of favela residences in Rio (RioOnWatch, 2021a).

The *Painel* is a robust example of how a network of grassroots organizations can make a difference in mapping the unmapped, that is, give visibility to COVID-19 cases and deaths that would normally remain undetected because they were not reported, either because of the lack of tests, or because cases were assigned to other neighborhoods. In July 2020, while official municipal government sources indicated that favelas in Rio had about 760 cases and 144 deaths, the *Painel* reported 5,410 cases and 751 deaths (Schmidt, Porcidonio, & Goulart, 2020). This comparison highlights how the dashboard achieves its goal to map the actual reality of slum residents—not the municipal government reality that goes onto the official dashboards.

Williamson points out that no one analyzes the *Painel's* data to recommend data-driven practical public health interventions in the favelas. Normally, this would be the role of the governments, which have been openly absent during this crisis. But even despite this absence, the *Painel* helped the favelas' communities to manage the pandemic. The same community leaders who help report cases also mobilize to deliver factual information to the population about disease spread and vaccines, in person or via WhatsApp, and help them with basic needs. For example, many tailors stopped their usual clothes production to start

producing masks for the community. Kadina Bastos (RioOnWatch, 2021b), a seamstress from the Vila Aliança community, says that in the beginning of the pandemic, their collective donated more than 2,000 masks. However, she notes that the prices of raw materials increased, and the government failed to help support them, instead funding big corporations for mask production, which could sell their products in the favelas at much cheaper prices. That led to a failed business and, as a result, many were unable to provide for their families. Indeed, after the pandemic started, 67% of favela residents reported not having enough money to purchase food (BBC_News, 2021). To mitigate this situation, the community leaders working with the *Painel* organized fundraisers to purchase food for the families in need (personal communication with favela community leaders, December 2021).

Another goal of the *Painel* is to draw attention to the basic infrastructural and mapping problems of favelas to incite proper government intervention. For example, the project's leaders plan on providing Rio's municipal government with the new, adjusted zip code data they have been developing for the *Painel*, so that favelas can be accurately included in official government maps and data-collection processes. They also intend to increase COVID-19 cases and deaths' data collection to include up to 90% of Rio de Janeiro favelas and do a regressive analysis of case counts, including the missing zip code data—those cases that were assigned to nearby neighborhoods—to better map how the pandemic actually affected favelas (RioOnWatch, 2021a).

Conexão Saúde

Among the network of favelas covered by the *Painel*, one in particular stands out for its organization in responding to the pandemic: the Maré Complex, a group of 16 favelas nearby the Rio de Janeiro International Airport. Maré's settlement started in the 1940s, and today, it has more than 140,000 residents, being considered one of the largest favelas in Latin America. Because of its size and history, Maré houses several NGOs that manage its community life. These NGOs fight for the residents' access to health and education, racial and gender equality, and promote human rights values in the community.

At the beginning of the pandemic, a group of researchers from Rede D'OR, a private research institute, partnered with Maré's NGOs *Redes da Maré*, *Conselho Comunitário de Manguinhos*, *SAS Brasil*, and *União Rio*, as well as with the Oswaldo Cruz Foundation (FioCruz), the country's main public health foundation, to develop a project called *Conexão Saúde*. As explained earlier, one of the main problems the communities faced was lack of tests, which left them in the dark about how widespread the pandemic was. Infection rates were literally invisible. With that in mind, researchers from Rede D'OR created the *Dados do Bem* mobile app, which helps to diagnose COVID-19 symptoms and recommends tests to the Maré residents (Figure 2). *Conexão Saúde* also set up more than 50 mobile testing stations all over Maré to make it easier for people to find a testing site. Fiocruz provided the lab support to process the tests. Results were delivered directly via the app within 24 hours (F. Bozza, personal communication, June 15, 2021).

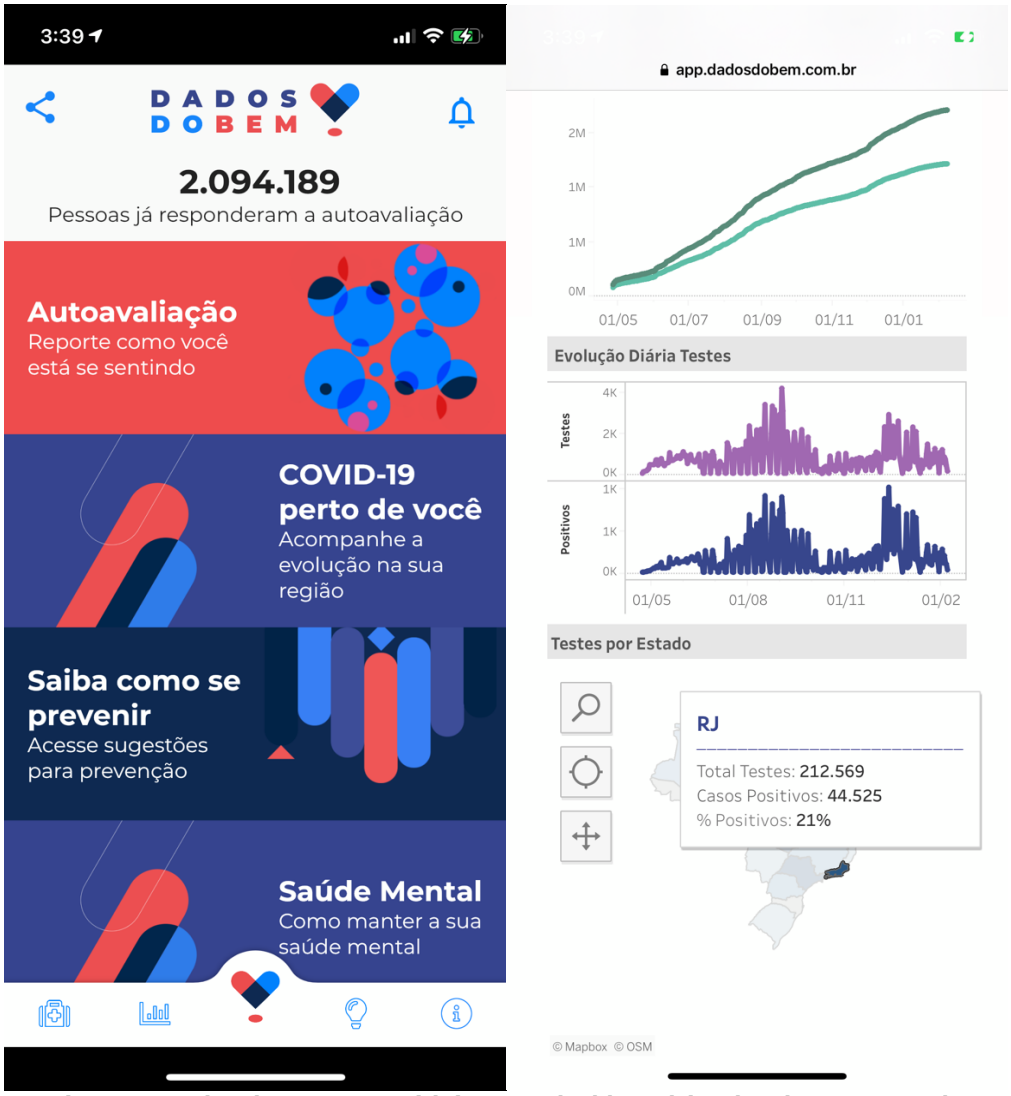

Figure 2. Dados do Bem app with its own dashboard (Dados do Bem, 2020).

After downloading the app, users can fill out a form that asks for their symptoms, and depending on the answers, the app recommends that they look for a testing station. After analyzing about 30,000 submissions, the researchers could identify which symptoms were more prevalent in infected individuals. With that data, they developed an algorithm that could predict very accurately the likelihood that someone might have been infected based on their self-reported symptoms, thus optimizing the recommendation for testing (Dantas et al., 2021). In a situation where tests are scarce and limited, this system optimized the process and made sure tests were allocated for those who really needed one. If the combination of symptoms indicates the person is probably infected, the app generates a bar code that can be scanned at the testing site.

As explained by Fernando Bozza, senior scientist at FioCruz foundation and Rede D'OR, *Dados do Bem* does not require people to have the app to get tested. Many arrive at the testing site with symptoms but no bar code, and so they get help from volunteers to download the app, fill out the form, and generate the code. Even if they do not have a mobile phone, people can still get a test. *Conexão Saúde* has tested about 250 people per day since July 2020. Test results feed a database displayed as a graph on the app, showing the community how many tests have been performed since the beginning of the pandemic, the community's positivity rate, and the most common symptoms for positive tests (Figure 2). It is worth noting that Brazil is one of the few countries that does not officially report test positivity rates, so having access to these data puts Maré ahead of many other cities and counties in the country when it comes to mapping the pandemic.

In addition to the test infrastructure provided by *Dados do Bem* and FioCruz, *Conexão Saúde* provides the Maré population with effective factual information about the pandemic. The app contains public health information about COVID-19 and mitigation strategies such as explanation about what COVID-19 is, its main symptoms, and how to prevent it. In addition, via the above-mentioned NGOs, they created communication campaigns via WhatsApp. Since many people already belonged to different WhatsApp groups, they developed podcasts with public health information that could be forwarded on WhatsApp and thus reach a larger population, even if they did not have the app. These podcasts instruct the population about social distance, proper hygiene, and isolation strategies.

Many people who live in favelas are not literate, but most do own mobile phones and use WhatsApp. Especially those who work in temporary jobs and are self-employed—that is, most of the favela population—depend on WhatsApp for conducting business, communicating with clients, transferring money, and advertising their services. Internet coverage, however, can be a challenge in favelas, because houses often do not have access to WiFi, and mobile phone providers do not place enough towers in the favelas. In addition, most people use prepaid services to control costs, do not have unlimited access to data, and do not own state-of-the-art smartphones (de Souza e Silva et al., 2011). To mitigate these problems, *Conexão Saúde* made a deal with mobile phone providers so that they would not charge people for data when using the *Dados do Bem* app, or the telemedicine services they offer via WhatsApp (Collucci, 2021).

As explained earlier, isolation is an inherent challenge in a favela, because slums are high-density communities, where many people live in multigenerational households and have jobs that do not allow them to work remotely. And, since most have temporary jobs, they also do not have the benefits of "sick days." As a result, more than just finding a test site, the major challenge after receiving a positive test result is how to stay away from others for a certain period of time. To overcome this challenge, *Conexão Saude* created the "Safe Home Isolation Program." In contrast to other initiatives in Asia and Africa, where people were sent to isolation centers, *Conexão Saúde* developed an infrastructure for people to safely isolate at home. Once someone tests positive, they are directed to stay at home for 14 days, along with their families. Each family is then provided with daily meals, a cleaning kit, plus a daily telemedicine service via WhatsApp. In a postisolation survey, patients reported that among all the benefits from the home isolation package, they mostly appreciated the cleaning kit, which included items like soap, detergent, hand sanitizer, water, and toothbrushes. These are expensive products for the low-income population, and since they are not

considered essential, they are often not part of people's regular purchases, says Bozza (personal communication, May 20, 2021).

One of the most remarkable impacts of this project was to decrease case-fatality rates in the Maré Complex by 90%. In July, when the project started, mortality rates in Maré were 19%, one of the highest death rates among the Rio de Janeiro favelas, and almost double that of the city of Rio de Janeiro, which was 12%. Four months after the project's implementation, in November, Maré's case-fatality rate dropped to 2.3%. In May 2021, almost a year after the start of the project, Maré had an average of 188 COVID-19 deaths per 100,000 people, while the average in the city of Rio was 359 per 100,000 (Collucci, 2021). Although *Conexão Saúde* has been successful at Maré, its organizers acknowledge that most of its interventions actually should have been facilitated by the government.

Where Do We Go From Here?

Favelas are often said to have a reality of their own. They are pockets of poverty inside wealthy areas in the cities and are often invisible to official governments—and to the wealthy areas that surround it. This invisibility becomes obvious in the lack of basic infrastructure, such as utility services, and a sharp economic contrast between the rich and poor areas in the city, which are often side by side. Favelas have a geography of their own, with narrow streets, sharp hills, and stairways, and no official addresses. They are hard to get in for people who do not live in them and are often considered violent and dangerous. But the truth is that most people who live in favelas are hard workers who simply do not have opportunities and social mobility, and as a result, do not have equal access to education and healthcare as their high-income neighborhoods counterparts.

Brazil does have a national public healthcare system called *Sistema Único de Saúde* (SUS; Unified Health System). SUS was created with the constitutional reform in 1988 as a human right with the intent to serve everyone in the country—including noncitizens—not just people living in poverty. The service, which includes a decentralized network of providers, including doctors, hospitals, and urgent care centers, is completely free. Without the means to pay for private insurance, most of the favela and low-income population in Brazil does depend entirely on the SUS services for their healthcare. In addition, many upper- and middle-class citizens also use SUS on a regular basis for urgent care and routine immunizations. Importantly, SUS was created based on the premise that communities should actively participate in the management of the system. This is done through municipal and local health councils, in which ordinary citizens can voice concerns about health issues in their communities and participate in decisions about resources and funding allocation (Moreira Ulhoa, 2012). Unfortunately, the Bolsonaro administration has consistently tried to privatize SUS, forging partnerships with private healthcare providers, which eventually could require people to pay for a service that is currently offered for free and exclude community participation (Gomes & Castilhos, 2020). Because of ongoing government neglect and a persistent lack of funding and resources, most communities feel excluded from the benefits of SUS, and this is why they organize themselves to create support networks that help them solve their own problems. The *Painel Unificador COVID-19 nas Favelas* and *Conexão Saúde* are two examples of these mutual aid networks (Béhague & Ortega, 2021) that emerged in the favelas to make the pandemic visible and solve a public health problem in the absence of the federal government's help. As I showed throughout this study, these

projects, in associations with existing NGOs and community leaders, helped mitigate the spread of COVID-19 in these communities by having volunteers go door to door to distribute food, masks, and hygiene kits and use megaphones and WhatsApp to educate residents about mask use, physical distancing, and handwashing. They also relied in local data collection about cases, deaths, and symptoms to map the reality of the pandemic at a local level and make their reality visible.

The birth and development of the *Painel Unificador COVID-19 nas Favelas* and *Conexão Saúde* projects demonstrate that mapping the spread of the virus is just one aspect of the already existing community networks that support favela residents. According to Béhague and Ortega (2021), public health experts around the world have much to learn from the grassroots horizontal networked organizations in the favelas. They also should look at the impact and benefits of a universal, free public health system, like SUS, in the lives of minoritized communities. These structures work because rather than being vertical, top-down public health approaches, they are built into preexisting networks of mutual aid, and are developed locally within the communities. So, rather than being created to specifically tackle COVID-19 problems, the same individuals already have a history of addressing associated problems like economic inequality, hunger, mental health, violence, and police repression.

John Snow's cholera outbreak map demonstrated that infections were originating from a specific well in a certain location pandemic, evidencing that disease outbreak maps do not only represent cases and deaths, but they also reveal hidden or invisible information about the outbreaks, such as where it is coming from. More recently, SARS, Ebola, and Zika GIS maps revealed how the mobility of people around the globe translated into the mobility of the diseases. With COVID-19, not only the official government dashboards helped to visualize the mobility and spread of the pandemic in real time at state and national levels around the world but also increasingly popular mobile maps fed by user-generated data helped many local communities manage the pandemic on their own. This is especially important in situations where there is scarce official public health data about the pandemic, as is the case of low-income communities in Brazil. This scenario is also true in many low-income communities and slums around the world, which lack government presence, public health interventions, basic sanitation, tests, and healthcare. As such, the cases discussed here can be models for thinking about how to solve similar situations in other developing countries around the world.

The *Painel's* strength is in supporting the network of connections among the favelas' community leaders, who meet every other week, the proper mapping of the pandemic in their communities, the better mapping of favelas' territories with zip codes, and the spread of scientific information to beat the virus. Likewise, *Conexão Saúde* was successful in decreasing deaths in the Maré Complex and providing a robust support for the community in the form of meals, telehealth, tests, and hygiene. In July 2021, when the city of Rio was still vaccinating groups above 40 years old, *Conexão Saúde* was able to organize the mass vaccination of Maré residents and could immunize almost 100% of the adult population (which includes mostly people in their 20s and 30s) in a weekend. The success of these projects also shows that using mapping strategies in combination with mobile devices and connections with community leaders and local NGOs can be powerful approaches to promote social justice and access, improving the lives of people who live in favelas.

However, although these two grassroots bottom-up initiatives did have a positive impact in their own communities, they are not enough to solve the pandemic problem at the national level. The lack of national guidelines and federal public health interventions for handling the pandemic in Brazil cannot be overstated. As of February 2022, it costed more than half a million Brazilian lives.

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