Frustrating the State: Surveillance, Public Health, and the Role of Civil Society

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About the Series

In this essay series, *Watching the Watchers: The New Frontier of Privacy and Surveillance under COVID-19*, McGill's Centre for Media, Technology and Democracy explores the policy, legal and ethical issues of (new) surveillance tactics in times of crisis.

In the wake of the 2020 global pandemic, governments and corporations around the world are adopting unprecedented data-gathering practices to both stop the spread of COVID-19 and transition to safer and more economically stable futures. This essay series examines how public and private actors are using pandemic response technologies to capitalize on this extraordinary moment of upheaval. It convenes a diverse group of experts to examine the policy, legal, and ethical challenges posed by the use of tactics that surveil and control populations around the world. With a focus on wide-ranging topics such as cybersecurity, racial justice, and worker surveillance, among others, this series offers a roadmap as policymakers confront the privacy and human rights impacts of crises like the novel coronavirus in the years to come.

Abstract

This essay draws on historical and contemporary examples of how states have exploited public health and safety concerns in order to expand surveillance of their subjects. In doing so, it demonstrates how current attempts to monitor and control the public during the ongoing COVID-19 pandemic are neither an aberration nor an unprecedented event as some have described. The essay also highlights the means with which targets of surveillance have resisted such efforts, challenging the notion that more data necessarily means better decisions and better health outcomes. It closes with recommendations for how we should rethink the issue of surveillance and the role civil society plays in countering its harms.

Introduction

From the moment the novel coronavirus began to spread, it became increasingly clear that an effective means for containing its transmission would require reliable and efficient contact tracing, documentation of new cases, deaths, and recoveries, and monitoring which communities and geographies were at a higher risk of contracting COVID-19. In other words, surveillance. Although the term may invoke myriad connotations, public health surveillance, in short, refers to "the ongoing, systematic collection, analysis, and interpretation of health-related data essential to planning, implementation, and evaluation of public health practice."[1] Indeed, good, reliable, and up-to-date data is essential in driving back a pandemic — few would argue against this. However, as country after country began proposing and enacting a slew of emergency measures, concerns over potential infringement on our privacy, freedom of movement, and other civil liberties mounted.

The pandemic coupled with the surge in digital surveillance has thus left many feeling as if we're living in unprecedented times. Indeed, they are weird times. Between weekly nose swabs and mandatory quarantines, for most of us this period will stand out as an extraordinary slice of history. But as this essay will illustrate by drawing from historical and contemporary examples of public health emergencies, neither state surveillance nor government overreach in times of crisis is an aberration or an unprecedented event — nor are the efforts by the targets of surveillance to resist, circumvent, or obfuscate being seen. History may not always repeat itself, but it does rhyme, and in the case of surveillance and public health, COVID-19 bears strong similarities to past health crises.

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The purpose of this essay is therefore a simple one: to remind ourselves that state surveillance — digital or otherwise, historical or contemporary — often risks infringement on our civil liberties and human rights. No matter the technology being employed or the century we're living in, the idealistic notion that more data means better decisions and better health outcomes is — although alluring — a potentially harmful idea, particularly for marginalized groups. Our current predicament of balancing privacy with public health is therefore yet another episode in the long march of history. If we take a step back and consider the past as well as the present, what might feel like unprecedented times is more like the movie *Groundhog Day*.

This essay will begin with an overview of state surveillance before examining historical and contemporary examples of their motivations and effects during public health crises. The section after covers civil society response and resistance to surveillance. Lastly, this essay closes on recommendations for the next health crisis.

Turning People Into Data

States have, for various reasons and motivations, the need to survey their subjects, or in the words of James C. Scott, to make their populations "legible." Scott, in his landmark book *Seeing Like the State*, illustrates how in order for states to better and more efficiently control their populations, be it for the purposes of taxation, conscription, or the prevention of rebellion, they need to find ways to organize, label, catalogue, document, and monitor people, property, and even nature.[2] In effect, to turn their subjects into manageable data points that can then be interpreted and manipulated. Early states, however, lacked such a "map" and so developed mandatory standards and processes to better know their people, and in turn, create data useful for administration and control — such as permanent surnames, standard weights and measures, and city grids. As Scott put it, "Legibility is a condition of manipulation."[3] However, in his analysis of Russian collectivization, forced villagization in Tanzania, and high modernist urban planning, such legibility does not always equate to better wellbeing. On the contrary, such schemes not only backfire, but can have drastically harmful effects on the societies they intend to help.

Scott further theorizes that such tragic instances, more often than not, emerge from the combination of four elements: the administrative ordering of nature and society; high-modernist ideology (i.e., strong belief or confidence in scientific and technological means to control and master society and nature through reordering and rational design); an authoritarian state willing and capable of using its coercive power to carry out such high modernist designs; and a weakened civil society.[4] Although Scott was referring to historical cases, these elements have found themselves replicated in combination once again. In our current COVID

crisis, not only do we have the ability and desire for large-scale data collection and surveillance, but authoritarian and illiberal leaders and, in some (perhaps many) cases, a worn and weary civil society.

Scott, of course, is not the only one to note the need to monitor and measure people for control or influence. Oscar H. Gandy, in his 1993 book, *The Panoptic Sort: A Political Economy of Personal Information*, uses evidence from government and corporate data collection practices, to argue how individuals, once broken down into evermore precise categories will be subjected to a discriminatory process that sorts people according to their economic and political value. Though written almost three decades ago, Gandy's descriptions of credit card companies' data collection

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and use could easily be applied to today's fetish for big data and microtargeting — as could his warnings on the potential negative effects this type of surveillance may have on privacy and data protection.[5] Similarly, Cal Newport, a Professor of Computer Science at Georgetown University, compares Facebook's misguided and ideologically-driven attempts to connect the world with high modernism's technocratic convictions, which as he (along with many others) points out has led to a whole host of problems.[6] More recently, *Reset* by Ron Deibert, Director of the Citizen Lab at the University of Toronto, outlines in great detail how social media and other networked digital technologies have resulted in what he refers to as the "great leap forward in technologies of remote control," where agencies of the state have unrivaled abilities to monitor us at a population level and at an individual level. Such surveillance, according to Deibert, can create life-threatening risks for some, and a "dystopian system of big-data population control" for the rest of us.[7]

It is no surprise then that at the onset of the coronavirus pandemic, civil society organizations immediately warned of the potential for governments to capitalize on the crisis in order to expand state power. In April, Amnesty International, for example, highlighted the potential negative implications for privacy and human rights that could arise from the use of artificial intelligence, location tracking,

and the private surveillance sector (e.g., Pallantir and NSO Group) in the name of combating COVID-19.[8] Similarly, Human Rights Watch issued a joint statement signed by over a hundred civil society organizations affirming that "States' efforts to contain the virus must not be used as a cover to usher in a new era of greatly expanded systems of invasive digital surveillance."[9] While these groups understand and acknowledge that technology will be needed to contain COVID-19, they are just as aware of the dangers and risks of expanded state surveillance. Writing back in 1971, Saul Alinsky, stressed that crises create opportunities for persuading the public.[10] Although he was writing mainly for left-leaning community organizers, the same holds true for political and corporate elites. Governments and corporations would be amiss if they were to let a good crisis go to waste. And if anyone knows this, it would be political dissidents, activists, minority groups, and organizers.
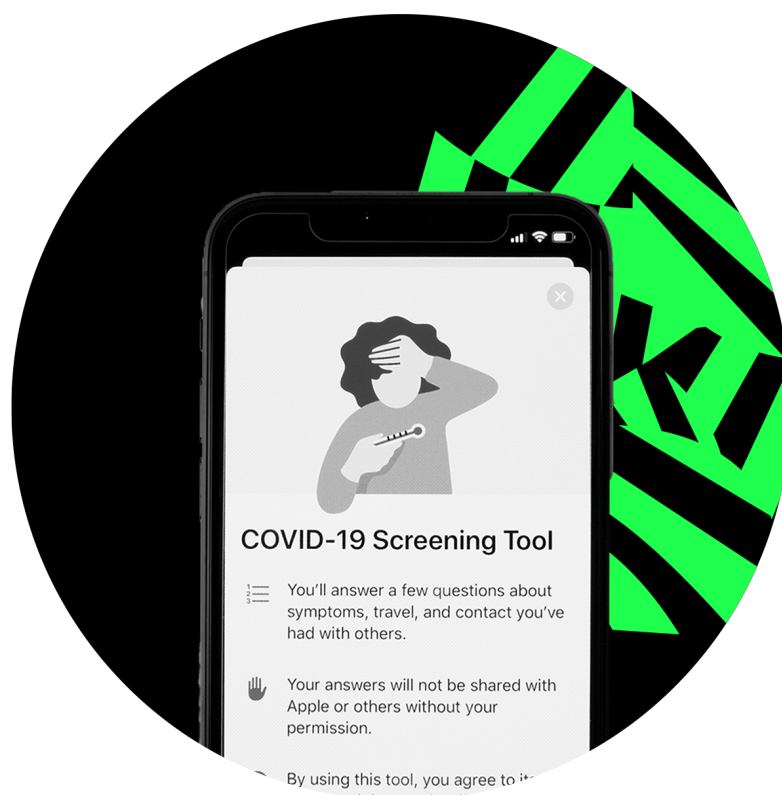
Fall-out and Manipulation

Public health and medical surveillance are rarely clean of politics, and in many cases are influenced by prejudice or discrimination.[11] In tracing the development of what we now refer to as public health surveillance, Bernard Choi notes that the concept began as early as 1662 when John Graunt introduced population-level data analysis as a means for studying the causes of disease in his book Natural and Political Observations Made upon the Bills of Mortality.[12] Following Graunt, Sir William Petty in 1687 made similar links between disease and data collection by coining the term "Political Arithmetic," noting that "the wisdom as to the validity of the data and the conservatism of interpretation requires persons with a keen political sense."[13] As statistical analyses became more popular, the term "political arithmetic" then expanded to include "anything of interest to government," with proponents arguing for its ability to enhance both statecraft and governance.[14] Petty further believed that through mathematics, governments could better order society and politics, and that such "measures of Truth" would also increase obedience to the state.[15] "This is the true political knowledge," claimed Scottish physician and polymath John Arbuthnot.[16] Whether the effects of such surveillance are positive or negative, however, is likely dependent on your socioeconomic status, identity, and the prevailing politics of the time.

Take for example Canada in the 1940s and 50s, when a mass medical survey of Inuit communities was undertaken in an effort to root out tuberculosis (TB). Instead of building new hospitals or expanding existing ones in the communities, the Canadian government chose to issue a large-scale evacuation of Inuit who were ill with TB, forcing many to leave their friends and families to go to hospitals and sanatoriums in southern Canada. [17] The patients were marked with numbers

on their hands, indicating whether or not they had TB, before being boarded onto a boat or plane, sometimes only hours after diagnosis. For those who tried to hide, helicopters were used to locate them and bring them to the boat.[18] Adding to the trauma, young children who recovered from TB were sometimes sent directly from the TB sanatoria to residential schools.[19] The cruel conditions, lack of transparency and informed consent, and forced separation has left a lasting trauma that informs how Inuit view the current healthcare system. For some, fear of TB and the treatment they endured has resulted in a reluctance of many Inuit to seek medical care,

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believing that present-day healthcare would result in similar.[20] consequences. As one participant in a study put it, "The only time I go see a doctor is when I am really sick."[21]

Going further back to the Victorian era in England, we have another example of harmful discriminatory surveillance — this time venereal disease (VD) among British soldiers. Beginning in 1864, the Contagious Diseases Act (CD Acts) were enacted, tasking local police with the surveillance of suspected prostitutes in the areas surrounding British military bases and encampments.[22] The thinking — as misguided, badly implemented, sexist, and classist as it was — was that prostitutes were the primary vectors of VD transmission, so by removing these women, men would be protected. Since any woman could theoretically be a prostitute, all women were at risk of surveillance, giving the police broad discretionary powers. Should a woman be deemed a prostitute she was subjected to fortnightly internal examinations and entered into a police registration system; if she was found to have gonorrhea or syphilis, she was forcibly detained in a hospital for a period of up to nine months. Notably, the CD Acts applied only to women, and as Judith Walkowitz argues, reflected a newfound interest in state intervention into the lives of the "unrespectable poor," turning sex into a public issue.[23] The discretionary powers given to policemen to surveil and arrest women thus allowed the state to control sexuality, while maintaining dominant ideas of class and gender roles.[24]

Moreover, the CD Acts were ineffective in actually reducing the transmission of venereal diseases.[25]

It may be tempting to dismiss such examples as historical anomalies or by-products of outdated thinking. But the need and desire to make populations legible is once again having deleterious effects, repeating and confirming past fears and concerns. Following a COVID-19 outbreak in the Itaewon district of Seoul, South Korea in May 2020, media outlets began reporting on the man who had initially tested positive, identifying the clubs he had visited as gay, as well as the names of their customers and where they worked. For queer communities that rely on anonymity to protect themselves against homophobia, this has put them in a tough situation, leaving many reluctant to get tested or share information with contact tracers. Almost two weeks after the outbreak, contact tracers had only managed to contact some 2,500 out of a list of more than 5,500 people who visited clubs in Itaewon, finding that the information given was often false.[26] Homophobia has since increased, with one LGBTQ activist noting that inquiries to his group have increased 70-fold, primarily from gay men who fear they could lose their jobs if they are tested and need to self-quarantine.[27] Speaking to the *Guardian*, one man said he felt "trapped and hunted down," explaining "If I get tested, my company will most likely find out I'm gay. I'll lose my job and face a public humiliation. I feel as if my whole life is about to collapse. I have never felt suicidal before and never thought I would, but I am feeling suicidal now."[28] The results of this, argues Timothy Gitzen, is that South Korea's widespread homophobia may be negatively interfering with the public health response, putting South Koreans at a higher risk of contracting the coronavirus.[29]

South Korea isn't the only country to experience surveillance fallout from COVID-19. Writing for *The Jakarta Post*, Irene Poetranto and Sinta Dewi Rosadi illustrate how the combination of poor data protection and surveillance has led to unnecessary invasion of privacy and harassment when two individuals who tested positive for COVID-19 in Indonesia had their personal information leaked. The individuals in question, a mother and daughter, were stigmatized in their community as hoaxes about them surged and reporters flocked to their

home, leaving them "mentally drained."[30] The authors note, likewise in this case, that reluctance to seek testing or medical services is a risk, and one that could jeopardize public health in return.

Furthermore, surveillance in times of crisis poses another threat. By granting states unfettered power through emergency orders, data collected through digital surveillance could be shared across agencies and used for purposes beyond the original intention of fighting COVID-19. In states where democratic backsliding has been underway, surveillance could be used to deter dissent and silence government critics. According to Verisk Maplecroft, a risk consultancy firm, Asia is now the highest risk region in both their "Right to Privacy" and "Freedom of Opinion and Expression" indices as "strongmen" in Asia capitalize on the pandemic.[31]

In the Philippines, for example, computer security experts have raised alarms over *StaySafe*, the country's official contact-tracing app, which they warn has excessive permissions with no clear guidance on how citizens' information will be used after the COVID-19 crisis.[32] Some of the permissions include access to personal data (e.g., text messages and contacts) or system features (e.g., phone camera and location). More red flags were raised when it was revealed that the country's National Bureau of Investigation, who is tasked with going after individuals for spreading "fake news," also has access to the data.

Meanwhile, Cambodia has also taken advantage of the crisis. Prime Minister Hun Sen, whose party controls the National Assembly and Senate, passed an incredibly expansive set of powers, including the very vaguely-worded "surveillance measures by any means for digital information in response to the State of Emergency."[33] The powers afforded by the new legislation prompted the United Nations Office of the High Commissioner for Human Rights to issue a warning to the government that it risked not only violating the right to privacy, but silencing free speech and criminalising peaceful assembly as well.[34] As Sean McDonald notes in his analysis of COVID-19 and the worrisome enthusiasm with which surveillance technologies are being implemented to fight COVID-19, government powers, once created, rarely go away, citing the U.S. Patriot Act as an example.[35]

Whether it's gonorrhea, tuberculosis, or COVID-19, crises have, since the establishment of the state, almost always invoked government intervention, and in many cases surveillance. That COVID-19 would do the same is therefore no surprise. But just as we can expect new "technologies of power" to be developed in the advent of a public crisis, so can we expect rebellion, resistance, and mutual support. James C. Scott, in the *Art of Not Being Governed*, shows how pre-colonial peoples in mainland Southeast Asia found ways to avoid being seen by the state, arguing that agricultural choices, migration to the hills, household structures, and even literacy are rooted in the desire to thwart being incorporated or appropriated by the state.[36] The preference of states to grow rice, for example, made subjects and crops more legible, turning once-scattered subjects into a "stable and dense population at the doorstep of the tax man and the military press-gang."[37] As a result, peoples averse to such coercion or in response to the burdens of the state, chose to flee to the hills and engaged in shifting cultivation instead, relying on "escape crops" like taro, cassava, or turnips.[38] Scott's *Weapons of the Weak*, also shows how peasants in a Malaysian village during the 1970s found ways to disrupt state control, from desertion to false compliance to sabotage.[39]

Opportunities for Resistance

Yet such examples represent only one end of the spectrum of resistance — actions that evade, subvert, or frustrate state control, but stop short of open and organized political activity. On the other end, however, we have collective resistance — explicit confrontation with the state through public agitation, community support, and mobilization. Alondra Nelson, in her book *Body and Soul: The Black Panther Party and the Fight against Medical Discrimination*, details the Party's health activism and their challenge to the healthcare state and the medical surveillance that left African Americans simultaneously underserved by mainstream medicine and overexposed to its harms.[40] From 1972 on, the Party made health activism a key component of their mission. They operated a network of free health clinics that offered basic preventive care, provided grocery giveaways to mitigate malnutrition, and screened thousands for sickle cell anemia. Point 6 on their ten-point platform demanded, "Completely free health care for all black and oppressed people." [41] In addition, they fought against the medicalization of violence, which sought to link violence (in particular violence carried out by Black men) to biology, which would further criminalize Black communities and the incarcerated and increase surveillance and control of such groups.[42] Unfortunately, this fight continues to this day. As we've seen with the pandemic, COVID-19 disproportionately affects Black communities due to uneven treatment and availability of health services, combined with longstanding distrust of the healthcare system.[43]

Similarly, following the passing of the Contagious Diseases Acts in the 1860s, women found ways to deter efforts by the state to monitor them. Some engaged in what Scott might refer to as "weapons of the weak," such as living outside the ten-mile radius of a designated protected area and commuting to work by train

each night. Others said they were menstruating, which was so appalling to the male magistrates that their cases were usually thrown out.[44] More threatening to the state than menstruation and these individual acts of subversion, however, was the Ladies National Association (LNA) for the Repeal of the Contagious Diseases Acts, which was established in 1869 by Elizabeth Wolstenholme and Josephine Butler. Their ability to mobilize support was unprecedented as the LNA was one of the first political groups run by, and for women. They and their allies engaged in public education about the CD Acts and why they needed to be repealed, actively sought media coverage, published manifestos, urged prostitutes to resist any registration or examination, and pressured elite political circles within Parliament.[45] One member of Parliament remarked to Butler, "We

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know how to manage any other opposition in the House or in the country, but this is very awkward for us, this revolt of women."[46] Not only did they fight to repeal the CD Acts, but they defended prostitutes during a time when moral outrage and the fear of impropriety were at near fanatical levels. The CD Acts, in effect, galvanized women to not only resist an ineffective, discriminatory, and dehumanizing practice, but mobilized women across different socioeconomic classes to participate in politics and agitate for change.

Current responses to COVID-19, likewise, have spurred both quiet subversion and civic mobilization. In response to the growing homophobia and hate speech in South Korea, activists have begun speaking out in support of queer communities. Hong Seok-Chun, an actor and television personality credited with being South Korea's first openly gay celebrity, implored those who had frequented the businesses linked to the outbreak in Itaewon to get tested. "Now is the time to be brave," Hong wrote on Instagram. "I, better than anyone, know the worries over outing, but right now what's most important is the health and safety of our families and society."[47] Civil society organizations have also come together to launch a hotline for anyone who wants to be tested anonymously, urging people to join together to "form a new community in the midst of a crisis and support each other."[48] In addition, a coalition of 23 civic

groups called "Queer Action Against Covid-19" is conducting a survey to determine the concerns facing LGBTQ individuals with regards to COVID-19.[49] Of the over 70 cases they've collected, the most concerning issues include tests being leaked to their workplace, bullying at school or work, and media-driven homophobia.[50] The group also monitors for excessive disclosure of personal information and continues to urge state agencies to protect personal information.[51]

As COVID-19 rages on (a second wave is mounting in Ontario at the time this was written), and countries continue to justify, implement, and experiment with digital tools, we should likewise expect communities and individuals to agitate for change or engage in subversion, using modern-day weapons of the weak. From giving false information in an effort to avoid being outed to mobilizing civic groups to advocate for new policies or privacy-preserving technology, friction will be likely, even in the most sophisticated of state surveillance systems.

Once More, for the People in the Back

In 1973, the Secretary's Advisory Committee on Automated Personal Data Systems submitted a report to the U.S. Department of Health, Education, and Welfare titled, *Records, Computers, and the Rights of Citizens*.[52] Concerned with the growing use of computerized record keeping, the report warns of the dangers of "oversimplified solutions to complex problems," noting that those most likely to be harmed would be "some of our most disadvantaged citizens." The report raises concerns over privacy, surveillance, deanonymization, inappropriate record linkage, and data repurposing. In a prescient and dismal warning, it concludes, "It is becoming much easier for record-keeping systems to affect people than for people to affect record-keeping systems."[53]

And yet, here we are again, almost fifty years later demanding the same things.

In an editorial published by *Nature* in response to the proliferation of digital tools being used to combat COVID-19, the authors raised key questions on the efficacy, accuracy, privacy, and security of these apps, stressing the need for rigorous research, due diligence, and a "cast-iron commitment from governments that the

> " Similarly, in a comprehensive review of digital tools that have been rolled out since COVID-19, the authors also stress that urgency is no justification for lowering scientific standards.

information being harvested is secure and will only ever be used for the reasons it is being requested.[54] Similarly, in a comprehensive review of digital tools that have been rolled out since COVID-19, the authors also stress that urgency is no justification for lowering scientific standards. Further, risk assessments (which are few and far between for the plethora of post-COVID technologies) should consider, in addition to scientific validity and accuracy, protecting privacy, preserving autonomy, avoiding discrimination, data repurposing, and inequality.[55]

It is understandable then that one may view the future of surveillance with pessimism. If even after fifty years we're still fighting the same fights and making the same arguments, how much have we really achieved in the way of protecting our privacy? And if the answer is not nearly enough, what can be done?

The Case for Civil Society

As we've seen with the fight to repeal the Contagious Diseases Acts, the Black Panther Party's health activism, and more recently, South Korea's pro-LGBTQ movement, an active civil society is necessary in pushing back against government overreach. By engaging in collective action, public agitation, and yes, even subversion, friction can be created over time if given enough pressure and intensity. Citizens wary of encroaching government surveillance and its negative effects should broaden their demands, not just for data protection and fair information practice, but for conditions that enable a thriving civil society.

This means shoring up other separate but overlapping areas of concern: freedom of expression, secure networks, access to the internet, an independent media ecosystem, academic freedom, government transparency, and funding availability. This list is by no means exhaustive but illustrates the bare minimum that must be met. In the case of the CD Acts, Josephine Butler and the Ladies' National Association were able to disseminate their writings, give rousing speeches, obtain valuable media coverage, and gain access to political elites in the British Parliament. In South Korea, LGBTQ advocacy organizations, though limited due to COVID-19 restrictions, are able to form alliances, obtain international and domestic media coverage, conduct research, and pressure the government without fear of retaliation. However, in countries like Cambodia or Myanmar, where state retaliation and crackdowns on dissent are a very real threat, the ability for civil society organizations to organize and agitate is far more limited. The facilitating conditions that enable CSOs to do their work must therefore be fought for in tandem with any efforts to contest harmful state surveillance.

Furthermore, surveillance data, if made publicly available when practicable and in keeping with protecting an individual's privacy, can better serve marginalized groups through an active civil society. Reporting demographics as part of public health surveillance helps us understand inequalities in healthcare access and medical treatment. In the early 1800s, for example, Louis-René Villermé, using mortality rates, population density, and income, was able to show the association between poverty and mortality.[56] Likewise, with COVID-19, demographic reporting has revealed the disparities in rates of contraction and mortality among White, Latinx, and Black communities.[57]

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There is no silver bullet or magic piece of legislation, but rather a long and unending road ahead. As future health crises arrive, it is very likely we will come upon the same arguments and calls to action again. The most effective bulwark against harmful surveillance — intentional or otherwise — is a vibrant and active civil society with teeth.

Conclusion

The hope that technology will solve everything is indeed tempting, but it is a siren call. Excessive surveillance combined with weak or nonexistent data protection, poor information security, inadequate healthcare infrastructure, lack of inclusion, and low trust in government institutions may backfire and exacerbate a pandemic. That we need good reliable public health surveillance to mitigate and prepare for health crises is not a question. But as the past has shown us, state surveillance in the name of public health is never an assured good.

Strong data protection and privacy by design are therefore essential, but not enough. In addition to strong legal and technical safeguards, we need to incorporate inclusion and equity, to ensure the most disadvantaged are well served and not neglected or harmed by the system. Chris Parsons, in his analysis of Canada's COVID Alert App, shows that although technically secure and designed with privacy protection in mind, there are still a number of non-technical issues with contact-tracing apps.[58] Questions over the adoption of the app and potential misuse when combined with existing social biases and structural inequality, for example, still remain unanswered.

Lastly, the best defense is a strong civil society that can pressure politicians, raise public awareness, and help set the agenda for privacy protection in a way that encourages social inclusion, public health, corporate accountability, and government responsibility. While we don't want to burden all our social ills on already resource-strapped groups and individuals — indeed, government and corporations should be, and are active participants in ensuring a liberal democracy — a strong civil society offers one line of defense against the potential harms of malicious surveillance and high modernist idealism.

As J.R. McNeill observes in his study of yellow fever and malaria in Caribbean geopolitics: "Mosquitos and pathogens could not make history on their own: human actions set the stage."[59] Though the time period he's reflecting on spans from 1620–1914, the same lessons apply today. Health emergencies are inevitable. But if and when the time comes again, let's make sure the stage has been set so that privacy, inclusion, and equity will not be left behind amidst the urgency and chaos.

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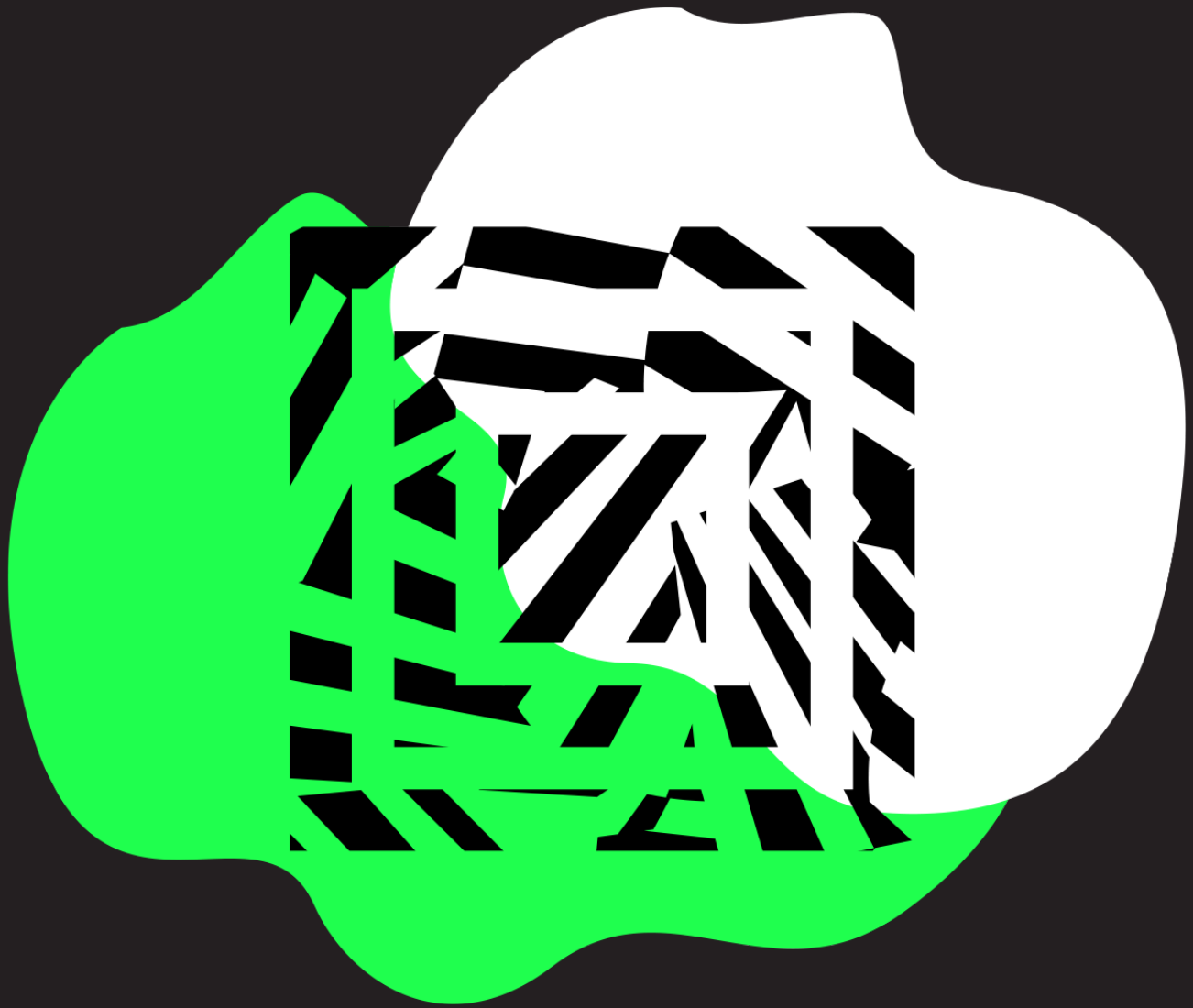
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