

Pandemic Surveillance Discrimination

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I. INTRODUCTION

The COVID-19 pandemic has laid bare the abiding tension between surveillance and privacy has been laid bare. Public health epidemiology has long utilized a variety of surveillance methods—such as contact tracing, quarantines, and mandatory reporting laws—to control the spread of disease during past epidemics and pandemics. Officials have typically justified the resulting intrusions on privacy as necessary for the greater public good by helping to stave off a larger health crisis. The nature and scope of public health surveillance in the battle against COVID-19, however, has significantly changed with the advent of new technologies. Digital surveillance tools, often embedded in wearable technology, have greatly increased the ability of governments and private corporations to monitor large sections of society while collecting massive amounts of personally identifiable data from millions of persons around the world—often with little to no regulatory oversight (or legal limits) on how that information may be later used. Surveillance responses to public health crises have also historically disproportionately targeted racialized communities, leading to a normalization of both racial discrimination and inequality.

The world certainly must use all means to end the devastating COVID-19 pandemic. We also need to be careful, however, to not undermine individual privacy rights or engage in racialized responses to the current crisis. This Essay examines the discord between public health surveillance and privacy rights and argues that the bio-

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surveillance technologies being used to respond to the COVID-19 pandemic—such as contact tracing apps, GPS ankle monitors and other wearables, the collection of cell phone location data, genomic testing, and targeted quarantines—can potentially exacerbate discrimination against racial minorities and immigrants. The Essay concludes with legal and policy solutions on how to utilize public health surveillance tools to prevent the spread of COVID-19 while guarding against privacy violations and racial bias.

II. THE RACIALIZATION OF PUBLIC HEALTH CRISES

Crises have a way of bringing out the worst in people. Crises, in particular, can facilitate the expression of racial bias against vulnerable populations as part of a broader psychological process to make sense of a suddenly chaotic and upended world.¹ Reactions to crisis events can lead people to avoid information that conflicts with their worldview,² engage in ideological defensiveness,³ and fall prey to biased information processing.⁴ And so it has been with the COVID-19 pandemic, as racial disparities in health outcomes have increased while immigrants and other racialized communities have been blamed for the spread of disease. This is a story we have seen before: a crisis engulfs the world; societies, already marked by racial inequalities, react by blaming communities of color, immigrants, and other marginalized groups; and governments respond to the social backlash with measures that only make those inequalities worse. Our socio-legal responses to public health crises in particular have historically facilitated discrimination against racialized communities while relying on scientific technologies to normalize the continued existence of racial inequality.

Public health responses to past epidemics (and pandemics) have tended to exacerbate the distinctions between citizens and non-citizens and White and non-White persons. Outbreaks of disease can trigger a racialized “othering” process, whereby certain population groups (namely immigrants and certain non-White racial groups) are wrongly blamed for outbreaks of disease while resurrecting dangerous ideas of

¹ See, e.g., John T. Jost et al., *System Justification: A Motivational Process with Implications for Social Conflict*, in JUSTICE AND CONFLICTS: THEORETICAL AND EMPIRICAL CONTRIBUTIONS 315, 321 (Elisabeth Kals & Jürgen Maes eds., 2012) (describing how people respond to system threats and social conflict through psychological reactions that rationalize the status quo and pre-existing social inequality).

² *Id.*; CTR. FOR DISEASE CTR. & PREVENTION, CRISIS & EMERGENCY RISK COMM’N: PSYCHOLOGY OF A CRISIS, at 3 (2019), https://emergency.cdc.gov/cerc/ppt/CERC_Psychology_of_a_Crisis.pdf.

³ See Jost et al., *supra* note 1 at 321.

⁴ *Id.*

racial biological difference. Our history is littered with racialized responses to health crises: the Black Death pandemic (which led to the persecution of Jewish communities),⁵ the 1793 Yellow Fever epidemic (which fostered discriminatory notions of racial differences in disease susceptibility),⁶ the 1918 “Spanish” Flu epidemic (where Black and Indigenous communities were wrongly blamed for disease spread),⁷ and the SARS epidemic (where Asian communities, in particular, were faced with rampant discrimination).⁸

Health crises are racially weaponized in that immigrant and non-White populations are seen as both potential disease threats to White “Americans,” as well as more biologically susceptible (or, in some cases, more resistant) to the disease itself. The public health measures enacted in reaction to this crisis-driven racialized fear of others—such as quarantines, immigration restrictions, and the enforcement of health mandates—are in turn disproportionately targeted in a manner that exacerbates race-based disparities.

III. SURVEILLANCE DISCRIMINATION

Public health surveillance—such as contact tracing and quarantines—has long been a proven and reliable method for combating epidemics and pandemics.⁹ The disproportionate surveillance of racialized communities, however, has also long been a method of social control, which can “reify boundaries, borders, and bodies along racial lines” often leading to discriminatory treatment.¹⁰ Any expansion of surveillance thus carries with it the risk of not only undermining individual privacy but also exacerbating the disproportionate surveillance of marginalized communities along race, poverty, and immigration dimensions.¹¹

⁵ Samuel K. Cohn, Jr., *The Black Death and the Burning of Jews*, 196 PAST & PRESENT 3, 3 (2007).

⁶ Rana Asali Hogarth, *The Myth of Innate Racial Differences Between White and Black People's Bodies: Lessons From the 1793 Yellow Fever Epidemic in Philadelphia, Pennsylvania*, 109 AM. J. PUB. HEALTH 1339, 1339 (2019).

⁷ Piper Hudspeth Blackburn, *How Racism Shaped the Public Health Response to the 1918 Spanish Flu Pandemic*, NORTHWESTERN UNIV.: THE COVID-19 ANALYZER (May 3, 2020), <https://nationalsecurityzone.medill.northwestern.edu/covidanalyzer/news/how-racism-colored-the-public-health-response-to-the-1918-spanish-flu-pandemic>.

⁸ Bobbie Person et al., *Fear and Stigma: The Epidemic Within the SARS Outbreak*, 10 EMERGING INFECTIOUS DISEASES 358, 358–59 (2004).

⁹ See generally FRANK M. SNOWDEN, EPIDEMICS AND SOCIETY: FROM THE BLACK DEATH TO THE PRESENT (2019).

¹⁰ SIMONE BROWNE, DARK MATTERS: ON THE SURVEILLANCE OF BLACKNESS 16 (2015).

¹¹ *Id.* (discussing the disparate impact of surveillance technologies and defining racialized surveillance as “a technology of social control where surveillance practices,

We have already witnessed racialized responses to the COVID-19 pandemic across the world. Discrimination and xenophobia against Chinese and other Asian communities have mushroomed, in no small measure fueled by former President Trump's characterization of the disease as the "Chinese virus" and "kung-fu flu," with 60 percent of Asian-Americans reporting being blamed by others for the pandemic and a surge in anti-Asian hate crimes.¹² Almost 40 percent of polled Americans report that anti-Asian racism has become more common since the start of the pandemic, while 30 percent report that anti-Black racism has increased.¹³

The disproportionate surveillance of racialized communities has similarly increased during the COVID-19 pandemic. In America, disturbing disparities in the COVID-19 surveillance of racial minorities have emerged. In New York City, 92 percent of people arrested for violating COVID-19 protocols (such as social-distancing requirements) were either Black or Latinx, while over 80 percent of persons issued summons were people of color.¹⁴ Researchers found that the majority of persons arrested for violating COVID-19 rules in Ohio were Black.¹⁵ A recent report found that people of color were two-and-a-half times more likely to be surveilled and punished for COVID-19 violations than

policies, and performances concern the production of norms pertaining to race and exercise a 'power to define what is in or out of place') (internal quotations omitted).

¹² Qin Gao & Xiaofang Liu, *Stand Against Anti-Asian Racial Discrimination During COVID-19: A Call for Action*, INT'L. SOC. WORK 1, 1-2 (2020).

¹³ Neil G. Ruiz, Juliana Menasce Horowitz & Christine Tamir, *Many Black and Asian Americans Say They Have Experienced Discrimination Amid the COVID-19 Outbreak*, PEW RES. CTR. (July 1, 2020), <https://www.pewsocialtrends.org/2020/07/01/many-black-and-asian-americans-say-they-have-experienced-discrimination-amid-the-covid-19-outbreak>.

¹⁴ Josiah Bates, *Police Data Reveals Stark Racial Discrepancies in Social Distancing Enforcement Across New York City*, TIME, May 8, 2020, <https://time.com/5834414/nypd-social-distancing-arrest-data>; Ashley Southall, *N.Y.C. Commissioner Denies Racial Bias in Social Distancing Policing*, N.Y. TIMES, May 13, 2020, <https://www.nytimes.com/2020/05/13/nyregion/nypd-social-distancing-race-coronavirus.html> (also finding that at least 300 out of 374 summonses issued by the New York Police Department for violating COVID-19 rules were to Black or Latinx people). The Legal Aid Society of New York has similarly found racial disparities in COVID-19 related arrests and summonses. *Racial Disparities in NYPD's COVID-19 Policing: Unequal Enforcement of 311 Social Distancing Calls*, LEGAL AID SOCIETY 1, 3-4 (2020), https://legalaidnyc.org/wp-content/uploads/2020/05/LAS_Racial-Disparities-in-NYPDs-COVID-19-Policing_5.20.20_5PM_FINAL.pdf.

¹⁵ Justin Jouvenal & Michael Brice-Saddler, *Social Distancing Enforcement is Ramping Up. So is Concern that Black and Latino Residents May Face Harsher Treatment*, WASH. POST (May 10, 2020), https://www.washingtonpost.com/local/public-safety/social-distancing-enforcement-is-ramping-up-so-is-concern-that-black-and-latino-residents-may-face-harsher-treatment/2020/05/10/b1bcf490-8fbd-11ea-9e23-6914ee410a5f_story.html.

White persons, with Black persons being targeted by government authorities for such violations at four-and-a-half times the rate of White people.¹⁶

Such patterns of racialized surveillance in response to COVID-19 have also occurred globally. African migrants have not only been subjected to widespread discrimination in China as a result of the pandemic but have also been selectively targeted—based on race—by government authorities for forcible testing and quarantining.¹⁷ In Bulgaria, the government has targeted the ethnic Roma community for increased surveillance, arrests, and quarantines in an effort “to protect the general population” from the “threat” posed by the Roma and persons of different ethnicities.¹⁸ More disturbingly, Bulgarian officials declared that the Roma are a public health threat that needs to be “controlled and contained,” and used airplanes to spray chemicals to purportedly “disinfect” Roma neighborhoods.¹⁹ In France, fines for violating COVID-19 rules were disproportionately enforced in areas with majority North and West African residents at three times the rate of other communities.²⁰ Throughout the world, governments have similarly subjected refugees and asylum-seekers to targeted quarantines, police abuse, and deprivation of basic human rights in countries.²¹ Pierrette Herzberger-Fofana, a former German Member of the European Parliament, observed that research has demonstrated that “racialised groups, black people, Roma people, people of north African origin and migrants are much more likely to be targeted and victims of police violence” in the enforcement of COVID-19 public health

¹⁶ PASCAL EMMER ET AL., UNMASKED: IMPACTS OF PANDEMIC POLICING, COVID19 POLICING PROJECT 30 (2020), <https://communityresourcehub.org/wp-content/uploads/2020/12/Unmasked.pdf>.

¹⁷ See Human Rights Watch, *China: COVID-19 Discrimination Against Africans*, HUM. RIGHTS WATCH (May 5, 2020), <https://www.hrw.org/news/2020/05/05/china-covid-19-discrimination-against-africans#>.

¹⁸ AMNESTY INT’L, POLICING THE PANDEMIC: HUMAN RIGHTS VIOLATIONS IN THE ENFORCEMENT OF COVID-19 MEASURES IN EUROPE 5 (2020), <https://www.amnesty.org/download/Documents/EUR0125112020ENGLISH.PDF>.

¹⁹ *Id.* at 10–11; see also Maria Cheng & Teodora Barzakova, *Some European Officials Use Virus as Cover to Target Roma*, ASSOCIATED PRESS (Oct. 15, 2020), <https://apnews.com/article/virus-outbreak-pandemics-police-discrimination-eastern-europe-2cbcd5ee070578b73b1bc35ebdb426e>. The Roma have been disproportionately policed in many other countries as well, with officials blaming Roma persons for the spread of COVID-19 and subjecting them to harsh quarantines and police abuses of force. AMNESTY INT’L, *supra* note 18, at 4–5.

²⁰ AMNESTY INT’L, *supra* note 18, at 20.

²¹ *Id.* at 9–17. In a detailed report of global human rights abuses in the wake of COVID-19, Amnesty International found that “enforcement of lockdown measures [has] rapidly served as a pretext for the unlawful use of force” by law enforcement. *Id.* at 21.

measures.²² Similarly, a report from the United Nations concluded that “people of African descent are reportedly being disproportionately controlled, harassed and profiled by law enforcement authorities, with other people being treated differently or not subjected to control at all.”²³

The rise of discrimination against racialized persons, often exacerbated by governmental policies, can ironically be traced in part to the well-documented race-based disparities in COVID-19 contraction and health outcomes.²⁴ Black, Latino, and Indigenous populations have hospitalization rates that are 4.5 to 5.5 times higher than the White population, and also have disproportionate death rates.²⁵ These disparities are compounded by the differential rates with which racial populations are obtaining access to the COVID-19 vaccines. For example, in Texas, Latinos make up only 15 percent of the population that has been vaccinated, despite accounting for 44 percent of cases and almost 50 percent of all deaths from the virus.²⁶ And in Mississippi, Black persons have received 15 percent of vaccinations, despite constituting 38 percent of cases and 42 percent of deaths.²⁷ Such race-based disparities, in turn, have fueled perceptions that non-White persons are more biologically prone to contracting (and dying from) COVID-19, leading to a resurgence of dangerous notions of racial

²² Daniel Boffey, *Policing of European Covid-19 Lockdowns Shows Racial Bias-Report*, GUARDIAN (June 24, 2020), <https://www.theguardian.com/world/2020/jun/24/policing-of-european-covid-19-lockdowns-shows-racial-bias-report>.

²³ *Racial Discrimination in the Context of the Covid-19 Crisis*, TOPICS IN FOCUS: RACIAL DISCRIMINATION (U.N. Hum. Rts. Off. of the High Comm’r, Geneva Switz.) June 22, 2020, at 3 (noting that “racial discrimination is manifested in who is penalized for ‘violating’ restrictions during the pandemic, with marginalised communities facing heightened risks”).

²⁴ Ying Liu et al., *Perceived Discrimination and Mental Distress Amid the COVID-19 Pandemic: Evidence from the Understanding America Study*, 59 AM. J. PREVENTATIVE MED. 481, 488–89 (2020) (tracing the rise in discrimination to media reporting of race-based disparities in contracting COVID-19).

²⁵ Daniel Wood, *As Pandemic Deaths Add Up, Racial Disparities Persist—And in Some Cases Worsen*, NPR (Sept. 23, 2020, 1:01 PM), <https://www.npr.org/sections/health-shots/2020/09/23/914427907/as-pandemic-deaths-add-up-racial-disparities-persist-and-in-some-cases-worsen>.

²⁶ Ari Shapiro, *Early Data Shows Striking Racial Disparities in Who’s Getting the COVID-19 Vaccine*, NPR (Jan. 28, 2021, 6:21 PM), <https://www.npr.org/sections/coronavirus-live-updates/2021/01/28/961703505/early-data-shows-striking-racial-disparities-in-whos-getting-the-covid-19-vaccin>.

²⁷ Nambi Ndugga et al., *Early State Vaccination Data Raise Warning Flags for Racial Equity*, KAISER FAMILY FOUND. (Jan. 21, 2021), <https://www.kff.org/policy-watch/early-state-vaccination-data-raise-warning-flags-racial-equity>.

biological differences.²⁸ While the social determinants of health clearly cause these disparities, there has long been an allure to thinking about “races” as distinct biological entities in order to rationalize racial inequality.²⁹ This rationalization is shocking, but not unexpected, as our social and governmental responses to past pandemics have historically advanced unfounded theories of race-based differences in disease susceptibility to justify discriminatory public health measures.³⁰ Unfortunately, discrimination against vulnerable populations can in turn impede the public health response to the pandemic.³¹

The racially disproportionate surveillance of racialized communities has been exacerbated by the use of new technologies to trace and monitor COVID-19. Proximity apps (such as the Apple and Google COVID-19 apps) have been promoted as a way to allow for digital contact tracing and exposure notifications, and are typically installed on cell phones and wearable technology.³² Location data from cell phones (“cell site location information”) has also been collected around the world to enforce quarantine requirements and engage in contact tracing.³³ Genetic samples collected from enhanced COVID-19 testing protocols have also been a key tool in reducing the transmission of COVID-19.³⁴ Similarly, traditional forms of police surveillance—such as

²⁸ Ying Liu et al., *Perceived Discrimination and Mental Distress Amid the COVID-19 Pandemic: Evidence From the Understanding America Study*, SCIENCE DAILY (July 7, 2020) (tracing the rise in discrimination to media reporting of race-based disparities in contracting COVID-19).

²⁹ See Christian B. Sundquist, *The Technologies of Race: Big Data, Privacy and the New Racial Bioethics*, 27 ANNALS HEALTH L. 205, 208 (2018).

³⁰ See, e.g., FRANK M. SNOWDEN, EPIDEMICS AND SOCIETY: FROM THE BLACK DEATH TO THE PRESENT 62–68 (2019); Necia B. Hobbes, *Out of the Frying Pan into the Fire: Heightened Discrimination & Reduced Legal Safeguards When Pandemic Strikes*, 72 U. PITT. L. REV. 779 (2011); Vanessa Northington Gamble, *“There Wasn’t a Lot of Comforts in Those Days:” African Americans, Public Health, and the 1918 Influenza Epidemic*, 125(3) PUB. HEALTH REPS. 114, 114–21 (2010).

³¹ Hogarth, *supra* note 6.

³² See Jennifer D. Oliva, *Surveillance, Privacy, and App Tracking*, in ASSESSING LEGAL RESPONSES TO COVID-19 40, 41 (Scott Burris et al. eds., 2020), https://www.publichealthlawwatch.org/s/Chp5_COVIDPolicyPlaybook-Aug2020-htfr.pdf.

³³ *Id.*

³⁴ NAT’L INST. ON AGING, *Why COVID-19 Testing is the Key to Getting Back to Normal* (Sept. 4, 2020), <https://www.nia.nih.gov/news/why-covid-19-testing-key-getting-back-normal>.

facial recognition software,³⁵ drones,³⁶ GPS ankle monitors,³⁷ thermal imaging,³⁸ and geofencing³⁹—have been used around the world to monitor public movement and enforce COVID-19 restrictions.

The potential for racial discrimination in the enforcement of COVID-19 rules, as well as in the collection of COVID-19 data, is heightened by the delegation of public health surveillance duties to local law enforcement agencies. Given the long history of the racialization of policing,⁴⁰ allowing individual police officers (rather than public health officials) to enforce pandemic regulations has led to significant racially disproportionate intrusions on privacy and, in some cases, freedom.⁴¹ State policies to share private health information collected by laboratories (testing for COVID-19 positive cases) and hospitals (engaging in both testing and treatment of COVID-19 patients) with law enforcement agencies have magnified such intrusions.⁴² A recent study appearing in the *Journal of Bioethical Inquiry* thus concluded that, as “vulnerable subpopulations pay a higher price for surveillance measures,” “[t]here is reason to worry that some types of COVID-19 technology might lead to the employment of disproportionate profiling, policing, and criminalization of marginalized groups.”⁴³

³⁵ Antoaneta Roussi, *Resisting the Rise of Facial Recognition*, NATURE (Nov. 18, 2020), <https://www.nature.com/articles/d41586-020-03188-2>.

³⁶ Birgit Schippers, *Coronavirus: Drones Used to Enforce Lockdown Pose a Real Threat to Our Civil Liberties*, CONVERSATION (May 26, 2020), <https://theconversation.com/coronavirus-drones-used-to-enforce-lockdown-pose-a-real-threat-to-our-civil-liberties-138058>.

³⁷ Lauren Kilgor, *Covid-19 has Led to a Worrisome Uptick in the Use of Electronic Ankle Monitors*, MIT TECHNOLOGY REVIEW (Oct. 8, 2020), <https://www.technologyreview.com/2020/10/08/1009822/covid-19-surveillance-electronic-ankle-monitors-opinion>.

³⁸ David Vergun, *Department Uses Thermal Imaging to Detect COVID-19*, U.S. DEP'T OF DEF. (May 6, 2020), <https://www.defense.gov/Explore/News/Article/Article/2178320/departments-uses-thermal-imaging-to-detect-covid-19>.

³⁹ See Yasheng Huang, Meicen Sun & Yuze Sui, *How Digital Contact Tracing Slowed Covid-19 in East Asia*, HARV. BUS. REV. (Apr. 15, 2020), <https://hbr.org/2020/04/how-digital-contact-tracing-slowed-covid-19-in-east-asia>.

⁴⁰ See generally Dorothy E. Roberts, *Abolition Constitutionalism*, 133 HARV. L. REV. 1, 19–29 (2019).

⁴¹ See *supra* pp. 1537–40.

⁴² See EMMER ET AL., *supra* note 16, at 28 (noting, for example, that the Governor of Arizona issued an executive order for an “enhanced surveillance advisory” allowing law enforcement agencies to access private medical data).

⁴³ Tereza Hendl et al., *Pandemic Surveillance and Racialized Subpopulations: Mitigating Vulnerabilities in COVID-19 Apps*, 17 J. BIOETHICAL INQUIRY 829, 829 (Aug. 25, 2020); Abby Dennis, *How Google's Surveillance Technology Endangers Communities of Color*, MEDIUM (May 20, 2020), <https://medium.com/breaking-down-the-system/how-googles-surveillance-technology-endangers-communities-of-color-c532d5f1f1ac>; David Uberti, *Police Requests for Google Users' Location Histories Face New Scrutiny*,

A related concern that technology has disproportionately impacted the privacy risks of marginalized communities lies in the fact that most of the surveillance technologies that have been deployed in the fight against COVID-19 were developed and overseen by private market actors (such as Google, Apple, and Palantir), as opposed to government health authorities (where a clear interest of such private actors is to monetize consumer health data). This concern is not mere speculation. Google's "Project Nightingale"—which was revealed just months before the COVID-19 pandemic was recognized in March of 2020—collects personal medical data from over fifty million Americans (such as birth records, medical diagnoses, lab results, and so forth) through an association with Ascension—the country's largest nonprofit health system.⁴⁴ The Project contains very few legal safeguards relating to how such data may be used and when such data must be de-anonymized.⁴⁵

Google has also been selling personal information and location data to law enforcement and other government actors through its Sensorvault database.⁴⁶ Law enforcement uses this data, which involves records of hundreds of millions of devices around the world, to identify suspects who were located near crimes.⁴⁷ With Sensorvault, data is initially anonymized. Yet, once law enforcement narrows the field of suspects, they can request (and Google will usually grant) that the data be *re-identified* with personal information (like names, addresses, race, any app subscriptions one has, browsing history, and so forth) to locate suspects.⁴⁸ This capability has led Google to transfer thousands of individuals' data to law enforcement, even though most or all of the persons unwittingly surveilled typically have no connection to the crime whatsoever.⁴⁹

The collection of COVID-19 health and surveillance information through private actors and law enforcement can lead to the disproportionate targeting of racialized groups and a resurgence of discredited biological conceptions of race. While there may well be a

WALL ST. J., July 27, 2020, <https://www.wsj.com/articles/police-requests-for-google-users-location-histories-face-new-scrutiny-11595842201>.

⁴⁴ Mary Beth Griggs, *Google Reveals 'Project Nightingale' After Being Accused of Secretly Gathering Personal Health Records*, VERGE (Nov. 11, 2019, 11:40 PM), <https://www.theverge.com/2019/11/11/20959771/google-health-records-project-nightingale-privacy-ascension>.

⁴⁵ *Id.*

⁴⁶ Jennifer Valentino-DeVries, *Tracking Phones, Google is a Dragnet for the Police*, N.Y. TIMES (Apr. 13, 2019), <https://www.nytimes.com/interactive/2019/04/13/us/google-location-tracking-police.html>.

⁴⁷ *Id.*

⁴⁸ *Id.*

⁴⁹ *Id.*

public health benefit in collecting such race-based data (as a tool to understand and combat race-based health disparities),⁵⁰ there are also privacy dangers that such information will be de-anonymized, used to justify enhanced policing of racialized communities, and increase social blaming of racial minorities and immigrants. As a recent article in *The Lancet* warns, such demographic data is “not necessarily related to a person’s health and might lead to stigmatization of particular ethnic or socioeconomic groups” and “to a surge in discrimination” against racial minorities.⁵¹

So, can our current privacy laws protect against the disproportionate surveillance of racial populations? Unfortunately, the answer is a resounding “no.” The United States’ sectoral approach to privacy protection is simply inadequate to respond to the very real (and often racialized) threats to privacy posed by the often-unregulated expansion of private surveillance technology. From a federal privacy law perspective, the Health Insurance Portability and Accountability Act (HIPAA) creates certain protections for “Individually Identifiable Health Information” by means of its Privacy Rule and Security Rule.⁵² HIPAA is inadequate to respond to the current privacy challenges created by the pandemic, however, because it does not have a private right of action; applies only to a very narrow range of health data and health institutions (such as covered entities and their “business associates”); and creates a number of “public purpose” exceptions (which could be used to transfer data to law enforcement agencies).⁵³ The Genetic Information Nondiscrimination Act is similarly insufficient to protect private health information collected during the pandemic, as it is extremely limited in scope and only regulates health insurance plans and employers with respect to discrimination against employees based on genetic information.⁵⁴ The 21st Century Cures Act provides federal health research subjects with certain rights regarding how their genetic data can be disclosed, and yet it is quite narrow in terms of its

⁵⁰ Joia Crear-Perry & Michael McAfee, *To Protect Black Americans from the Worst Impacts of COVID-19, Release Comprehensive Racial Data*, SCI. AM. (Apr. 24, 2020), <https://blogs.scientificamerican.com/voices/to-protect-black-americans-from-the-worst-impacts-of-covid-19-release-comprehensive-racial-data>.

⁵¹ Urs Gasser et al., *Digital Tools Against COVID-19: Taxonomy, Ethical Challenges, and Navigation Aid*, 2 LANCET 425, 428 (2020) (noting that “stratifying populations on these grounds might reinforce existing divides that leave particular groups more vulnerable to the pandemic”).

⁵² Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (1996).

⁵³ *Id.*

⁵⁴ Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (2008).

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application and exceptions allowing disclosure that can undermine privacy rights.⁵⁵ In a similar vein, various Federal Trade Commission (FTC) regulations, such as the Health and Data Breach Notification Rules, allow the FTC to hold private companies liable for certain privacy violations or consumer misrepresentations. And yet, these regulations are also limited by their terms in responding to the full panoply of privacy issues raised by COVID-19.⁵⁶ Our hodgepodge of state privacy laws is similarly inadequate to respond to a crisis of national (and international) proportions.

An appeal to federal constitutional privacy rights also would not serve as a sufficient legal framework for protecting privacy. The United States Supreme Court decisions in *Whalen v. Roe*, *Ferguson v. City of Charleston*, *United States v. Jones*, and *Carpenter v. United States* provided some limited, yet important, privacy rights. For example, *Whalen* recognized a Fourteenth Amendment privacy right to ones' health data against disclosure by a state actor;⁵⁷ *Ferguson* recognized a limited Fourth Amendment privacy right in health data;⁵⁸ *Jones* recognized a Fourth Amendment privacy right to GPS location data;⁵⁹ and *Carpenter* recognized a Fourth Amendment right to ones' cell site location information.⁶⁰ But these rights are very limited when applied to the current context, as they do not apply to the actions of private actors (including employers) but instead relate to surveillance by government actors.⁶¹

IV. CONCLUSION

The "enduring tension"⁶² between public health surveillance and privacy creates a dilemma for our COVID-19 response. How can we balance the need for public health surveillance measures with the strong likelihood that such measures may be applied in a racially

⁵⁵ 21st Century Cures Act, Pub. L. No. 114-255, 130 Stat. 1033 (2016).

⁵⁶ 16 C.F.R. §§ 318.1–318.8 (2009).

⁵⁷ *Whalen v. Roe*, 429 U.S. 589, 605–06 (1977).

⁵⁸ *Ferguson v. City of Charleston*, 532 U.S. 67, 84 (2001).

⁵⁹ *See United States v. Jones*, 565 U.S. 400, 430 (2012).

⁶⁰ *Carpenter v. United States*, 138 S. Ct. 2206, 2269 (2018).

⁶¹ Notably, even those Fourth Amendment rights tied to government action are limited by a number of judicially recognized exceptions, such as the Special Needs doctrine (which one can see as being successfully raised to allow for expanded surveillance by law enforcement actors). *See* Orin S. Kerr, *The Questionable Objectivity of Fourth Amendment Law*, 99 TEX. L. REV. 447, 456–61 (2021).

⁶² Amy Fairchild, Ronald Bayer & James Colgrove, *Privacy and Public Health Surveillance: The Enduring Tension*, AM. MED. ASS'N J. ETHICS (Dec. 2007), <https://journalofethics.ama-assn.org/article/privacy-and-public-health-surveillance-enduring-tension/2007-12>.

discriminatory manner? How can we protect the privacy rights of racialized communities while remaining committed to critical public health measures such as contact tracing, quarantines, and expanded COVID-19 testing?

We might begin by recognizing that both privacy and non-discriminatory public health surveillance can co-exist. Protecting individual privacy rights is often essential to protect the public health from disease threats in that, without such rights, people may refuse to share information with the government that could assist with its pandemic response and contact tracing. We can see this in racialized communities' heightened mistrust of COVID-19 public health measures (such as vaccines), given our history of racially disproportionate health and law enforcement surveillance.⁶³ But we must also recognize that our current sectoral approach to privacy is ill-suited to protecting privacy rights and guarding against discrimination in a pandemic: we have a mish-mash of privacy laws and regulations ranging from consumer protection, to education privacy, to medical privacy, and everything in between. Our HIPAA and Genetic Privacy laws, as discussed earlier, are woefully inadequate to respond to the privacy concerns raised by modern technology. A national omnibus approach to privacy could fill some of these gaps, for example, by ensuring that health data information is protected even when collected by an actor that is not a HIPAA entity or "business associate," as well as by creating meaningful biometric information privacy laws. Two recent legislative proposals are promising, and yet limited in their scope. The COVID-19 Consumer Data Protection Act, sponsored by Senator Roger Wicker and others, is much too limited to respond to the racial privacy issues implicated by the pandemic—creating broad exceptions for employer-based surveillance and including no enforceable private right of action.⁶⁴ The Public Health Emergency Privacy Act, sponsored by Senators Richard Blumenthal and Mark Warner, is more promising in that it requires opt-in consent, data minimization, limits on disclosure to government actors, restrictions on the commercialization of health data, nondiscrimination provisions, and a private right of action.⁶⁵ And yet it contains very broad exceptions for contact tracing and information maintained by HIPAA entities.⁶⁶

⁶³ Simar Singh Bajaj & Fatima Cody Stanford, *Beyond Tuskegee—Vaccine Distrust and Everyday Racism*, 12 *NEW ENG. J. MED.* 384 (2021).

⁶⁴ COVID-19 Consumer Data Protection Act of 2020, S. 3663, 116th Cong. (2020).

⁶⁵ Public Health Emergency Privacy Act, S. 3749, 116th Cong. (2020).

⁶⁶ *Id.*

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A federal omnibus approach to privacy must coalesce around clear privacy norms and values while being guided by racial justice principles that normalize access to vaccines and health care.⁶⁷ A race-conscious approach to COVID-19 privacy would share many common features: opt-in consent; anonymization of data to prevent re-identification; private rights of action to ensure the enforceability of privacy violations; norms of proportionality, transparency, and data minimization; strict limitations on how such data may be used (including provisions that prevent the sharing of health surveillance data with law enforcement and immigration authorities, and restrictions on the commercialization of private data); and the creation of a robust nondiscrimination policy (such that health data could not be used to deny health insurance, employment, education, and other social benefits). But this approach will be limited in its protection against racialized surveillance unless COVID-19 enforcement powers are removed from law enforcement agencies and placed in the hands of public health authorities.⁶⁸ With these guiding principles, we can begin creating new laws to prevent health surveillance from becoming a system of entrenched racialized surveillance and exploitation.

⁶⁷ Carrie Hanlon & Elinor Higgins, *States Use Race and Ethnicity Data to Identify Disparities and Inform Their COVID-19 Responses*, NAT'L ACAD. FOR ST. HEALTH POL'Y (Apr. 13, 2020), <https://nashp-staging.rcvmnfm3-liquidwebsites.com/states-use-race-and-ethnicity-data-to-identify-disparities-and-inform-their-covid-19-responses>.

⁶⁸ EMMER ET AL., *supra* note 16, at 70–71.