

NEW GLOBAL HEALTH SURVEILLANCE TECHNOLOGIES AND THE PROTECTION OF COMMUNITY AND PATIENT PRIVACY

By: Sam F. Halabi*

I. INTRODUCTION

As the world moves toward a new international agreement on pandemic preparedness, prevention, and response, surveillance technologies are one of the priority topics.¹ Over the course of the COVID-19 pandemic, public health planners all over the world deployed new technologies and approaches to identify where outbreaks were occurring, how to monitor and regulate travel and commerce to minimize the spread of the virus, and to communicate information with patients, providers, and institutions that would aid the individual and public health response.²

* Senior Associate Vice-President for Health Policy & Ethics, Colorado State University; Professor, Colorado School of Public Health; Senior Scholar, O'Neill Institute for National and Global Health Law, Georgetown University. J.D. Harvard, MPhil Oxford (St. Antony's College), BA, BS, Kansas State University.

¹ WORLD HEALTH ORG., *World Health Assembly Agrees to Launch Process to Adopt Historic Global Accord on Pandemic Prevention, Preparedness and Response* (Dec. 1, 2021), <https://www.who.int/news/item/01-12-2021-world-health-assembly-agrees-to-launch-process-to-develop-historic-global-accord-on-pandemic-prevention-preparedness-and-response> [<https://perma.cc/NRT4-HMMW>]; *Wanted: Rules for Pandemic Data Access That Everyone Can Trust*, NATURE (June 1, 2021), <https://www.nature.com/articles/d41586-021-01460-7> [<https://perma.cc/TBS5-QW7N>].

² Chris Buckley, Vivian Wang & Keith Bradsher, *Living by the Code: In China, Covid-Era Controls May Outlast the Virus*, N.Y. TIMES (Jan. 30, 2022), <https://www.nytimes.com/2022/01/30/world/asia/covid-restrictions-china-lockdown.html> [<https://perma.cc/E62H-HDTA>]; Deborah Brown & Amos Toh, *Technology is Enabling Surveillance, Inequality During the Pandemic*, HUMAN RIGHTS WATCH (Mar. 4, 2021, 12:01 AM), <https://www.hrw.org/news/2021/03/04/technology-enabling-surveillance-inequality-during-pandemic> [<https://perma.cc/L3RS-CVNB>]; Lorie Donelle, Jodi Hall, Brad Hiebert, Jacob J. Shelley, Maxwell J. Smith, Jason Gilliland, Saverio Stranges, Anita Kothari, Jacquelyn Burkell, Tommy Cooke, Jed Long, James M. Shelley, Deanna Befus, Leigha Comer, Marionette Ngole & Meagan Stanley, *Digital Technology and Disease Surveillance in the COVID-19 Pandemic: A Scoping Review Protocol*,

BMJ OPEN (Oct. 29, 2021), <https://bmjopen.bmj.com/content/11/10/e053962> [<https://perma.cc/9U2G-9CJW>] (“The use of existing digital surveillance technologies has also been leveraged and redirected to support pandemic management. To date, the use of technology to mitigate the spread of COVID-19 within and across countries has achieved varying levels of success, dependent on

For example, wastewater surveillance has been deployed by governments to detect the presence of SARS-CoV-2 long before residents in nursing homes, neighborhoods, and dormitories showed symptomatic infection.³ Ministries of Health in China, Singapore, Thailand, Vietnam, and others used mobile phone surveillance to identify and promptly respond to possible outbreaks.⁴ Several U.S. states entered into agreements with data analysis firms to use cell phone data for related purposes.⁵ Dozens of countries deployed individualized QR codes tied to vaccination status, while the European Union formalized their use through region-wide regulation.⁶ While the actual impact of these interventions remains under analysis by researchers, even assuming correlation with wild success as a public health tool, it is crucial to consider the implications of

indicators of success (eg, disease containment (testing, vaccinations), mortality, educational/school attendance, employment rate, real gross domestic product), which vary geographically. Globally, governments are considering, or are currently using, digital surveillance technologies (eg, cellphone geolocation, closed-circuit cameras, apps) and mass public data collection (eg, wastewater surveillance) to detect and mitigate the spread of the COVID-19 virus, and to ensure compliance with public health measures.”).

³ Colleen C. Naughton, Fernando A. Roman Jr., Ana Grace F. Alvarado, Arianna

Q. Tariqi, Matthew A. Deeming, Kyle Bibby, Aaron Bivins, Joan

B. Rose, Gertjan Medema, Warish Ahmed, Panagis Katsivelis, Vajra Allan, Ryan Sinclair, Yihan Zhang & Maureen N. Kinyua, *Show Us the Data: Global COVID-19 Wastewater Monitoring Efforts, Equity, and Gaps*, MEDRXIV (Nov. 28, 2021), medrxiv.org/content/10.1101/2021/03/14/21253564v2.full.pdf [https://perma.cc/UA2F-DATR] (“Over 200 universities, 1,000 sites, and 55 countries with 59 dashboards monitor wastewater for SARS-CoV-2 RNA. However, monitoring is primarily in high-income countries (65%) with less access to this valuable tool in low and middle income countries (35%). Data are not widely shared publicly or accessible to researchers to further inform public health actions, perform meta-analysis, better coordinate, and determine equitable distribution of monitoring sites.”).

⁴ Buckley, Wang & Bradsher, *supra* note 2; Adam Ang, *Vietnam Launches Unified Mobile App for COVID-19 Prevention and Control*, HEALTHCARE IT NEWS (Oct. 5, 2021, 2:54 AM), https://www.healthcareitnews.com/news/asia/vietnam-launches-unified-mobile-app-covid-19-prevention-and-control [https://perma.cc/NF58-PL96]; Takashi Nakano, *Singapore Mandates Use of Tracking App As It Fights COVID's Spread*, NIKKEI ASIA (Oct. 29, 2020, 16:59 JST), https://asia.nikkei.com/Spotlight/Coronavirus/Singapore-mandates-use-of-tracing-app-as-it-fights-COVID-s-spread [https://perma.cc/E4QA-W3HA]; Pichayada Promchertchoo, *Data Privacy Concerns Over Thailand's COVID-19 Contact Tracing App Amid New Wave of Cases*, CHANNEL NEWS ASIA (Feb. 8, 2021, 6:32 AM), https://www.channelnewsasia.com/asia/transparency-thailand-covid19-contact-tracing-app-mor-chana-297901 [https://perma.cc/9S9F-24WK].

⁵ Lindsey Van Ness, *For States' Covid Contact Tracing Apps, Privacy Tops Utility*, PEW CHARITABLE TRUSTS (Mar. 19, 2021), https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2021/03/19/for-states-covid-contact-tracing-apps-privacy-tops-utility [https://perma.cc/57T3-7W42] (“Over the past year, 24 states and Washington, D.C., have spent millions developing and promoting the Apple and Google-based apps or systems. The tech giants made the basic platform free, but states have spent anywhere from \$9,600 in North Dakota to \$3 million in Washington state on app development and marketing. More than 28 million people in the United States have downloaded the mobile apps or activated exposure notifications on their smartphones. The systems use Bluetooth technology and are both voluntary and anonymous.”).

⁶ *EU Digital COVID Certificate*, EUR. COMM’N, https://ec.europa.eu/info/live-work-travel-eu/coronavirus-response/safe-covid-19-vaccines-europeans/eu-digital-covid-certificate_en [https://perma.cc/98G8-ENRJ] (“The EU Digital COVID Certificate Regulation entered into application on 1 July 2021. EU citizens and residents will now be able to have their Digital COVID Certificates issued and verified across the EU.”).

privacy and community stigma.

Although wastewater can be analyzed to reveal the presence of viruses, it can also reveal DNA, illicit drugs, and consumption of other products that may produce or exacerbate stigma.⁷ Governments in Germany, Singapore, and Vietnam, among many others, have used cell phone data not only for identifying outbreaks, but for criminal evidence gathering and prosecution.⁸ U.S. state governments that entered into agreements for mobile apps to collect relevant data evidently had little idea how to negotiate or manage the terms demanded by third-party companies to use data extracted from cell phones.⁹

This paper proceeds in three parts. Part II details technologies that were newly deployed over the course of the COVID-19 pandemic; understanding this terrain is essential for new technologies, or technologies deployed in novel ways, to prevent future pandemics. Part III analyzes the privacy vulnerabilities exposed by these new virus detection technologies and classifies them for their potential to jeopardize patient and community rights to confidentiality and privacy. Part III also outlines the promises governments must make to patients and communities, including promises not to misuse personal information. Part IV provides solutions to the privacy vulnerabilities identified in Part III, including in the U.S., and outlines international agreements that must be in place for data to be shared across international borders. Part IV also discusses enforceable causes of action by private citizens against entities that fail to exercise due care in the collection and security of sensitive information and international agreements that must be concluded to address gaps between countries' legal approaches.

⁷ Ryo Honda, Michio Murakami, Akihiko Hata & Masaru Ihara, *Public Health Benefits and Ethical Aspects in the Collection and Open Sharing of Wastewater-Based Epidemic Data on COVID-19*, DATA SCI. J. (Sept. 14, 2021), <https://datascience.codata.org/articles/10.5334/dsj-2021-027/> [<https://perma.cc/A24H-RJE4>] (“Wastewater surveillance renders potentially high public health benefits when a small catchment is targeted; however, it possibly leads to stigmatization and discrimination against the targeted group.”); Nour Sharara, Noriko Endo, Claire Duvallet, Newsha Ghaeli, Mariana Matus, Jennings Heussner, Scott W. Olesen, Eric J. Alm, Peter R. Chai & Timothy B. Erickson, *Wastewater Network Infrastructure in Public Health: Applications and Learnings From the COVID-19 Pandemic*, PLOS GLOB. PUB. HEALTH (Dec. 2, 2021), <https://journals.plos.org/globalpublichealth/article?id=10.1371/journal.pgph.0000061> [<https://perma.cc/CRS4-GSNJ>] [hereinafter *Wastewater Network*].

⁸ Rachel Pannett, *German Police Used a Tracing App to Scout Crime Witnesses. Some Fear That's Fuel for COVID Conspiracists*, WASH. POST. (Jan. 13, 2022, 8:19 AM), <https://www.washingtonpost.com/world/2022/01/13/german-covid-contact-tracing-app-luca/> [<https://perma.cc/DG43-JYAZ>]; Andreas Illmer, *Singapore Reveals Covid Privacy Data Available to Police*, BBC (Jan. 5, 2021), <https://www.bbc.com/news/world-asia-55541001> [<https://perma.cc/D39G-84SM>] (“Officials had previously explicitly ruled out the data would be used for anything other than the virus tracking. But parliament was told on Monday it could also be used ‘for the purpose of criminal investigation’. Close to 80% of residents are signed up to the TraceTogether programme, which is used to check in to locations.”); Bill Hayton & Tro Ly Ngheo, *Vietnam's Coronavirus Success Is Built on Repression*, FOREIGN POL’Y (May 12, 2020, 2:37 PM), <https://foreignpolicy.com/2020/05/12/vietnam-coronavirus-pandemic-success-repression/> [<https://perma.cc/3BDF-NFM4>].

⁹ See U.S. GOV’T ACCOUNTABILITY OFF., EXPOSURE NOTIFICATION: BENEFITS AND CHALLENGES OF SMARTPHONE APPLICATIONS TO AUGMENT CONTRACT TRACING 19–23 (2021).

II. INDIVIDUAL AND COMMUNITY SURVEILLANCE TECHNOLOGIES DEPLOYED OVER THE COVID-19 PANDEMIC

A. *A Brief History of the Pandemic*

Atypical cases of pneumonia circulated in the city of Wuhan in Hubei province, China since at least November, 2019.¹⁰ In late December of 2019, the first cases of COVID-19, the disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), were distinguished in Wuhan from the atypical pneumonia used to describe the disease before.¹¹ City and provincial officials struggled with how to manage the novel pathogen and whether and how to report it to national authorities.¹² Subsequently, national authorities did not effectively report the urgency and impact of the virus to the World Health Organization (WHO). Physicians in Taiwan, seeing the atypical cases in travelers from the mainland, alerted ProMED, an infectious disease surveillance and reporting service.¹³ After two requests, WHO received official information from the government of the People's Republic of China.¹⁴ On January 3, 2020, Chinese researchers made the genetic sequence of the virus available, setting off a race to develop diagnostics, therapeutics, and vaccines that might address the unfolding public health threat.¹⁵ On January 20, 2020, WHO declared COVID-19 a public health emergency of international concern, the most significant alert it is legally authorized to issue. On March 11, 2020, WHO declared COVID-19 a pandemic, a classification that remains without clear criteria or effect.¹⁶ As of this writing, COVID-19 has killed

¹⁰ Scott LaFee, *Novel Coronavirus Circulated Undetected Months Before First COVID-19 Cases in Wuhan, China*, UC SAN DIEGO HEALTH (Mar. 18, 2021), <https://health.ucsd.edu/news/releases/Pages/2021-03-18-novel-coronavirus-circulated-undetected-months-before-first-covid-19-cases-in-wuhan-china.aspx> [https://perma.cc/G9RH-NZP5].

¹¹ Marco Cascella, Michael Rajnik, Abdul Aleem, Scott C. Dulebohn & Raffaella Di Napoli, *Features, Evaluation, and Treatment of Coronavirus (COVID-19)*, NAT'L CTR. FOR BIOTECHNOLOGY INFO. (Feb. 5, 2022), <https://www.ncbi.nlm.nih.gov/books/NBK554776/> [https://perma.cc/55HC-UAPA].

¹² Sam Halabi & Kumanan Wilson, *The Independence of National Focal Points Under the International Health Regulations (2005)*, 63 HARV. INT'L. L.J. 101 (forthcoming 2022).

¹³ ProMED is a web service used to identify unusual health events related to emerging and re-emerging infectious diseases. *About ProMED*, PROMED, <https://promedmail.org/about-promed/> [https://perma.cc/V5T4-YHAH].

¹⁴ Agence France-Presse, *WHO Revises Coronavirus Timeline To Clarify Its China Office Raised Alert, Not Authorities*, S. CHINA MORNING POST (July 4, 2020, 2:28 PM), <https://www.scmp.com/news/china/science/article/3091820/who-revises-coronavirus-timeline-clarify-its-china-office-raised> [https://perma.cc/ULC8-T94F] (“The World Health Organisation was alerted by its own office in China, and not by Chinese authorities, to the first cases in the early stages of the coronavirus pandemic, according to an updated account from the UN health body.”).

¹⁵ See Amy Maxmen, *Scientists Struggle To Probe COVID's Origins Amid Sparse Data From China*, NATURE (Mar. 17, 2022), <https://www.nature.com/articles/d41586-022-00732-0> [https://perma.cc/3VN9-KFT6].

¹⁶ Clare Wenham, Matthew Kavanagh, Alexandra Phelan, Simon Rushton, Maike Voss, Sam Halabi, Mark Eccleston-Turner & Mara Pillinger, *Problems With Traffic Light Approaches to Public Health Emergencies of International Concern*, 397 LANCET 1856 (May 15, 2021).

approximately 987,000 people in the United States and 6.2 million worldwide.¹⁷

B. Deployment of Surveillance Technologies

Between those designations and the availability of safe and effective vaccines, which did not occur until approximately one year later in wealthy countries, and remains elusive in poor ones, communities, provinces, states, and national governments scrambled to develop means to identify who was infected, alert those with whom the infected had come into contact, and deploy measures to prevent further spread of the virus.¹⁸ Individual and community-level technologies play a major role in this effort.¹⁹ Mobile phone data use included location and travel data, and medical and health data, while separate surveillance approaches focused on news media data and government data. At the household level, efforts prioritized online consumption data, data collected by intelligent equipment, and epidemic prevention data.²⁰ At the community level, wastewater surveillance was adopted in approximately 55 countries, frequently alerting public health responders to outbreaks before symptomatic infections manifested.²¹

1. Mobile Phone-Based Applications, Data, Prevention, and Response

a. Call Data Records

Call data records are collected routinely by mobile phone operators and may reveal time and duration of the call, the GPS location of a cell tower, and unique identifiers.²² As part of the COVID-19 response, such information may help in assessing changes in population-level mobility and clustering

¹⁷ *COVID-19 Data Explorer: Daily New Confirmed COVID-19 Deaths per Million People*, OUR WORLD IN DATA, <https://ourworldindata.org/explorers/coronavirus-data-explorer> [https://perma.cc/8HQZ-BVCV].

¹⁸ *Coronavirus (COVID-19) Vaccinations*, OUR WORLD IN DATA, https://ourworldindata.org/covid-vaccinations?country=OWID_WRL [https://perma.cc/KW99-CSMY]; Kuldeep Dhama, Khan Sharun, Ruchi Tiwari, Shubhankar Sircar, Sudipta Bhat, Yashpal Singh Malik, Karam Pal Singh, Wanpen Chaicumpa, D. Katterine Bonilla-Aldana & Alfonso J. Rodriguez-Morales, *Coronavirus Disease 2019–COVID-19*, *Clinical Microbiology Rev.*, Oct. 2020, at 1, 2.

¹⁹ Sera Whitelaw, Mamas A. Mamas, Eric Topol & Harriette G. C. Van Spall, *Applications of Digital Technology in COVID-19 Pandemic Planning and Response*, 2 *LANCET DIGITAL HEALTH* 435, 435 (2020).

²⁰ Jun Wu, Jian Wang, Stephen Nicholas, Elizabeth Maitland & Qiuyan Fan, *Application of Big Data Technology for COVID-19 Prevention and Control in China: Lessons and Recommendations*, *J. MED. INTERNET RES.* (Oct. 22, 2020), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7561444/> [https://perma.cc/8YJD-GS9A].

²¹ See Naughton, Roman Jr., Alvarado, Tariqi, Deeming, Bibby, Bivins, Joan Rose, Medema, Ahmed, Katsivelis, Allan, Sinclair, Zhang & Kinyua *supra* note 3; Christopher G. Daughton, *Wastewater Surveillance for Population-Wide COVID-19: The Present and Future*, *SCI. TOTAL ENVIRON.* (Sept. 20, 2020), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7245244/> [https://perma.cc/6XVF-42N7].

²² Kerina Helen Jones, Helen Daniels, Sharon Heys & David Vincent Ford, *Challenges and Potential Opportunities of Mobile Phone Call Detail Records in Health Research: Review*, *JMIR MHEALTH UHEALTH* (July 2019), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6072975/> [https://perma.cc/73VP-G2D4].

behaviors, understand the risk of importation of the virus from different regions, retrace the introduction and spread of the virus during an outbreak, and inform modeling of disease spread.²³

However, call data records also face significant limitations.²⁴ Those records assume that aggregate level data is adequately representative of the behavior of individuals infected with the virus, which may be erroneous.²⁵ Relatedly, call data records cannot distinguish between high and low-risk probabilities of transmission from those individuals.²⁶ For regions with few cell towers (which globally are significant), the data is limited.²⁷ The data naturally biases response to those who use mobile phones on cellular networks rather than when WiFi-enabled.²⁸

b. GPS Location Data

Location data may be collected through smartphone applications and may provide time stamps, GPS locations of the phones, and other unique identifiers.²⁹

An episode where a spring break event became a super-spreader event revealed how this type of information is gathered and used:

X-Mode got the data that was used to create Tectonix's spring breakers map. A company called Unacast used trackers in its SDK to grade counties on how well their residents socially distanced and stayed indoors. Then there's Cuebiq, which collected location data through its SDK and shared that information with the New York Times for multiple articles about how social distancing changed as stay-at-home orders were lifted and states reopened.³⁰

²³ Ayumi Arai, Erwin Knippenberg, Moritz Meyer & Apichon Witayangkurn, *The Hidden Potential of Call Detail Records in the Gambia*, 3 DATA AND POL 'Y e9, e9-3 (2021).

²⁴ See Jones, Daniels, Heys & Ford, *supra* note 22; see also Katherine Klise, Walt Beyeler, Patrick Finley & Monear Makvandi, *Analysis of Mobility Data to Build Contact Networks for COVID-19*, PLoS ONE (Apr. 15, 2021), <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0249726> [<https://perma.cc/VWJ8-U6MC>].

²⁵ Jones, Daniels, Heys & Ford, *supra* note 22.

²⁶ See *id.*; see also Katherine Klise, Walt Beyeler, Patrick Finley & Monear Makvandi, *Analysis of Mobility Data to Build Contact Networks for COVID-19*, PLoS ONE (Apr. 15, 2021), <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0249726> [<https://perma.cc/VWJ8-U6MC>].

²⁷ See generally, MAPS MANIA, *Worldwide Cell Tower Distribution* (Feb. 18, 2021), <https://googlemapsmania.blogspot.com/2021/02/worldwide-cell-tower-distribution.html> [<https://perma.cc/J38H-WRME>].

²⁸ See generally Amy Wesolowski, Nathan Eagle, Abdisalan M. Noor, Robert W. Snow & Caroline O. Buckee, *The Impact of Biases in Mobile Phone Ownership on Estimates of Human Mobility*, J. R. SOC. INTERFACE., Apr. 2013, at 1.

²⁹ Jennifer Valentino-DeVries, *How Your Phone Is Used to Track You, and What You Can Do About It*, N.Y. TIMES (Aug. 19, 2020), <https://www.nytimes.com/2020/08/19/technology/smartphone-location-tracking-opt-out.html> [<https://perma.cc/7X9P-U29Z>].

³⁰ Sara Morrison, *The Hidden Trackers in Your Phone, Explained*, VOX (July 8, 2020, 10:30 AM), <https://www.vox.com/recode/2020/7/8/21311533/sdks-tracking-data-location> [<https://perma.cc/7UBF-5YGJ>] ("SDKs themselves are not trackers, but they are the means through which most tracking through mobile apps occurs. Simply put, an SDK is a package of tools that helps an app function in some way. Apple and Android offer operating system SDKs so developers can build their apps for their respective devices, and third parties offer SDKs that allow developers to

As with call data records, GPS data may be used to assess changes to population-level mobility and clustering behaviors, to understand risk of importation from different areas and localities, to retrace disease introduction and spread, and inform models about future infection.³¹ Not only is this data biased, however, but it is also difficult to anonymize and keep safe from privacy invasions.³²

c. Bluetooth Data

Bluetooth data may be collected by Bluetooth-enabled phones and can provide time stamps, proximity, and duration of interactions between two or more devices with individual identifying markers.³³ Bluetooth data may reveal the proximity between people and how long they interacted and assess changes in interactions over time.³⁴ These interactions may be more relevant to contact rates in a given population over a longer time horizon.

According to Privacy International:

Bluetooth is arguably one of the more accurate technologies in terms of proximity identification, in this instance, proximity to other phones using a specified app. Arguably, it is also the least intrusive form of tracking given that it is based on proximity to other phones using the app rather than actual location, e.g., GPS or cell tower data. In this context, it can be understood more so as an interaction tracking tool. Data can be ‘localised’ and shared in accordance with a policy, e.g., the Bluetooth devices you connect to are not shared unless for example you come into contact with someone who believes they have Covid-19 (as testing is still relatively rare). It is unclear whether anonymisation *may* in reality be possible; Bluetooth technology still has the potential to deanonymise vast swaths of the population and if implemented like Singapore’s Trace Together, share sensitive personal data.³⁵

d. Opt-in Application Data

Exposure data was also sought by U.S. state governments over the course of the COVID-19 pandemic. They entered commercial partnerships to make

add certain features to those apps quickly and with minimal effort.”).

³¹ BENJAMIN BOUDREAUX, MATTHEW A. DENARDO, SARAH W. DENTON, RICARDO SANCHEZ, KATIE FEISTEL & HARDIKA DAYALANI, RAND CORP., DATA PRIVACY DURING PANDEMICS 17 (2020).

³² Christopher A. Cassa, Shaun J. Grannis, J. Marc Overhage & Kenneth D. Mandl, *A Context-sensitive Approach to Anonymizing Spatial Surveillance Data: Impact on Outbreak Detection*, 13 J. AM. MED. INFORMATICS ASSOC. 160, 165 (2006).

³³ Andrew Crocker, Kurt Opsahl & Bennett Cyphers, *The Challenge of Proximity Apps for COVID-19 Contact Tracing*, ELEC. FRONTIER FOUND. (Apr. 10, 2020), <https://www.eff.org/deep links/2020/04/challenge-proximity-apps-covid-19-contact-tracing> [<https://perma.cc/6Q9V-8NUE>].

³⁴ *Id.*

³⁵ PRIVACY INT’L, *Bluetooth Tracking and COVID-19: A Tech Primer* (Mar. 31, 2020), <https://privacyinternational.org/explainer/3536/bluetooth-tracking-and-covid-19-tech-primer> [<https://perma.cc/5F9V-NXDZ>].

available apps that could be voluntarily downloaded by users interested in notifications about COVID-19 exposure and proximity of close contacts.³⁶ In some countries, similar kinds of apps were mandated as a matter of law, especially as delta and omicron variants surged in their countries.³⁷

Opt-in application data includes Bluetooth and/or GPS location data to track interactions between individuals and collect data passively through enabled phones, while actively tracking when users respond to prompts.³⁸ Opt-in data is theoretically specific to the app, but could include time stamps, proximity, duration of interaction, and any specific questionnaire responses.³⁹

Opt-in data enables rapid tracing and quarantining of exposed individuals with fewer resources and allows for measured behavior to be linked to an individual's infection status.⁴⁰ As vaccines have become more available worldwide (although still overwhelmingly more so in wealthier countries), "opt-in" apps have also been made compulsory for travel and entry into businesses and other establishments.⁴¹

2. Community Surveillance, Prevention, and Response

a. Wastewater Surveillance

Early research into COVID-19 symptoms revealed that evidence of infection manifested not only in cough, fever, and difficulty breathing, but also in feces of both symptomatic and asymptomatic individuals.⁴² The realization that SARS-CoV-2 could be detected in advance of symptomatic infection sparked an effort worldwide to use wastewater detection—most often at the community or institutional level—to identify outbreaks before they occurred and to contain them.⁴³ COVID-19 is not the first disease for which wastewater promised to be a significant sentinel.⁴⁴ Noroviruses, hepatitis A, and polio have

³⁶ See generally U.S. GOV'T ACCOUNTABILITY OFF., *supra* note 9.

³⁷ Takashi Nakano, *Singapore Mandates Use of Tracing App As It Fights COVID's Spread*, NIKKEI ASIA (Oct. 29, 2020, 16:59 JST), <https://asia.nikkei.com/Spotlight/Coronavirus/Singapore-mandates-use-of-tracing-app-as-it-fights-COVID-s-spread> [https://perma.cc/T6NA-K837].

³⁸ Kyra H. Grantz, Hannah R. Meredith, Derek A. T. Cummings, C. Jessica E. Metcalf, Bryan T. Grenfell, John R. Giles, Shruti Mehta, Sunil Solomon, Alain Labrique, Nishant Kishore, Caroline O. Buckee & Amy Wesolowski, *The Use of Mobile Phone Data To Inform Analysis of COVID-19 Pandemic Epidemiology*, 11 NATURE COMMUNICATIONS 4961, 4962 (2020).

³⁹ *Id.* at 4965.

⁴⁰ *Id.*

⁴¹ *Id.*

⁴² Warish Ahmed, Nicola Angel, Janette Edson, Kyle Bibby, Aaron Bivins, Jake W. O'Brien, Phil M. Choi, Masaaki Kitajima, Stuart L. Simpson, Jiaying Li, Ben Tscharke, Rory Verhagen, Wendy J.M. Smith, Julian Zaugg, Leanne Dierens, Philip Hugenholtz, Kevin V. Thomas & Jochen F. Mueller, *First Confirmed Detection of SARS-CoV-2 in Untreated Wastewater in Australia: A Proof of Concept for the Wastewater Surveillance of COVID-19 in the Community*, SCI. TOTAL ENVIRON. 728 (2020).

⁴³ Jordan Peccia, Alessandro Zulli, Doug E. Brackney, Nathan D. Grubaugh, Edward H. Kaplan, Arnau Casanovas-Massana, Albert I. Ko, Aryn A. Malik, Dennis Wang, Mike Wang, Joshua L. Warren, Daniel M. Weinberger, Wyatt Arnold & Saad B. Omer, *Measurement of SARS-CoV-2 RNA in Wastewater Tracks Community Infection Dynamics*, 38 NATURE BIOTECHNOLOGY 1164, 1164 (2020).

⁴⁴ Maria Hellmér, Nicklas Paxéus, Lars Magnus, Lucica Enache, Birgitta Arnholm, Annette

similarly been promising areas where wastewater surveillance has effectively predicted outbreaks and subsequent response.⁴⁵ In the United States, before COVID-19, wastewater surveillance was not generally implemented at the national level despite its utility for disease detection.⁴⁶ As of August 2021, the CDC rolled out its National Wastewater Surveillance System, which covers 37 states, four cities, and two territories.⁴⁷

“Wastewater surveillance, the measurement of pathogen levels in wastewater, is used to evaluate community-level infection trends, augment traditional surveillance that leverages clinical tests and services (e.g., case reporting), and monitor public health interventions.”⁴⁸ Wastewater analysis has been deployed across diverse and multifaceted reservoirs and contexts.⁴⁹ In the Netherlands, test buses were deployed to an area of undertesting.⁵⁰ In New Zealand, public health officials paired case data with wastewater data to determine where and for how long to impose lockdown measures.⁵¹ Municipal sewer analysis has been the most common as has select institutional efforts aimed at, for example, universities or long-term care facilities.⁵²

b. Drone-based Surveillance and Enforcement

So far, eighteen countries have deployed drones for a range of purposes during the COVID-19 pandemic, including to analyze the relationship between distancing or lockdown measures and the actual distance between people in areas under surveillance.⁵³ Some countries deployed drones as a part of experimentation and tests, while others maintained their regular drone operations.⁵⁴ Three countries in Sub-Saharan Africa, namely Rwanda, Ghana and Malawi reported the use of drones to deliver regular medical commodities,

Johansson, Tomas Bergström & Heléne Norder, *Detection of Pathogenic Viruses in Sewage Provided Early Warnings of Hepatitis A Virus and Norovirus Outbreaks*, 80 APPL. ENVIRON. MICROBIOL. 6771, 6772 (2014).

⁴⁵ *Id.*

⁴⁶ Centers for Disease Control and Prevention (CDC), *National Wastewater Surveillance System (NWSS)*, <https://www.cdc.gov/healthywater/surveillance/wastewater-surveillance/wastewater-surveillance.html> [https://perma.cc/W7C5-X9DQ].

⁴⁷ *Id.*

⁴⁸ Amy E. Kirby, Maroya Spalding Walters, Wiley C. Jennings, Rebecca Fugitt, Nathan LaCross, Mia Mattioli, Zachary A. Marsh, Virginia A. Roberts, Jeffrey W. Mercante, Jonathan Yoder & Vincent R. Hill, *Using Wastewater Surveillance Data to Support the COVID-19 Response—United States, 2020-2021*, 70 MORBIDITY AND MORTALITY WEEKLY REP. 1242, 1244 (2021).

⁴⁹ For examples of how and where wastewater analysis has been deployed, see Dutch Sewage Surveillance Use Case, <https://storymaps.arcgis.com/stories/8888f5bfb4704180afeda3d476f2aa63> (last visited Jan. 21, 2022) [https://perma.cc/H3A2-BK3R]; Maria Hellmér, Nicklas Paxéus, Lars Magnus, Lucica Enache, Birgitta Arnholm, Annette Johansson, Tomas Bergström & Heléne Norder, *Detection of Pathogenic Viruses in Sewage Provided Early Warnings of Hepatitis A Virus and Norovirus Outbreaks*, 80 Appl. Environ. Microbiol. 6771, 6772 (2014).

⁵⁰ *Id.*

⁵¹ *Wastewater Network*, *supra* note 7, at 4.

⁵² *Id.*

⁵³ UNICEF, *How Drones Can Be Used To Combat COVID-19*, <https://www.unicef.org/supply/media/5286/file/%20Rapid-guidance-how-can-drones-help-in-COVID-19-response.pdf> [https://perma.cc/P5BV-PF64].

⁵⁴ *Id.*

COVID-19 supplies, and medical samples since the beginning of the pandemic.⁵⁵ All three countries had existing drone operations prior to the COVID-19 pandemic.⁵⁶ Therefore, drone operations were adapted in all three countries to respond to the increased demand of medical commodities and COVID-19 supplies.⁵⁷

c. Internet search, Google Trends, and Related Surveillance

Google Trends offers an aggregate analysis tool that allows researchers to correlate internet search data with epidemiological data.⁵⁸ Public health responders, for example, could analyze specific search terms related to COVID-19 and use that data to anticipate or address a future outbreak.⁵⁹ These relationships can be further studied for time-lag, geographic, and temporal relationships between searches and outbreaks.⁶⁰

3. Effectiveness of Surveillance Technologies over the Course of the COVID-19 Pandemic

a. Effectiveness of Mobile Phone Based Technologies

The success record of these technologies is mixed. A metastudy, or a larger study reviewing dozens or hundreds of smaller ones, of mobile phone-based interventions concluded that:

[D]espite that the current research evidence is fragmented and requires greater methodological rigor, mobile apps have been found to benefit citizens, health professionals, and decision makers in facing the COVID-19 pandemic. In particular, mobile apps can help in solving several COVID-19-related challenges by increasing the reach of reliable information to both citizens and health professionals, decreasing misinformation and confusion, tracking symptoms and mental health of citizens, home monitoring and isolation, discovering new predictors, optimizing health care resource allocation, and reducing the burden of hospitals.⁶¹

A 2021 metastudy, on the other hand, found that, even beyond user hesitation related to privacy, a number of technical and design flaws limited the effectiveness of mobile phone-based technologies:

Our research study has highlighted the hindrances in the successful deployment of COVID-19 contact tracing apps. The use of mobile technologies for contact tracing has been met with a number of challenges,

⁵⁵ *Id.*

⁵⁶ *Id.*

⁵⁷ *Id.*

⁵⁸ See Parmeshwar Satpathy, Sanjeev Kumar & Pankaj Prasad, *Suitability of Google Trends™ for Digital Surveillance During Ongoing COVID-19 Epidemic: A Case Study from India*, DISASTER MEDICINE PUBLIC HEALTH PREPAREDNESS (2021).

⁵⁹ *Id.*

⁶⁰ *Id.*

⁶¹ Haridimos Kondylakis, Dimitrios G. Katehakis, Angelina Kouroubali, Fokion Logothetidis, Andreas Triantafyllidis, Ilias Kalamaras, Konstantinos Votis & Dimitrios Tzouvaras, *COVID-19 Mobile Apps: A Systematic Review of the Literature*, 22 J. MED. INTERNET RES. 12, 12 (2020).

many of which also emerged in the contextual evaluation of user reviews on COVID-19 contact tracing apps as described in our study. Among these, the most popular were technical malfunctions and drainage of battery. Other challenges included privacy. This is anticipated, as you cannot expect to trace and track peoples' movements by a government authority without addressing privacy issues. Nonetheless, in addition to privacy, there were many other challenges and limitations hindering the anticipated efficacy from contact tracing apps.⁶²

b. Effectiveness of Community-Based Digital Technologies

The record of community-based surveillance is also mixed, although analysis of wastewater has largely been one of success worldwide. Analysis of internet searches has shown that there is not a significant predictive benefit for public health measures. In an analysis of Google Trends data used in India, Parmeshwar Satpathy, Sanjeev Kumar, and Pankaj Prasad found that peaks in searches—both at the national level and in five high-COVID-19-burden states—corresponded with media coverage or government declarations on the ongoing pandemic.⁶³ A separate study by U. Venkatesh and Periyasamy Aravind Gandhi found that Google Trends analysis could predict outbreaks two to three weeks earlier than routine surveillance.⁶⁴ In the United States, a team of researchers at the Mayo Clinic analyzed data from January to April 2020 and found that Google Trends analysis could predict COVID-19 outbreaks up to approximately 16 days, but only in some states (e.g., Arizona, Florida, Minnesota, and New York).⁶⁵

Wastewater surveillance has proven far more effective relative to investment than most of the above-categories of technological surveillance deployed.⁶⁶ Used as an early warning system for COVID-19 outbreaks, wastewater surveillance, especially in areas where other surveillance options are limited, can give one to six days' advance notice to public health responders.⁶⁷ Separately, wastewater surveillance data may give a more accurate picture of how many infections have actually occurred relative to the

⁶² Mahmoud Elkhodr, Omar Mubin, Zainab Iftikhar, Maleeha Masood, Belal Alsinglawi, Suleman Shahid & Fady Alnajjar, *Technology, Privacy, and User Opinions of COVID-19 Mobile Apps for Contact Tracing: Systematic Search and Content Analysis*, 23 J. MED. INTERNET RES. 1, 12 (2021).

⁶³ Satpathy, Kumar & Prasad, *supra* note 58.

⁶⁴ U. Venkatesh & Periyasamy Aravind Gandhi, *Prediction of COVID-19 Outbreaks Using Google Trends in India: A Retrospective Analysis*, 3 HEALTHCARE INFORMATICS RES. 1, 1 (2020).

⁶⁵ Shyam J. Kurian, Atiq Ur Rehman Bhatti, Mohammed Ali Alvi, Henry H. Ting, Curtis Storlie, Patrick M. Wilson, Nilay D. Shah, Hongfang Liu & Mohamad Bydon, *Correlations Between COVID-19 Cases and Google Trends Data in the United States: A State-by-State Analysis*, 11 MAYO CLIN PROC. 2303, 2305 (2020).

⁶⁶ Sara Reardon, *Wastewater Monitoring Offers Powerful Tool for Tracking COVID and Other Diseases*, SCIENTIFIC AMERICAN (Mar. 3, 2020), <https://www.scientificamerican.com/article/wastewater-monitoring-offers-powerful-tool-for-tracking-covid-and-other-diseases/> [https://perma.cc/SXW4-496X].

⁶⁷ Scott W. Olesen, Maxim Imakaev & Claire Duvallet, *Making Waves: Defining the Lead Time of Wastewater-Based Epidemiology for COVID-19*, 202 WATER RES. 1, 2 (2021).

number of laboratory confirmed cases.⁶⁸ Wastewater surveillance may also detect “bursts” in infection or identification of superspreader events.⁶⁹ “For example, given daily wastewater sampling through a holiday or special event, such as Thanksgiving or the Superbowl in the US, how many excess infections occurred specifically because of that event?”⁷⁰

III. PRIVACY IMPLICATIONS AND THREATS RELATED TO COVID-19 SURVEILLANCE TECHNOLOGIES

A. *The Conceptual, Constitutional, and Human Rights Importance of Privacy*

In a world of ever-changing technology and constantly developing societal expectations, the idea of privacy continues to evolve. Defined as “the claim of individuals, groups, or institutions to determine for themselves when, how, and to what extent information about them is communicated to others,”⁷¹ privacy has become of particular concern to many due to the existence of data that is simple and inexpensive to access and difficult to control.⁷²

The greatest debate regarding privacy revolves around regulation and policymaking, where, conceptually, privacy serves as a check upon corporate and governmental intrusion and overreach.⁷³ In the formulation made famous by Samuel Warren and Louis Brandeis, privacy is a fundamental right: people have a right to a private life free from invasion, as well as for the “general right of the individual to be let alone.”⁷⁴

Legal scholar Fred Cate argued that there are five principles that provide guidance as to the reach and limits of privacy in the digital context: balance of competing interests, free flow of information, the meaning of privacy, the severity of the harm threatened if privacy is not protected, and the preference for self-help and individual action.⁷⁵ According to his analysis, the law should only protect expectations of privacy that are real and reasonable, meaning the information cannot already be disclosed or made available to the public.⁷⁶ Generally, “disclosure is the rule; privacy is an exception.”⁷⁷

⁶⁸ See Will Feuer, *HHS wants to test 30% of U.S. wastewater for the coronavirus as an ‘early warning system’*, CNBC (Sept. 25, 2020, 2:22 PM), <https://www.cnbc.com/2020/09/25/hhs-wants-to-test-30percent-of-us-wastewater-for-the-coronavirus.html> [<https://perma.cc/P9HB-55UV>].

⁶⁹ Olesen, Imakaev & Duvall, *supra* note 67.

⁷⁰ *Id.*

⁷¹ Fred H. Cate, *Principles of Internet Privacy*, 32 CONN. L. REV. 877, 877 (2000).

⁷² *Id.*

⁷³ Cameron F. Kerry & John B. Morris, *Framing a Privacy Right: Legislative Findings for Federal Privacy Legislation*, THE BROOKINGS INST. (Dec. 8, 2020), <https://www.brookings.edu/research/framing-a-privacy-right-legislative-findings-for-federal-privacy-legislation/> [<https://perma.cc/LS7L-AWXZ>].

⁷⁴ Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193, 205 (1890).

⁷⁵ See Cate, *supra* note 71, at 879–891.

⁷⁶ *Id.* at 885.

⁷⁷ *Id.* at 886.

As surveillance technologies proliferate, these principles will come into increasing conflict. Data on individuals can be aggregated not only as part of public health response, but also as part of governmental coercion and corporate excess.⁷⁸ Use of patient records and other personal data has led to significant discoveries, the development of new health services, and an overall improvement in health care and public health.⁷⁹ On the other hand, harvesting of sensitive personal data can lead to discrimination, stigma, and social exclusion, at the hands of both private and public actors.⁸⁰

These concerns and countervailing interests are discussed below.

B. Mobile Phones

As the number of COVID-19 infections grow worldwide and variants proliferate, the need for a way to safely monitor and track the disease remains an essential task for municipalities, states, provinces, national governments, and international organizations. Wastewater surveillance, call data records, contact tracing applications, and downloadable mobile applications intended to track and record via Bluetooth all the people with whom a person testing positive for the disease has neared remain fundamental tools.⁸¹ The goal is to slow the spread of COVID-19 by notifying those devices which have come close to an infected person so that those users can self-isolate and prevent further dissemination.⁸²

The pandemic has also provided actual and pretextual bases for states to increase surveillance on individuals and groups *unrelated* to public health purposes, or use health data in ways that affect privacy interests.⁸³ Under authoritarian regimes, surveillance generally is undertaken to identify and silence content that the government does not want publicized.⁸⁴ During the pandemic, governments use the pretext of COVID-19 surveillance to monitor cell phone locations of individuals.⁸⁵ Other countries rely on the private sector to monitor individuals. In Germany, Italy, and Austria, location data is being turned over to public health officials by telecommunications companies.⁸⁶ In the United States, Google and Apple partnered to develop contact-tracing

⁷⁸ See Kerry & Morris, *supra* note 73.

⁷⁹ See generally SHARYL J. NASS, LAURA A. LEVIT & LAWRENCE O. GOSTIN, *BEYOND THE HIPAA PRIVACY RULE: ENHANCING PRIVACY, IMPROVING HEALTH THROUGH RESEARCH* (2009).

⁸⁰ *Id.*

⁸¹ Claire Downing, *COVID-19 Contact Tracing: A Wolf in Sheep's Clothing?*, FAIR OBSERVER (June 10, 2020), <https://www.fairobserver.com/business/technology/claire-downing-covid-19-contact-tracing-data-privacy-surveillance-civil-liberties-news-16161/> [<https://perma.cc/JSV8-GFNM>].

⁸² *Id.*

⁸³ *Id.*

⁸⁴ Adrian Shahbaz & Allie Funk, *THE CRISIS OF SOCIAL MEDIA 2* (Freedom House ed., 2019).

⁸⁵ Katherine Jacobsen, *Amid COVID-19, the Prognosis for Press Freedom Is Dim. Here Are 10 Symptoms To Track*, CPJ, <https://cpj.org/reports/2020/06/covid-19-here-are-10-press-freedom-symptoms-to-track/> [<https://perma.cc/D5W9-92QX>].

⁸⁶ *Id.*

technology, “they have the ability to accomplish something that no government by itself could: nearly perfect location tracking of most the world’s population.”⁸⁷ Other smaller companies have also begun work on similar technologies.⁸⁸

Since individuals, especially in East Asia, Europe, and North America, interact with their phones on a daily basis, there is an opportunity to use this data for the benefit of public health during the pandemic, but there are also risks to privacy.⁸⁹ As Mark Zuckerberg wrote on the topic, “[It’s important] that any data collected is used solely for responding to public health emergencies... Fighting the pandemic has required taking unprecedented measures across society, but it should not mean sacrificing our privacy.”⁹⁰ While extreme circumstances such as the COVID-19 pandemic may require more extreme tactics to combat it, some worry that global or national emergencies may create the new normal on what surveillance is acceptable moving forward.⁹¹

However, despite this security promise, there are still privacy concerns over the use of the data collected. With the potential of location tracking and the input of personal health information, like COVID-19 testing results, symptoms, and contact information, there is much concern over what companies and governments will do with the information collected after the pandemic has ended, as well as the possibility of this data being used in marketing and other non-health-related matters.⁹² “[A] pandemic is not the time to grant the private sector and governments further reason to abuse civil liberties.”⁹³

Privacy concerns affect not only abstract civil liberties, but the actual utilities of the applications. According to a poll organized by the Washington Post, three in five Americans reported they would be “unable or unwilling to use the infection-alert system under development by Google and Apple.”⁹⁴ This was either due to lack of access to a smartphone with the capabilities to use the application, or for those with access, the lack of concern that they

⁸⁷ Jack Goldsmith and Andrew Keane Woods, *Internet Speech Will Never Go Back to Normal*, THE ATLANTIC (Apr. 26, 2020), <https://www.theatlantic.com/ideas/archive/2020/04/what-covid-revealed-about-internet/610549/> [<https://perma.cc/TTD5-3VJH>].

⁸⁸ Downing, *supra* note 81.

⁸⁹ Trevor Wheelwright, *2022 Cell Phone Usage Statistics: How Obsessed Are We?*, REVIEWS.ORG (Jan. 24, 2022), <https://www.reviews.org/mobile/cell-phone-addiction/> [<https://perma.cc/QM5G-4NYV>].

⁹⁰ Mark Zuckerberg, *Opinion: Mark Zuckerberg: How Data Can Aid the Fight Against Covid-19*, THE WASH. POST (Apr. 20, 2020), <https://www.washingtonpost.com/opinions/2020/04/20/how-data-can-aid-fight-against-covid-19/> [<https://perma.cc/2R3D-VAXX>].

⁹¹ Jacobsen, *supra* note 85.

⁹² *Id.*

⁹³ Downing, *supra* note 81.

⁹⁴ Craig Timberg, Drew Harwell & Alauna Safarpour, *Most Americans Are Not Willing or Able To Use an App Tracking Coronavirus Infections. That’s a Problem for Big Tech’s Plan To Slow The Pandemic*, THE WASH. POST (Apr. 29, 2020), <https://www.washingtonpost.com/technology/2020/04/29/most-americans-are-not-willing-or-able-use-an-app-tracking-coronavirus-infections-thats-problem-big-techs-plan-slow-pandemic/> [<https://perma.cc/LSV3-TCRG>].

would be in any danger of being infected.⁹⁵ A study by Oxford University predicts that 60 percent participation in contact tracing in each country is necessary to wipe out the pandemic, although any involvement will greatly reduce the impact of the disease.⁹⁶ While it was reported that there was some trust in these companies to not abuse the system, a major concern was respect for privacy.⁹⁷

C. Wastewater Surveillance

While analytically different with respect to privacy concerns, wastewater analysis raises relevant issues. Recent advances in wastewater analysis have provided means for extracting novel types of information.⁹⁸ Approaches in use today follow viral movement through a locality, identify high concentrations of opioids, or even ascertain the genealogy of individuals residing in the area.⁹⁹ As methods, analytical approaches, and potential applications proliferate, privacy and ethical considerations are gaining in importance.

As a team of researchers from the Institute of Electronic and Electrical Engineers concluded:

“Today, pathogens can be surveilled in wastewater; and it is not difficult to imagine tracking other information, such as human movement, in the near future. Without proper attention to key issues, e.g., privacy, tomorrow’s cities could easily become the epicenter of surveillance societies. As WBE expands to incorporate emerging genetics research, now is the time to consider the ethical, societal, and privacy concerns of such practices.”¹⁰⁰

IV. SOLUTIONS

While these advancements may do great work in providing internet users with correct information relating to COVID-19 and aggregating data to the

⁹⁵ *Id.*

⁹⁶ *Digital Contact Tracing Can Slow or Even Stop Coronavirus Transmission and Ease Us Out of Lockdown*, UNIV. OF OXFORD (Apr. 16, 2020), <https://www.research.ox.ac.uk/article/2020-04-16-digital-contact-tracing-can-slow-or-even-stop-coronavirus-transmission-and-ease-us-out-of-lockdown> [<https://perma.cc/97Y9-TABA>].

⁹⁷ *See id.*

⁹⁸ Danielle Jacobs, Troy McDaniel, Arvind Varsani, Rolf U. Halden, Stephanie Forrest & Heewook Lee, *Wastewater Monitoring Raises Privacy and Ethical Considerations*, 2 IEEE TRANSACTIONS ON TECH. & SOC’Y 116, 116 (2021).

⁹⁹ *Id.*; *Wastewater Analysis and Drugs — A European Multi-City Study*, EUR. MONITORING CENTRE FOR DRUGS AND DRUG ADDICTION (Mar. 2022), https://www.emcdda.europa.eu/publications/html/pods/waste-water-analysis_en [<https://perma.cc/Q8KR-DAHA>]. *See generally* Orsolya Anna Pipek, Anna Medgyes-Horváth, László Dobos, József Stéger, János Szalai-Gindl, Dávid Visontai, Rolf S. Kaas, Marion Koopmans, Rene S. Hendriksen, Frank M. Aarestrup & István Csabai, *Worldwide Human Mitochondrial Haplogroup Distribution From Urban Sewage*, SCI. REPS., Aug. 12, 2019 at 1; David Lyon, Professor, Queens Univ., Talk for Festival del Diritto: Surveillance Society (Sept. 28, 2008).

¹⁰⁰ Jacobs, McDaniel, Varsani, Halden, Forrest & Lee, *supra* note 98.

benefit of the public's health, it is important that they are implemented with full transparency and that these extreme measures do not extend beyond the pandemic.¹⁰¹ These extreme measures of surveillance to fight the pandemic should not undermine democracy and civil liberties."¹⁰² The most important laws protecting health privacy in the U.S., the Health Information Portability and Accountability Act and the Privacy Act of 1974, either do not apply to most gatherers and processors of surveillance data, create exceptions for such surveillance, or are entrusted to the Federal Trade Commission to enforce an agency that has neither the resources nor the personnel to do so.

This paper advocates an approach like that of the Public Health Emergency Privacy Act, which would allow individuals to sue to enforce collectors and users of sensitive information where breaches occur. It further advocates the conclusion of international agreements that would address gaps where one country's approach to data is more lax than another, and so collectors and disseminators of data locate their operations in more lenient jurisdictions.

A. *United States*

1. **Mobile Phones**

In response to privacy concerns, several proposed congressional bills aim to regulate how mobile phones collect and handle individuals' personal health information.¹⁰³ While there are technically 12 privacy-related bills¹⁰⁴ that have support in both chambers, this analysis will only focus on those that have played a major role in the discourse on COVID-19 surveillance and privacy, and are not narrowly tailored to serve a grant-supporting function for states or researchers.

Introduced by a group of Republican Senators, including Roger Wicker (R-MS), John Thune (R-SD), Jerry Moran (R-KS), Deb Fischer (R-NE), and Marsha Blackburn (R-T), the first of these bills was the COVID-19 Consumer Data Privacy and Security Act (two years ago named the Consumer Data Protection Act).¹⁰⁵

This was followed shortly after by the Democratic party's Public Health Emergency Privacy Act, sponsored by Senators Richard Blumenthal (D-CT) and Mark Warner (D-VA) and Representatives Anna Eshoo (D-CA), Jan Schakowsky (D-IL), and Suzan DelBene (D-WA).¹⁰⁶ Senator Warner recently

¹⁰¹ See Jacobsen, *supra* note 85.

¹⁰² Sahar Vardi, *Are Governments Violating Human Rights and Civil Liberties in Coronavirus Response?*, AM. FRIENDS SERV. COMM. (Sept. 10, 2020), <https://www.afsc.org/blogs/news-and-commentary/are-governments-violating-human-rights-and-civil-liberties-coronavirus> [<https://perma.cc/KRJ7-KF3T>].

¹⁰³ Müge Fazlioglu, *Privacy Bills in the 117th Congress*, INT'L ASS'N OF PRIV. PRO. (Aug. 24, 2021), <https://iapp.org/news/a/privacy-bills-in-the-117th-congress/> [<https://perma.cc/F2J9-3AFX>].

¹⁰⁴ *Id.*

¹⁰⁵ S. 3663, 116th Cong. (2020).

¹⁰⁶ S. 3749, 116th Cong. (2021).

re-introduced the bill.¹⁰⁷

The Exposure Notification Privacy Act was introduced by Senators Maria Cantwell (D-WA), Amy Klobuchar (D-MN), and Bill Cassidy (R-LA) in 2020, although pieces of that bill have now been disbursed among both those named above and smaller, specialized bills.¹⁰⁸

Although similar in their overall goals of privacy protection, these three bills differ slightly in the way this protection is achieved. “In order for a more narrowly focused COVID privacy bill to become law, House and Senate negotiators will have to similarly overcome these same differences with different flavors.”¹⁰⁹

These certainly are not the only legislative proposals in action at this time, but they are the most promising. But no matter what Congress decides, “it is imperative that any other data protection legislation introduced must apply to both corporations and governments, to prevent both misuse of data and targeting of minorities and dissenters.”¹¹⁰

a. COVID-19 CONSUMER DATA PRIVACY and SECURITY ACT

The Republican-sponsored bill known as the COVID-19 Consumer Data Privacy and Security Act requires that companies controlling the data collected by these types of contact tracing applications “obtain affirmative consent from individuals before collecting, processing or transferring their personal health information to track the spread of the virus.”¹¹¹

As written, the bill allows individuals not wishing to disclose this data to opt out of this process, and requires that companies must disclose beforehand what the collected data will be used for and the methods they will use to handle this information.¹¹² To further protect user privacy, the bill also requires that these companies delete or remove any identifying information from the data collected after it is no longer needed for COVID-19 research and tracking purposes.¹¹³

This particular plan would be governed by the Federal Trade Commission and would only cover data collected to follow the movement and symptoms of

¹⁰⁷ Junaid Odubeko & Andrew Tuggle, *A Second Chance for the Public Health Emergency Privacy Act*, JD SUPRA (Mar. 2, 2021), <https://www.jdsupra.com/legalnews/a-second-chance-for-the-public-health-3911099/> [<https://perma.cc/6YLC-FWRU>].

¹⁰⁸ S. 3861, 116th Cong. (2020).

¹⁰⁹ Christian T. Fjeld & Christopher Harvie, *Cantwell-Cassidy Exposure Notification Privacy Act – A Bipartisan Bill on Disease Contact Tracing*, MONDAQ (June 9, 2020), <https://www.mondaq.com/unitedstates/reporting-and-compliance/977358/cantwell-cassidy-exposure-notification-privacy-act-a-bipartisan-bill-on-disease-contact-tracing> [<https://perma.cc/JMQ9-H345>].

¹¹⁰ Downing, *supra* note 81.

¹¹¹ Sam Sabin, *Senate and House Democrats Introduce COVID-19 Privacy Bill Targeting Contact Tracing Apps*, MORNING CONSULT (May 14, 2020, 3:11 PM), <https://morningconsult.com/2020/05/14/covid-19-data-privacy-legislation-democrats/> [<https://perma.cc/7V2M-X59R>].

¹¹² Mimi Nguyen, *Federal Privacy Law in Response to COVID-19 on the Rise: The COVID-19 Consumer Data Protection Act of 2020 vs. The Public Health Emergency Privacy Act*, JD SUPRA (June 5, 2020), <https://www.jdsupra.com/legalnews/federal-privacy-law-in-response-to-26186/> [<https://perma.cc/C9XU-6WTR>].

¹¹³ *Id.*

the disease, show how communities are complying with social distancing regulations, and for purposes of contact tracing.¹¹⁴

b. PUBLIC HEALTH EMERGENCY PRIVACY ACT

Similar to the COVID-19 Consumer Data Privacy and Security Act, the Public Health Emergency Privacy Act, “aims to ensure that the data collected is protected from over-surveillance and abuse.”¹¹⁵ The Public Health Emergency Privacy Act helps to protect private information from being used for purposes other than public health by requiring that companies obtain an individual’s affirmative express consent and delete collected data within 60 days of the pandemic ending.¹¹⁶ It too, allows individuals to opt out, making information provided for use in the application entirely voluntary.¹¹⁷

This bill takes it a step further, however, addressing another public concern that the collected data will inhibit one’s constitutional rights.¹¹⁸ Since use of contact tracing applications would give big tech companies like Apple and Google access to information that might later prevent someone from accessing certain resources or activities, like voting, the Public Health Emergency Privacy Act prevents “segregating, discriminating in, or otherwise making unavailable the goods, services, facilities, privileges, advantages, or accommodations of any place of *public* accommodation except as authorized by a State or Federal Government entity for a *public health* purpose.”¹¹⁹ Further, it orders that regular reports be made to ensure that the tools used for data collection for these applications are not negatively impacting civil liberties.¹²⁰

Also, the Public Health Emergency Privacy Act focuses more on the role of states in protecting consumer privacy, rather than emphasizing solely federal involvement.¹²¹ Therefore, enforcement of this act would be done by either the Federal Trade Commission or by each individual state’s attorney general.¹²² In addition, protection is also not limited to private use of personal health information, but includes some use by government entities as well.¹²³

The final noteworthy difference between the two is that the Public Health Emergency Privacy Act permits both private and public rights of action, allowing civil lawsuits to be filed for actual damage resulting from violation,

¹¹⁴ *Id.*

¹¹⁵ Sabin, *supra* note 111.

¹¹⁶ *Id.*

¹¹⁷ *Id.*

¹¹⁸ *Id.*

¹¹⁹ Public Health Emergency Privacy Act, S. 3749, 116th Cong. § 2 (2020).

¹²⁰ Sabin, *supra* note 111.

¹²¹ Joseph Marks & Tonya Riley, *The Cybersecurity 202: Commission That Pushed a Cybersecurity Overhaul Hopes Coronavirus Boosts the Effort*, WASH. POST (May 15, 2020), <https://www.washingtonpost.com/news/powerpost/paloma/the-cybersecurity-202/2020/05/15/the-cybersecurity-202-commission-that-pushed-a-cybersecurity-overhaul-hopes-coronavirus-boosts-the-effort/5ebdb3ea88e0fa17cde00363/> [https://perma.cc/CYG2-F395].

¹²² Nguyen, *supra* note 112.

¹²³ *Id.*

an ability not granted by the Republican bill.¹²⁴

c. EXPOSURE NOTIFICATION PRIVACY ACT

While the first two proposed bills for privacy protection and regulation of contact tracing apps are divided by party and thus might have trouble being written into law, the Exposure Notification Privacy Act has bipartisan support.¹²⁵

Like its two predecessors, this bill also requires affirmative express consent, meaning permission to use one's personal data cannot be assumed from inaction, with the added ability to withdraw said consent.¹²⁶ However, it also requires consent to be non-conditioned, protecting individuals from being denied access to certain employment opportunities and access to facilities just because of contact with someone who has tested positive for COVID-19 or was provided a COVID-19 diagnosis.¹²⁷

Unlike the Republican and Democratic bills, the Exposure Notification Privacy Act requires any company operating and collecting personal health information to collaborate and cooperate with public health officials in the management of the application.¹²⁸ As a result, any COVID-19 diagnosis reported on the app must be an "authorized diagnosis" to help with accuracy and reliability of the service.¹²⁹ And like the Public Health Emergency Privacy Act, violations can lead to civil penalties as assigned by the Federal Trade Commission, which would enforce the act alongside state attorneys general.¹³⁰

Similar to the other two bills, this bipartisan proposal requires deletion of data, but in this case either on a rolling basis or as requested by the individual.¹³¹ This ensures greater protection and a lesser chance that the information provided will be used for non-public health purposes in the future.

In general, the Exposure Notification Privacy Act is narrower in scope, applying specifically to online services dedicated to "digitally notifying individuals exposed to an infectious disease," whereas the other two bills refer to "agencies" or "organizations" that work with covered information.¹³²

d. State Governments

In the absence of federal law, states have adopted varied approaches to privacy.¹³³ In 2021, Virginia and Colorado joined California in enacting "comprehensive" privacy legislation, expanding rights for consumers and

¹²⁴ *Id.*

¹²⁵ *Exposure Notification Privacy Act: Bipartisan Bill Introduced to Regulate Covid-19 Contact Tracing Apps*, JD SUPRA (June 19, 2020), <https://www.jdsupra.com/legalnews/exposure-notification-privacy-act-68763/> [<https://perma.cc/Y3XD-VMY4>].

¹²⁶ Fjeld & Harvie, *supra* note 109.

¹²⁷ *Id.*

¹²⁸ *Id.*

¹²⁹ Exposure Notification Privacy Act, S. 3861, 116th Cong. § 3 (2020).

¹³⁰ *Id.* § 10.

¹³¹ *Id.* § 6.

¹³² *Id.* § 2.

¹³³ Daniel J. Solove & Woodrow Hartzog, *The FTC and the New Common Law of Privacy*, 114 COLUM. L. REV. 583, 587 (2014).

obligations for businesses.¹³⁴ Meanwhile, dozens of other state legislatures have continued working to craft new privacy legislation although most efforts have not led to the passage of new laws.¹³⁵

2. Wastewater

There is virtually no law regulating privacy implications of wastewater treatment. Lance Gable, Natalie Ram, and Jeffrey Ram analyzed the possibilities for privacy rights through a Fourth Amendment lens, noting that current search-and-seizure jurisprudence seems unlikely to develop protections under traditional “expectation of privacy” jurisprudence, and that wastewater sampling may easily lead to more rights-restrictive measures imposed on communities that are otherwise stigmatized, vulnerable, or disadvantaged.¹³⁶ Although personally identifiable information is not available from wastewater analysis, or at least not without prohibitive cost and effort, wastewater sampling, demographic, community, or collective stigma may result.¹³⁷

B. International

1. EU General Data Protection Regulation

Internationally, there are few agreements that apply to privacy as implicated by newer public health surveillance technologies.¹³⁸ The European General Data Protection Regulation covered gathering of individual data, especially sensitive health information, in emergency contexts in the same manner as it did in routine contexts.¹³⁹ Generally, the processing of special categories of personal data (“sensitive personal data”), including genetic data, biometric data, and data concerning health, is prohibited under the GDPR unless certain conditions apply.¹⁴⁰ Health care databases using coded sensitive personal data must either obtain explicit consent from the data subject or

¹³⁴ Zoe Argento & Philip Gordon, *As Colorado and Virginia Follow California’s Lead in Enacting Data Privacy Laws, Employers Must Start Planning to Address an Inevitable Trend*, LITTLER (July 8, 2021), <https://www.littler.com/publication-press/publication/colorado-and-virginia-follow-californias-lead-enacting-data-privacy> [https://perma.cc/TJ3E-X4KG].

¹³⁵ *Id.*

¹³⁶ Lance Gable, Natalie Ram & Jeffrey L. Ram, *Legal and Ethical Implications of Wastewater Monitoring of SARS-CoV-2 for COVID-19 Surveillance*, 7 J. OF L. & THE BIOSCIENCES 1, 7 (2020).

¹³⁷ Rachel M. Kwiatkowska, Anouk Ruhaak, Barbara Kasprzyk-Hordern, Francis Hassard, Lian Lundy, Mariachiara Di Cesare, Matthew Hickman & Andrew C. Singer, *Wastewater-Based Epidemiology and Group Privacy: The Elephant in the Sewer?*, OSF PREPRINTS (Dec. 7, 2021), <https://osf.io/q8rcd/> [https://perma.cc/2TUS-5R5C].

¹³⁸ RACHEL F. FEFER, CONG. RSCH. SERV., R45584, *DATA FLOWS, ONLINE PRIVACY, AND TRADE POLICY* (2019) (“There is no globally accepted standard or definition of data privacy in the online world, and there are no comprehensive binding multilateral rules specifically about cross-border data flows and privacy.”).

¹³⁹ See Tobias Schulte in den Baeumen, *The Protection of Personal Data in Health Information Systems – Principles and Processes for Public Health*, WORLD HEALTH ORG.: EUROPE (2021), <https://apps.who.int/iris/bitstream/handle/10665/341374/WHO-EURO-2021-1994-41749-57154-eng.pdf?sequence=1&isAllowed=y> [https://perma.cc/266C-ERBR].

¹⁴⁰ Gabe Maldoff, *How GDPR Changes the Rules for Research*, IAPP (Apr. 19, 2016), <https://iapp.org/news/a/how-gdpr-changes-the-rules-for-research/> [https://perma.cc/Q22K-NH67].

process the data under the scientific research exemption set out in the GDPR, which maintains separate eligibility criteria.¹⁴¹ As with HIPAA in the United States, anonymized data is not covered by GDPR, even though there are significant vulnerabilities in anonymization and reidentification.¹⁴² As Laura Bradford, Mateo Aboy, and Kathleen Liddell argued, the GDPR's principle based protections of individual data are probably the best protection for individual data in the world so far as the COVID-19 response has gone.¹⁴³ But the GDPR is not only limited by anonymization, but by other limitations.¹⁴⁴ It does not apply to data processed during the course of an activity that falls outside of the law of the European Union and it does not apply to government agencies and law enforcement when data is collected and processed for the prevention, investigation, detection, or prosecution of criminal offenses, the execution of criminal penalties, or for preventing threats to public safety, among other exceptions.¹⁴⁵

2. The Pandemic Treaty

The World Health Organization, in partnership with 194 governments worldwide, is in negotiations to form a pandemic treaty, which aims to not only enhance international tools used for infectious disease surveillance, but to facilitate data sharing should an event like the origin of SARS-CoV-1, SARS-CoV-2, Ebola, or related pathogen emerge.¹⁴⁶

Despite editorial and peripheral calls for the security of information and for privacy, the issue has hardly been raised over the course of negotiations.¹⁴⁷ Human Rights Watch's Kyle Knight has articulated perhaps the most detailed call in *BMJ*, writing that: "Digital health has boomed during covid-19. A treaty should address the need for universal access to the internet and digital technology, while upholding rights to digital privacy and non-discrimination, and promoting strict regulation of use of health data."¹⁴⁸

¹⁴¹ EUROPEAN DATA PROT. BD., *EDPB Document on Response to the Request from the European Commission for Clarifications on the Consistent Application of the GDPR, Focusing on Health Research* (Feb. 2, 2021), https://edpb.europa.eu/sites/default/files/files/file1/edpb_replyec_questionnaire_research_final.pdf [<https://perma.cc/QU7R-MMEX>].

¹⁴² Maldoff, *supra* note 140.

¹⁴³ Laura Bradford, Mateo Aboy & Kathleen Liddell, *COVID-19 Contact Tracing Apps: A Stress Test for Privacy, the GDPR, and Data Protection Regimes*, 7 *J. L. & BIOSCIENCES* 1 (2020).

¹⁴⁴ DATAGUISE, *GDPR Principles: Purpose Limitation*, <https://www.dataguise.com/gdpr-knowledge-center/purpose-limitation-principle/> [<https://perma.cc/8DYR-EZZB>] (last visited Mar. 31, 2022).

¹⁴⁵ Derek Hawkins, *The Cybersecurity 202: Why a Privacy Law Like GDPR Would Be a Tough Sell in the U.S.* (May 25, 2018), <https://www.washingtonpost.com/news/powerpost/paloma/the-cybersecurity-202/2018/05/25/the-cybersecurity-202-why-a-privacy-law-like-gdpr-would-be-a-tough-sell-in-the-u-s/5b07038b1b326b492dd07e83/> [<https://perma.cc/DF37-NCLY>].

¹⁴⁶ Lawrence O. Gostin, Sam F. Halabi & Kevin A. Klock, *An International Agreement on Pandemic Prevention and Preparedness* (Sept. 15, 2021), <https://jamanetwork.com/journals/jama/fullarticle/2784418> [<https://perma.cc/B856-XMFH>].

¹⁴⁷ *Wanted: Rules for Pandemic Data Access That Everyone Can Trust*, *NATURE* (June 1, 2021), <https://www.nature.com/articles/d41586-021-01460-7> [<https://perma.cc/WQ3N-55U8>].

¹⁴⁸ Kyle Knight, *An International Pandemic Treaty Should Center on Human Rights*, *HUMAN RIGHTS WATCH* (May 10, 2021, 8:00 AM EDT), <https://www.hrw.org/news/2021/05/10>

V. CONCLUSION

The development of new surveillance and response technologies raise important new possibilities for infectious disease detection and response. However, they also raise novel issues of privacy and how information gathered may be used in ways that undermine democratic institutions and empower authoritarian regimes and authoritarian tendencies in democratic ones. This paper has identified and analyzed these tools, as well as some legal measures that may address these possibilities. None of these solutions are comprehensive, and many have not yet been adopted. In the United States, an important step is to ensure that those injured by privacy breaches may bring direct actions against those responsible, rather than rely on the poorly resourced FTC which in any case has limited enforcement authority. Internationally, there must be a multilateral agreement that addresses critical gaps between countries' laws. The answer will ultimately lie in the balance between security and liberty that characterizes many critical public issue questions.