1.1 COVID-19 Stuns the World

In the winter and early spring of 2020, COVID-19 stunned the world. It emerged first in December 2019, in Wuhan, the capital city of Hubei province in central China. As people rushed home for the annual Lunar New Year Festival in late January, the disease spread quickly and widely away from the city of its apparent origins. Shortly thereafter, outbreaks erupted across the globe. A Champions League football (soccer) match held in Milan, Italy, in mid-February turned triumph to tragedy, infecting thousands in northern Italy. The Life Care Center, a nursing home in Washington State, was just the first of many senior care centers in the United States and across the world hard hit by the virus. Within a short six months, over seven million people had been diagnosed with the disease, and just under 6% of them had died.

How could such a public health disaster have unfolded? The world was ripe for a pandemic maelstrom, in many ways. Just over 100 years had passed since the last great pandemic, the 1918–1919 influenza pandemic at the end of the first World War (Barry 2004; Honigsbaum 2019). Other outbreaks of new diseases had come and apparently gone, or at least not travelled very far: SARS, avian influenza, H1N1 influenza, and Ebola. Smallpox had been eradicated and polio brought under control in many areas by vaccination. Even HIV, despite its trail of death and misery, had largely been tamed to a chronic disease, at least where treatment was available. As infectious disease lost salience, so did surveillance.

At the same time, forceful rapids were eroding the capacities of public health. Inequality and unrest were rising. Responses to refugee crises drew the attention of international organizations. Political polarization was growing along with mistrust of government and science, especially in the United States but elsewhere as well. The Trump Administration increasingly threatened or withdrew the United States from international organizations. The World Health Organization’s credibility had
lagged due to questionable handling of the H1N1 influenza pandemic in 2009 and the Ebola outbreak of 2014–2016 in West Africa. Although the International Health Regulations had entered into force in 2007, fewer than a quarter of states parties had implemented required core capacities by the target date of five years later (Suthar et al. 2018).

Inadequate attention to surveillance was part of the problem. Initial reports from China downplayed risks of human-to-human transmission of the novel coronavirus that was causing respiratory infections in Wuhan. The actual extent to which China improperly suppressed information remains contested. As international travel continued and cases were identified in Europe and the United States in late January, the WHO still judged that it lacked sufficient information to declare a Public Health Emergency of International Concern until January 30, 2020 (WHO 2020). Testing was insufficiently available to detect community spread of the disease even as late as six months into the pandemic. Leaders of some governments, particularly President Trump in the United States, downplayed the importance of surveillance and the critical need to obtain and use the information it provided. Some governments actively suppressed accurate information about the spread of the pandemic. Right-wing groups used social media to circulate misinformation and stoke mistrust of public health measures, even to the point of asserting COVID-19 to be a hoax (Bridgman et al. 2020; Jamieson and Albarracin 2020; Simonov et al. 2020). In short, surveillance was inadequately conducted, communicated, trusted, and acted upon.

We will never know how the COVID-19 pandemic would have unfolded with better surveillance for public health. What we do know is that the pandemic brought widespread death, disease, and economic loss. If surveillance had helped to mitigate even some of this pain, its utility would have been unquestionable.

Our goal in this volume is to present an account of the ethics and politics of surveillance for public health. Pandemics of the level of COVID-19 or the Great Influenza of 1918–1919 may strike only once every hundred years but the critical need is to be ready for them. Our hope is that our work can serve as a basis for warranted trust in surveillance, explaining both its importance and ethical limits. As COVID-19 so tragically illustrates, the world needs sustainable surveillance now more than ever.

1.2 The Ubiquity of Surveillance

Surveillance is often called the “eyes” of public health. With today’s technologies, it is fair to say that surveillance may also be the ears, nose, tongue, and even touch of public health. Surveillance has evolved far beyond counting the population and finding cases of dangerous disease to include an almost unimaginable range of ways to understand and address the health of individuals, groups, and populations.

This book is about the ethics and politics of public health surveillance. It places ethical questions about surveillance in the context of political theory, public policy,
and the law. The authors are a political scientist and a professor of law and philosophy with specialties in comparative politics, comparative public policy, European politics, regulation, health law, disability law, and bioethics. We do not claim to produce a comprehensive theory of surveillance; the practice is too protean. Rather, we consider the most common surveillance practices by and for public health, how they developed and are continuing to evolve, their benefits, risks, and the ethical challenges they raise. Overall, the goal is to consider whether, why, and how, public health surveillance can be conducted ethically and sustainably. For public health surveillance also encounters resistance, from armed rebels attacking health care workers, to people hiding from contact tracers, to political actors concerned to keep public fears at bay, to privacy advocates seeking destruction of data collected or used without permission. Sometimes these responses succeed and sometimes they are fully justified, sometimes they are both, sometimes they are neither and sometimes they cause grievous harm. Continued and effective surveillance requires warranted trust on the part of those under surveillance and trustworthiness on the part of those conducting the surveillance. Yet when surveillance for public health may be readily linked to surveillance for national security or to surveillance for moral condemnation, trust may no longer be warranted or achieved. Discussions of the ethics of public health surveillance are not a subject of ideal political theory; this is a book about pressing ethical problems for an imperfect, often unjust, and risky world.

Surveillance is ubiquitous. Across the globe, closed circuit cameras stare down from nearly every corner, license plate capture cameras record vehicles passing through intersections, and cell phone towers triangulate users’ locations with remarkable precision. Monitors of air and water quality may be linked to geolocation data collected by personal cellphones to reveal exposure risks. Medications may come with sensors that enable prescribers to monitor whether they have been ingested by patients. Internet sites trace users’ browsing habits over time and social media sites analyze interconnections among users. Restaurant reservations, ticket purchases, and product purchases can be recorded, saved, analyzed, and repurposed as well. Online book merchants can determine what people start reading, what they emphasize with underlining, how long they linger on particular passages, and when they abandon a manuscript. Predictive analytics generate suggestions about where people may be and what they may be doing—and may profile whether their activities pose risks to themselves or others. Neither time nor distance limits the potential for individuals to be tracked and traced in myriad ways.

Quite complete portraits of individuals’ lives can be assembled from the information available in electronic form today. Features of their own health, the health of those around them, and the health effects of their social circumstances are particularly useful pieces of these portraits. Individuals’ geolocations reveal visits to health care providers from abortion clinics to dialysis facilities and their web searches indicate interests in health information and products. Changes in patterns of behavior—such as ceasing to go out to dinner or drive to the grocery store—may reveal changes in health status. Information given out by individuals may contain or allow direct inferences about the health of those around them, as when new parents join social media support groups for children with rare genetic diseases or adults in
midlife search reports about the quality of nearby dementia care facilities. Predictive analytics may yield inferences about individuals even when no data from them have been used to generate the algorithms imputing characteristics to them. Online medical records may be part of the mix, too, if they are not protected by effective security and privacy rules, or if they are made available in supposedly de-identified form; these records contain far more than medical information and are particularly valuable for identity thieves.

Social media with its global ubiquity offers unparalleled opportunities to collect data at a high level of granularity. At its best, social media empowers people to gather much needed information and connect with others with similar interests and concerns. At its worst, it can spread fear, confusion, or complacency. Surveillance thus goes beyond assembling portraits of individuals to identifying, fostering, or even creating networks. Networks may be made up of people with direct connections to one another. Or, they may include people with shared characteristics who have never encountered one another, even indirectly. Surveillance has the potential to identify everyone with the same rare gene variant, the same common ancestor, the same unusual dietary preferences, the same opposition to vaccination, or the same political views. With such surveillance, networks can be served information, misinformation, alerts, or calls to action. Networks can also be given information about how to communicate with one another or meet one another at a common time and physical place or virtual space. Networks can crowd-source, bringing people together to solve problems, attack outsiders, or create chaos. And, networks can be used to assess what are perceived to be political threats, from efforts at regime change to bioterrorism. Information gleaned from surveillance enhances the power of social media for better or worse, in ways we are only beginning to understand.

Moreover, information gained through surveillance is not static. Surveillance information can be fed into learning systems, such as learning health care systems or learning public health systems. These systems, continually updated in real time, can generate recommendations based on algorithms that in turn are continually learning about their predictive success or failure. These recommendations may include where to deploy surveillance. Exploring the potential of such “artificial” intelligence (AI) for health care is only in the beginning stages, but it is already clear that information gleaned from surveillance is at the heart of these efforts. It is also clear that the algorithms used in AI may be biased in ways that are unjust or damaging to some and that advantage others.

Growing unease attends such ubiquitous surveillance. Responses to its benefits, power, and threats have varied. The European Union General Data Protection Regulation (EUR-Lex 2016) is perhaps the most comprehensive and protective legal structure, allowing a right to be delisted by search engines and requiring real-time consent to some uses of specified forms of identifiable sensitive information, including health information, albeit with an exception for information necessary for public health. Even in the US, with its far more freewheeling approach to information distribution and use, the Supreme Court has held that police must have a warrant to justify searches of cell phone location data collected over a month-long period of time (Carpenter 2018). The era in which an executive of a (now-failed)
information technology company could casually remark that “you have zero privacy anyway; get over it!” (Sprenger 1999) appears on the wane. How far the pushback against surveillance has gone, how far it will go, how it will apply to health, and what results it may have, remain to be seen, however.

Recent controversies over the benefits, risks, and ultimate justifiability of surveillance have attended primarily to two areas: the use of surveillance by the state for national security and public safety, and the use of surveillance by private sector companies for marketing and other forms of economic gain. A third area has recently come under scrutiny as well: the use of big data, at least some of which has been gathered through surveillance, for political gain and influence in elections. Despite the importance of ensuring the public safety, critics see ubiquitous state surveillance as a profound threat to individual liberty. Assemblages of consumer preferences by actors in the private sector may allow advertising and information to be tailored to individuals’ interests but may also target them for manipulation or price gouging. Racial, ethnic, or religious profiling may create or entrench injustice against people in disfavored groups or believed to fall into these groups. The use of social media to exercise hidden influence on elections has been seen as the newest threat to democracy. At its worst, surveillance can place individuals or groups under unjustified suspicion, locate them, shame them, cause them economic harm, marginalize them politically, and even target them for extermination.

Surveillance for public health purposes has been largely left aside in this contentious fray, at least until the appearance of COVID-19. Public health surveillance has many benefits: detecting disease outbreaks, preventing disease spread, identifying environmental toxins, improving health care, and bettering overall population health. But it shares some of the concerns that have been voiced about surveillance more generally, particularly those about threatening liberty, profiling, targeting, stigmatizing, discriminating and otherwise harming individuals or groups. Moreover, public health surveillance may not be easily isolated from surveillance that is less benign, as when information collected to improve pain management is repurposed as evidence for criminal prosecutions or immigrants’ need for medical care identifies them for deportation. Indeed, public health surveillance may itself be seen as a national security measure, protecting a nation from disease or insect invasions or identifying the enemies within. When surveillance for security and surveillance for health intertwine in ways people find objectionable, however, loss of trust may be the unfortunate result. Sustaining surveillance requires maintaining this delicate balance between information needed for health and protecting people against uses they regard as objectionable or worse.
1.3 Public Health and Population Health

Surveillance may be by public health, of public health, or for protecting and improving public health. That is, it may be conducted by recognized public health officials, be of the health of the public, or be conducted to safeguard or better the health of the public. These are different enterprises and raise different ethical questions (e.g. Lee et al. 2010; Faden and Shebaya 2016).

In a landmark report on the future of public health in the United States, the Institute of Medicine (IOM) defined “public health” as “what we, as a society, do collectively to assure the conditions in which people can be healthy.” This requires that continuing and emerging threats to the health of the public be successfully countered. According to the IOM in 1988, these threats included immediate crises, such as the AIDS epidemic; enduring problems, such as injuries and chronic illness; and impending crises foreshadowed by such developments as the toxic by-products of a modern economy (IOM 1988, p. 1). These problems are so complex and diverse, the IOM concluded, that the governmental presence in public health must reach beyond public health agencies and must be joined by the work of private organizations and individuals. At the same time, the IOM judged that the information and assessment function of public health is uniquely governmental and not to be delegated, writing that it is the duty of the public health agencies to “regularly and systematically collect, assemble, analyze, and make available information on the health of the community, including statistics on health status, community health needs, and epidemiologic and other studies of health problems” (IOM 1988, p. 7).

Views of public health that would narrow it to the activities of public health agencies argue that grants of authority to public agencies to protect and improve health must be distinguished from grants of authority to other public agencies and from activities in the private sector because of the coercive powers exercised by public health (e.g. Rothstein 2002, 2009). In advancing this view, Rothstein was especially concerned to distinguish public health from national security at a time when, after the 9/11 attacks on the World Trade towers, the United States was on high alert about potential threats from bioterrorism.

Still broader views distinguish surveillance of population health from the activities of public health agencies. Population health studies trends in the health of sets or subsets of people. Promoting population health may require addressing social determinants of health such as housing, education, structural inequality, or the protection of human rights (e.g. Goldberg 2009). Addressing the social determinants of health may require going far beyond the traditional activities of public health agencies to other governmental agencies and perhaps also to the work of many non-state actors. Non-state actors brought into play, however, may have different goals such as their own commercial ends. Moreover, these actors may be subject to different kinds of oversight than governmental agencies, raising further questions for trust in surveillance.

In the background must be the recognition that relationships between public health and the private sector are continuing to evolve. This evolution is complex and
multifaceted and both local and global. Lines between clinical care and public health, personalized medicine and population health, public health and social service and activist groups, and public health and medical research are blurring and changing. The occurrence of these changes is not a new phenomenon. The relationship between public health and clinical medicine has evidenced tension throughout the ages, over explanations of disease, competencies, responsibilities, and resources. With the advent of the germ theory of disease, public health in the form of sanitation such as clean water was increasingly superseded by clinical medicine, both in the public’s eye and in support from public dollars. As public health expanded case identification and contact tracing, physicians were often a source of resistance to these intrusions into their relationships with patients, as Chapter 3 describes. The Institute of Medicine in 1988 bemoaned the fragmentation of the public health system as funds were diverted away from government through tax cuts. Later writers have claimed that there have been continuing trends of public expenditures away from public health and towards health care for individuals (Tran et al. 2017). The ratio of individual health care expenditures to public health funding is particularly high in the United States; the average ratio of social expenditures to health expenditures is 2.0 in OECD countries, whereas it is .91 in the United States (Zimmerman et al. 2015). Expenditures on precision medicine efforts to tailor clinical care to individual genetic differences have raised concerns that funding will be directed away from attention to social determinants of population health, forgetting the observation of Geoffrey Rose (2001) that factors explaining sickness in individuals such as genetics may not explain variation in sickness between populations (Chowkwanyun et al. 2018; Ramaswami et al. 2018). Expenditures on health care may be expected to continue to grow as populations age, placing pressures on government budgets that may further undermine funding for public health. Indeed, funding in the U.S. Affordable Care Act that was initially intended for the Prevention and Public Health Fund was cut to pay for Medicare reimbursements to physicians and meet other expenses for ACA implementation (Keith 2018). Educational programs of public health schools are recognizing that their graduates are more likely to be working in commercial settings, non-profit settings, and other governmental agencies than in traditionally defined public health agencies (Krasna et al. 2019).

1.4 Surveillance for Health and Surveillance for Security

Surveillance may have many different goals. Specification of these goals is critical, as collection of information without the tools to make use of it is an empty enterprise (Harries et al. 2018). In a world in which gun violence is rampant and threats of bio-terrorism loom, surveillance for security and surveillance for health may understandably seem interconnected. Pressures may intensify to share data about individual mental health for public safety and about diagnoses of unexpected health events for national security. Information about health may be put to other purposes as well, such
as finding and deporting undocumented immigrants. Responses to these pressures may serve essential health-protective goals, such as detecting COVID-19 outbreaks, release of anthrax spores, or sarin gas. But they may also reflect fear, demonization of the other, and political repression. When public health fails in either direction—failing to keep people safe or over-reaching in the pursuit of aggrandizement—it may no longer be trusted by the public or important sectors of it. The justifiable—and likely realistic—result will be the loss of trust in surveillance and its eventual instability. Hence the title of this volume, “sustaining surveillance”: our goal is to explore the ethical problems that can undermine surveillance and the promises that can enable it to continue reliably and responsibly in the context of warranted trust.

In U.S. law, the power of the state to protect the public health has been cemented against individual rights. Individual rights are often challenged as the apparent gravity of a public health threat grows. In the 1873 Slaughterhouse Cases (1873), the Supreme Court limited the privileges and immunities clause of the newly-adopted Fourteenth Amendment to rights in the U.S. constitution, permitting the state to establish a business monopoly for a slaughterhouse that agreed to comply with what the state claimed were health and safety standards. The Supreme Court has upheld the authority of the state to compel vaccination (Jacobson 1905) and sterilization of those believed to be intellectually disabled, however erroneously (Buck 1927). In the latter case, which is heavily criticized but has never been overruled, Justice Holmes opined, “the public welfare may call upon the best citizens for their lives” (Buck 1927, 207). The constitutional protection against arbitrary searches and seizures has analogized protection of public health to protection of national security (Fairchild et al. 2007, 16). In a quickly overruled decision upholding the warrantless search of a home for rat infestation by a health inspector, the Supreme Court said that the inviolability of the home must yield when the community seeks to maintain minimal standards of health and wellbeing (Frank 1959). Fairchild and colleagues also describe the interrelationship between concerns about biological warfare and the development of surveillance systems during the Cold War (2008, 17). Since the 9/11 attacks on the World Trade towers, mandated by the Public Health Security and Bioterrorism Preparedness and Response Act of 2002, the U.S. has continued to develop systems for syndromic surveillance to sense both potential bioterrorism and outbreaks of disease (e.g. Gould et al. 2017).

The analogy between health and security also has been invoked on the side of protecting liberty. The decision to allow the rat-catcher to enter the home without a warrant was met by a vehement dissent from four justices—Chief Justice Warren and Justices Black, Brennan, and Douglas—who argued that allowing arbitrary searches and seizures by the health department would also allow the government to conduct arbitrary searches for subversives (Frank 1959). The decision was overruled a mere eight years later with the ascendance of the liberal majority of the Warren Court, which determined that health department searches to abate a public nuisance required a warrant (Camara 1967). This decision did not abate the ultimate authority of the state to protect health and security, however; it only subjected that authority to the guarantees of due process. In the only Supreme Court decision regarding requirements to report individual health data to public health, the Court
upheld the reporting requirements so long as the data were adequately protected from disclosure. This decision is highly relevant to surveillance activities today, as it involved the state’s creation of a data base of controlled substance prescriptions to avoid drug misuse (Whalen 1977).

Debates about access to firearms in the United States are a particularly telling example of how surveillance for public health purposes and surveillance for public safety may intertwine and raise troubling issues of profiling, discrimination, and individual liberty. Gun violence is both a public health issue and a public safety issue. In the wake of mass shootings in the U.S., proposals have been pressed to identify people with diagnosed mental illness and restrict their ability to purchase guns. Advocates for people with mental illness strongly oppose these proposals, on grounds that they violate the rights of people with mental illness, that people with mental illness are very unlikely to present risks of violence, and that in fact people with mental illness are far more likely to be victims than perpetrators of violence. Advocates also point out that access to mental health services is woefully lacking for many in the U.S. Increasing access to these services would be both fairer and more effective preventive measures, mental health advocates claim. Moreover, people who do pose risks of violence may be difficult to identify, whether or not they are also mentally ill. Into this mix, proposals have surfaced to the effect that data analytic techniques might be able to predict people who are at risk of committing violent acts and whose immediate access to guns should therefore be limited. Similar proposals have surfaced about possibilities of identifying people who are at imminent risk of suicide. These proposals of course raise challenging questions about reliability and the risks of both false positives and false negatives. But with increasing accuracy they also bring into sharp focus the interplay between public health and security and the ethical challenges of both furthering the overall public good and respecting the individuals who make up that public.

1.5 Framing the Ethics of Public Health Surveillance

This book stands at the intersection of major theoretical developments in the ethics of public health, the ethics of data use, and philosophy of public policy. Public health ethics is no longer primarily utilitarian. Fair information practice principles are undergoing reevaluation in light of the exploding world of big data and learning health care systems. The philosophy of public policy is developing accounts of the relationship between ideals and the imperfections of a world of structural injustice and individual failures to act justly. A brief survey of some of these developments is helpful for understanding the discussion to follow of more specific surveillance practices.

Until about the last quarter-century, public health ethics was seen primarily as utilitarian: what means would be most effective in enhancing the overall health of the public? Human rights—whether political, economic, or social—were placed at best orthogonally to the goal of overall public health, at times furthering it but at times standing in the way. Individual rights—to informed consent, privacy and
confidentiality, or to decline or even receive treatment—could present roadblocks to the overall improvement of public health. To be sure, rights protection might be of instrumental value, if assurance that their rights were protected would encourage people with dangerous infections to seek care that could prevent or retard contagion. But rights might also stand in the way of requiring people to share information or to undergo needed treatment. Spurred in particular by the efforts of the late Jonathan Mann against HIV/AIDS during the 1990s, public health ethics has changed significantly. For example, Nancy Kass, in one of the most influential frameworks for the analysis of ethical issues in public health, balances achieving public health goals of furthering health against privacy, fairness, and liberty and self-determination (Kass 2001).

As public health ethics has been developing accounts of individual rights and fairness in addition to pursuing goals of protecting and promoting health, the critical need for effective surveillance to identify and hopefully prevent pandemic disease in a global world has come to the center of recent international health policy. In 2005, the World Health Organization (WHO) adopted new International Health Regulations. In effect since 2007, the Regulations give the WHO far broader authority to declare public health emergencies of international concern. They also impose on states parties the obligation to notify WHO of events that might constitute these emergencies and to maintain surveillance capacities adequate “to detect, assess, notify, and report events in accordance with these Regulations” (WHO 2005, Art. 5(1)). States parties are also to make efforts to collaborate with each other to the extent possible in detecting and responding to these events, providing technical and logistical support, and mobilizing financial resources to develop their surveillance obligations. These Regulations have been put to the test with at best mixed success in several recent events, most notably the 2009 H1N1 influenza pandemic and the outbreak of Ebola in West Africa in 2014–2016. If the United States had continued the strategy of withdrawing from the WHO according to the notice given by President Trump, the impact of the Regulations could have been further strained.

In late 2017, the WHO issued guidelines on ethical issues in public health surveillance (WHO 2017). Characterizing surveillance as the “radar” of public health, the Guidelines (at 14) define surveillance broadly as “the continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice.” Such surveillance may include not only disease and injury, but also important public events and environmental conditions that may affect health, as well as vital statistics that may reveal health trends. The Guidelines specifically contrast research (including epidemiological research), where the rights paradigm of individual informed consent holds sway, with public health surveillance where values such as the public good and social solidarity take precedence. The Guidelines rely on a backbone of four ethical considerations—the common good, equity, respect for persons, and good governance—to develop a list of seventeen more specific guidelines. These guidelines include topics such as the obligation to develop effective surveillance capabilities, limits on the purposes for which data may be used, transparency, global obligations of support, respect for community values, harm mitigation and risk
disclosure, data integrity and security, obligations on the part of individuals to contribute information, effective communication of results, and data sharing.

The Guidelines are justifiably characterized by those involved in their creation as the first systematic effort to assess surveillance from the perspective of public health ethics (Fairchild et al. 2017). But they are only a beginning, useful but cautious. They are limited in focus to surveillance by public health, but surveillance for public health can extend far beyond what public health agencies do. Their primary goal is ethical development of the infrastructure needed to detect emergencies—certainly a critical goal, but not the only one. Although extensive, this list of guidelines is skeletal at best and contains little analysis of how ethical considerations might be balanced when guidelines point in different directions. Moreover, as the authors recognize, surveillance capacities and methods are rapidly changing in this era of big data. In what follows, we will draw on and refer to this very useful document where relevant.

Information ethics have also been developing rapidly since the dawn of the computer age. In 1973, stimulated by concerns about automated data systems, the U.S. Department of Health, Education, and Welfare published a report titled Records, Computers, and the Rights of Citizens (DHEW 1973). The report developed a set of fair information practice principles and urged that they become the backbone of an all-encompassing U.S. privacy law. These principles included transparency about data collection, protection for the individual’s ability to find out what information was being collected and to correct errors, and the requirement that data not be collected for one purpose and used for another without the individual’s consent. Although the upshot of the HEW report was only a US federal Privacy Act applying to agencies of the federal government, FIPs, as they have become known, have been highly influential on the development of data privacy policies ever since, from the Data Protection Regulation of the European Union to the Health Insurance Portability and Accountability Act security and privacy rules for protecting health information in the United States (Gellman 2019).

In the years after their initial formulation, FIPs have been challenged as both over- and under-protective. On the side of what is arguably over-protective in light of public health data needs, FIPs rely on a model of individual notice and consent for data collection and use. This model is highly constricting for public health uses of data, both because of the time and resources involved and because of the likelihood that some individuals will value privacy so highly that they will refuse to consent to any uses of data beyond their own health care. Both US and EU regulatory structures permit use of individual information for public health without the notice and consent of FIPs, to the extent required by law. This exception for public health might be judged as necessary for protection or as a giant loophole allowing the state to run roughshod over individual rights. Or, the conclusion might be drawn that it is too extreme either to give public health free rein over the use of information if legislatively permitted or mandated, or to require individual informed consent for data collection or use.

An intermediate solution has been to distinguish information about individuals that is thought to be identifiable and information that is anonymous or deidentified.
Many regulatory structures about the collection or use of information, including regulations governing research with human subjects, draw this line. With the advent of complex data sets and increasingly sophisticated statistical tools, however, the line between identification and deidentification has come under question. When data sets are combined, the enriched information they contain may allow significant percentages of individuals to be reidentified. Some argue in addition that uses of fully anonymized data may be problematic, if it allows groups to be stigmatized or inferences to be drawn about individuals in virtue of their membership in groups. Another solution is to rely more heavily on the FIPs of transparency about data collection and use and about purpose limitation to reassure individuals about the appropriateness of data use.

Finally, debates in the philosophy of public policy have come to grips with our world of structural injustice and individual failures to behave justly. Spurred by John Rawls’s account of an ideal of liberal justice (1971), which famously set aside what justice might require in less than favorable circumstances, theorists have developed “non-ideal” or “partial compliance” approaches. These take many forms but ask the general question whether the requirements of justice are different in circumstances of injustice than in circumstances where justice prevails.

Much recent discussion in political philosophy has attended to claims that Rawlsian ideal theory neither can nor should be applied to the real world of serious injustice. In a very helpful conceptual map of this terrain, Laura Valentini (2012) distinguishes three areas of theorizing about departures from the ideal: obligations of some when significant numbers of others are failing to fulfill their obligations, the extent to which feasibility of realization should constrain normative political philosophy, and requirements of justice in transitioning from the non-ideal to the ideal.

Each of these areas of non-ideal theory raises central questions for the ethics of public health surveillance. What are the obligations of some states when other states are refusing to comply with ethical requirements, either to provide data or to support their efforts to do so? If some states suppress urgently needed information about outbreaks of contagion, may others respond by refusing to help with needed medical equipment or vaccines, or even by withdrawing from international cooperative organizations? What are the obligations of individuals to allow information about themselves to be shared when others are hiding information that might be critical to their health? How do practical constraints such as costs, willingness to comply, or the availability of information, affect what surveillance should ethically do? Should protection of individual rights and liberties be weighed differently in the effort to ameliorate structural injustices that are damaging health than they would be weighed in more favorable circumstances? Some believe that ideal justice is at least relevant to answering questions about what to do in an imperfectly just world. Others believe that theorizing about justice in non-ideal contexts is simply different from theorizing in ideal contexts and should not be guided by images of ideal justice (e.g. Wolff 2017; Sen 2009).

This volume is rooted firmly in the territories of non-ideal theory. As such, we do not assume that a complete and final framework for the ethics of surveillance and
public health should be our goal. Rather, as partial compliance theorists we believe it is important to proceed on two fronts: identifying particular ethical pitfalls to be avoided and understanding promises it is realistic to pursue. These strategies of non-ideal theory structure our book.

1.6 Core Ethical Considerations for Surveillance

Data collection and use for public health must always be understood as a balance between some individuals or groups and others. Although public health as practiced by public agencies tries to be health for all, and to be so equitably, what it can do is limited. Resources, including time and talent, are in short supply. Private actors may supplement public health surveillance but may have different goals, for example deciding where to locate businesses in a community, what products to develop and how to price them, or how to manage a labor force. Discussion of the ethics of these uses and users of information for public health must include benefits, risks, and equities. Uses of data that are unexpected or disconcerting may destabilize surveillance. Destabilization is especially likely if surveillance by private actors for commercial gain is blended or confused with surveillance by public agencies for the overall good. Destabilization may also occur with uses of data that offend, that generate resentment, or that demean. Uses of data that cause direct harm—or the fear of direct harm or even the anecdote or urban legend of direct harm—may also threaten the continued integrity of surveillance. When private actors enter the mix, there may be much less control about transparency, about data that are collected and stored, and about how data are analyzed and used.

Here, then, are some basic considerations to apply to any forms of surveillance for public health. These considerations begin with some of the Fair Information Practice principles (FIPs), but go beyond them in ways that are explained as the argument of this volume develops.

Transparency. Surveillance should always be publicly known. What information is collected, how it is processed and maintained, and who is responsible for the information should be matters of public record. This does not mean that individual pieces of information should be public; that information might compromise the individuals it concerns. Rather, it only means that there should be no secret surveillance operations.

Purpose specification. Information collected by and for public health should be used for health. This can include research about health improvement; there is no clear line between public health activities and public health research. Information for public health should not be diverted to other purposes, such as national security or commercial advantage, without further authorization. If appropriate, such further authorization may mean individual or community consent.

Harm minimization. Any risks to individuals and groups from data collection and use should be identified and minimized to the extent possible. If harms are
unavoidable, compensation should be considered, including in the form of access to health care.

“Giving back.” In what follows, we will be arguing that at least some information, even information about individuals, should be shared with public health. Health is a collective, not merely an individual good—as societies have learned to their regret with COVID-19. Information for public health is a social responsibility. This does not mean that all information about individuals is within the purview of public health, but it does mean that individual consent is not always needed for public health access to information. It does mean, however, that this access should only be conducted within appropriate purpose specification. Moreover, giving back goes both ways. To the extent possible, individuals should be made aware of what is being achieved when information is shared with public health. Such sharing of the benefits is critical to enlisting ongoing support for public health efforts.

Equity. Burdens and benefits of public health should be equitable. Public health has responsibilities to address health inequities and social determinants of health to the extent that they contribute to health inequities. Public health that works for some but not for others will not be sustainable in the long run.

These principles are stated quite abstractly and must be applied in nuanced ways. We will explain and defend them over the course of this volume. However, unless attention is paid in some important ways to each of them, surveillance may not be met with warranted trust and ultimately may not be sustained.

1.7 Plan of the Volume

We start in Part I with traditional forms of surveillance: counting population numbers, finding cases of deadly disease and tracing their contacts, and unearthing toxins in the environment. Each of these forms of surveillance has been and remains an important part of the armamentarium of public health. Yet each also reveals problems that must be avoided if surveillance is to be sustainable. They have been joined by forms of technologically enhanced data collection and use that raise further problems of privacy and injustice.

Counting population numbers allows governments to assess trends in the health of the population and to identify the ravages of disease. Yet counting numbers can also lead to stigmatization of populations, resistance, and suspicion of what the numbers are thought to yield. One lesson to draw from historical mistakes such as the identification of native Hawai’ians with leprosy, of Chinese with plague, or of Haitians with HIV is the need for trust in and trustworthiness of science and how it is communicated. Chapter 2 explores counting population numbers and some pitfalls of ethics in the science of surveillance.

Finding cases of deadly disease and tracing their contacts can stop disease spread. But it can also impose immediate risks on the individuals thus identified. It
can threaten their physical security, personal relationships, economic security, employment, and even health. It can violate basic rights and—as Chapter 3 describes—result in calls for protection of rights that may backfire on public health. Contact tracing that is enhanced by locational tracking or other uses of smart phones may exacerbate these tensions between halting disease and protecting individuals. Case finding and contact tracing also must be coupled with the recognition that potential spreaders may require support for their needs and their health.

Before the role of microorganisms in causing disease was understood, public health sought to address environmental uncleanliness: odors, sewage, and the “miasma” of bad air. With the germ theory of disease came the focus on individuals as transmitters of disease, to the detriment of attention to the environment. Yet, as Chapter 4 details, decisions about what to surveille can be as important to ethical surveillance as decisions about how to surveille. Failures to attend to inequities in surveillance can undermine willingness to participate. When some believe that data about themselves is being used solely to the benefit of others, resentment is an understandable result.

Enhanced computing power and the advent of the internet have brought new forms of data, new methods of collecting that data, and new forms of storing and analyzing that data. It has also brought powerful new private actors into surveillance efforts, both for commercial purposes and for public health. Chapter 5 considers the issues of privacy and justice that these new methods raise.

Chapter 6 takes up what has been called the “new” public health. In the world today, non-contagious diseases take a far greater toll on health than contagious diseases. Public health has understandably reached out to surveille and address these threats to health. Obesity, lack of exercise, poor diet, alcohol and substance abuse, all cause ill health. Yet intervention with individuals’ choices about how to live their lives has been portrayed as the “nanny” state and criticized as unjustified paternalism. On the other hand, many of these so-called diseases of despair are rooted in social factors beyond the individual. Here, we argue, public health surveillance must take care not to over-promise and over-reach if its efforts are to be regarded as warranted. Instead, it must proceed with respect for persons, acknowledging that people may have different values including about the importance of health.

In reaction to paternalism and violations of individual rights, paradigms of informed consent from bioethics and research ethics have been brought into discussions of the ethics of surveillance. Some insist that consent to data use is both necessary and sufficient for permissible surveillance, along the lines of strict views of FIPs. Models for opting in, or opting out, of data use have been developed, as have models of group or community consent. In Chapter 7, we consider the ethical imperatives behind these models, of transparency, participation, and respect for individuals as determining their own conceptions of their good. We suggest how these imperatives may be recognized without full requirements for consent and the barriers these might pose for public health.

In the final chapter, we bring our earlier discussions together by seeing what can be learned from the critical failures of surveillance for COVID-19. In many ways, societies had lost sight of the importance of surveillance. There were continuing
failures to address the core questions we have identified that encourage people to support, participate in, and believe in the information provided by surveillance. Only by continuing to consider and provide answers to these questions can trust in data use be warranted and surveillance ultimately sustained. Establishing trust in data use is only part of the picture, however. Ultimately, people must also see the benefits of data use for their own lives if support for surveillance is to be sustained.

References

Barry, John M. 2004. The great influenza: The story of the deadliest pandemic in history. London: Penguin Books.
Bridgman, Aengus, Eric Merkley, Peter John Loewen, Taylor Owen, Derek Ruths, Lisa Teichmann, and Oleg Zhilin. 2020. The Causes and Consequences of COVID-19 Misperceptions: Understanding the Role of News and Social Media. Harvard Kennedy School Mis/information Review (June 18) [online] https://misinforeview.hks.harvard.edu/article/the-causes-and-consequences-of-covid-19-misperceptions-understanding-the-role-of-news-and-social-media/. Accessed 10 July 2020.
Buck v. Bell, 274 U.S. 200 (1927).
Camara v. Municipal Court of the City and County of San Francisco, 387 U.S. 523 (1967).
Carpenter v. United States, 585 U.S. ___, 138 S. Ct. 2206, 201 L. Ed. 2d 507 (2018).
Chowkwanyun, Merlin, Ronald Bayer, and Sandro Galea. 2018. “Precision” Public Health—Between Novelty and Hype. New England Journal of Medicine 379 (15): 1398–1400.
Department of Health, Education, and Welfare. 1973. Records, Computers and the Rights of Citizens: Report of the Secretary’s Advisory Committee on Automated Personal Data Systems July 1973. Electronic Privacy Information Center. https://epic.org/privacy/hew1973report/default.html. Accessed 11 July 2020.
EUR-Lex. 2016. REGULATION (EU) 2016/697 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 27 April 2016 on the Protection of Natural Persons with Regard to the Processing of Personal Data and on the Free Movement of Such and Repealing Directive 95/46/EC (General Data Protection Regulation). https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex:32016R0679. Accessed 11 July 2020.
Faden, Ruth R., and Sirine Shebaya. 2016. Public Health Ethics. In The Stanford Encyclopedia of Philosophy (Winter 2016 Edition), ed. Edward N. Zalta. https://plato.stanford.edu/archives/win2016/entries/publichealth-ethics/. Accessed 1 Aug 2020.
Fairchild, Amy L., Daniel Wolfe, James Keith Colgrove, and Ronald Bayer. 2007. Searching Eyes: Privacy, the State, and Disease Surveillance in America. Berkeley: University of California Press.
Fairchild, Amy L., Ronald Bayer, and James Colgrove. 2008. Privacy, Democracy and the Politics of Disease Surveillance. Public Health Ethics 1 (1): 30–38.
Fairchild, Amy L., Angus Dawson, Ronald Bayer, and Michael J. Selgelid. 2017. The World Health Organization, Public Health Ethics, and Surveillance: Essential Architecture for Social Well-Being. American Journal of Public Health 107 (10): 1596–1598.
Frank v. Maryland, 359 U.S. 360 (1959).
Gellman, Robert. 2019. Fair Information Practices: A Basic History. https://bobgellman.com/rg-docs/rg-FIPhistory.pdf. Accessed 10 July 2020.
Gmeinder, Michael, David Morgan, and Michael Mueller. 2017. How Much Do OECD Countries Spend on Prevention? OECD Health Working Paper No. 101. https://www.oecd-ilibrary.org/docserver/f19e803c-en.pdf?expires=1562104557&id=id&acname=guest&checksum=53EB160DCC6B0CDD6BC1F876D167175A. Accessed 2 July 2019.
Goldberg, Daniel S. 2009. In Support of a Broad Model of Public Health: Disparities, Social Epidemiology, and Public Health Causation. Public Health Ethics 2 (1): 70–83.

Gould, Deborah W., David Walker, and Paula W. Yoon. 2017. The Evolution of BioSense: Lessons Learned and Future Directions. Public Health Reports 132 (aSuppl): 7S–11S.

Harries, A.D., M. Khogali, A.M.V. Kumar, S. Satyanarayana, K.C. Takarinda, A. Karpati, P. Olliaro, and R. Zachariah. 2018. Building the Capacity of Public Health Programmes to Become Data Rich, Information Rich and Action Rich. Public Health Action 8 (2): 34–36.

Honigbaum, Mark. 2019. The pandemic century, one hundred years of panic, hysteria and hubris. New York: W. W Norton and Company.

Institute of Medicine. 1988. The Future of Public Health. Washington, DC: National Academies Press.

Jacobson v. Massachusetts, 197 U.S. 11 (1905).

Jamieson, Kathleen Hall, and Dolores Albarracin. 2020. The Relation Between Media Consumption and Misinformation at the Outset of the SARS-CoV-2 Pandemic in the US. The Harvard Kennedy School Misinformation Review (April) [online]. https://misinforeview.hks.harvard.edu/wp-content/uploads/2020/04/April19_FORMATTED_COVID-19-Survey.pdf. Accessed 10 July 2020.

Kass, Nancy E. 2001. An Ethics Framework for Public Health. American Journal of Public Health 91 (11): 1776–1782.

Keith, Katie. 2018. New Budget Bill Eliminates IPAB, Cuts Prevention Fund, and Delays DSH Payment Cuts. Health Affairs Blog (Feb. 9). https://www.healthaffairs.org/do/10.1377/hblog20180209.194373/full/. Accessed 4 Aug 2020.

Krasna, Heather, Julie Kornfeld, Linda Cushman, Shuyue Ni, Pantelis Antoniou, and Dana March. 2019. The New Public Health Workforce: Employment Outcomes of Public Health Graduate Students. Journal of Public Health Management and Practice. epub ahead of print. https://doi.org/10.1097/PHH.0000000000000976.

Lee, Lisa M., Steven M. Teutsch, Stephen B. Thacker, and Michael E. St. Louis, eds. 2010. Principles and practice of public health surveillance (3rd ed.). New York: Oxford University Press.

OECD. 2019. Health Spending (Indicator). https://doi.org/10.1787/8643de7e-en. Accessed 10 July 2020.

Ramaswami, Ramya, Ronald Bayer, and Sandro Galea. 2018. Precision Medicine from a Public Health Perspective. Annual Review of Public Health 39: 153–168.

Rawls, John. 1971. A Theory of Justice. Cambridge, MA: Harvard University Press.

Rose, Geoffroy. 2001. Sick Individuals and Sick Populations. International Journal of Epidemiology 30: 427–432.

Rothstein, Mark A. 2002. Rethinking the Meaning of Public Health. Journal of Law, Medicine and Ethics 30: 144–149.

———. 2009. The Limits of Public Health: A Response. Public Health Ethics 2 (1): 84–88.

Sen, Amartya. 2009. The Idea of Justice. Cambridge, MA: Harvard University Press.

Simonov, Andrey, Szymon K. Sacher, Jean-Pierre H. Dubé, and Shirsho Biswas. 2020. The Persuasive Effect of Fox News: Non-Compliance with Social Distancing During the Covid-19 Pandemic. NBER Working Paper No. 27237 (June). National Bureau of Economic Research. https://www.nber.org/papers/w27237. Accessed 10 July 2020.

Tran, Linda Diem, Frederick J. Zimmerman, and Jonathan E. Fielding. 2017. Public Health and the Economy Could Be Served by Reallocating Medical Expenditures to Social Programs. SSM—Population Health 3: 185–191.
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Valentini, Laura. 2012. Ideal vs. Non-ideal Theory: A Conceptual Map. *Philosophy Compass* 7 (9): 654–664.

*Whalen v. Roe*, 429 U.S. 589 (1977).

Wolff, Jonathan. 2017. Forms of Differential Social Inclusion. *Social Philosophy and Policy* 34 (1): 164–185.

World Health Organization (WHO). 2005. International Health Regulations. [http://apps.who.int/iris/bitstream/handle/10665/246107/9789241580496-eng.pdf?jsessionid=623AB24B3BB0E8CF92F14D7956DBDF12?sequence=1](http://apps.who.int/iris/bitstream/handle/10665/246107/9789241580496-eng.pdf?jsessionid=623AB24B3BB0E8CF92F14D7956DBDF12?sequence=1). Accessed 11 July 2020.

———. 2017. WHO Guidelines on Ethical Issues in Public Health Surveillance. [http://apps.who.int/iris/bitstream/handle/10665/255721/9789241512657-eng.pdf?sequence=1](http://apps.who.int/iris/bitstream/handle/10665/255721/9789241512657-eng.pdf?sequence=1). Accessed 11 July 2020.

———. 2020. Timeline of WHO’s Response to COVID-19 (last updated 30 June 2020). [https://www.who.int/news-room/detail/29-06-2020-covidtimeline](https://www.who.int/news-room/detail/29-06-2020-covidtimeline). Accessed 10 July 2020.

Zimmerman, Emily B., Steven H. Woolf, and Amber Haley. 2015. *Understanding the Relationship Between Education and Health*. Washington, DC: Agency for Healthcare Research and Quality. [https://www.ahrq.gov/professionals/education/curriculum-tools/population-health/zimmerman.html](https://www.ahrq.gov/professionals/education/curriculum-tools/population-health/zimmerman.html). Accessed 31 July 2020.