Chapter 3
Case Identification and Contact Tracing

3.1 Background

Identifying cases of contagious disease and following chains of transmission stemming from them is a traditional mainstay of public health efforts. For example, the first “Healthy People” report of the U.S. Surgeon General explained in 1979—just before awareness of the arrival of HIV/AIDS—that “surveillance—a basic tactic for disease control” requires finding cases of disease or significant exposure, reporting these cases, determining the implications of these reports, and responding appropriately with control measures (DHHS 1979, 9–29). With COVID-19, case identification and contact tracing have been relied upon extensively although they have been less effective where infection has already spread widely.

Such case identification and contact tracing may interrupt chains of infection transmission, protecting both individuals and society more broadly. But it may be seen as intrusive and risky for identified individuals who may be shunned, quarantined, or condemned. At first glance, the strategy of finding people who may spread disease presents a conflict between the overall social good and the interests or rights of the unfortunate individual. This chapter argues, however, that pitting case identification and contact tracing as the individual against society is far too simple. If individual cases are taken seriously not only as potential spreaders of disease but also as people who may be harmed by illness or quarantine, the ethical conflicts posed by their identification can be mitigated in ways that may also enhance the strategy’s success.

In this chapter, we attempt to present a balanced case for contact tracing. One disadvantage is that it may be too little too late. Another is that it may inflict significant harm on individuals, as the story of Typhoid Mary illustrates. It also may reflect prejudices and predominant social mores. Case identification has darker sides of prejudice, isolation, and condemnation—that sustain arguments for insisting on individual informed consent before examination and treatment, as well as for
protection of patient confidentiality. Still, contact tracing may be one of the most important methods for public health to identify and contain disease spread. It is best justified, however, when its benefits are widely known and acted upon, when it is conducted justly, and when its harms are fully addressed.

### 3.2 Typhoid Mary and Case Identification

Typhoid Mary was a famous example of the success of case identification to discover an individual as a source of infection spread. Her story continues to provide lessons for surveillance today. On the one hand, she demonstrates a clear achievement of case identification. On the other hand, she reveals how treating these cases as mere subjects of infection dehumanizes both sides and may be complicated by racism and opprobrium. Case identification also focuses on the individual rather than on the social circumstances in which she is found. Sustaining surveillance requires respect and equitable and humane responses to those identified as sources of infection. It also requires recognizing and addressing the social circumstances and potentially also injustice in which these cases of infection occur.

According to George Soper (1939), the epidemiologist who identified her, Mary Mallon was a household cook in New York in the early decades of the twentieth century. Investigation of a typhoid outbreak at the summer home of the wealthy Warren family on Oyster Bay, Long Island, suggested Mallon as the cause. Tracing Mallon’s work history identified seven other socially prominent households with unexpected typhoid cases while Mallon was employed as their cook. When Mallon resisted examination, she was arrested and detained. Bacterial cultures indicated conclusively that she was a symptom-free carrier of typhoid. Based on these findings, Mallon was locked up as a danger to society. She was released almost three years later, after pledging that she would give up her profession as cook, take other precautions, and report regularly to the Department of Health—commitments that she immediately violated. Mallon was located again five years later, when a typhoid outbreak at a women’s hospital was traced to her as the cook. This time, she was confined indefinitely on an isolated island where she remained until her death twenty-three years later. Ultimately, 53 typhoid cases and three deaths were linked to Mallon.

Mallon’s lodging during her final long confinement was a pleasant bungalow. She was paid for doing laboratory work and was occasionally allowed to visit nearby New York City, but she was otherwise isolated. Her isolation was painful to her and her treatment remains controversial. Novels have personalized Mallon’s own grief in contrast to depictions of her as an unfeeling monster (Keane 2013). Mallon was Irish and Irish immigrants were disfavored at the time as poor and Catholic. Historians have documented the influence of these anti-immigrant and classist sentiments on her pursuit and confinement (Leavitt 1997). By the time Mallon died, New York health officials had identified about 400 other asymptomatic
carriers of typhoid, none of whom were reportedly confined in the way Mallon was (Marineli et al. 2013).

Mallon’s identification and management were characteristic of U.S. public health activities at the time, although the extent of her confinement was extreme. Addressing public health concerns about typhoid fostered the professional organization of public health activities. The American Public Health Association (APHA), formed in 1872, acquired the *Journal of the Massachusetts Boards of Health* in 1911 and began publishing it as the *American Journal of Public Health* (*AJPH*), a journal still in publication today. The APHA sought to professionalize public health as a means to address the elevated rates of typhoid in the US, rates far higher than in Europe. The APHA lent its support to aggressive anti-typhoid efforts, including education, physician reporting, and carrier identification and containment. The well-publicized discovery of Mallon and the resulting success in stopping her from continuing to infect others lent impetus to these efforts.

Not incidentally, Mallon’s identification also played an important scientific role in confirming the germ theory of disease and subsequent scientific developments based on it. By the time her case came to light in the beginning of the twentieth century, the miasma theory of disease—which attributed transmission to the unhealthy odors prevalent in crowded urban areas—was increasingly being supplanted by improved scientific understanding of the role of microorganisms like the typhoid bacillus. In the U.S., state health departments had established scientific laboratories to analyze the presence of infectious diseases, first in Massachusetts where W.T. Sedgwick developed methods for identifying fecal bacteria in water as the cause of typhoid fever during the 1880s (Committee 1988, p. 63). Cities and states established disease registries and reporting requirements, not only for contagious conditions but also for cancer (Committee 1988, p. 66). Over the course of the twentieth century, prevention and treatment improved greatly as well, opening new possibilities for the success of case identification and contact tracing methods. Sulfa drugs that could be used to treat diseases such as pneumonia and gonorrhea came into use in the late 1930s and penicillin in the 1940s. Vaccination against tetanus became routine in the 1940s and the Salk polio vaccine was introduced in the mid-1950s. Gamma globulin therapy as an immune booster for people who had suffered exposures to contagious disease was first used in the 1930s. And these are but a few examples.

With this burgeoning scientific knowledge, public health efforts increasingly focused on controlling the spread of disease from individual to individual. Public health officials directed their efforts to finding individual cases of disease and tracing their contacts so that preventive measures and any necessary treatment could be put into place. Amy Fairchild and colleagues describe how the professionalization of public health was linked to growing knowledge of bacteriology (Fairchild et al. 2007, p. 3).

According to its critics, however, the shift from the miasma theory to the germ theory of disease encouraged public health activities to move in directions that were not always beneficial in improving overall health. The community improvements of the sanitarians gave way to assignment of individual responsibility for disease, often
tinged with moralism and racial or cultural critique. U.S. public health largely withdrew from the fields of public sanitation improvements and social reform that had been so successful and moved instead to detecting individual targets as sources of disease and aiming measures at these individuals to prevent disease spread. Education in personal and domestic hygiene loomed increasingly important as a public health strategy. Self-improvement rather than social improvement became the prescribed norm. The historian Nancy Tomes (1997) relates how the change in understanding of tuberculosis from hereditary weakness to chronic contagious disease spurred efforts at household cleanliness and the improvement of an individual’s constitution to resist disease. Bodily discharges were viewed as the source of infection and home hygiene as critical to prevention. While Progressive social reformers at the turn of the twentieth century debated the role of substandard housing and poverty in disease causation, Tomes contends (286), they also considered high rates of tuberculosis “as a poor reflection on the cleanliness and temperance of specific ethnic and racial groups,” sentiments that, as we discuss later in this chapter, also influenced attitudes towards sexually transmitted diseases. Such sentiments have not entirely disappeared, as revealed by the remarks of an Ohio legislator who attributed racial differences in COVID-19 infection rates to poor hygiene practices. Reportedly, he was fired from his position as an emergency physician because of his overtly racist speculation (Gabriel 2020).

Medical historian Allan M. Brandt adds the changing nature of the American family and the interest in eugenics to this picture. By the turn of the twentieth century, Americans were having fewer children, divorce had become more common, and growing numbers of women were pursuing careers (1985, p. 7). The sociologist E.A. Ross had proposed the theory of “race suicide” in 1901: that as Anglo-Saxon families were gradually having fewer and fewer children, they were becoming overwhelmed in numbers by children of color and children of immigrants. Brandt relates how the resulting anxiety spurred efforts both to reduce the fertility rates of those judged to be less desirable through eugenic measures and to increase the fecundity of those judged reproduction-worthy through health promotion measures including venereal disease control. Growing medical knowledge about the transmission of sexually transmitted infections (STIs) and their role in causing infertility lent urgency to efforts to identify the infected and either treat them or prevent them from engaging in behaviors believed to risk disease spread. These medical efforts intertwined with the moral attitudes and social circumstances of the times in shaping approaches to disease identification and control.

As a result of this shift in responsibility for disease prevention from the social to the individual, public health in the U.S. did not return to playing a significant role in promoting workplace safety or environmental protection until late in the twentieth century (Fairchild et al. 2010). COVID-19 outbreaks in meat packing plants laid bare continuing deficiencies in workplace safety. Nor did public health address the social determinants of health—that is, the social conditions that affect the health of populations—in ways that it might otherwise have done during much of the twentieth century. Instead, U.S. public health located disease causation and remediation, along with the potential for responsibility and blame, squarely in individuals. This individualist
paradigm for public health can be viewed as part of a more general U.S. emphasis on individual responsibility for health and on health care for individuals rather than public health measures. Typhoid Mary was emblematic of this individualism: a case of disease to be found, condemned for the harm she had caused, and isolated.

3.3 Contact Tracing

Contact tracing starts with an “index case” like Typhoid Mary, a person with a contagious disease who has become known to public health authorities. (An index case may not be a “primary case,” the first person through whom a disease is introduced into a population; and a primary case may not be such an index case unless it becomes known to public health.) The person is then interviewed, asked about contacts to whom the disease might have been transmitted, and treated or isolated if necessary. Then, public health authorities follow up by interviewing and testing the named contacts, treating or isolating them if necessary, and asking them about any further contacts. The chains may break, and thus the method lose efficacy, if the index case cannot be found or interviewed or does not name all relevant contacts, or if the contacts in turn cannot be found or do not give information.

Even when contact tracing works reasonably well, it has advantages and disadvantages as a method for reducing disease spread. It does find cases that may not otherwise have been recognized and allows for their education, isolation, or ideally treatment. Yet it may be expensive and ineffective in altering spread, depending on a disease’s mode of transmission. Its efficacy also depends on the stage of disease spread within a population; it is most effective in the early stages of an outbreak or when other protective measures have reduced the numbers of new cases to a manageable level (Moore et al. 2020). It is intrusive and may generate resentment and secrecy, ultimately undermining its very aims if people refuse to cooperate.

The method of case identification and contact tracing is simplest and least expensive if specific types of easily recognized encounters are required for disease transmission. Sexual intercourse is an obvious example: people are likely to know that it has happened and the identity of the person with whom it occurred. Contagious diseases that are transmitted by airborne droplets are not as susceptible to the methodology, however. For example, someone who rode on a bus may not remember sneezing during the ride and surely is unlikely to know who else was on the bus. Nor can contact tracing be readily used for diseases that are transmitted by fomites, surfaces such as countertops or doorknobs that can harbor infectious agents. The length of time an infectious agent may survive on a fomite, moreover, may vary by factors such as temperature and humidity (Boone and Gerba 2007).

Coronavirus, different types of which can cause infections from colds to SARS to COVID-19, is an example of an infectious agent that can be transmitted by both airborne droplets and fomites. Successful tracing would need to follow the movements of the index case and find anyone who has been in an area or had contact with
any surface for some period of time after it had been touched by the index case. Technologies such as location tracking have been called on to help fill in these gaps with COVID-19, but their efficacy and acceptability remain in question, as we discuss later in this chapter. It is thus not surprising that infectious diseases that are transmitted by sexual contact or direct contact with bodily fluids have drawn the bulk of public health interest in contact tracing as a surveillance method. But mode of transmission is not the only reason for this attention: moral condemnation of those transmitting diseases through sex has also played a major role in how these diseases have been judged and managed by public health.

Even when it may be effective in following paths of disease transmission so that new cases can be identified and treated (or, if treatment is not possible, isolated), surveillance through contact tracing is time-intensive and intrusive. The process takes resources even if the contacts of the index case are known, identified, relatively easy to locate, and readily treatable. Moreover, when a disease has a long incubation period, contacts may need to be followed for an extended time to determine whether they have become infected. The incubation period for influenza is comparatively short—an average of two days—but the incubation period for measles averages 10–12 days and the period for Ebola may be as long as 21 days. Although our knowledge is still evolving, for COVID-19 it may take up to 14 days for individuals to develop symptoms, and people may be at their most contagious before any symptoms appear. Estimates are that as much as 40% of transmission may come from people who have not yet developed symptoms or who may never become symptomatic (Moore et al. 2020). Effective testing programs may therefore need to test both symptomatic and asymptomatic people. Incubation periods for other diseases may be far longer: the incubation period for mononucleosis can be a month or two and for tuberculosis as long as six months. Methods of testing may be embarrassing or intrusive, ranging from cheek swabs to swabs high up in the nasal cavity, pinpricks to blood draws, and excrement collection to biopsies. Applied mathematics can be used to model the comparative cost-effectiveness of contact tracing for diseases with these and other varying characteristics (Armbruster and Brandeau 2007). When diseases are not particularly serious, however, contact tracing may not be worth its costs.

Contact-tracing can be targeted in ways that are increasingly cost-effective, such as by concentrating on high risk exposure situations like nursing homes or prisons (Moore et al. 2020). Targeted tracing will still involve intruding on at least some individuals identified as possible disease sources, however. Contacts who are highly socially networked and who thus may have infected many others will be particularly valuable to find from the perspective of cost-effective reduction in disease spread.

In addition, when a disease has become widely established in a population, contact tracing likely is not the best strategy for addressing it (Moore et al. 2020). If a very high percentage of people in a population are already infected, contact tracing may simply put effort into finding people who have already been infected from other sources. Approaching everyone in the population directly with education and offers of available treatment could potentially be far more effective in reducing infection rates than following chains from index cases. So might other disease
mitigation strategies such as the mask wearing recommended for COVID-19. Such more universal approaches also have the advantage of detaching the presence of infection from its source and thus from any suggestion that blame might be attributed to individuals suspected of transmission. Universal education campaigns, however, have sometimes met with resistance precisely because of this detachment. The history of case identification and contact tracing has—not surprisingly—been linked to diseases drawing moral opprobrium, especially those that are transmitted through sex, or associated with members of disfavored groups such as Typhoid Mary.

Finally, when people do not trust the government, and identify public health with the government, contact tracing may be very difficult. Some of the surge of the COVID-19 pandemic in the United States coincided with the murder of George Floyd by police officers and the Black Lives Matter protests that followed. Initial reports suggested that tracers were successful in getting names of contacts from fewer than half of those identified as infected with COVID-19 in New York and other major U.S. cities (Otterman 2020).

3.4 Progressivism, Moral Purity, and Sexually Transmitted Infections

Sexually transmitted infections (STIs) such as syphilis and gonorrhea were at the heart of case identification and contact tracing as the methods developed. This history is important not to forget even as contact tracing is deployed for contagious diseases that do not carry this particular stigma, such as COVID-19. Not surprisingly, the methods were tinged with the moral judgments associated with these diseases—and may still be tinged with finger-pointing or worse in some societies. Case identification and contact tracing were also associated with the Progressive movement in the United States—a movement that, as its name suggests, was attracted to social and scientific progress but also with eugenics and the moral rectitude of many of its proponents. In the context of this history, case identification and contact tracing were primarily about protecting society from diseases identified with moral failure, rather than protecting its victims from social ills. As mores change, however, contact tracing may become more—or less—acceptable for different diseases.

Known for centuries, syphilis may have arisen in the Americas, as contemporary methods of skeletal analysis now suggest, and been carried back to Europe by explorers from Spain—an illustration from an earlier time period of the role of global travel in the transmission of disease (Rothschild 2005). However, other explanations also place syphilis in Europe before exploration of the Americas. Soldiers throughout history have been a primary source of syphilis transmission. After Charles VIII of France invaded Naples in 1494, returning soldiers brought a virulent form of the disease back with them (Frith 2012). Metals such as mercury were used in hopes of treatment but with highly toxic side effects.
Medical knowledge about STIs changed radically as the nineteenth century moved into the 20th. Gonorrhea and syphilis were identified as different diseases with specified bacterial causes. Gonorrhea’s longer-term effects such as pelvic inflammation and scarring in women, infertility in men, or eye infections and blindness came to be recognized. The early stage of syphilis infection was linked to sequelae such as the nerve or joint damage of the disease in its tertiary stage. The first effective treatment for syphilis—an arsenic-based form of chemotherapy known as salvarsan, followed several years later by the less-toxic but nonetheless grueling neo-salvarsan—was introduced about 1910; it required a long course of injections and had significant side effects.

The Crimean War in the 1850s, the U.S. Civil War in the 1860s, and then World War I, had each brought new waves of syphilis transmission to domestic populations. Faced with long periods of time away from families or friends and deployments that were often tedious and more often unpleasant or frightening, soldiers unsurprisingly sought out prostitutes or sex. Countries with soldiers stationed overseas took opposing approaches to the problem of disease transmission through prostitution. Some—Britain is an example—pursued primarily a regulatory strategy, seeking to ensure that prostitutes remained “clean” of disease. Others—the U.S. is a notable example—pursued a strategy of condemning prostitution and attempting (without apparent success) to discourage its soldiers from seeking commercial sex. According to Frith (2012), STIs were second only to influenza for soldiers’ lost days for duty during World War I, accounting for nearly seven million days in which soldiers were unavailable. Clearly the military had incentives to make efforts to reduce the impact of these diseases, and civilian populations did as well.

The first legislation regulating STIs was the UK Contagious Diseases Acts of 1864 and 1866. Impelled by high rates of STIs among soldiers returning from the Crimean War, the Acts required compulsory registration of prostitutes and their police supervision, regular examination, and hospital detention of prostitutes found to be infected (Adler 1980). The strategy of the Acts was to permit prostitution but subject those engaging in it to compulsory management. This approach drew sharp criticism from early feminists and advocates of moral purity in the late Victorian era. Although the Acts were repealed in Britain in 1886 as part of efforts to abolish prostitution, historian Philippa Levine (1996) describes how similar regulatory strategies remained in play in British colonies such as India, where imperialists urged their continuation for the protection of British soldiers and British military power. Britain deployed a force of some 60,000 soldiers in the direct rule of India, soldiers who were thought to require some sexual services from prostitutes. Disease control measures were imposed on prostitutes and not on the soldiers who frequented them, however, to the chagrin of incipient nationalist movements. Regulatory strategies were also pursued in France and in Germany, with prostitution limited to specified areas of cities, registration and examination of prostitutes, and arrests and fines for those plying the trade clandestinely (Brandt 1985, 35). By contrast, with minimal exceptions of initiatives led by physicians who had been educated in Europe, most U.S. jurisdictions prohibited prostitution rather than attempting regulation. Nevada was an exception, reflecting the openness of the west
and Gold Rush days, but even Nevada regulated prostitution and confined it primarily to smaller towns and rural areas (Symanski 1974). Becoming STI-infected was viewed as punishment for promiscuity. Moralists argued that regulation would encourage sin rather than protecting against its resulting harms. The U.S. Mann Act, criminalizing transportation of women across state lines for “immoral purposes,” was enacted in 1910, just before World War I. Regulation of STI transmission was thus a policy stage on which conflicting views about colonialism, gender, and moral purity played out.

The world wars of the twentieth century likewise brought clashing views about STI control into play. Here, moralism in the U.S. was especially strong. During World War I, while some nations tried to protect their soldiers with condoms or to encourage supposedly safer forms of prostitution, the U.S. military instituted chastity campaigns. Posters graphically depicted the ravages of syphilis and gonorrhea and their ability to hide in the bodies of enticing but unclean women. The sex education film “Fit to Fight,” shown to recruits, urged soldiers to resist sex in support of the war effort and portrayed prostitutes as enemy agents undermining military resolve (Brandt 1985, 67). Anti-alcohol campaigns became part of the mix, too, as prostitution was associated with bars and saloons; prohibition itself was the law of the land in the U.S. from 1920 to 1933. Training camps for soldiers featured entertainment, organized athletics, and chaperoned visits from wives and girlfriends. As medical historian Brandt describes (1985), however, medical testing of soldiers revealed that over 10% of newly enlisted soldiers were already infected with STIs and that rates in some camps were as high as 25%. The shock of these statistics fueled social hygienists’ pursuit of U.S. national efforts against venereal disease and alcohol.

Efforts against STIs and related “immorality” only intensified when U.S. soldiers nonetheless quite predictably returned from the first world war with infections. Because under the U.S. federal system responsibility for public health lies largely at the state level, states were in the forefront of these efforts. Some states responded with coercive measures to prevent disease spread.

These responses were intertwined with the politics of the day, including Progressivism and feminism. The Progressive era in U.S. politics is generally considered to have extended from the 1890s through the end of the first world war. Spurred by the unfettered growth of capitalism, shifts from rural life to urban industrialization, and increasing social inequality, Progressivism opposed corruption and favored the introduction of social science methods into government. Progressives pushed for economic and social reform, including measures such as worker’s compensation and social security.

But there were morally grimmer sides to Progressivism: racism, eugenics, and opposition to immigration. Many Progressives advocated social Darwinism, promoting birth control and mandatory sterilization of those believed to be unfit to promote healthy births for a healthy population. Economist Thomas Leonard describes these “illiberal” tendencies of the Progressive era as paradoxically both rooted in social science and failing to apply the insights of social science to understand the potential biases of Progressivism itself. He writes, “Progressive Era reform
at once uplifted and restrained, and did both in the name of progress. In practice, only white men of Anglo-Saxon background escaped the charge of hereditary inferiority, and even members of this privileged group were condemned as inferiors when they, as with *The Jukes* and other ‘white trash’ families studied by eugenicists, were judged deficient in intellect and morals” (Leonard 2016, xiii). Sex outside of marriage and sexually transmitted infections were considered marks of unfitness. Moreover, preventing people from breeding was cheaper and simpler than supporting them and their offspring.

Progressivism was also associated with paternalism in the pursuit of the betterment of individuals. Although the typical characterization of the Progressive era is that it featured a shift from rural to urban politics, sociologist Kristin Luker argues that the movement can be better understood as the shift from “familial patriarchy” to “social patriarchy” (1998, p. 601). Groups such as the American Social Hygiene Association and the Woman’s Christian Temperance Union, along with many women’s clubs across the country, advocated a single standard of sexual abstinence until marriage. Their success in defending women’s equality was modest, however; and, in Luker’s view, this purity movement was largely amalgamated in the service of medicalized social hygiene directed primarily towards the regulation of female sexual conduct. Laws against prostitution were enacted or strengthened and a number of new women’s prisons or reformatories were constructed. By 1918, according to Luker, 32 states had compulsory quarantine laws for venereal disease and federal government statistics indicated that 30,000 women were taken into custody during the 27 months of U.S. involvement in World War I. In her doctoral dissertation, sociologist Nicole Perry (2015) describes how Kansas quarantined over 5000 women, primarily low-income and working class and suspected of having STIs, in a prison farm during the 1920s and 1930s.

Beginning in the 1890s with Connecticut, many U.S. states passed laws regulating who could marry. These laws were initially eugenic, prohibiting the “feeble minded,” “imbeciles,” epileptics, and others regarded as of unsound mind from marrying. Not long after, they were joined by laws restricting marriage when people tested positive for venereal disease. The statutes used “venereal disease” to refer to these infections, with the connotations of illicit love that this terminology suggested. Washington’s comprehensive statute enacted in 1909, for example, prohibited marriage by anyone who was a “common drunkard, habitual criminal, epileptic, imbecile, feebleminded person, idiot or insane person, or person who has theretofore been afflicted with hereditary insanity, or who is afflicted with pulmonary tuberculosis in its advanced stages, or any contagious venereal disease…” (Lindsay 1998). By the outset of World War II, twenty US states required STI testing for issuance of a marriage license and nineteen required prenatal testing of pregnant women. These statutes varied from primarily health-promoting goals to goals that were more frankly punitive. In Virginia only, those who tested positive were permitted to marry without a waiver from the state health department, so long as the partner was fully informed and agreed to the marriage and both agreed to treatment recommended by the health department. The rationale for the Virginia approach was that it would encourage more people to come forward for testing. The state was concerned that its
residents had been avoiding the testing requirement by marrying out of state or by continuing in what the state regarded as an illicit relationship (DePorte 1941). Other states flatly prohibited marriage for those identified as infected unless a waiver was granted by public health authorities. Although rates of positive tests were lower than expected, some observers hypothesized that the explanation was that people who knew or suspected that they were infected avoided the testing (Brandt 1985, 149). States also enacted statutes mandating prenatal testing of pregnant women; these laws revealed higher rates of infection than the premarital testing laws and resulted in significantly lower rates of infants born with congenital syphilis.

This reformist but repressive zeal targeted STIs, especially syphilis, for case identification and contact tracing. Case identification and contact tracing were widely enacted into state law and became the central method for STI control in the U.S. (Brandt 1985; Gostin and Hodge 1998). The moral opprobrium directed towards illicit sex played an important part in shaping the structures for reporting and tracing individuals judged responsible for STI transmission, especially in the U.S. but elsewhere as well. Condemnation of prostitution or sex outside of marriage, opposition to birth control, and public health efforts to reduce burdens of disease intertwined as the structure for implementing these methods developed. Social class played a role in enforcement; according to Fairchild et al. (2007, p. 9), physicians exercised discretion in favor of their more privileged patients in making decisions about when to report cases to public health officials. Racism was part of the mix, too, as blacks and immigrants were considered more likely to be promiscuous and thus infected.

In the U.S., Thomas Parran was the leading advocate of case identification and contact tracing for STI control. His views were complex and can be more readily aligned with public health goals of disease prevention than with the social moralism of many other proponents of case identification. However, Parran was at best an ambiguous figure for the future of public health. As Chapter 2 describes, Parran is now thought to have been associated with the early stages of the Tuskegee syphilis study that remains a symbol among U.S. Blacks for mistrust of public health interventions. Parran began his career in rural sanitation and then became chief of the U.S. Public Health Service’s Division of Venereal Disease in 1926, where “he worked to sway public sentiment away from moral condemnation of venereal diseases and toward consideration of syphilis as a medical condition and threat to public health” (Snyder 1995, p. 630). A challenge for Parran was breaking the veil of silence that had reemerged around venereal disease during the 1920s (Brandt 1985, 122). Federal funding for disease control had fallen off and opposition to treatment had grown, fueled by opposition to the supposedly loose morals of the Roaring ‘20s and the belief—shared by Parran—that ready availability of prophylaxis would encourage unsafe behavior. As the depression took further toll on federal funding, Parran left the federal government in 1930 to become New York State health commissioner. There, he confronted continued repression of discussions about sex; in 1934, he was not allowed by CBS radio to deliver an address over the radio that mentioned syphilis or gonorrhea (Brandt 1985, 122). He also confronted continued
opposition to treatment as encouraging immorality and the stark reality that few people during the depression could afford the costs of care.

Later, as U.S. Surgeon General from 1936 to 1948, Parran was in an especially strong position to campaign against syphilis. Parran “brought a scientific, bureaucratic approach to the venereal problem [as] a career public health officer” (Brandt 1985, p. 138). Parran’s efforts made remarkable inroads into silence about STI infections and especially their impact on women; an article he coauthored in the respected and widely read women’s magazine *Ladies’ Home Journal* brought information about STIs into highly traditional circles. Importantly, Parran’s plan was multifaceted, including testing, treatment, and public education. He urged the establishment of free and confidential testing centers in high risk areas, to be followed promptly by treatment. Parran argued as well that there should be public funding for treating all infected persons.

In 1938, the U.S. Congress enacted the National Venereal Disease Control Act, acknowledging the national scope of the problem of STIs and the need for the federal government to play a significant role in addressing it. The Act included funding for research and for grants to state public health departments to use in developing plans for disease control activities. Funding for treatment was limited, however; one difficulty was avoiding the charge of physicians and the American Medical Association that public funding would be a start on the road to “socialized” medicine. Nonetheless, Parran’s efforts achieved notable success: Tramont and Boyajian (2010) cite data that in 1942, according to census figures, 580,000 people were newly infected with syphilis; but after Parran’s campaign, the rate of new infections had fallen to 120,000 cases a mere 10 years later. The success is even more impressive given that the only treatment available at the time, neo-salvarsan, was expensive, time-consuming and risky; penicillin became available for treatment of syphilis only in 1942.

These methods were joined in many states by other interventions, such as the duty to report those believed to be infected and the duty to warn their sexual partners. Because in the U.S. responsibility for the public welfare lies primarily with the states, these reporting requirements are typically established by state statutes and implementing regulations. (The federal government might use its power to regulate interstate commerce to regulate disease threats but has not done so; control of the country’s external borders does lie with the federal government and it has imposed restrictions on entry for those with specified infectious conditions.) Statutes may list reportable diseases and give public health agencies the authority to identify reportable conditions through administrative rulemaking. These structures will specify what individuals or institutions are required to report, which conditions are reportable, and where reports should be made. States may use these case reports to investigate outbreaks and to follow up contacts of individuals who may be contagious. States today also publish reports of disease trends and, under agreement with the U.S. CDC, share information regarding disease outbreaks and trends (CDC 2019).

The city of Chicago was particularly enthusiastic about implementing syphilis control measures and became a flagship city for the national effort. As Poirier (1995) describes in her comprehensive literary history of the events, in the late 1930s
Chicago instituted a massive campaign to test and treat syphilis. The experience of the Chicago Syphilis Control Program illustrates the methods of case identification and contact tracing at their best and worst.

On the one hand, aided by publicity from the *Chicago Tribune* and other media outlets, the Program achieved high visibility and brought widespread attention to syphilis. Initial letters mailed to one million residents offered free testing that was to be voluntary, conducted by the family’s own physician, and with the promise of complete confidentiality about results. To avoid stigma, everyone was invited to be tested; organizations such as the *Tribune* encouraged testing by their employees and meetings of Lions clubs and the American Legion also offered testing. Dr. Ben Reitman, an unconventional physician who periodically rode the railroads home-lessly himself and was the lover of the leftist Emma Goldman, provided treatment and prophylaxis for prostitutes, the homeless, and the poor without question and usually with respect for them and their life circumstances. Treatment was publicly funded for many and these people received medical care that would otherwise have been unavailable to them. Treatment rates were especially high among African Americans in Chicago, who with the public funding had unprecedented levels of access to care. Rates of infection fell in the city; Chicago had the lowest rate of syphilis among those entering the military in WWII (Brandt 1985, 152).

But the Chicago Syphilis Control Program also had more troubling aspects. The tests for syphilis in use at the time had high false positive rates—possibly as high as 25% (Brandt 1985, 152). People who tested positive falsely may have received unnecessary but toxic treatment. A series of *Chicago Tribune* stories revealed physicians who set up fraudulent practices supposedly to identify and treat the infected. While testing was voluntary for most Chicagoans, it often was not voluntary for those accused of crime. The Chicago Women’s Court ordered testing of anyone charged with prostitution and hospitalization of those with positive test results. Other courts required testing and imposed fines sufficient to keep supposed offenders in treatment. Far from the goal of universal testing that would dilute stigma, Poirier contends, these aspects of the Program were applied in discriminatory ways, for example targeting the women selling sex rather than the men buying it as immoral offenders (1995, 85). Free testing was offered, but people were encouraged to visit their private physicians, both to save costs and to avoid opposition from the Chicago Medical Society that free testing would impact their members economically. Cooper (2001) contends that testing was primarily conducted on those accessing public sources of health care, as people who had resources could pay for private testing or avoid testing altogether. Although reporting rates from private physicians did increase, they remained low and the result was inequitable understanding of the scope of the epidemic and needed responses to it. African Americans and the poor more generally were disproportionately represented in the statistics, thus creating the potential for stigmatization of these groups. Privacy was another concern; employers were encouraged to test their employees and labor advocates rightly feared that people testing positive would be excluded from health insurance plans until they had been treated successfully (as people with positive tests were at the *Tribune* itself), would be charged higher rates for health insurance, and would be
denied life insurance. Schools and universities required testing for entrance, with some such as Northwestern refusing admission to those testing positive (Poirier 1995, 131).

Penicillin became available as an effective and comparatively safe treatment for syphilis beginning in 1942. Risks of a positive test could thus be mitigated—and benefits maximized—as people could delay testing until after undergoing treatment or could receive curative treatment after a positive test. Case identification and contact tracing are least burdensome to individuals undergoing them when treatment such as this is readily available, as it became for both syphilis and gonorrhea. In such circumstances, there are direct benefits to the person receiving a positive test result: treatment and cure. Such situations are a double win, both for the person who receives treatment and for others to whom he or she might have passed on disease. At least, they are such a double win if adverse consequences do not accompany knowledge that the treatment has occurred. In contexts in which knowledge of STI treatment brings damaging rejection—divorce, disownment, expulsion from school, excommunication from a religious community, or job loss, for example—patient confidentiality becomes an issue. Patients may reasonably seek to avoid treatment if the resulting harms to them are significant. Others affected either by the non-treatment or by the conduct that resulted in the STI—such as a spouse who does not suspect a partner’s unfaithfulness—might reasonably reply that knowledge of the STI and whether treatment has occurred is of critical importance to their health or to the conduct of their lives. Finally, treatment shortages, as occurred with Penicillin G Benzathine, the recommended method for treating syphilis, may also occur and depress access to treatment (Nurse-Findlay et al. 2017).

The period after World War II was in some respects a golden age for antimicrobial treatment, not only of sexually transmitted infections but also of many other infectious diseases. New classes of antibiotics were becoming available and drug resistance was minimal. Case finding opened possibilities for treatment, benefiting individuals as disease victims and remediating them as potential vectors. Conflicts between protecting individuals from harm and reducing disease spread appeared to have largely ended, and an era begun in which the interests of individuals and the public health were fully aligned.

The appearance of HIV/AIDS in the late 1970s, however, brought sobering challenges to this rosy optimism. AIDS also sharpened the ethical conflicts raised by case reporting and contact tracing. On the one hand, the moralism of the Progressive era was long in the past. Supported by the emerging field of bioethics, patient advocates called for respect for the individual autonomy of patients and the recognition of social responsibilities in fighting disease. For quite some time, however, AIDS was met with fear, condemnation of those affected, and the deadly consequences of unchecked disease spread.
3.5 HIV/AIDS: Disease Control and Confidentiality

Retained tissue samples now suggest that sporadic cases of HIV or a closely related infection may have appeared in humans as early as the 1920s but died out without significant spread. How the current form of pandemic HIV infection emerged remains contested; most likely, the primary form of HIV infection emerged in Kinshasa in the Democratic Republic of the Congo from consumption of infected primates. What became the present-day pandemic was initially identified as a mysterious immune deficiency associated with unusual infections such as thrush and pneumocystis pneumonia and rare cancers such as Kaposi’s sarcoma. Because many of the initially identified cases in the U.S. occurred in gay men or Haitians, the disease was associated with these groups and further stigmatization of them.

People with AIDS (“acquired immune deficiency syndrome”) were subject to devastating infections because of catastrophic falls in levels of the T cells critical to fighting infections. The disease initially killed primarily young, previously healthy men who became infected and by 1994 had become the leading cause of death among young adults in the U.S. The cause of the T cell destruction was identified by 1983 as the HIV virus, dispelling the mystery of causation. Initial tests for HIV became available in 1985; these had high false positive rates and tests with greater specificity were developed subsequently (Alexander 2016). The discovery that HIV is a retrovirus also led to recognition of its transmission only through direct exposure to bodily fluids such as blood or semen. Fears of casual transmission were not easily allayed in the general population, however, and people with HIV were initially barred from schools, employment, athletic competitions, and many other venues.

Worldwide, AIDS spread rapidly through infected blood supplies, sex workers, and maternal-child transmission (Mann 1987). In some areas, the disease virtually eliminated an entire generation of young adults. By 1988, the WHO estimated that between 5 and 10 million people were infected and that the virus would spread to every country (Samuels et al. 1988). By far the greatest burden of disease was in impoverished areas of sub-Saharan Africa and South and Southeast Asia. Even in resource-rich countries such as the U.S., the greatest burdens of disease were among poor and minority populations. Writing in the *American Journal of Public Health* special issue on AIDS in 2002, Richard Parker characterized AIDS as a disease of structural injustice. Yet AIDS was also a disease that struck people at all economic levels and that became a locus for patient activism and gay activism in more prosperous areas.
3.5.1 HIV Disease Control

Not surprisingly, HIV/AIDS brought intense ethical challenges to STI disease control strategies based on case identification and contact tracing. AIDS advocates contended that testing performed without voluntary and fully informed consent violated people’s rights to decide what should be done with their bodies. Required case reporting or other disclosures (for example, to sexual partners) were seen as serious violations of confidentiality, with the risk of deterring people from getting tested. Many of the early AIDS patients in the U.S. were in the arts and highly educated and advocacy on behalf of AIDS patients was forceful and effective. AIDS also came on the scene in the era of gay civil rights activism; unsurprisingly, groups such as the Gay Men’s Health Crisis formed almost immediately after initial publicity about identification of the illness. AIDS advocates pushed back against anti-gay actions such as closures of the bathhouses in San Francisco, arguing that these venues could become sources not of disease transmission but of education and community support. Advocates also urged access to health care and the right to try therapies that had not yet been approved by the Food and Drug Administration. Activists also argued strongly for informed consent before testing and protection of the confidentiality of test results. In these arguments, they were joined by defenders of autonomy in the emerging field of bioethics which emphasized informed consent and patient confidentiality.

In the initial decades of the pandemic, AIDS patients in the U.S. faced realistic concerns that reporting would subject them to personal condemnation from family and friends, loss of employment, loss of insurance, quarantine, or even criminal prosecution. (Fallone 1988). Before modes of transmission were understood, blood transfusions were a common source of HIV infection; hemophiliacs who were treated with clotting factor made from multiple blood donations were at particularly high risk. Ryan White, one of the first young hemophiliacs diagnosed with HIV (in 1984), was barred from attending school in the town in Indiana where he lived. His fight to return to school gained national attention; even after the Indiana state health commissioner made clear that HIV could not be transmitted by casual contact, some parents pulled their children out of the school when Ryan returned. The federal statute providing funding for HIV treatment was named after Ryan White and enacted shortly after his death in 1990.

HIV infection also played a central role in changes in the U.S. insurance market that froze out people with pre-existing conditions. Patients with HIV were expensive, particularly early in the epidemic, as they had high rates of hospitalization, although they turned out in the longer run to be less expensive than initially predicted (Scitovsky 1988). Insurers increasingly denied coverage to people with HIV or excluded HIV-related illnesses from the coverage they did provide. By 1989, all states but California had laws permitting insurers to test people for HIV as a condition of health insurance (Lambert 1989). Insurers backed away from community rating—the practice of charging premiums based on the risk of average individuals in the community—to experience rating, calculating premiums based on an
individual or a group’s prior utilization history. Surveillance information about disease prevalence in various populations enabled these actuarial calculations. People with histories of expensive treatment for HIV/AIDS were priced out of the insurance market as a result. So were groups: some insurers denied coverage to groups such as florists that were believed to have high percentages of gay workers at potential risk for HIV. Larger employers moved increasingly towards maintaining the reserves needed to meet their own costs of insurance, thus avoiding state law coverage mandates (Padgug et al. 1993). The U.S. Supreme Court let stand a lower court decision permitting an employer to reduce lifetime coverage for AIDS-related illnesses from $1 million to $5000 when faced with covering an employee with a positive diagnosis (McGann 1991). When people with AIDS were no longer able to work, they lost health insurance from their employers. Burdens of providing care fell especially hard on public hospitals and community-funded clinics. Only with the Affordable Care Act (ACA) has the U.S. moved back in the direction of insurance that cannot deny people coverage or set premiums because of conditions they already have, although as late as 2020 these protections remained under legal challenge.

Many jurisdictions adopted punitive stances in fear of what initially was a fatal disease transmitted in ways unknown. As the virus was identified and transmission understood, support for criminalization of HIV transmission was fueled by moral judgments that people with HIV were responsible for their illnesses because of their intravenous drug use or sexual behavior. These statutes typically made it a crime for people who knew they were HIV positive to engage in behavior thought to create risks of exposure to others. These statutes were not based on evidence that they would increase the likelihood that people would learn their HIV status and avoid infecting others. To the extent that they only subjected people who knew their HIV status to punishment, the incentives they created were to avoid knowledge and thus likely were counterproductive. Nor were they based in evidence that they would reduce either rates of HIV or rates of exposure-prone conduct such as needle sharing (Yang and Underhill 2018). But these punitive statutes remain widespread. Indeed, when California modified its law in 2017 to reduce punishment for HIV transmission to a misdemeanor, and then only when the transmission was intentional and to a sexual partner who was unaware of the offender’s HIV status, it went against the clear trend of 34 states that still criminalized HIV transmission. Moreover, enforcement of these statutes in the U.S. has been inconsistent and has had a disparate impact on Blacks.

Outside of the U.S., some jurisdictions resorted to quarantine to stem the tide of the HIV pandemic. Cuba began a widespread program of mandatory screening, first among people who had been outside of the country and thus might have been exposed to the disease and then among all hospitalized patients, pregnant women, and people diagnosed with STIs (Bayer and Healon 1989). Observers reported that informed consent was not required, at least initially. People identified as HIV positive were quarantined in sanatoria located away from cities. Their care was paid for, they continued to be paid salaries or a stipend even though they were unable to work, and they were given passes for monitored visits with families and friends. Cuba justified the program as part of its overall public health approach to health
care. Cuba did continue to have very low rates of HIV positivity, with the principal risk factor for infection being sexual contacts while abroad. Cuba also had high rates of treatment of those who became infected. Critics pointed out the risk of confinement of people with false positive tests, the great expense of the program, and the serious deprivation of individual rights that it involved (Pérez-Stable 1991). Others argued that the program should be considered more sympathetically, both because of the benefits it achieved in limiting infection rates and because it was conceived primarily as an initial emergency response. By 1990, as treatment became available, Cuba converted to a voluntary educational and day treatment program while allowing residents of sanitoria to continue to live there if they so wished (Anderson 2009). Moreover, observers also reported that Cuba required informed consent to testing and contact tracing, although it placed far more pressure on people to reveal their contacts than might have occurred elsewhere (Anderson 2009).

As international public health responses to AIDS developed, policy makers also urged incorporation of international human rights norms into HIV policy. AIDS policy stimulated the introduction of human rights into public health ethics. Jonathan Mann, initially as director of the WHO Global Program on AIDS, developed a systematic human rights approach to the disease (Fee and Parry 2008). Mann argued for the rights of those who had become infected, most importantly rights to non-discrimination, access to health care, and protection from coercive interventions such as quarantine. Mann believed that public health goals in disease prevention could be brought into harmony with protections of political and social rights. He contended that HIV flourished where inequality prevailed and that the health of the majority could only be protected if the rights of people at risk were respected. After a change in leadership at the WHO, Mann resigned; several years thereafter, he perished in the crash of a SwissAir plane. But Mann left a legacy of the importance of human rights for HIV policy and public health policy more generally (Gruskin 2002, 2002a).

Thus, from the beginning AIDS was associated with stigmatization of groups such as gay men, intravenous drug users, or Haitians—the last because some of the earlier identified cases were in Haitians or those who had visited Haiti (Castro and Farmer 2005; Parker and Aggleton 2003). According to one report, even the contact tracers themselves were stigmatized from mistaken beliefs that they too might have become infected (Kampf 2008). These beginnings shaped HIV advocacy towards the bioethics paradigm of individual informed consent in the U.S., the paradigm we discuss further in Chapter 7. Commentators urged careful counseling and informed consent procedures prior to any HIV testing or research (Gillon 1987). Providers and others interested in HIV prevention also voiced the realistic fear that public awareness of required reporting would deter people from getting tested. As an alternative, they proposed establishment of anonymous testing venues (Kegeles et al. 1990).
Confidentiality and Reporting Test Results

Confidentiality of their medical information was paramount among the protections urged for patients with HIV. As the epidemic grew, public health law scholar Larry Gostin (1986, 227) argued for widespread voluntary testing and complete protection of the confidentiality of test results. British bioethicist and primary care physician Raanan Gillon (1987) argued that except in extraordinary circumstances HIV test results should not be shared by specialists with the patient’s primary care physician without the patient’s agreement. These “extraordinary” circumstances were the possibility that a patient with no regard for others would put innocents at risk of infection. Even in such circumstances, Gillon nonetheless worried that disclosure would threaten to undermine patients’ trust in the medical profession. Such commitments to absolute confidentiality were rare, however.

Risks to immediate partners were the foremost concern raised about such strong confidentiality protections. These risks were often visualized as involving “innocent” spouses who might have no idea of their partner’s infidelity. As with STIs in the earlier part of the twentieth century, risk judgments about AIDS were intertwined with moral judgments about infidelity, lack of concern for the partner, and in some cases underlying ambiguities in gender identity that may have played a role in the infidelity. For example, in a case study published in 1987 in the Hastings Center Report, commentators debated whether a physician should tell a patient’s fiancée of the risk that he was HIV positive when the patient declined to do so himself. The patient was described, somewhat pejoratively, as “bisexual,” as having likely acquired the infection during one of his “homosexual encounters,” and as fearful that revealing his condition would “ruin his marriage plans” (Winston and Landesman 1987, 22). Winston urged disclosure to protect the fiancée. Although Landesman judged confidentiality to be paramount, he too seriously entertained the obligation to disclose out of concern for the partner, especially when the physician did not practice in circumstances in which disclosure was likely to jeopardize his patient’s trust.

Professional organizations also weighed in about partners. The American Medical Association stated that there is a duty to protect partners and recommended in an ethics opinion that if all efforts to persuade the patient to disclose failed, the physician should report the condition to authorities. If authorities failed to act, the physician should then notify and counsel the endangered partner (Lin and Liang 2005). In addition, in the Law and Medicine column of the Journal of the American Medical Association, Bernard Dickens (1988) outlined for physicians how law in the U.S. supported the duty to warn identified individuals at risk. Analogies were drawn to the Tarasoff decision (1976) in which the California Supreme Court had held that psychiatrists might have a reasonable duty to warn of their patients’ immediate likelihood of violence. Raising an ethical red flag about these recommendations, one study of physicians conducted after the AMA ethics opinion indicated a greater likelihood that physicians would breach confidentiality if the patient were Black than if the patient were white (Schwartzbaum et al. 1990).
The risk of abuse was another critical concern raised about direct partner notification, particularly when it suggested that the partner might have had sex with, or shared needles with, others. Data in the U.S. suggested that HIV positive minority women in particular were at risk of domestic violence from their partners. Public health scholars argued that programs should screen for domestic violence before discussing with their female patients whether their partners should be informed about their infections (Kass and Gielen 1998). Scholars also contended that pre- and post-test counseling should include a safety plan for women and that given the low frequency of female-to-male transmission safety of the woman should override duties to the partner when the risk of violence was high. (North and Rothenberg 1993). Many states passed laws requiring partner notification, even without the consent of the patient; legal scholar Karen Rothenberg urged repeal of these statutes because of the risks of notification to women (Rothenberg and Paskey 1995).

The standard methodology of contact tracing does not involve direct notification of partners by physicians, however. Instead, physicians are required by law to report positive test results to the relevant public health authorities. To some extent, this relieves physicians of direct responsibility for any duty to reveal. Physicians can explain to their patients that they are required by law to report the information rather than seeming to make the choice themselves. Public health then makes confidential contact with the person who had the positive test result and asks him or her to name contacts who might have been exposed. This does give the person who is the identified index case some protection—he or she may be able to conceal contacts, will know that any named contacts are likely to be reached by public health, and will be assured that the identity of the possible source of the exposure will not be revealed—but concealment may be discouraged or illegal. In some states, concealment of the identity of contacts may subject the index case to criminal liability. All states receiving Ryan White funds must make good faith efforts to notify spouses of anyone reported to the public health department with a positive HIV test (HIV.gov 2018).

Even when the partner notification comes through professional public health methods, it may have serious implications for relationships. When partners are identified as positive, and their spouses or other sexual partners are notified, the information may reveal characteristics of the partner previously unknown to the other. Efforts to conceal the identity of the possible exposure source may be impractical if the partner has been in a monogamous sexual relationship. Contact tracing in such cases may be how some women become aware of their husband’s bisexuality or homosexuality. It may also be how one partner learns of drug use by the other. This information may be met with grief, rejection, or anger—and, as discussed above, with psychological or physical abuse.

Challenges to the efficacy of these partner notification programs are significant. Health departments may lack resources, may be unable to find index cases or their contacts, and may not be able to obtain relevant information from index cases (Magaziner et al. 2018). Incomplete partner notification is more likely for men having sex with men, for Blacks, and for people who engage in risk behavior such as anonymous sex (Edelman et al. 2014). Given these challenges, different strategies may be preferable. One strategy is “enhanced partner notification,” counseling index
cases about how to communicate their status and providing them with support when they do. Another strategy is patient-delivered partner therapy, which provides index cases with the means for their partners to be treated without the need for a separate medical examination. Success of these alternatives is reportedly mixed as well and may depend on the STI in question and the context, according to a Cochrane report about the evidence from studies in many locations across the globe (Ferreira et al. 2013). Even in the U.S., domestic violence remains a significant concern for patients faced with any of these strategies and may continue to limit their use (John et al. 2018).

Other critics of these current strategies for management of the HIV epidemic urge the importance of addressing social and economic contexts for disease prevention. Efforts to identify individuals judged responsible for disease transmission and follow and control their behavior, these critics say, will fail to target environments vulnerable to HIV spread (Kazanjian 2012). They may also fail to provide the information and support needed to encourage people to seek out testing and to share information about their HIV status with their partners.

### 3.5.3 HIV Today

The first anti-retroviral effective for treating HIV, AZT (zidovudine) was approved in the U.S. in 1987. Today, combination therapies have turned HIV into a manageable chronic disease for most although not for all. Successful treatment also reduces viral load to levels that make transmission very unlikely. PrEP—preexposure prophylaxis—is now also available that can provide largely effective prevention for people engaging in high risk activities.

These developments have brought changes to the balance in public health recommendations about consent to testing. In 2006, the CDC issued revised recommendations for HIV testing that characterized it as routine. “Routine” means that testing is presented as part of standardly indicated medical care instead of only after an extensive structure of consent and counseling. Patients may opt out, but the expectation is that far fewer are likely to do so. The CDC recommendations were that for all patients, HIV screening should be performed at least once and that persons at high risk for infection should be screened annually. For pregnant women, the recommendation was also that screening should be included in prenatal blood tests and should be repeated in the third trimester in areas of high rates of HIV infection among pregnant women (Branson et al. 2006). This transition was defended ethically because of the availability of treatment and the role of treatment in prevention but generated ethical controversy as well. Although today HIV is more of a chronic disease than an inevitably fatal one, knowledge of their HIV status continues to subject people to risks. As just described, the majority of U.S. jurisdictions still criminalize knowing transmission of HIV. People with HIV may have difficulty with employment or insurance, may face rejection from family and friends, and may be subject to violence from their intimate partners. These risks were higher when compounded by other factors of disadvantage such as race or poverty. These risks also were more
severe at the outset of the HIV epidemic, so it should come as no surprise that AIDS advocacy emphasized the importance of informed consent to testing despite the possibility that it would discourage individuals from knowledge of their HIV status and reduce the ability of public health to deal successfully with the pandemic.

Still, these therapies are expensive and not always effective. Pre-exposure prophylaxis (PrEP) has also become available for those engaging in risky behavior and seeking to reduce their risks of infection. However, a continuing course of PrEP costs about $2000 per month in the U.S. and is not always covered by health insurance plans; moreover, people taking PrEP may be denied disability or life insurance (McNeil 2018). The evidence is that PrEP use is far less frequent among African American and Latino patients—groups in which HIV incidence remains high (CDC 2018). Data from trials in France and in Canada suggest that on demand PrEP may be far less expensive, receive better patient adherence, and be highly successful in preventing HIV transmission (Molina et al. 2017).

According to UNAIDS (2018), the agency of the United Nations founded in 1996 to fight spread of the disease, 78 million people worldwide had become infected by AIDS by 2018 and over 35 million had died. UNAIDS began pursuing a fast track strategy in 2014 aimed to bring the AIDS pandemic under control by 2030, with control defined as 90-90-90—a 90% rate of diagnosis of those infected, a 90% rate of treatment of those diagnosed, and a 90% rate of viral suppression in those undergoing treatment (UNAIDS 2018a). As of the halfway point to the 2020 benchmarks, the program had fallen behind in some areas of major concern. Progress has been particularly good in areas of eastern and central Africa hard hit by the epidemic, with significant increases in treatment rates and concomitant declines in mortality. Although rates of new infection fell significantly in areas with effective access to treatment and PrEP, rates remained high in other areas. Rates of untreated children remained particularly high. Declines in new infections were lowest in the Americas and new infection rates rose significantly in the Middle East and Eastern Europe. In addition, there are fears that resistant forms of HIV are appearing that may prove difficult to treat (Garrett 2018). Surveillance remains critically important to monitor these developments.

### 3.6 Ethical Tensions

Case finding and contact tracing bring potential tensions between the individual and the overall social good into sharp focus. On the one hand, respect for individual rights may seem to support the importance of informed consent, confidentiality, and freedom to choose whether to be tested for a disease or to have test results used to protect others. It may also seem to favor rights to gain swift access to potentially effective medications even before testing for safety and efficacy are complete. Respect for individual rights also supports protection of people in research, even
when that might slow the development of useful knowledge for the communities in which they live. On the other hand, choices made by individuals may put others at risk, such as their partners, the children they bear, or the patients they treat. Case identification and contact tracing may be necessary and effective ways to reduce disease spread. Yet if use of these methods discourages people from any encounters with health care at all, the result may backfire not only for the disease in question but for other aspects of health as well. When prevention or treatment are readily available, direct efforts to educate people about a disease and what might be available to them could prove more beneficial for individuals and more effective in reducing disease altogether than any efforts to trace individual chains of disease from an index case. These are the apparent tensions between respect for the individual and protection of others who may be harmed. We say “apparent,” however, because these tensions emerge most forcefully when autonomy is understood in a particular, individualistic way.

### 3.6.1 Individualistic Autonomy and Informed Consent

The field of bioethics, maturing just as the AIDS crisis flowered, brought individual autonomy to the fore of medical decision making. The initial edition of the *Principles of Biomedical Ethics*, by Beauchamp and Childress, was published in 1979, and has been a core reference text in the field through multiple editions ever since. The volume argued for what became the classic litany of bioethics principles: autonomy, beneficence, non-maleficence, and justice. Autonomy reflected the ideas of dignity, integrity, and self-determination that had been critical in the Declaration of Helsinki adopted in 1964 by the World Medical Association (WMA) to protect human subjects in research (2019). The WMA declaration, spurred by the recognition of research atrocities not only in Nazi Germany but also in the U.S. and elsewhere, insisted on free and voluntary informed consent as an ethical condition of participation in research studies.

Use of the term “autonomy” as the ethical underpinning for informed consent had overtones beyond voluntariness and full information. The idea of autonomy was drawn from the Kantian vision of people as individual rational agents. As such, it was rooted both in rationality and in individualism. Freed from the constraints of their desires and interests, Kantian individuals laid down the moral law for themselves, subject only to the constraints of universal rationality. As such rational beings, willing universally, they would will that they treat others as they would want to be treated themselves, free of the bonds of emotions or desires or presupposed connections to others.

Such Kantian autonomy has been vigorously criticized by feminists and communitarians. Feminists developed views of the importance of relationships to identity, arguing that individuals are not metaphysically separate selves but selves-in-relationships to others. People are mothers or fathers, friends or enemies, Christians or Jews, Americans or French or Chinese. Oppressive relationships are
problematic, but relationships themselves—to friends, families, communities, countries, or even the natural world—are not. Communitarians argued further, and controversially, that any individual choices take place in the context of community ties and values. Although communities may be oppressive and people should be free to leave—as Amy Gutmann (1985, 319) famously pointed out, in Salem they felt compelled to burn witches—the shared values of community are part of the moral landscape and perhaps even take precedence over individual values and interests. These disputes are of course far more complex than a brief, caricature-like sketch, can give, and we explore them further in Chapter 7. But it is important to recognize that much of the early bioethics support for informed consent was rooted in individualism.

The models of consent thus employed in bioethics started with individuals’ values and preferences, not with relationships or communities. Individuals should understand their conditions, the treatment options available to them (including no treatment), and the risks, benefits, and likely outcomes of each of these treatment options with respect to their values. Consenting individuals were supposed to be able to deliberate in a way that would enable them to apply their knowledge to choose the alternative that best reflected their values. People with cognitive impairments or mental illness might be capable of giving informed consent in this way, although they might need extra support to do so. So-called “vulnerable” populations—children, pregnant women, prisoners—or people who have suffered disadvantage or discrimination might also require special attention to ensure their informed consent.

Discussions in bioethics emphasized this model of informed consent in both clinical care and research regarding HIV/AIDS. In clinical care, advocates argued for a full consent process prior to HIV testing and for pre- and post-test counseling. Recommendations for the consent process included explanations of the potential personal and social risks of testing. Counseling was to help people deal with the consequences of test results and might include both psychological support and referrals for needed social services. For example, Carol Levine and Ron Bayer argued in the *American Journal of Public Health* that despite the possibility that early intervention might delay the onset of disease, screening asymptomatic individuals in high risk populations must be fully voluntary and take place only after careful informed consent. They wrote: “It is precisely when medicine’s capacity to enhance patient welfare appears to be increasing that there is a danger that important ethical concerns can be overridden or disregarded. This is especially so in the case of AIDS …” (1989, 1661).

This consent model for HIV testing gained support in public policy as well. Laws were enacted requiring informed consent prior to HIV testing and protecting the confidentiality of test results to encourage people to learn their HIV status. The American Hospital Association recommended to its members that general consents to blood testing obtained on admission to the hospital did not include HIV testing and that such testing solely for the protection of health care workers should be discouraged, as these workers could instead be expected to avoid exposure by the use of CDC-recommended universal precautions such as gloves and masks (Swartz 1987).
Informed consent mandates for HIV testing were not without critics, however. In 1987 members of the British Medical Association voted that HIV testing should be at the physician’s discretion acting in the patient’s best interest and should not necessarily require consent. The BMA vote echoed the sentiments of a dermatologist who wrote to the *British Medical Journal* that he should be able to test to rule out HIV as a cause of eczema without alarming a patient who was about to be married. This physician’s letter protested the “almost hysterical approach” of the British National Health Service in requiring consent for HIV testing (Shrank 1987). The British Medical Association’s lawyers soon spoke out, however, publishing guidance that such testing might subject physicians to criminal liability for battery or to civil liability for negligent failure to obtain informed consent (BMA 1987). Other commentators questioned “AIDS exceptionalism” and argued that there was no apparent difference between HIV testing and other blood tests with respect to consent (e.g. Cohen 1988).

### 3.6.2 Access to Experimental Drugs for HIV

Autonomy was also used to support AIDS patients’ efforts to access drugs that might be useful in treating their disease. At the outset, AIDS was a fatal disease and patients argued that they should be at liberty to try therapies with a chance of working even though the safety and efficacy of these therapies had not been fully investigated. Access to treatment could also encourage testing and identification of persons with HIV infection. In response to what were seen as sympathetic appeals on behalf of desperately ill patients and FDA bureaucracy and delays, a parallel fast track was developed for approval of drugs to treat HIV. The fast track was controversial, especially after patients receiving early access to the investigational drug dideoxyinosine died at rates higher than expected. In response, the Institute of Medicine (IOM) convened a conference to discuss the controversy and pointed out the importance of continued ethical monitoring of the early access program, its impact on patients, and its consequences for the development of effective treatments (IOM 1990). The IOM criticized what it regarded as extreme arguments that because patients have little to lose their access to drugs should not be restricted for their failure “to recognize the association between desperation and vulnerability … People with HIV infection do have something to lose: they can waste time, energy, and hope—or even become sicker—on substances that would never reach the marketplace through normal channels” (IOM 1990 Ch. 2) The report also pointed out that without funding for health care, patients with HIV might be dependent on participation in drug trials in order to receive any care at all.

Another set of criticisms of the fast track relied on the possibility of deleterious consequences for others. One problem was that the rush to access might undermine participation in the clinical trials needed to gain adequate information about the safety and efficacy of novel therapies. Relatedly, uncontrolled use of experimental therapies might result in unrepresentative adverse events that could lead to premature rejection of a promising opportunity. Or, it might generate unrepresentative
success and resulting premature optimism leading to widespread but fruitless use. Widespread use of novel therapies might have more general population effects as well, if people believe that their disease has been sufficiently managed and engage in risky behaviors, or if people use the therapy unevenly and resistant strains of infection develop. Advocacy on behalf of HIV-positive patients for access to experimental therapies has developed into a more general movement for “right to try” laws, now adopted in the vast majority of U.S. states and by the U.S. federal government (Joffe and Lynch 2018).

For surveillance, one potentially problematic result of “right to try” is that use of new therapies may become dispersed without systematic collection of information about the consequences. If novel therapies move into clinical practice without monitoring, information may never be developed about effects on subpopulations, either beneficial or deleterious, or rarer side effects and how to recognize or manage them. Needs for such knowledge about patients’ experiences with untested therapies may provide arguments for patients to share information and for increased surveillance to collect it. On the other hand, if “right to try” is coupled with ongoing collection of information about patient outcomes and if the possibility of gaining early access to care encourages participation, the consequences for surveillance may improve.

### 3.6.3 Research Ethics and HIV

Concerns about informed consent were especially intense when clinical trials about HIV were conducted in developing countries that could not (or did not) afford the costs of HIV care. The effects of these trials continue to resonate for surveillance, not always well. Large geographical areas of central and southern Africa were hit particularly hard by the HIV pandemic. Clinical trials were designed to test whether in these circumstances short-course anti-retroviral therapy in the perinatal period could reduce the risks of maternal-fetal transmission of disease. Critics of the trials were outraged because the research compared short-course anti-retroviral therapy just before birth to placebo—no treatment—rather than to the better treatment that had been offered when similar trials were conducted in the U.S. (Lurie and Wolfe 1997).

The justification for the trials was that no treatment was all that was available for the participants without the trial. Moreover, the only likely treatment that might become available in their circumstances was the short-term therapy, and it was important to see whether even that could make a difference in the conditions in which it might eventually be implemented. Defenders contended that the ethical permissibility of the trials should be assessed against the background of the locations in which they were conducted, and that it was thus unfair to compare the placebo-controlled AIDS trials to the Tuskegee syphilis study in the U.S. where treatment was available and had been deliberately withheld from participants for many years (Varmus and Satcher 1997).
Nonetheless, the critics contended that researchers should be held to the same standards whether they were conducting a study in the U.S. or elsewhere. Research is not clinical care, so, it is inappropriate to rely on the availability of clinical care to assess the ethics of the research. Critics also argued that informed consent to participation in the trials was deeply problematic, as participants lacked the education and experience to understand what might be happening or the resources to be able to consider alternatives freely. Moreover, critics argued, the idea of individualized informed consent was alien to the communities in question, where models of decision-making were communal rather than individual. To meet this concern, some researchers explored communal models of consent such as the traditional community forums (*mabaraza*) used in East Africa (Vreeman et al. 2012), models that we explore further in Chapter 7. Others argued that researchers had obligations to provide participants or others in their community with continuing effective treatment or other benefits such as improved access to primary care (Shaffer et al. 2006). Marcia Angell (2000), then editor of the *New England Journal of Medicine*, explained a decision to publish one of these controversial studies by saying that although she thought the researchers’ obligations should not vary with the context, others judged the research to be acceptable because of its potential benefit.

Another example of controversial research in Africa also has resulted in continuing problems for public health. During a meningitis epidemic in Nigeria in 1996, Pfizer conducted a clinical trial of its experimental antibiotic Trovan. Charges about the trial included that it had not been properly approved by the Nigerian authorities, that participants had not given informed consent, that the drug was inappropriate for use in sick children, and that public health personnel were diverted from public health to the Pfizer research (Ezeome and Simon 2010). The trial became the subject of *The Constant Gardener*, a movie dramatizing exploitation by pharmaceutical companies. Pfizer eventually paid compensation to the families of four children (Smith 2011). In the aftermath of the trial, critics urge higher standards of informed consent for global medical research (e.g. Annas 2009). Memories of the trial may be part of the explanation for suspicions about public health efforts to encourage polio vaccination in the affected region of Nigeria (Closser et al. 2015).

Similar issues about informed consent and the ethics of research may also come into play where information is gathered for public health purposes. The line between “research” and “public health” may itself be obscure, if both gather data to produce generalized knowledge. This blurring suggests the importance of ensuring that information gained by public health is used for health.

### 3.7 COVID-19 and Enhanced Contact Tracing

The COVID-19 pandemic has features that are especially challenging for contact tracing (Moore et al. 2020). Because people may be highly contagious before any symptoms appear—or even without ever having symptoms—index cases may come to light too late to prevent wide community spread. Possibilities of spread through
aerosolized droplets and fomites mean that people may become infected without ever knowing about their contacts. In some communities, mistrust of public health and concerns about racism have dampened willingness to share information. Nonetheless, information about the whereabouts and possible contacts of infected individuals, especially when they were asymptomatic or pre-symptomatic, became critical to the effort to stop the spread of this highly contagious disease.

Different countries took different routes towards enhancing contact tracing to address these COVID-19 challenges. Some in addition used smart technology to monitor whether people were conforming with orders to remain sequestered to avoid risks of their spreading disease. These enhancements raised significant concerns about privacy and coercion and met with mixed success at least during the initial six months of the pandemic. It is fair to say that the more intrusive the methods the more they appear to have contributed to pandemic control, although other factors may have been at work as well. Here, we discuss ethical questions raised by these methods as they contributed to contact tracing. In Chapter 5, we consider further issues raised by novel data sources and uses, some of which have been used in combination with enhanced contact tracing methods.

China used a mandatory approach to collecting information and monitoring behavior, according to descriptions available from news reports. Everyone is required to use software on their smart phones to indicate their contagion risk. The system generates a color code—red, yellow, or green—for each user. The color code is based on personal integrity reporting and comparisons with information held by the government (Xinhuanet 2020). The code is dynamic, updated with information about the user’s own status and status of the area in which the user has been. Code status is checked upon entry to places such as shopping malls or subway stations; people without their codes or who are not “green today” are turned away. Yellow status means continued self-quarantine for at least seven days and red status for up to fourteen. According to reports, the system was developed by Chinese internet companies working in tandem with the government and police may be notified of individuals’ locations (Mozur et al. 2020).

Reports have surfaced that use of the method is not limited to COVID-19 surveillance. One Communist Party official reportedly stated that the tracking app should be an “intimate health guardian” that is “loved so much that you cannot bear to part with it” (Zhong 2020). Reports also suggest that data collected by the apps may be used for purposes other than health, including policing. While China has reportedly been very effective in stopping the outbreak, and in responding to new bursts of infection, its method allows for other forms of surveillance that may significantly limit individual liberty and result in other harms to individuals.

In its efforts to trace cases of COVID-19, South Korea also used a non-voluntary method that centralized data compilation. In contrast to China, South Korea limited any use of the data it collected to COVID-19 surveillance. When patients were confirmed with COVID-19, South Korea compiled a dossier that was designed to provide as complete as possible a picture of where they might have been. Dossiers included smartphone data, credit card transactions, immigration information, and footage from security cameras (Jo 2020). These dossiers were then used to identify
and notify possible contacts as well as to identify hotspots such as bars where a number of transmissions might have taken place (Lin and Martin 2020). Information about virus hotspots was publicized so that people who might have been at the scene could learn about their possible risks. Although individual information was only released by number rather than by personal identifiers, some people were reidentified by their movement histories and “doxed” or otherwise stigmatized (Jo 2020; Kim 2020). After the South Korean Human Rights Commission urged further privacy protections, the guidelines were amended to exclude disclosure of any information that could be personally identifiable (Jo 2020). However, routes that a confirmed-positive patient traveled could still be disclosed, leading to ongoing concerns about individual privacy and the consequences for businesses named as sites visited by infected persons (Kim 2020). In addition, people who are isolated due to exposures have apps that track their whereabouts to make sure they are adhering to the restrictions. Importantly, none of the information gathered in Korea for COVID-19 surveillance could be used for any purpose other than disease outbreaks, including public safety or national security. One commentator suggests this might be called “virtuous surveillance—a radically transparent version of people-tracking that is subject to public scrutiny and paired with stringent legal safeguards against abuse” (Kim 2020).

In cooperation with technology companies, a variety of groups have been developing more privacy-protective ways to enhance contact tracing by using smart devices. These methods differ by whether they rely on centrally stored data or data stored only on individual phones and by the extent of user control. Data storage on individual phones is the most privacy protective. However, evidence as of this writing suggests that it is the least useful—although this may change if people perceive this method as trustworthy and effective and thus are encouraged to sign up for it.

One technology uses mobile location data to trace where an individual has been. Individuals carrying their cellphones may be traced by triangulating cellphone towers with which a user’s phone has been in contact to attempt to determine their precise locations. The information is not stored on the individual’s phone but is stored by the telecommunications companies. Another location tracing technology uses GPS (global positioning system) information collected by apps running on cellphones. Mapping apps, fitness apps, or apps recommending nearby restaurants collect this information. It is often harvested for commercial purposes such as advertising or risk assessment based on knowledge of the app user’s habits. Such locational information may be highly sensitive, revealing that an individual has entered a cancer treatment center, an abortion clinic, a cannabis dispensary, or a shop selling sex toys, among many other possibilities. Governments may also seek access to the information to determine the individual’s whereabouts (as indicated by the cellphone location or from the apps); in 2018, the US Supreme Court held that month-long collection of locational data from cellphone records without a search warrant violated the user’s right to privacy (Carpenter 2018).

Locational data from cellphones can be used to trace the movements of individuals who have been diagnosed with COVID-19. Because it is time-stamped, it can also identify individuals who may have been in the same location for times when
exposure might have been possible. Geolocational tracking may help to jog individuals’ memories about places they visited while they may have been contagious and who they may have encountered during these visits. Privacy advocates and advocates of human rights have raised concerns about these methods, however. Unless individuals have the ability to abandon their phones when they go to sensitive locations, turn off any geolocation functionality, or consent to use of this data for contact tracing, use of the information will not be with their consent or under their control. Critics are also very concerned that if individual geolocation data becomes available to public health it may be used by police, security, or immigration authorities to track movements. Human Rights Watch (2020) has identified some emergency decrees for use of geolocation data in COVID-19 tracking that may lead to human rights abuses. Privacy concerns led the state of Utah to turn off the locational tracking function in its COVID-19 app, Healthy Together, leaving the app without one of its initial selling points (Rodgers 2020).

Bluetooth technology is more protective of individual privacy. This technology—used for example to enable wireless linkage between cellphones and earphones—picks up signals indicating proximity with other similarly equipped devices. Use of Bluetooth does not require locational information although the two can be combined. Data can be stored on individual devices rather than centrally collected. A partnership between Apple and Google has built an infrastructure that allows individuals to download an app that creates an encrypted identifier for their device (Nield 2020). That app will record the identifiers for any devices also using the app that are in sufficiently close proximity to be picked up by Bluetooth—a distance up to about 30 feet (Greenberg 2020). An individual who tests positive for COVID-19 and who also has the app can then send a signal to other app users that lets them know that a device with the individual’s encrypted identifier has been close to them, and they should take steps to be tested and to isolate. As originally described, the app did not share either locational information or the information about the potential exposure source—just the fact that there was device proximity sufficient to suggest the possibility of exposure. The approach seemed more likely to be attractive to people with strong privacy protective concerns. However, reports surfaced in July 2020 that when used on Android systems Google might pick up locational information from some users and countries using the app sought clarification (Singer 2020). The disadvantage of this technology is its limited efficacy and the possibility that it may create a false sense of security if people believe it will reveal any exposures they might have experienced (Cohen et al. 2020). Without locational information, it will not identify devices that passed through the area at an earlier or later time but that could be an exposure source. Moreover, it only works if a sufficient number of people voluntarily download the app and enter any positive test results into it.

Indeed, the COVIDSafe app used by Australia is an apt illustration of the difficulties in rolling out this Bluetooth approach. Individuals are invited to download the app and provide their name, mobile number, postcode, and age range (Australia Health 2020). They then receive a confirming text message to complete the installation. An encrypted reference code is created as a unique identifier. Then, as app
users go about in the world, they must keep their phone running with the app turned on and Bluetooth enabled. Whenever a phone running the app gets sufficiently close to another user’s phone, it notes the date, time, distance and duration of the contact, along with the encrypted reference code of that user, but not the location of the contact. The information, stored only in the app on the user’s phone, is automatically fully deleted after 21 days, the outside window of possible infection. If a user tests positive, a public health contact tracer contacts the user in the usual way. The interviewer asks whether the user has the app and is willing to allow data from the app to be used in contact tracing—another point at which the user has the option whether to participate. If the user agrees, encrypted information from the app is uploaded to a secure information storage system. Health officials then use the information to identify contacts and proceed in the ordinary way for contact tracing. The only difference between this method and contact tracing that is not digitally enhanced is the information provided by the app about proximity with other users.

Australia was initially very optimistic about the potential for the app. However, several months into the pandemic, it appeared that the app had not added very much to Australia’s success in pandemic control, possibly identifying at most one case of infection that would not have been caught through ordinary contact tracing methods (Taylor 2020). One problem was user uptake. Australia set a target of about 40% of the population using the app but appears to have fallen about 1.5 million users short of that target. Some Australians do not have smartphones, others use them inconsistently, and others were unable or uninterested in downloading the app. Poll data indicated that Australians did not think that the app would be particularly effective or that the threat of the virus was sufficiently great to warrant use of the app.

Another more significant problem with COVIDSafe was an initial difficulty for use of the app on Apple iPhones. Apple privacy protections required that the app run on the screen of the phone, an impractical requirement for most users because of battery use. The Apple-Google interface moves the Bluetooth connection process to the operating system but will not give identifying information about the phones with which the user has been in contact. Instead, it will send alerts to other users that their phones have had a potential exposure. It is then up to these other users to follow up and get tested. The COVIDSafe app would need to be retrofitted to employ this functionality.

Other countries rolled out apps that incorporated the Apple-Google interface. Latvia launched its app, Apturi (Stop) Covid, at the end of May 2020. Latvia’s app was designed to work within the country but with the possibility of interfacing with other European countries such as Germany (Reuters 2020).

Digitally enhanced contact tracing thus presents an informative example of the balance between surveillance efficacy and protection of what many see as individual rights. Methods that are most effective are not very protective of individuals, especially if they are not voluntary, store information centrally, and allow information to be used for purposes other than pandemic tracing. China illustrates perhaps the most problematic version of these methods for individuals as victims; South Korea’s method is more protective but still includes some secondary risks. Methods that are very privacy protective are unlikely to add much to traditional contact
tracing, as the Australian example indicates. Making the methods non-voluntary and adding geolocation data to them greatly increases efficacy. But it also emphasizes the importance of transparency and controls on data use other than for pandemic surveillance.

### 3.8 Informing the Subjects of Reports

Laws require many contagious diseases to be reported to public health. Reporting requirements may extend beyond efforts to control contagion through case finding and contact tracing. In Chapter 5, we consider some of these other data collections by public health, including disease registries and tracking the incidence of non-contagious conditions such as cancer or birth defects. Here, we focus primarily on reports of contagious diseases that track disease spread and are used for contact tracing. Unless their providers tell them, patients may be unaware that reporting is taking place. This question of notice presents conflicting risks for surveillance.

On one side, some fear that informing patients about reports may increase reluctance to seek care and reduce patients’ trust in how their physicians manage their medical records. People who know their contagion has been reported may also seek to evade public health officials. Public suspicion may be aroused by the knowledge that governmental entities possess information, even when that information has been deidentified and is not shared for the purpose of tracking contagion. Moreover, informing patients requires an additional step on the part of the physician that may result in patient requests for further explanations and time-consuming reassurance, although the burdens of notification can be reduced with electronic communication. Protection of those who make reports, who may not always be physicians, is also a concern. Finally, as we discuss in detail in Chapter 5, state law protections for information possessed by public health are uneven.

On the other side, there are significant advantages to informing people that they have been the subject of reports to public health. Mistrust may result if people learn that data have been shared without their knowledge. Transparency is often a starting point for trust, as the lack of transparency is for mistrust. Knowledge that the information has been revealed can enable people to take steps to protect themselves if further disclosures occur. The case for informing people that information has been shared is especially strong when public health data safeguards are relatively weak. This allows people to take steps to protect themselves such as informing others of their conditions in a way that is designed to allay concerns and mitigate unfavorable reactions to the extent possible. When information about data sharing and use is public, moreover, watchdog organizations may also act to protect the public or groups within the public from data misuse.

Informing people is a way of letting them know about the possible benefits of public health, too. People can be told about the knowledge gained from shared data for themselves and for their community. Information about public health data use may include information for patients about treatment that may be available for their
conditions. Regular updates can tell communities what is being accomplished with public health data and how it contributes to improving health. These factors, we think, will in most contemporary circumstances weigh in favor of routinely informing individuals and the public when data have been shared with public health. The more that people recognize the benefits of public health data use for themselves and their community, and the more they receive information and support for their own health, the more sustainable surveillance will be.

3.9 Summary

Identification of index cases, in combination with tracing their contacts, remains a commonly recommended form of surveillance to increase treatment frequency and reduce disease spread. When chains of transmission can be followed easily, its efficacy is greatest. It may be especially helpful in situations in which a new disease is introduced into a community in which it was not already widespread. Its benefits are clearest, and risks reduced, when effective treatment is readily available.

Case identification and contact tracing may cause significant harm to those it implicates, however. Historically these methods have been associated with judgments of moral condemnation, particularly of individuals judged to be the sources of sexually transmitted diseases. These risks were especially clear at the outset of the HIV/AIDS epidemic, as the disease was deadly, untreatable, and its modes of transmission were poorly understood. Because of these risks to individuals, testing for HIV/AIDS initially required elaborate informed consent. Controversies arose about whether patient confidentiality ought to be protected. Arguments for breaching confidentiality were judged to be strongest when unknowing partners were at immediate risk, but with the recognition that relationships could be forever altered and individuals’ personal and economic security severely threatened. Panic about the possibility that health care providers could transmit disease—or that disease might otherwise be transmitted in workplaces—gradually subsided in the face of evidence that the initial panic was unwarranted.

Case identification and contact tracing therefore raise a balance of ethical considerations which may weigh differently depending on the context. They are most morally compelling when their benefits can be maximized, their harms can be minimized, and better alternatives for disease prevention are lacking. In the best of circumstances, when persons who have become infected can be identified without stigma, and treated without shame, they are an ethically sustainable form of public health surveillance.
References

Adler, Michael W. 1980. The Terrible Peril: A Historical Perspective on the Venereal Diseases. *British Medical Journal* 281: 206–211.
Alexander, Thomas S. 2016. Human Immunodeficiency Virus Diagnostic Testing: 30 Years of Evolution. *Clinical and Vaccine Immunology* 23 (4): 249–253.
Anderson, Tim. 2009. HIV/AIDS in Cuba: A Rights-Based Analysis. *Health and Human Rights* 11 (1): 93–104.
Angell, Marcia. 2000. Investigators’ Responsibilities for Human Subjects in Developing Countries. *New England Journal of Medicine* 342: 967–969.
Annas, George. 2009. Globalized Clinical Trials and Informed Consent. *New England Journal of Medicine* 360: 2050–2053.
Armbruster, Benjamin, and Margaret Brandeau. 2007. Contact Tracing to Control Infectious Disease: When Enough is Enough. *Health Care Management Science* 10 (4): 341–355.
Australian Government Department of Health (Australia Health). 2020. COVIdSafe app. https://www.health.gov.au/resources/apps-and-tools/covidsafe-app#:~:text=The%20COVIdSafe%20app%20helps%20find,with%20someone%20with%20COVId%2019. Accessed 15 July 2020.
Bayer, Ronald, and Cheryl Healon. 1989. Controlling AIDS in Cuba: The Logic of Quarantine. *New England Journal of Medicine* 320: 1022–1024.
Beauchamp, Tom L., and James F. Childress. 1979. *The Principles of Biomedical Ethics*. New York: Oxford University Press.
Boone, Stephanie A., and Charles P. Gerba. 2007. Significance of Fomites in the Spread of Respiratory and Enteric Viral Disease. *Applied and Environmental Microbiology* 73 (6): 1687–1696.
Brandt, Allan M. 1985. *No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880*. New York: Oxford University Press.
Branson, Bernard M., H. Hunter Handsfield, Margaret A. Lampe, Robert S. Janssen, Allan W. Taylor, Sheryl B. Lyss, and Jill E. Clark. 2006. Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings. *Mortality and Morbidity Weekly Report* (Sept. 22)/55(RR14): 1–17.
British Medical Association (BMA). 1987. HIV Antibody Testing: Summary of BMA Guidance. *British Medical Journal* 295 (10 Oct): 940.
Carlisle, Nate. 2019. Utah’s Controlled Substance Database Susceptible to Hacking, Auditors Warn. Salt Lake Tribune [online] (Feb. 13). https://www.sltrib.com/news/politics/2019/02/13/utahs-controlled/. Accessed 15 July 2020.
Castro, Arachu, and Paul Farmer. 2005. Understanding and addressing AIDS-related stigma: from anthropological theory to clinical practice in Haiti. *American Journal of Public Health* 95 (1): 53–59.
Carpenter v. United States, 585 U.S. ___, 138 S.Ct. 2206 (2018).
Centers for Disease Control & Prevention (CDC). 2019. National Notifiable Diseases Surveillance System (NNDSS). https://wwwn.cdc.gov/ndss/. Accessed 15 July 2020.
———. 2018. HIV Prevention Pill Not Reaching Most Americans Who Could Benefit—Especially People of Color (Mar. 6). https://www.cdc.gov/nchhstp/newsroom/2018/croi-2018-PrEP-press-release.html. Accessed 15 July 2020.
Closser, Svea, Anat Rosenthal, Kenneth Maes, Judith Justice, Kelly Cox, Patricia A. Omidian, Ismaila Zango Mohammed, Aminu Mohammed Dukku, Adam D. Koon, and Laetitia Nyirazinyoye. 2015. The Global Context of Vaccine Refusal: Insights from a Systematic Comparative Ethnography of the Global Polio Eradication Initiative. *Medical Anthropology Quarterly* 30 (3): 321–341.
Cohen, Carl. 1988. Commentary on Case Studies: What is the Difference Between and HIV and a CBA? *The Hastings Center Report* 18 (4): 19–20.
Cohen, I. Glenn, Lawrence O. Gostin, and Daniel J. Weitzner. 2020. Digital Smartphone Tracking for COVID-19—Public Health and Civil Liberties in Tension. *Journal of the American Medical Association* 323 (23): 2371–2372.

Committee for the Study of the Future of Public Health (Committee). 1988. *The Future of Public Health*. Washington, DC: National Academy Press.

Cooper, Elizabeth B. 2001. Social Risk and the Transformation of Public Health Law: Lessons from the Plague Years. *Iowa Law Review* 86: 869–947.

Department of Health and Human Services (DHHS). 1979. *Healthy People: The Surgeon General’s Report on Health Promotion And Disease Prevention*. https://profiles.nlm.nih.gov/spotlight/nm/catalog/nlmuid-101584932X94-doc. Accessed 15 July 2020.

Deporte, J.V. 1941. Premarital and Prenatal Tests for Syphilis. *The Lancet* 238 (6150): 59.

Doe v. University of Maryland Medical System Corporation, 50 F.3d 1048 (4th Cir. 1995).

Doe v. Marselle, 675 A.2d 835 (Conn. 1996).

Dickens, Bernard. 1988. Legal Limits of AIDS Confidentiality. *Journal of the American Medical Association* 259 (23): 3449–3451.

Dillard v. O’Kelley, 961 F.3d 1048 (8th Cir. 2020).

Doe v. University of Maryland Medical System Corporation, 50 F.3d 1261 (4th Cir. 1995).

Edelman, E.J., K.S. Gordon, M. Hogben, S. Crystal, K. Bryant, A.C. Justice, and D.A. Fiellin. 2014. Sexual Partner Notification of HIV Infection Among a National United States-Based Sample of HIV-Infected Men. *AIDS & Behavior* 18 (1): 1898–1903.

Evans, Erica. 2017. How a 2015 Law Change Affected Law Enforcement’s Fight Against the Opioid Crisis. Deseret News [online] (Dec. 6). https://www.deseretnews.com/article/900005271/how-this-2015-law-change-affected-the-fight-against-the-opioid-crisis.html. Accessed 15 July 2020.

Ezeome, Emmanuel R., and Christian Simon. 2010. Ethical Problems in Conducting Research in Acute Epidemics: The Pfizer Meningitis Study in Nigeria as an Illustration. *Developing World Bioethics* 10 (1): 1–10.

Fallone, Edward A. 1988. Preserving the Public Health: A Proposal to Quarantine Recalcitrant AIDS Carriers. *Boston University Law Review* 68 (2): 441–506.

Fairchild, Amy L., David Rosner, James Colgrove, Ronald Bayer, and Linda P. Fried. 2010. The EXODUS of Public Health: What History Can Tell Us About the Future. *American Journal of Public Health* 100 (1): 54–63.

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.

Ferreira, A., T. Young, C. Mathews, M. Zunza, and N. Low. 2013. Strategies for Partner Notification for Sexually Transmitted Infections, Including HIV. Cochrane Database of Systematic Reviews 3(10): CD002843. https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD002843.pub2/abstract. Accessed 15 July 2020.

Frith, John. 2012. Syphilis—Its Early History and Treatment until Penicillin and the Debate on its Origins. *Journal of Military and Veterans’ Health* 20 (4): 49–58.

Gabriel, Trip. 2020. Ohio Lawmaker Asks Racist Question About Black People and Hand-Washing. *The New York Times* [online] (June 11). https://www.nytimes.com/2020/06/11/us/politics/steve-huffman-african-americans-coronavirus.html. Accessed 25 July 2020.

Garrett, Laurie. 2018. Welcome to the Next Deadly AIDS Pandemic. *Foreign Policy* (July 25) [online]. https://foreignpolicy.com/2018/07/25/welcome-to-the-next-deadly-aids-pandemic/?utm_source=PostUp&utm_medium=email&utm_campaign=Editors%20Picks%20%7C%207/25/2018%20-%20BSA&utm_keyword=Editor#39;s%20Picks%20OC. Accessed 15 July 2020.

Gillon, Raanan. 1987. AIDS and Medical Confidentiality. *British Medical Journal* 294 (27 June): 1675.

Gostin, Larry. 1986. The Nucleus of a Public Health Strategy to Combat AIDS. *Law, Medicine and Health Care* 14 (5–6): 226–230.
Gostin, Lawrence O., and James G. Hodge Jr. 1998. Piercing the Veil of Secrecy in HIV/AIDS and other Sexually Transmitted Diseases: Theories of Privacy and Disclosure in Partner Notification. *Duke Journal of Gender Law & Policy* 5: 9–88.

Greenberg, Andy. 2020. How Apple and Google Are Enabling Covid-19 Contact-Tracing. *WIRED* [online] (April 10). https://www.wired.com/story/apple-google-bluetooth-contact-tracing-covid-19/. Accessed 15 July 2020.

Gruskin, Sofia. 2002. The UN General Assembly Special Session on HIV/AIDS: Were Some Lessons of the Last 20 Years Ignored? *American Journal of Public Health* 92 (3): 337–338.
———. 2002a. Ethics, Human Rights, and Public Health. *American Journal of Public Health* 92 (5): 698.

Gutmann, Amy. 1985. Review: Communitarian Critics of Liberalism. *Philosophy and Public Affairs* 14 (3): 304–322.

Health Insurance Portability and Accountability Act Rule (HIPAA), 45 C.F.R. § 164.512(b) (2019).

HIV.gov. 2018. Limits on Confidentiality: HIV Disclosure Policies and Procedures. https://www.hiv.gov/hiv-basics/living-well-with-hiv/your-legal-rights/limits-on-confidentiality. Accessed 15 July 2020.

Human Rights Watch. 2020. Mobile Location Data and Covid-19: Q&A (May 13). https://www.hrw.org/news/2020/05/13/mobile-location-data-and-covid-19-qa. Accessed 15 July 2020.

Institute of Medicine (IOM). 1990. *Expanding Access to Investigational Therapies for HIV Infection and AIDS: March 12–13, 1990 Conference Summary*. Washington, DC: National Academies Press.

John, Steven A., Jennifer L. Walsh, Young If Cho, and Lance S. Weinhardt. 2018. Perceived Risk of Intimate Partner Violence Among STI Clinic Patients: Implications for Partner Notification and Patient-Delivered Partner Therapy. *Archives of Sexual Behavior* 47 (2): 481–492.

Jo, Eun A. 2020. South Korea’s Experiment in Pandemic Surveillance. *The Diplomat* [online] (April 13). https://thediplomat.com/2020/04/south-koreas-experiment-in-pandemic-surveillance/. Accessed 15 July 2020.

Kampf, Antje. 2008. ‘A ‘little world of your own’: stigma, gender, and narratives of venereal disease contact tracing. *Health: An Interdisciplinary Journal for the Social Study of Health. Illness and Medicine* 12 (2): 233–250.

Kazanjian, Powel. 2012. The AIDS Pandemic in Historic Perspective. *Journal of the History of Medicine and Allied Sciences* 69 (3): 351–382.

Kass, Nancy, and Andrea Carlson Gielen. 1998. The Ethics of Contact Tracing Programs and Their Implications for Women. *Duke Journal of Gender Law & Policy* 5: 89–102.

Kegeles, SusanM., Joseph A. Catania, Thomas J. Coates, Lance M. Pollack, and Bernard Lo. 1990. Many people who seek anonymous HIV-antibody testing would avoid it under other circumstances. *AIDS* 4 (6): 585–588.

Keane, Mary Beth. 2013. *Fever*. New York: Scribner’s.

Kim, Max S. 2020. Contact Tracing. *The New Yorker* [online] (April 17). https://www.newyorker.com/news/news-desk/seouls-radical-experiment-in-digital-contact-tracing.

Lambert, Bruce. 1989. AIDS Insurance Coverage is Increasingly Hard to Get. *The New York Times* [archive online], https://www.nytimes.com/1989/08/07/us/aids-insurance-coverage-is-increasingly-hard-to-get.html. Accessed 15 July 2020.

Leavitt, Judith Walzer. 1997. *Typhoid Mary: Captive to the Public’s Health*. Boston: Beacon Press.

Leonard, Thomas C. 2016. *Illiberal Reformers: Race, Eugenics & American Economics in the Progressive Era*. Princeton: Princeton University Press.

Levine, Carol, and Ronald Bayer. 1989. The Ethics of Screening for Early Intervention in HIV Disease. *American Journal of Public Health* 79 (12): 1661–1667.

Levine, Philippa. 1996. Rereading the 1890s: Venereal Disease as “Constitutional Crisis” in Britain and British India. *The Journal of Asian Studies* 55 (3): 585–612.

Lin, Laura, and Bryan A. Liang. 2005. HIV and Health Law: Striking the Balance Between Legal Mandates and Medical Ethics. *Virtual Mentor* 7 (10): 687–692.
Lin, Liza, and Timothy W. Martin. 2020. How Coronavirus is Eroding Privacy. *The Wall Street Journal* [online] (April 15). https://www.wsj.com/articles/coronavirus-paves-way-for-new-age-of-digital-surveillance-11586963028. Accessed 15 July 2020.

Lindsay, Matthew J. 1998. Reproducing a Fit Citizenry: Dependency, Eugenics, and the Law of Marriage in the United States, 1860–1920. *Law and Social Inquiry* 23: 541–585.

Luker, Kristin. 1998. Sex, Social Hygiene, and the State: The Double-Edged Sword of Social Reform. *Theory and Society* 27 (5): 601–634.

Lurie, Peter, and Sidney M. Wolfe. 1997. Unethical Trials of Interventions to Reduce Perinatal Transmission of the Human Immunodeficiency Virus in Developing Countries. *New England Journal of Medicine* 337: 853–856.

Magaziner, Sarah, Madeline C. Montgomery, Thomas Bertrand, Daniel Daltry, Heidi Jenkins, Brenda Kendall, Lauren Molotnikov, Lindsay Pierce, Emer Smith, Lynn Sosa, Jacob J. van den Berg, Theodore Marak, Don Operario, and Philip A. Chan. 2018. Public Health Opportunities and Challenges in the Provision of Partner Notification Services: The New England Experience. *BMC Health Services Research* 18: 75. https://doi.org/10.1186/s12913-018-2890-7. Accessed 15 July 2020.

Mann, Jonathan. 1987. AIDS—A Global Challenge. *Health Education Journal* 46 (2): 43–45.

Marineli, Filio, Gregory Tsoucalas, Marianna Karamanou, and George Androutsos. 2013. Mary Mallon (1869–1938) and the History of Typhoid Fever. *Annals of Gastroenterology* 26 (2): 132–134.

McGann v. H & H Music Company, 946 F.2d 401 (5th Cir. 1991).

McNeil, Donald G., Jr. 2018. He Took a Drug to Prevent AIDS. Then He Couldn’t Get Disability Insurance. *The New York Times* (Feb. 12) [online]. https://www.nytimes.com/2018/02/12/health/truvada-hiv-insurance.html. Accessed 15 July 2020.

Molina, Jean-Michel, Isabelle Charreau, Bruno Spire, Laurent Cotte, Julie Chas, Catherine Capitant, Cecile Tremblay, Daniela Rojas-Castro, Eric Cua, Armelle Pasquet, Camille Bernaud, Claire Pintado, Constance Delaegerre, Luis Sagoan-Teyssier, Soizic Le Mestre, Christian Chidllic, Gilles Pialoux, Diane Ponscarme, Julien Fonsart, David Thompson, Mark A. Wainberg, Veronique Doré, and Laurence Meyer. 2017. *The Lancet: HIV* 4 (9): PE402–PE410.

Moore, Kristine, Jill DeBoer, Richard Hoffman, Patrick McConnon, Dale Morse, and Michael Ostergren. 2020. *COVID-19: The CIDRAP Viewpoint, Part 4: Contact Tracing for COVID-19: Assessing Needs, Using a Tailored Approach* (June 2). CIDRAP. https://www.cidrap.umn.edu/sites/default/files/public/downloads/cidrap-covid19-viewpoint-part4.pdf. Accessed 14 July 2020.

Mozur, Paul, Raymond Zhong and Aaron Krolik. 2020. In Coronavirus Fight, China Gives Citizens a Color Code, With Red Flags. *The New York Times* [online] (March 1). https://www.nytimes.com/2020/03/01/business/china-coronavirus-surveillance.html. Accessed 15 July 2020.

National Cancer Institute (NCI). 2019. About the SEER Program. https://seer.cancer.gov/about/. Accessed 15 July 2020.

Nield, David. 2020. How Covid-19 Contact Tracing Works on Your Phone. *WIRED* [online] (June 7). https://www.wired.com/story/covid-19-contact-tracing-apple-google/. Accessed 15 July 2020.

North, Richard L., and Karen J. Rothenberg. 1993. Partner Notification and the Risk of Domestic Violence against Women with HIV Infection. *New England Journal of Medicine* 329: 1194–1196.

Nurse-Findlay, Stephen, Melanie M. Taylor, Margaret Savage, Maeve B. Mello, Sanni Saliyou, Manuel Lavayen, Frederic Seghers, Michael L. Campbell, Françoise Birgirimana, Leopold Ouédraogo, Morkor Newman Owiredu, Nancy Kidula, and Pyne-Mercier Lee. 2017. Shortages of Benzathine Penicillin for Prevention of Mother-to-Child Transmission of Syphilis: An Evaluation from Multi-Country Surveys and Stakeholder Interviews. *PLoS Medicine* 14 (12): e1002473. https://doi.org/10.1371/journal. Accessed 15 July 2020.
Otterman, Sharon. 2020. N.Y.C. Hired 3,000 Workers for Contact Tracing. It’s Off to a Slow Start. *The New York Times* [online] (June 21). https://www.nytimes.com/2020/06/21/nyregion/nyc-contact-tracing.html. Accessed 15 July 2020.

Padgug, Robert A., Gerald M. Oppenheimer, and Jon Eisenhandler. 1993. AIDS and Private Health Insurance: A Crisis of Risk Sharing. *Cornell Journal of Law and Public Policy* 3 (1): 55–81.

Parker, Richard. 2002. The Global HIV/AIDS Pandemic, Structural Inequalities, and the Politics of International Health. *American Journal of Public Health* 92 (3): 343–347.

Parker, Richard, and Peter Aggleton. 2003. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine* 57 (1): 13–24.

Pérez-Stable, Eliseo J. 1991. Cuba’s Response to the HIV Epidemic. *American Journal of Public Health* 81 (5): 563–567.

Perry, Nicole. 2015. Diseased Bodies and Ruined Reputations: Venereal Disease and the Construction of Women’s Respectability in early 20th Century Kansas. https://kuscholarworks.ku.edu/bitstream/handle/1808/25635/Perry_ku_0099D_14388_DATA_1.pdf?sequence=1. Accessed 15 July 2020.

Poirier, Suzanne. 1995. *Chicago’s War on Syphilis, 1937–1940: The Times, the Trib, and the clap Doctor*. Urbana/Chicago: University of Illinois Press.

Reuters. 2020. Latvia to Launch Google-Apple Friendly Coronavirus Contact Tracing App. Reuters Technology News [online] (May 25). https://uk.reuters.com/article/us-health-coronavirus-tech-latvia/latvia-to-launch-google-apple-friendly-coronavirus-contact-tracing-app-idUKKBN23118I. Accessed 15 July 2020.

Rodgers, Bethany. 2020. Utah’s Expensive Coronavirus App Won’t Track People’s Movements Anymore, Its Key Feature. Salt Lake Tribune [online] (July 11, 2020). https://www.sltrib.com/news/politics/2020/07/11/states-m-healthy-together/. Accessed 15 July 2020.

Rothenberg, Karen H., and S.J. Paskey. 1995. The Risk of Domestic Violence and Women with HIV Infection: Implications for Partner Notification, Public Policy, and the Law. *American Journal of Public Health* 85 (11): 1569–1576.

Rothschild, Bruce M. 2005. History of Syphilis. *Clinical Infectious Disease* 40 (10): 1454–1463.

Samuels, Michael E., Jonathan Mann, and C. Everett Koop. 1988. Containing the Spread of HIV Infection: A World Health Priority. *Public Health Reports* 103 (3): 221–223.

Schwartzbaum, Judith A., John R. Wheat, and Robert W. Norton. 1990. Physician Breach of Patient Confidentiality among Individuals with Human Immunodeficiency Virus (HIV) Infection: Patterns of Decision. *American Journal of Public Health* 80 (7): 829–834.

Scitovsky, Anne A. 1988. The Economic Impact of AIDS in the United States. *Health Affairs* 7 (4): 32–45.

Shaffer, D.N., V.N. Yebei, J.B. Ballidawa, John E. Sidle, J.Y. Greene, Eric M. Meslin, Sylvester J.N. Kimaiyo, and William M. Tierney. 2006. Equitable Treatment for HIV/AIDS Clinical Trial Participants: A Focus Group Study of Patients, Clinician Researchers, and Administrators in Western Kenya. *Journal of Medical Ethics* 32: 55–60.

Shrank, Alan B. 1987. Letter: Is Testing for HIV Without Consent Ever Warranted? *British Medical Journal* 294 (14 Feb.): 445.

Singer, Natasha. 2020. Google Promises Privacy With Virus App but Can Still Collect Location Data. *The New York Times* [online] (July 20). https://www.nytimes.com/2020/07/20/technology/google-covid-tracker-app.html. Accessed 20 July 2020.

Smith, David. 2011. Pfizer Pays Out to Nigerian Families of Meningitis Drug Trial Victims. *The Guardian* [online] (Aug. 12). https://www.theguardian.com/world/2011/aug/11/pfizer-nigeria-meningitis-drug-compensation. Accessed 15 July 2020.

Snyder, Lynne Page. 1995. The Career of Surgeon General Thomas J. Parran, Jr., MD, (1892–1968). *Public Health Reports* 110: 630–632.

Soper, George A. 1939. The Curious Career of Typhoid Mary. *Bulletin of the New York Academy of Medicine* 15 (10): 698–712.

*Southern Illinoisan v. Illinois Department of Public Health*, 844 N.E. 2d 1 (Ill. 2006).
References

Steven Joffe, Holly Fernandez Lynch. 2018. Federal Right-to-Try Legislation — Threatening the FDA’s Public Health Mission. *New England Journal of Medicine* 378 (8): 695–697.

Swartz, Martha. 1987. AIDS Testing and Informed Consent. *Journal of Health Politics, Policy and Law* 13 (4): 607–621.

Symanski, Richard. 1974. Prostitution in Nevada. *Annals of the Association of American Geographers* 64 (3): 357–377.

*Tarasoff v. Regents of the University of California*, 551 P.2d 334 (1976).

Taylor, Josh. 2020. How Did the CovidSafe App Go from Being Vital to Almost Irrelevant? *The Guardian* [online] (May 23). https://www.theguardian.com/world/2020/may/24/how-did-the-covidsafe-app-go-from-being-vital-to-almost-irrelevant. Accessed 15 July 2020.

Tomes, Nancy. 1997. Moralizing the Microbe: The Germ Theory and the Moral Construction of Behavior in the Late-Nineteenth-Century Antituberculosis Movement. In *Morality and Health*, ed. Allan M. Brandt and Paul Rozin, 271–296. New York: Routledge.

Tramont, Edmund C., and Shant S. Bohajian. 2010. Learning from History: What the Public Health Response to Syphilis Teaches Us About HIV/AIDS. *Journal of Contemporary Health Law & Policy* 26: 253–299.

UNAIDS. 2018. ABOUT: Saving Lives, Leaving No One Behind. http://www.unaids.org/en/whoweare/about. Accessed 15 July 2020.

———. 2018a. Miles To Go: Closing Gaps, Breaking Barriers, Righting Injustices. http://www.unaids.org/sites/default/files/media_asset/miles-to-go_en.pdf. Accessed 15 July 2020.

Varmus, Harold, and David Satcher. 1997. Ethical Complexities of Conducting Research in Developing Countries. *New England Journal of Medicine* 337: 1103–1005.

Vreeman, Rachel, Eunice Kamaara, Allan Kamands, David Ayuku, Winstone Nyandiko, Lukoye Atwoli, Samuel Ayaya, Peter Gisore, Michael Scanlon, and Paula Braithstein. 2012. A Qualitative Study Using Traditional Community Assemblies to Investigate Community Perspectives on Informed Consent and Research Participation in Western Kenya. *British Medical Journal Medical Ethics* 13: 23.

Winston, Morton, and Sheldon Landesman. 1987. Case Studies: AIDS and the Duty to Protect. *Hastings Center Report* 17 (1): 22–23.

World Medical Association. 2019. Declaration of Helsinki. https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/. Accessed 15 July 2020.

Xinhuanet. 2020. Alipay Health Code Landed in 100 Cities in 7 Days, Digital Epidemic Prevention Ran Out of “Chinese Speed” (Feb. 19). http://www.xinhuanet.com/tech/2020-02/19/c_1125596647.htm.

Yang, Y. Tony, and Kristen Underhill. 2018. Rethinking Criminalization of HIV Exposure—Lessons from California’s New Legislation. *New England Journal of Medicine* 378: 1174–1175.

Zhong, Raymond. 2020. China’s Virus Apps May Outlast the Outbreak, Stirring Privacy Fears. *The New York Times* [online] (May 26). https://www.nytimes.com/2020/05/26/technology/china-coronavirus-surveillance.html.