Chapter 4
Surveillance and Equity: Identifying Hazards in the Environment

In the preceding chapter, we emphasized that surveillance must not result in people being harmed because of who they are or the groups with which they are associated. In this chapter, we take up another injustice in surveillance: where surveillance looks. Surveillance may be directed towards protecting the health of some, but not the health of others in the community. These inequities in surveillance may undermine trust, particularly if data gathered from those who are not benefited by surveillance is used to benefit others who are better off.

4.1 Health Equity

Health equity is a core goal of public health practice. The WHO Guidelines place improving equity—that is, reducing inequality that is morally relevant—as a central goal of surveillance:

> Public health surveillance can further the pursuit of equity by identifying the particular problems of disadvantaged populations, including global communities, providing the evidence for focused health campaigns and identifying the basis of unfair differences in health. (WHO 2017a, p. 21)

On this view, what makes inequality morally relevant is its unfair impact on disadvantaged populations.

The Robert Wood Johnson Foundation (RWJ) discussion of wealth and health inequity similarly emphasizes unfairness to disadvantaged populations:

> Health equity means that everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay; quality education and housing; safe environments; and health care. For the purposes of measurement, health equity means reducing and ultimately eliminating disparities in health and its
determinants that adversely affect excluded or marginalized groups. (Braveman et al. 2018, p. 1; see also Braveman et al. 2017)

RWJ describes “excluded or marginalized groups” as those who have been “pushed to society’s margins, with inadequate access to key opportunities”; they include people of color, people living in poverty especially across generations, religious minorities, people with physical or mental disabilities, LGBTQ persons, and women. (Braveman et al. 2017, p. 4) According to RWJ, in choosing where to focus, public health organizations may consider whether groups suffer multiple disadvantages and where maximal impact can be achieved, among other factors. (Braveman et al. 2017, p. 4) Also according to RWJ, public health should engage these groups in making decisions about surveillance and subsequent actions to improve health equity; we discuss the importance of engagement more fully in Chapter 7 on communities and consent.

Scholars of health equity such as Sir Michael Marmot emphasize that achieving equity requires far more than improving access to health care or improving health care quality. (Institute of Health Equity 2010; WHO Commission 2008). Beyond health care, social determinants of health such as education, employment, sustainable communities, and systemic racism, play major roles in health outcomes. Put succinctly, “health inequalities that could be avoided by reasonable means are unfair.” (Institute of Health Equity 2010, 3).

Surveillance may help in improving health equity. Or, it may compound inequity, both for the information it reveals and the information it does not reveal. If population subgroups are left out of surveillance, information about their disadvantages may not come to light. Predictive algorithms applied to skewed data sets will yield skewed predictions; for example, concerns have been raised that the use of artificial intelligence algorithms in diagnoses of skin cancers will be less accurate among Blacks if they are developed using data primarily from Caucasian patients (Adamson and Smith 2018). If information about other population groups reveals disadvantage, they may be the recipients of efforts to improve equity—efforts that are well intentioned but that have the potential to further deepen the disadvantages of those who are never noticed. How information gained from surveillance is communicated poses an additional set of problems, among them concerns that it will be in languages or forms not well understood or risks that people who are already disadvantaged will be further targeted because of the information revealed.

Providing the information needed to assess inequity—how great it is, whether it is located in particular pockets of a population, and whether progress has been made in improving equity—is a core task of public health surveillance. With the emphasis on social determinants of health, surveillance may need to be broadened beyond health care and health status. Instead, circumstances of daily life and the environments in which people live will loom in importance. For this reason, we use surveillance of environmental hazards to health as our primary illustration for the discussion of equity in surveillance; readers should keep in mind, however, that similar issues will attend equity in surveillance of other topics such as contagious or chronic diseases.
4.2 Environmental Hazards and Public Health Surveillance

Along with preventing the spread of contagious disease, reducing threats from environmental hazards has been the other primary goal of traditional public health. These hazards may be found in the natural world or in the built environment and may be exacerbated by the interface between the two. Today, pressing needs to assess environmental hazards are complicated by impacts of climate change that are generating rapidly shifting and unanticipated health challenges and patterns of disease.

Identification of natural reservoirs of disease, such as swamps where mosquitoes breed or caves where bats dwell can be crucial information for averting the transmission of diseases to humans. Human invasion into previously unsettled areas can lead to the transmission of novel zoonotic infections such as Ebola from non-human animals to humans. Environmental toxins such as lead, mercury, or asbestos, also can prove devastating to human health. Microbes in soil or water can cause diseases such as tetanus.

Sanitary movements emerged across the centuries to address the hazards created by crowded living conditions, such as sewage, garbage, odors, and smoke. One of the most famous examples of public health success was Sir John Snow’s isolation of the Broad Street pump as the source of a cholera epidemic in London in 1854 discussed in detail in Chapter 2; his removal of the pump handle stopped the epidemic from further spread. Sanitation was the goal most identified with improvements in living conditions in increasingly urbanized and crowded environments.

Today, many of the environmental concerns of the early sanitarians—sunlight, clean water, trash collection, and sewage disposal—would be recognizable as aspects of the social determinants of health. Surveillance that attends to health-affecting conditions in the natural or constructed environment may identify social inequities. Conversely, the failure to surveil for such conditions may also be inequitable.

Several features of environmental surveillance should be noted at the outset as relevant from the perspective of equity. Environmental surveillance may reveal information about benefits or burdens that cannot be confined to particular individuals or groups or that may be more particularized. Environmental surveillance may reveal information about hazards that are relatively confined geographically or that cannot be confined within political borders. And, environmental surveillance may press questions about the scope of public health and surveillance. As environmental surveillance observes the conditions in which people live, it may also be perceived as unduly intrusive or threatening.
4.2.1 Public Goods

An important complication of environmental surveillance is that the information it reveals may be about what are known as “public goods.” Public goods are defined by economists as goods which by their nature cannot be restricted to individuals who pay for them. They are non-excludable—if they are provided for some they will also be enjoyed by others—and non-rivalrous—if some enjoy them others will still be able to enjoy them too. Clean air is a primary example. Air is ambient and everyone breathes it. The benefits of reductions in particulate emissions then cannot be confined to those who pay for them. Nor does one person’s breathing clean air reduce the opportunity for others of doing so. Masks contrast: society could address the problem of air pollution by selling masks through the market to those who are able and willing to pay for them and who can deal with the burdens of wearing them. Presumably such market arrangements would also feature a variety of masks of different quality, so those who could pay more might have improved filtration capacity or masks of lighter weight or greater beauty.

Much of what may be done to address environmental issues such as clean air involves public goods in this sense. Everyone benefits—or loses—to at least some extent when information is gleaned about pollution levels that then leads to either increased enforcement of existing standards or imposition of heightened standards. So-called “free riders” can receive the benefit of air quality improvement without paying any of the costs of its production. This raises equity problems: some members of the population will bear the costs of cleaner air while others will enjoy it for free, and both costs and benefits of the good’s production may also be inequitably enjoyed.

Transportation policy is a good example of how the costs of producing clean air may not be distributed equitably. Suppose surveillance reveals high levels of the fine particulate emissions associated with automobile exhaust. Policies that rely on voluntary behavior change such as encouraging the use of public transit or limiting driving trips will allow some to free ride on the good efforts of others. Other policy options may seek to spread costs more widely, such as a gas tax that increases the costs of driving private vehicles, but may still have inequitable effects. Those who are better off in the population may be able to pay the surcharge to drive private vehicles whereas those with fewer resources may find themselves consigned to using public transit. Although the wealthier in this scenario do pay increased taxes, the impact of these costs on them may be far more limited than the full costs of shifting to public transit for those who are worse off and who may experience infection risks on crowded buses, longer commutes to jobs, reduced employment opportunities because public transit is not available to desirable jobs, or difficulties in finding child care that is consistent with transit schedules. Redistributive adjustments such as directing the increased gas tax revenues to improvements in public transit may mitigate the inequities, but these adjustments may not be politically practical, may not solve problems such as infection risks, and in any event may not fully make up for the increased burdens.
Also importantly from the perspective of equity, the benefits and burdens of these improvements may not be distributed equally. For example, emission reductions may not create the same levels of pollution reduction in all parts of an urban area; parts of the metropolis located at higher altitudes may benefit more than lower lying areas where remaining pollution settles. Unfortunately, these distributive differences may bear more heavily on those who are already worse off: people who can only afford less expensive property near toxic sites, low-lying marshland, or areas of sewage disposal. To take another example, rising ocean levels due to global climate change present especially sharp challenges to the availability of clean water in impoverished areas of the globe where droughts are severe and flooding contaminates water sources. (UN Water 2019).

### 4.2.2 Political Borders

Some factors that affect disease prevalence or severity are relatively localized within political borders but others are not. Once again, air quality is a good illustration: local conditions may affect the extent to which particulates are trapped by inversions. Depending on their mass, particulates may remain locally or travel far and wide. Seeds, insects, microbes, and animals cross borders, too; plague-carrying fleas hopped political jurisdictions with impunity over the centuries. Rivers may run between political jurisdictions and effluents discharged upstream will make their way through downstream areas. If an upstream or upwind jurisdiction does not become aware of a toxic emission, it may fail to provide critical information to downstream or downwind jurisdictions in time to prevent serious harm to inhabitants of these lower regions. Even apparently local discharges such as mine tailings may leak into ground water or aquifers and eventually end up across state or national lines. Climate change may be the most universal of all such examples; emissions behaviors in high-consumption countries such as the United States will affect everyone regardless of the jurisdiction in which they live. These changes will have major impacts on population health, from heat waves to changes in the habitat of mosquitoes or other disease carrying insects.

Political borders present problems for the equity of surveillance in several ways. According to the WHO (2019), on average countries across the globe have achieved 71% of the surveillance attributes required by 2018. Africa region countries have achieved the lowest level of required capacities, at 59%. These capacities include financing, human resources, laboratory capabilities, and monitoring at the border. They also include the ability to detect zoonotic events and the possibility of animal-human transmission, unsafe food, chemical events, and radiation exposures. Importantly for others, they also include risk communication, which was at only 57% globally. This figure means that just over half of the countries across the globe had achieved WHO required attributes for risk communication; while the Africa region was the lowest at 39%, South-East Asia was at 60% and the Americas and the
Western Pacific were at 63%—less than two-thirds. Only Europe, at 65%, approached two-thirds of countries achieving the requisite abilities.

Many different factors account for these gaps. Some areas are simply more difficult to surveille because of the nature of the terrain or the lack of infrastructure such as roads or communication systems. Cultural factors or mistrust may explain why people are unwilling to share information. Jurisdictions may have very different resources available to devote to surveillance and limited health care infrastructure to serve as points of contact for information. Jurisdictions also may make different judgments about the resources to devote to surveillance, what to surveille, or whether to reveal the results of surveillance. The current International Health Regulations encourage States Parties to collaborate in detection and to mobilize resources for developing countries to build and maintain their surveillance capabilities (WHO 2016, Article 44). However, this provision is only an encouragement and does not impose requirements on States Parties. The upshot for equity is that the costs of developing surveillance capabilities may be more burdensome in comparison to resources in some countries than in others.

On the other side, failures to surveille may also have inequitable consequences. Countries with greater resources may be less vulnerable to detection failures elsewhere as their better detection capabilities may help to fill in the gaps. But this will not be perfect, especially for conditions that require detection in real time to prevent spread; it may be even more deadly for countries lacking their own surveillance capabilities. The spread of the Ebola epidemic from Guinea across West Africa in 2014 was one recent illustration of the tragic potential of such failures. The spread of COVID-19 is an even greater tragedy, although perhaps attributable more to delays in communicating information and acting on it, rather than to an initial failure to recognize the emerging infection. A further complication for inequity is that countries with more limited surveillance capabilities may also be more heavily impacted by factors that give rise to the need for surveillance, such as swampland, downstream territory, or a warm climate.

We would be remiss, however, by failing to note the potential benefits of jurisdic-
tional differences for surveillance. In the United States, it has become canonical to assert that federalism allows for the states to function as laboratories. States may experiment with different surveillance methods and learn from one another. Jurisdictions may also have the local knowledge that enables them to take local conditions into account, from the landscape to cultures and religions. To the extent that it is easier to develop trust in local governmental units than in units that function from afar, surveillance may be better carried out at local rather than national or global levels.
4.2.3 Intrusion

At first appearance, environmental surveillance may seem to pose far less in the way of privacy challenges than forms of surveillance that require contact with individuals or information from their health records. Monitors of air or water quality set up in neighborhoods, for example, do not collect information about the local inhabitants. Yet these indicators may be indirect sources of information about people who live nearby that may result in deleterious consequences for them. How this information is communicated may be important, too. Consider as an example people evacuated from the area around the Chernobyl nuclear power plant disaster. If people are labeled “Chernobyl survivors” without further explanation or understanding, the result could be fear or stigmatization. Fear could result, for example, by confusion between having suffered a radiation exposure and being radioactive; this confusion is widespread, as illustrated also by suspicions of food that has been sanitized by radiation exposure as subjecting those who eat it to radiation. Labelling COVID-19 the “Wuhan virus” or the “Chinese virus” has been used to stigmatize, too.

Environmental surveillance may also pose intrusion risks if information gleaned from the environment suggests the need to inspect homes. Surveillance of water discharged into a sewer from a home, for example, could indicate the presence of disease in the home and lead to efforts to search the home. Technologies for remote detection of chemical and biological agents are developing rapidly and may yield information that suggest further exploration of intimate space.

Information gleaned from environmental surveillance may ultimately suggest the need to access human bodies more intimately. Understanding what is called the “microbiome”—the thousands of different species of microorganisms that inhabit the human body—is just beginning but already has yielded important information about human health and disease. Each human has a unique microbiome, shaped by exposures, diet, and interactions with the person’s genetic makeup. This microbiome is a delicate balance of deleterious and beneficial organisms that are critical to digestion and immune status among other aspects of human health. Research is yielding findings such as the relationship between the microbiome and susceptibility to diabetes or risks of preterm birth (iHMP Consortium 2019). Studies of the microbiome are also yielding information that may prove critical to addressing health inequities such as the increased prevalence of preterm birth among women of African ancestry. Shifts in the microbiome may be harbingers of shifts in human disease susceptibility and thus may become information critical to surveillance. Yet detection of these shifts may require samples of excrement or even samples obtained directly from areas of the human body such as the gut or the reproductive tract, both areas of the body regarded as particularly sensitive by many.

To summarize briefly: environmental surveillance is a critical aspect of public health surveillance. It may bring to light health inequities associated with social determinants of health. Yet it may itself be inequitable in both the burdens and benefits it imposes. These inequities are complicated by the fact that some environmental goods such as clean air are goods that can be experienced by everyone, albeit to
different extents, regardless of whether they contribute to production of the goods. They are also complicated by the fact that environmental factors often cross political jurisdictions which may have very different capacities and approaches to surveillance. Finally, although environmental surveillance may on the surface not appear to raise privacy questions, because the information it gathers in the first instance may not be about individuals at all, it would be misleading to conclude that privacy is not implicated by this form of surveillance. Environmental surveillance may lead indirectly to conclusions about people and the need for further examination of their living spaces or even their bodies. We now turn to deeper exploration of equity in surveillance, using the example of how water is, or is not, surveilled.

### 4.3 Water Surveillance Disparities

Among the most serious problems for disadvantaged populations is the lack of clean water, a basic necessity (WHO Commission 2008, p. 14). The UN Sustainable Development Goal for clean water and sanitation targets achieving access to safe and affordable drinking water, reducing polluting and minimizing release of hazardous chemicals, and achieving access to adequate and equitable sanitation. (UN 2018a) Across the globe today, three in ten people lack access to safe drinking water, six in ten lack access to safe sanitation, 2.4 billion people lack even basic sanitation, and nearly 1000 children die daily from preventable water-related diarrheal diseases. Safe water is not just a problem for poorer nations, however. In the United States, children in Flint, Michigan, were exposed to high levels of lead for over a year after a change in the source of their water. A 2018 report of the European Environmental Agency rated only 38% of Europe’s surface waters as in good chemical status (EEA 2018, p. 6).

Environmental surveillance is critical to identify health hazards such as unsafe water. Threshold problems of equity attend how this surveillance is deployed, as environmental hazards for some may pass without attention while hazards for others are scrupulously monitored. Further problems of equity are consequent to what the information brought by surveillance reveals, such as precipitous declines in property values after information comes to light that a development was built in an area of high toxicity. Equity issues also arise with respect to possible responses to the hazards identified through environmental surveillance. The account of surveillance equity we develop here is rooted in the understanding that equity may be constructed differently in contexts of injustice rather than for a more perfect world. Public health surveillance today takes place in a world of deep poverty and stunning affluence; it will prove unsustainable if it fails to take these inequities into account.

Many factors attend gaps in surveillance equity. Water systems may be fragmented and privately rather than publicly run. Aging infrastructures are expensive to maintain and bad news about their condition may not be politically welcomed. Water is an economical and often unobserved site for waste disposal from profitable industries such as mineral extraction or large-scale agriculture. Water is used in
fracking or other methods of petrochemical extraction. Drinking water is especially difficult to surveil as it may come from multiple small sources: rainfall collection, wells, streams and rivers, small community water systems, and other dispersed sources. Yet, as we explore below, serious gaps in water surveillance are an illustrative example of problems of equity in surveillance.

4.3.1 Clean Water, the UN, and the WHO

In 2010, the United Nations General Assembly adopted Resolution 64/292 recognizing safe and clean drinking water and sanitation as a human right that is essential for the full enjoyment of life and all human rights (United Nations General Assembly 2010). Advocates of water justice pushed for the resolution. Support for the resolution was not unanimous, however. Most notably, both the United States and Canada abstained from the vote. As indicated above, a goal of the United Nations Sustainable Development Goals is access to clean water and sanitation (UN 2018b). The 2018 report on progress towards this goal indicated the need for accelerated efforts if these goals are to be met and noted especially the damaging effects of conflict and instability. It also singled out the need for improved management within countries of water resources, accelerated cooperation among countries sharing water resources, and a disturbing decline of more than 25% of official development assistance for water-related activities (United Nations 2018b).

Beginning with 1990, the WHO and UNICEF established a water supply monitoring program, publishing regular updates during the Millennium Development Goal period. These updates are continuing with the 2030 Agenda for Sustainable Development, which also emphasizes the importance of safe water. However, despite these efforts, reliable estimates for access to safely managed drinking water were available for only 96 countries (35% of the global population) (WHO 2017b, p. 3). While these figures suffice to indicate broad problem areas, they are by no means adequate; in the judgment of the WHO, “there are major data gaps, and effective monitoring of inequalities…will require significant improvements in the availability and quality of data underpinning national, regional and global estimates of progress” (WHO 2017b, p. 9). Data are often not subdivided by income or by sub-region even when national level data are available; disparities between urban and rural areas are thus comparatively under-recognized (WHO 2017b, p. 34). Data gaps are also particularly noteworthy for schools and health care facilities, institutional types where access to safe water, sanitation, and hygiene facilities are critical because of their impact on children and people who are already frail (WHO 2017b, p. 44).

These gaps in knowledge cannot be attributed solely to disparities between the developed and the developing world. In the U.S., the Safe Drinking Water Act of 1974 requires monitoring and notifying consumers of safety violations with the potential to cause serious health effects. However, the requirement of public notice when drinking water exceeds lead action levels was only added by Congress after
the devastating discovery of lead levels in the water system in Flint, Michigan (Tiemann 2017). The now-infamous example of Flint was not only a failure of water system management but also a failure to surveil drinking water conditions in a largely poor and minority community.

### 4.3.2 Flint, Michigan: A Surveillance Failure in a Wealthy Country

The serious effects of exposure to lead are well-known. In adults, they include abdominal pain, fatigue, headaches, irritability and aggression, loss of memory, pain in the extremities, nervous system damage, infertility and stillbirth. Children and developing fetuses are affected even more severely; risks of lead exposure include reduced cognitive function, mental retardation, inattention, hyperactivity, and antisocial behavior (CDC 2017).

Flint is a city of about 100,000 located in central Michigan, just over an hour’s drive from Detroit. Although the site where General Motors was founded, Flint has become chronically depressed as automobile factories have closed and moved elsewhere. Today, Flint is a majority Black city, with a median household income under $30,000/year. Nearly 40% of Flint’s residents live below the poverty level (US Census Bureau 2019).

In 2014, Flint’s water supply was shifted from Detroit to the local Flint River to save costs. At the time, Flint had the highest cost to consumers of all water districts in the nation. Flint’s water problems thus stand out in more than one way. After the shift, the corrosive river water leached lead from aging city pipes and bacterial contaminants entered the water supply. At one point, residents were urged to boil water because of bacterial contamination. Water in several homes tested at very high lead levels, yet city and state agencies continued to reassure city residents that their water was safe. After a water quality expert called attention to the role of corrosion and a group of local physicians reported high lead levels in children (Erb 2015), Flint residents were finally informed about the problems with their water and its likely cause (Hanna-Attisha et al. 2016). Fifteen state and local officials were criminally charged as a result of their actions to conceal the problems with the water (Egan 2017). A significant decline in reading scores among Flint children may be attributable to the lead exposure (Atkin 2018). So may be higher rates of stillbirths and miscarriage among Flint women (Grossman and Slusky 2017). The Michigan Civil Rights Commission (2017) has concluded that systemic racialization rather than intent by individual bad actors played a critical role in the water crisis. The city of Flint has a long history of racially segregated housing and tax structures that redirected resources from the city to the more affluent and white surrounding suburbs. These structures were largely responsible for the economic woes that had placed the city into the receivership arrangement that precipitated the water crisis (Highsmith 2015).
But Flint is not an isolated case. Many US cities with aging infrastructure have corroding pipes that allow lead and other contaminants to enter drinking water. Residents have learned about these risks belatedly or in some cases not at all (Wines and Schwartz 2016). Reports about schools, too, indicate high lead levels in drinking fountains and other water sources used by children in cities such as Jersey City, New Jersey (Wines et al. 2016).

At present, the U.S. Environmental Protection Agency (EPA) lead standard for safe drinking water is 15 parts per billion. Critics question this standard as based primarily on apparent existing levels in housing rather than evidence of safety (Wines and Schwartz 2016). Current regulatory structures leave out many municipal water systems from monitoring requirements, depending on the source of their water (Wines et al. 2016). Schools also are typically not water suppliers regulated by the U.S. Safe Drinking Water Act—exactly the kind of omission of concern to the WHO report singling out the gaps in knowledge about the safety of water supplies to hospitals or schools. Schools do come under the lead monitoring and reporting requirements of the U.S. Lead Contamination and Control Act, which include the requirement to replace drinking water fixtures that contain excessive lead amounts. However, monitoring in schools has been uneven at best (Wines et al. 2016). Replacing old lead pipes in cities or drinking fountains in schools is expensive. There is also significant political opposition to EPA involvement in setting local standards.

These reports of lead contamination in aging U.S. cities take place against a background of historical injustices, economic dislocation, and settlement patterns that have affected Blacks more severely than other groups. These urban areas also have aging infrastructures and high percentages of older schools. During the 1950s, they were sites for freeways built to improve transit for those living in more affluent suburbs; these freeways are an additional major source of lead exposure. Jersey City is but one case in point, with a majority of schools over 80 years old and a freeway extension cutting through it that has contaminated local parks used by children with lead (Mota 2016). Income inequality has concentrated poorer residents in areas of cities where housing costs are lowest. Redlining—the practice of rating neighbourhoods or borrowers in a manner that makes mortgage financing difficult or more expensive to obtain—functioned historically to concentrate Blacks in these areas. Not only a practice of private banks, redlining was an official practice of the Federal Housing Administration, which color-coded neighbourhoods according to their perceived risks to investors (Rothstein 2017). Once thought to have faded into history, discriminatory redlining appears to have been ongoing in areas of the country such as urban New Jersey, as a recent settlement with that state’s largest savings bank reveals (Swarns 2015).

The problem of lead in drinking water has been known for many years, as have the background factors that have put poor and minority children at greater risk of significant exposure than their more fortunate counterparts. But the U.S. informational infrastructure about exposures to lead—and other contaminants as well—has seriously lagged. There is no systematic way of collecting information about lead levels in many water supplies, including those serving schools. Testing is required
in only a small number of homes in large water systems, and then at quite extended
intervals and based on protocols that are subject to criticism (Wines and Schwartz
2016). Baseline data to assess the impact of the Flint water crisis had to be extrapo-
lated from a mixture of documents not entirely consistent in their methods of data
collection (Drum 2016). Yet these data are fundamental to health, especially for
children.

In the background of the structure of water surveillance in the U.S. is that water
sanitation and delivery to customers is highly complicated and fragmented. The
U.S. has some 52,000 water districts. Only about 400 of these serve more than
100,000 persons. Beginning in the 1920s during the Progressive Era, water supply,
quality and treatment increasingly became publicly owned and managed.
Progressives argued that safe drinking water needs were more likely to be addressed
by the public sector than the private sector. Today, however, the number of privately-
owned water districts is greater than the number of public districts in 17 states,
Puerto Rico, and the District of Columbia. In many rural and suburban areas, small
privately-run water districts are large in number but small in the number of house-
holds and business served. The number of private sector firms continues to contract
across the country. Federal and to a lesser extent state laws govern water quality and
supply. Water district managers recognize that maintaining both adequate supplies
and reliable water quality requires increased funding but are reluctant to rely on
increased fees for water usage to meet demand. They are seeking federal and state
support, arguing at the federal level that water quality is a national responsibility
given standards are federally determined.

Concerns over water quality have emerged across the U.S., particularly since the
Flint crisis. Community water systems located in rural areas have the highest per-
centage of violations, over 9%. The southwest is the region of the country with the
highest patterns of repeat violations. Minority communities are also more likely to
experience water quality violations (Allaire et al. 2018). These disparities may
reflect a failure of state level regulatory competence caused by underfunding, disin-
terest, or these districts’ lesser ability than metropolitan water districts with their
greater resources and political capability to secure federal resources. The funding
ethics of federalism plays a role too, as federal authorities may establish regulatory
regimes but anticipate that the state will significantly contribute to their realization.
Or, states may lack sufficient domestic support or resources for the infrastructural
investment to make to meet federal expectations.

4.4 Inequity in Safe Water Surveillance

These failures to surveille water quality are clearly harmful to human health, but it
is a further question whether they are inequitable. Not every failure that is deleteri-
ous to health is also a wrongful inequality. For example, inadequate sanitation in an
expensive private club may result in an outbreak of salmonella among its patrons
but does not treat these patrons unfairly in comparison to others in the same society.
Nor are the club’s patrons disadvantaged; indeed, it is their very privilege that exposes them to the private club’s mistakes. Typhoid Mary infected her wealthy clients, but she did not subject them to inequity; indeed, it was only because of their privileged socioeconomic status that they were able to employ a private cook for their vacation homes in the first place.

In this section, we sketch three reasons for believing that failures of water surveillance are inequitable. First, they are unequally distributed among those who are better off and those who are worse off. Second, they have particularly serious consequences for those who cannot protect themselves, notably children. Finally, they are corrosive in the sense that they contribute to the worsening impacts of already existing inequities.

As used in the WHO Guidelines, “equity” refers to morally problematic inequality. Equity attends to inequalities that damage the most vulnerable unfairly. It can thus be situated as a particular issue within more over-arching theories of justice, without presupposing a full theory of justice. What is required for determining inequity is identification of those who are most disadvantaged and most vulnerable. This is not to say that more over-arching justice is irrelevant to inequity. Inequities take place in a wide variety of social circumstances and background justice or injustice is among these variables. Some inequities may be more or less isolated pockets within a more generally just society, as judged by one or more basic theories of justice. Other inequities—such as the ones identified in Flint—take place against a background of more extensive problems of social justice such as racism. As we described in the Introduction, the significance of such contexts of injustice is referred to in contemporary political philosophy as “non-ideal” theory or “partial compliance” theory, an approach that addresses the relevance of background injustice for addressing questions such as health inequity. We’ll return in the final section of this chapter to the significance of framing water surveillance as a partial compliance problem after the fuller description of inequities in water surveillance that follows.

Several commentators have recently developed data-based accounts of water inequity both in the US and elsewhere. In so doing, these commentators have found the lack of available data methodologically challenging. Data are particularly lacking about some communities more likely to be disadvantaged—that is, there is an inequity in the available data. In a widely-referenced study, VanDerslice (2011) explored demographic characteristics of U.S. communities exposed to poor water quality, documenting their concentration in poor urban areas, rural areas with significant Latina/o populations especially in the San Joaquin Valley of California and colonias along the US-Mexico border, and tribal lands. Data needed for assessing demographic characteristics of communities served by community water systems, however, were not available so reliable disparity assessments were difficult to ascertain. Balazs and Ray (2014) use data from the San Joaquin Valley in California to explore how social and political factors affect the ability to address water contamination. Another recent study, building on VanDerslice, compared reported drinking water violations to population demographics. This study indicates that the failure in Flint may not be isolated; exposure to harmful contaminants as measured by repeat
drinking water violations is significantly higher in community water systems serving poor and minority populations, especially when those populations have high percentages of people who lack health insurance (McDonald and Jones 2018). Another recent study of access to safe water in the U.S. underscores disparities in water affordability, especially in areas in need of infrastructure repair and with declining tax bases available to pay for these improvements; this study parallels what is known about problems with water affordability in developing areas of the world (Mack and Wrase 2017). These studies are suggestive of serious problems in water equity in the US and invite further, more systematic research.

A second reason why failures of adequate water surveillance are inequitable is their disproportionate impact on children. (WHO 2017a, p. 36) As highlighted by the example of Flint, children are especially susceptible to damage by high levels of lead that may be found in drinking water. Arsenic, another frequent contaminant of drinking water, is also associated with neurotoxicity to the developing brains of children, including deficits in intelligence and memory (Tolins et al. 2014). The behavioural and cognitive sequelae of these exposures can have lasting effects on the lifetime opportunities of these children. Children who have been damaged by lead exposures may be less able to succeed in school, as the initial data from Flint cited earlier in this chapter suggest, with compounding effects on employment and health status. Over a third of the million and a half deaths from diarrheal disease annually are in children under the age of 5; a significant portion of these illnesses can be prevented by safe water (WHO 2018). These waterborne illnesses also cause malnutrition and increased susceptibility to other illnesses, further reducing the opportunities of these children. The impact of shortages of safe water are also borne disproportionately by women who must use water in domestic labour and spend increasing amounts of time and energy bringing safe water to the household when it is available (Sultana 2018). The need for such domestic labour also has a disproportionate effect on girls, who are more likely to drop out of school to serve household needs.

Finally, through their widespread effect on opportunities, water disparities compound and deepen existing inequities. They are corrosive disadvantages in the sense outlined by Wolff and De-Shalit (2007): disadvantages that interact with other disadvantages such poverty or lack of education to further entrench the unjust circumstances of those who are subject to them. Given this potential for corrosive disadvantage, it is important to take care that surveillance does not add to the ways in which the situation of these already-vulnerable populations are compromised—as, for example, migrants might be targeted if disease transmission from unsafe drinking water is identified with them.

To summarize: for at least three reasons, disparities in access to safe drinking water and the failure to collect the information needed to identify these disparities violates basic equity. These reasons are that their burdens are distributed unequally, they disproportionately affect those who cannot protect themselves, and they compound already-existing injustice. To be sure, surveillance of water quality is difficult and expensive and may compete for other scarce funds available for surveillance. The point of this discussion has not been to resolve these difficult problems of
equity within surveillance; suffice it to say for now that the health importance of access to safe water and the extent to which this access is itself an issue of equity creates a strong case for including water quality among an equitable system of surveillance.

4.5 Background Injustice and Surveillance Inequities

These inequities in access to safe water are in many cases attributable to existing injustice. Extractive industries create large quantities of waste and runoff that, if not properly managed, flood acids, mercury, and heavy metals into water supplies. Little, if any, of the benefits of these industries redound to the local population who are most affected by the water pollution (UN Environmental Programme 2017). Vast dams build for hydroelectric power are controversial not only because they displace local populations but also because they change patterns of erosion and create standing water that becomes new reservoirs for disease. In a thoughtful recognition of both the real benefits of dams for irrigation, water consumption, electricity generation, and flood control, dams have “been marred in many cases by significant environmental and social impacts which, when viewed from today’s values, are unacceptable” (World Commission on Dams 2000, p. ix). To take just one disease-related effect of dams, increased rates of the parasitic disease schistosomiasis have been widespread after dam construction across Africa. Like diarrheal diseases, this condition causes higher morbidity among young children who are both more likely to exposed and who bear greater burdens of disease (Sokolow et al. 2017).

Occurring as they do within circumstances of injustice, these inequities present the question of the relevance of existing injustice to public policy, such as policy about surveillance. In the Introduction, we set out these two assumptions made by Rawlsian ideal theory (Rawls 1971): a compliance assumption and a favorable circumstances assumption. The compliance assumption hypothesized that sufficient numbers of relevant agents comply with demands of justice. The favorable circumstances assumption postulated that natural and historical conditions are favorable to the realization of justice.

Neither the compliance nor the favorable circumstances assumption holds in vast areas of the world today, in the assessment of a wide variety of theories of justice. Sketched in the briefest outline, the compliance assumption fails where corruption is widespread, where terrorist groups routinely threaten basic social institutions, or where corporations extract resources without any attention to the harms to health the resulting waste might cause. The favorable circumstances assumption fails where topsoil is so eroded that crops will not grow, where deforestation is extensive, where drought stretches on for years, or where lowlands are susceptible to widespread flooding after heavy rainfall or increasingly intense storm systems. The two failures intertwine, too, as when resource extraction leads to deforestation or crop failures augment the streams of refugee populations that are subject to exploitation by human traffickers.
As we sketched in the introduction, attention to non-ideal circumstances has been extensive in recent theorizing about justice. Several importantly different questions have drawn significant attention in these discussions. (Valentini 2012) Some consider what moral obligations individuals or societies have in circumstances of widespread failure of the compliance assumption, the favorable circumstances assumption, or both of these assumptions. For example, what obligations do others have to support surveillance in a country in which corruption is widespread and the results of surveillance may be inaccurate due to bribery, or where funding to support health improvements may be diverted? Should the primary goal of surveillance in such circumstances be only to identify hazards that could become health emergencies of international concern beyond that country’s borders, as Ebola might become but rising rates of infant mortality would not? Or, should efforts still be directed to identifying hazards to the health of people within the country, such as improper sanitation that causes diarrheal disease in infants?

Other non-ideal theorists consider the extent to which feasibility of realization should constrain determinations about what should be done. Such feasibility considerations might include dangers to health workers conducting surveillance, difficulties in gathering needed data, or problems about whether any results of surveillance can be put into play to improve health outcomes. For example, what is the relevance to surveillance obligations of the lack of health infrastructure, of public reluctance to seek care, or of the likelihood of widespread efforts to conceal health information such as Ebola infection? One plausible response to these kinds of problems is that it would be preferable to spend scarce resources elsewhere, where benefits of surveillance are more likely to be gained. The result, however, might be further worsening of the health of already highly vulnerable populations. If so, equity might require efforts to address the circumstances that are creating obstacles to surveillance.

A still further aspect of non-ideal theory concerns the relationship between ideals and what ought to be done in non-ideal circumstances. Questions for surveillance in this regard would revolve around the relevance, if any, of ideal surveillance systems to the systems that should be put into place in the real world. Should ideal surveillance be the guide? What if there are side effects of guiding policy in the direction of the ideal, such as unanticipated risks to groups who are identified with particular health deficiencies? Or, should risks of further inequity to some constrain surveillance of others? On the views of some theorists, we should develop surveillance plans that strive to move us closer to ideal requirements. On the views of others, theorizing in non-ideal contexts is simply different from theorizing in ideal contexts and the latter cannot be a guide to the former (e.g. Wolff 2017; Sen 2011). In the remainder of this chapter, we develop examples of what equitable surveillance would require for each of these non-ideal theoretic questions. In so doing, we emphasize that non-ideal circumstances vary greatly; equity may require quite different approaches depending on the context.
4.6 Failures of Compliance: Water Surveillance or Health Emergencies of International Concern?

As suggested above, the compliance assumption fails in many countries today. This failure presents difficult questions about the obligations of those with resources to try to support surveillance where resources are necessary for it to take place. Surveillance is expensive and choices may be necessary about where to allocate scarce resources. So, it might be argued, surveillance of water conditions may assume lesser priority where corruption is likely to interrupt efforts at amelioration. Instead, surveillance should be directed only at conditions that are likely to spread and present dangers to others providing support for the surveillance. To put the point bluntly, surveillance should focus first on preventing pandemics such as COVID-19, especially in countries that do not cooperate and that depend on others for support of any public health efforts.

Perhaps most directly relevant to obligations to support water quality surveillance is the observation that in some countries monetary assistance aimed to improve water quality may be diverted by corrupt officials. The Berlin-based Water Integrity Network (WIN) monitors corruption as it affects water supplies. To quote just a few examples of such corruption documented in a 2016 WIN report:

- In Benin, € 4 million of Dutch funding vanished from the Ministry of Water in 2015.
- In Malawi, a reformed public financial management (PFM) system was misused to divert US$ 55 million from public funds to the private accounts of officials.
- The Nairobi City Water and Sewerage Company in Kenya loses 40 per cent of its supply to theft and leaks while poor residents are forced to buy water from vendors at ten to 25 times the price they would pay the water utility.
- In South Africa, eThekwini Metropolitan Municipality in KwaZulu-Natal lost more than a third of its water in one year because of illegal connections and vandalism, costing US$ 44 million. (WIN 2016, pp. 23–24).

Under such circumstances, are surveillance obligations changed by the presence of compliance failures? Some might argue that they are: that if funds to address water quality issues will be diverted, then surveillance of water quality in that area should be of lower priority than surveillance for other purposes, most importantly to identify public health emergencies that may become of international concern like a COVID-19 pandemic. The argument would be that resources for surveillance are scarce and choices must be made about where to spend them. If an area is likely to mis-spend any resources that would be provided to ameliorate bad water conditions, then perhaps surveillance of local conditions, such as water that exposes the local population to lead poisoning or infant diarrhea, should be of lower priority. Instead, resources should be spent elsewhere, where they could accomplish greater good. Moreover, if the resources are to be provided by countries that have interests in their own protection, perhaps those countries might justifiably prioritize any surveillance in a corrupt area that protects against risks of disease spread elsewhere. The high
surveillance priority for identifying emerging global health emergencies of international concern would remain, but water quality issues affecting only the local population would be de-prioritized, on this view. The reply to this reasoning given by the WIN report is the importance of transparency: if we never know what is happening to the local population because of unsafe water, inequity will go unrecognized and unaddressed.

Documents from the WHO take differing positions on what is recommended in such circumstances of non-compliance. On the one hand, the WHO Guidelines judge that the global community has an obligation to support countries that lack adequate resources for surveillance in developing their surveillance capacities. Its reasoning in support of this view seems to extend beyond the interests of countries providing support in protecting themselves from disease spread. The Guidelines’ stated rationale is that “equity provides the ethical foundations for claims to international support.” (WHO 2017a, p. 32) If so, equity would provide an argument for supporting surveillance at least to identify the deficiencies and their effects on the health of the local population, even if nothing can immediately be done to improve the situation. This is the WIN position about the importance of transparency. The Guidelines also make clear that the priorities of the supported country may result in a different balance, although tradeoffs are not acceptable in situations of “gross injustice of violations of human rights” (WHO 2017a, p. 23). The Guidelines find further support for such surveillance both in preventing global spread of disease and in the need for international support to address environmental factors. (WHO 2017a, p. 25) Thus, the WHO Guidelines do not locate the obligation for support solely in whether there are risks of disease spread.

On the other hand, the WHO Guidelines also bring out considerations that would count against support for water issues affecting the local population in areas where corruption is widespread. The Guidelines state that when countries are failing to protect fundamental rights or interests, international support should be contingent on rectifying these wrongs. (WHO 2017a, p. 32) This point would suggest that when the compliance condition is significantly violated, the obligation to support surveillance might cease until the extent of non-compliance recedes. Finally, Article 44 of the WHO International Health Regulations urges, but does not require, wealthier countries to support required surveillance capacities in impoverished areas (WHO 2016). These capacities are aimed to detect potential health emergencies of international concern, not information that might be of use in addressing local health inequities.

Another possibility in situations of widespread non-compliance is that the obligations of others to address inequities are enhanced. On this view, if many are looking the other way, perhaps even corruptly, about the existence of deeply problematic inequities, others might have stronger obligations to step in and help. These might be seen as either a change in duties or as charitable considerations that are not obligatory but are supererogatory. The analysis also might be different depending on whether the actor is a professional, an international governmental organization or a state, or a non-governmental organization.
An enlightening example to explore the obligations of professionals under circumstances of non-compliance might be Dr. Mona Hanna-Attisha, the pediatrician in Flint, Michigan, who exposed the town’s water crisis. Hanna-Attisha spent countless hours and endured significant frustration in calling attention to the elevated lead levels she was seeing in her patients. (Hanna-Attisha 2018) For her efforts, she has been honored as a hero, receiving multiple awards (AWIT 2019). Heroism is supererogatory, not what ordinary people are expected to do.

On the other hand, Hanna-Attisha’s own view is that she just did what she was obligated to do as a physician caring for her patients: “As physicians we have taken an oath to stand up as the healers and the protectors. We were fighting for the future that lives and grows inside our children and this was not a fight we could lose. Not on my watch.” (Hanna-Attisha 2016) On this view, as a physician she had special obligations to go further than others in countering the effects of non-compliance.

This issue of the special obligations of health care providers when others are not doing their part has been discussed extensively in the context of individual risks of exposure to potentially fatal diseases, such as COVID-19, Ebola or SARS (e.g. Ruderman et al. 2006). Positions on this vary, from the view that undertaking a professional role incurs obligations to treat without exception, to the view that people with special obligations to others such as children have competing duties, to the view that undertaking significant personal risks should be up to the individual professional. An additional consideration is fairness in undertaking such special obligations, so that professionals have an obligation to take up their fair share of the slack, but not more. Hanna-Attisha’s risks were not to her life, but to her reputation, her health due to stress, and her family life. She saw herself as doing what a good pediatrician would do, but on more limited views of professional obligations she was going far beyond the call of duty.

Many of the possible surveillance actors in circumstances of non-compliance are international organizations, states, or a variety of non-state actors. Here, one question is whether governmental organizations should augment rather than reducing surveillance aid in circumstances of non-compliance. As indicated above, the WHO Guidelines suggest the reverse—that efforts to support surveillance may be suspended at least when non-compliance is sufficiently serious that it violates human rights. The Guidelines also invoke reciprocity (e.g. p. 43), so that if others are not doing their part, obligations of aid may be suspended rather than enhanced. The role of governmental organizations in furthering international cooperation might suggest that reciprocity is an important consideration for them as well.

Non-state actors with extensive resources such as the Gates Foundation have taken up a good deal of the space in international aid efforts. Whether any conclusions should be drawn from this about their obligations is disputed. Some contend that such organizations are voluntary and charitable and so should be permitted to select their own priorities. Others argue that they are subject to obligations such as the obligations of equity. (E.g. Beliuž 2015; Editorial 2009; Wadman 2007).

On such a contrary view, equity arguably requires non-state actors to do more rather than less for those subject to the greatest inequities when others are non-compliant. This view rests squarely on equity to those who are most severely
disadvantaged by the non-compliance, particularly children and others subject to corrosive disadvantage. This equity argument might be thought to apply with particular force to certain non-state actors because of the purposes they have undertaken and the roles they have come to play. On this view, non-state actors might be subject to other problems of partial compliance such as feasibility but would continue to have special obligations of equity because of the role they play. We consider these issues about the role of non-state actors further when we discuss the use of new sources of data and new actors in the next chapter.

4.7 Surveillance Under Feasibility Challenges

Feasibility is another important partial compliance consideration: the moral landscape of what ought to be done might shift depending on what may be achieved under existing circumstances. Feasibility might apply either to conducting the surveillance itself or to bringing about any hoped-for change as a result. The role of corruption in blocking change, discussed in the preceding section, is a feasibility consideration, albeit one that arises because of widespread wrongful behavior. In the preceding section, we considered the import of the wrongfulness of the behavior; here, we attend to the role of feasibility more directly, considering primarily the feasibility of surveillance itself. An important caution here is that judgments about feasibility are complex and may involve assumptions about what people are willing to do and what resources they are willing to commit. Judgments of this kind are not judgments about capability per se, but rest on further normative considerations (Southwood 2018).

The humanitarian medical organization Médecins Sans Frontières (MSF) illustrates how threats to health care workers can adversely affect surveillance. In the spring of 2019, in the midst of an uncontrolled Ebola epidemic in the Democratic Republic of Congo, MSF was forced to suspend activities at two Ebola treatment centers that had been attacked (MSF 2019a). MSF continued to support treatment facilities elsewhere in the area and to attempt to shore up surveillance to identify new cases—while reminding the world that it was still searching for three MSF health care workers who had been abducted in the region six years earlier. But it was unwilling to subject its workers to further serious risk when they, their facilities, and the patients they served might be destroyed. This example comes close to incapability; dead workers cannot gather data.

In other circumstances, however, strategic efforts may address apparent infeasibility. MSF provides examples of such strategies too. In the Rohingya refugee camps in Bangladesh, where 650,000 people now live, MSF’s first effort on entering the camp was to assess the water supply. They found that drinking water was being drawn from pumps located next to latrines and sewage was flowing directly into the aquifer that provided water. MSF’s initial step to address this potential health crisis in the camp was to distribute water filters to the most vulnerable, young children and people with compromised immune systems, as a temporary step until safer
water sources could be established. MSF then drilled bore holes so that water could be drawn from a source other than the surface aquifer being polluted from the latrines. These strategies of disease prevention were emergency steps, even as other efforts were being pursued to vaccinate camp residents against contagious diseases (MSF 2019b). The video telling this story ends with a note that feasibility depends on context: the cautious observation that these efforts were possible in the camps in Bangladesh but might not be possible elsewhere.

Addressing the effects of global climate change is sometimes met by a general feasibility objection: we have already done so much damage that remediation would be fruitless. Critics of such expressions of despair rightly point out that while some strategies may be foreclosed—continued habitability of low-lying islands such as Nuatambu and others of the Solomon Islands, or of coastal areas such as those in Bangladesh—other strategies remain possible. These strategies, too, may involve assessment of water. For example, in some areas of Bangladesh farmers have been able to adapt to water level changes by diversifying economic activity from farming to fishing rather than by migrating. Where increased salinity of the water has also occurred, however, relocation is more likely. (Chen and Mueller 2018) Feasibility may suggest changes in what is surveilled or how surveillance is conducted, but not in whether to surveil in the first place.

Feasibility concerns have also been raised about whether to communicate the results of surveillance to affected individuals. The WHO Guidelines hold that “results of surveillance must be effectively communicated to relevant target audiences” (WHO 2017a, p. 42). The Guidelines also raise questions about whether surveillance results should always be conveyed, particularly when there is nothing that the person can do with the information and when the information is likely to be stigmatizing or otherwise damaging. They urge a balance of considerations: feasibility, the possibility of taking action, and the potential benefit to the individual. In the judgment of the Guidelines, the balance should be struck in favor of communication, except in rare cases when significant harm might be caused. Anti-paternalism and respect for persons support this conclusion: people should be able to know what surveillance reveals about what has happened to them, even when there is little or nothing to be done to improve their conditions. At a minimum, such information may empower communities to try to take steps to prevent further harms than the ones they have already experienced. Failure to provide this information would add another inequity to communities that are already experiencing significant other inequities.

4.8 Water Surveillance and Ideal Surveillance

Another partial compliance concern is the relevance of ideals to actions in non-ideal circumstances. Should we decide what to do about surveillance in the here-and-now by developing a model of what good surveillance would look like, and engage in planning in the here-and-now to try to move more closely to that goal? A “yes”
answer to this question faces several challenges: developing a model of ideal surveillance in the first place, ascertaining what at any given point in time would count as progress towards it, and considering other consequences of such supposedly progressive choices. We begin with doubts about the project of developing a model of ideal surveillance.

Proposals for ideal surveillance systems that have been advanced press questions about what makes surveillance ideal. Bentham’s Panopticon—all seeing and all knowing—would obtain all information about everyone, instantly and forever. Such perfect surveillance has met with immediate objections: awareness of the existence of constant observation would threaten individual privacy, freedom of thought, autonomy, identity, and sense of self. Ideal surveillance, it would seem, is not the same as omnipresent information-gathering; rather, if it is to be ideal, it must take its place among other goods in human life.

Environmental surveillance does not yield immediately identifying information about individuals, however. Measuring the water quality in an area is not the same as measuring the effect of drinking that water on the health of an individual. So perhaps ideal environmental surveillance could be complete information in a way that would not be threatening to individuals’ other values. One answer to this objection is that it may not be easy to separate surveillance of the environment from surveillance of individuals within the environment. As we described earlier in this chapter, environmental surveillance may lead to more intrusive forms of surveillance. Another answer is that complete information is not the same as usable information, and choices will still need to be made in terms of relevance and organization about whatever information is to be collected. We thus have doubts about the enterprise of constructing an account of an ideal surveillance system, even for environmental matters such as water quality.

Setting these doubts aside, however, there are also problems about whether progress towards more ideal surveillance should be the primary aim when circumstances are less than ideal. What if efforts to gather more complete information needed to improve health would threaten some groups? Can more information be bad and, if so, what should be done about getting it? The WHO Guidelines for ethical surveillance recognize these concerns, using data that might reveal stigmatized behavior as an example (WHO 2017a, p. 27).

The Guidelines’ response to this difficulty is procedural: communities should be engaged in creating and implementing oversight mechanisms to identify risks and benefits of surveillance for themselves. According to the Guidelines, these oversight mechanisms should be chosen in a manner that is transparent and accountable to the communities concerned. The oversight mechanisms should try to ensure that information gathered for surveillance is only used for public health purposes and not for other purposes that could threaten individuals in the community by revealing confidential information about them (WHO 2017a, p. 29). Oversight mechanisms should also continuously monitor for risks of harm (WHO 2017a, p. 34).

Nonetheless, the WHO Guidelines also recognize that harms may be unavoidable. When serious health emergencies are possible, surveillance may be necessary whatever the community’s views about potential harms to them. In such
circumstances, the Guidelines urge efforts to identify risks in advance and mitigate them where possible. Mitigation efforts should include protections against harm to those who surveil and those who report illness, including health care workers and humanitarian organizations. When harms prove inevitable, mitigation efforts should include compensation. (WHO 2017a, p. 34) Examples of compensation are sick pay for those deprived of work or payments for culled poultry stock. Moreover, according to the WHO Guidelines, when risks of harm cannot be eliminated, they should be proportional to the benefits to be gained from surveillance. (WHO 2017a, p. 35).

Another ethical consideration is whether the benefits of surveillance accrue to those experiencing the harm.

Experience with mitigation efforts is not always encouraging, however. After cases of avian influenza were identified in West Bengal, flocks were culled but the compensation received did not come close to making up for the economic losses, let alone the losses to communities that resulted from the culling (Chakraborti 2009). In the United States, homeowners in areas identified with environmental toxicities have found themselves with steep losses in housing values (Currie et al. 2015). Housing values in Flint had been on the upswing before the water crisis but fell sharply in its aftermath (Goldstein 2016).

Overall, the approach of the WHO Guidelines to risks of improved surveillance can be characterized as oversight, transparency, and community involvement. But there are difficulties in relying on these procedural mechanisms in some partial compliance contexts. The most obvious are barriers to creating oversight mechanisms in the first place. An extensive literature addresses the problem of failed states where even rudimentary mechanisms of civil society may need to be built from the ground up. MSF (2019c) has an illuminating term for what might be possible in circumstances in which surveillance is not: “Témoignage – translated as bearing witness – is the act of raising awareness, either in private or in public, about what we see happening in front of us.”

Another problem is trying to understand what community thoughts, reactions, or preferences might mean and how we might assess the community’s voice. We consider in Chapter 7 how community may be defined and engaged. Here, we point out the role of equity concerns in such circumstances. Community choices may vary in the extent that they attend to the needs of the most vulnerable, especially those who cannot speak for themselves. Children do not participate directly in the political process and must rely on others for adequate representation of their interests. As we noted at the beginning of this chapter, environmental issues are complicated by the possibility of free riders, individuals who are able to experience the benefits of public goods without themselves bearing any of the costs of their production. Procedures for gathering community input may find it difficult to counter the incentives of these free riders. Communities may also seek to avoid costs to themselves from environmental hazards while being willing to allow the risks to occur in the backyards of other communities.

Most importantly, efforts to address equity should focus on those who are most vulnerable, those who cannot speak for themselves and who may be subject to what Wolff and De-Shalit (2007) called “corrosive” disadvantage. Corrosive
disadvantages are disadvantages that interact, creating even greater disadvantages than either would on its own. For example, exposure to poor environmental conditions such as lead in the water might interact with inadequate educational systems to result in downward spiraling lives for children growing up in these circumstances. Corrosive disadvantages in turn may make it more difficult for people who are subject to them to participate adequately in community decision making.

4.9 Summary

If a goal of public health is health equity, equity in surveillance is imperative. Surveillance equity requires attention to what is ignored as well as to what is more immediately salient. Environmental surveillance is complicated by incentives to free ride and to allow hazards to occur elsewhere so long as there are no apparent risks of spread. In an unjust world, efforts to address equity must attend most urgently to corrosive disadvantages and their impact on those who are least able to protect themselves.

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