7.1 Introduction

What is or should be the role of consent in public health? Should the role of consent be different if the public health action involves surveillance rather than efforts to change behavior to improve health? Should either individual or community consent be required for the exercise of surveillance? If community consent is required, what constitutes the community and how might it give consent? By definition, public health serves the many, not the one, or at least not only the one. Yet individual choice is the locus of prevailing models of informed consent to health care. So how does consent apply to public health, if at all? And how should it apply? If individual consent should not apply to some or all activities of public health, should there still be consent-like aspects in the process of conducting these activities?

As we discussed in Chapter 6, writers of a libertarian bent such as Jessica Flanigan (2013) answer that public health activities should be analogized to individual health care, and that public health may not interfere with individuals without their informed consent, just as health care providers may not impose care on unwilling patients even when the imposition involves sharing information, unless what is at stake is preventing clear harm to others. At the other end of the spectrum, some insist that individual health care and public health are entirely different enterprises and while consent may be required for the former it is irrelevant to the latter. Still others explore new community-based or population-based understandings of what group consent should and can mean. This chapter explores how the ethical considerations of respect for persons that lie behind informed consent can be reflected in the roles of public health, groups, communities, and populations in surveillance.

Core to the debates about consent are potentially contrasting paradigms of public health, health care research, and individual health care. Ethical frameworks developed in bioethics have successfully argued that in medical research and in the practice of medicine consent should be exercised by individuals, not by groups. By
contrast, public health has the health of communities and populations as its long-standing mission. Whether these more individualistic approaches of health care ethics and the ethics of research should be applied to public health, even when its activities consist of surveillance rather interventions to effect changes in behavior, is the topic of this chapter.

Public health takes as its focus of responsibility the community or the population, not the individual. As described by the Bloomberg School of Public Health at Johns Hopkins University (2019):

Here’s a good way to describe the essence of public health.

In the medical field, clinicians treat diseases and injuries one patient at a time. But in public health, we prevent disease and injury. Public health researchers, practitioners and educators work with communities and populations. We identify the causes of disease and disability, and we implement large-scale solutions.

Public health is distinct from medical research and health care in its authority to exercise police powers to act for the general welfare. This difference may give rise to both instrumental and non-instrumental reasons for exploring consent. The instrumental assumption is long-standing that public health will enjoy greater success in securing its goals if it does not rely solely on the exercise of the state’s authority. Instead, more may be gained for the public health mission by engaging members of the community in listening and in developing shared goals. Some argue that this may be best done through a consent or consent-like process on the part of community leaders or community members. Public health and medical research are in some respects quite similar in their use of data from and about individuals. Like non-interventional medical research with human subjects, much public health surveillance and analysis uses data from and about individuals to develop general knowledge; the difference is that the focus of developing the knowledge may be improving the health of populations rather than the treatment or health care delivered to individuals, although these lines readily blur. These similarities lead some to conclude that consent is required for public health uses of data while others contend that community engagement should be conceptualized differently from individual informed consent.

Beyond what might be needed for the effective exercise of public health authority is its legitimacy. Non-instrumental reasons for exploring consent may begin with assumptions that exercise of political authority over the individual requires the consent of those governed. The need for legitimacy is no less pressing when the activities involve efforts to protect or improve health. However, because their health is also a feature of individual persons, the relationship between consent of the governed and individual consent is complex and intertwining. Additional layers of complexity arise when individuals are members of communities or groups in addition to being subject to political authorities.

This chapter explores four basic themes about consent in public health surveillance. First, community and population differ and have each been given varied meanings in the public health literature. These differences have implications for ethics in the conduct of surveillance. Second, cooperation and volunteerism have
been judged to have value in the conduct of public health surveillance, but their role is complex and evolving. Third, the goals of public health are substantively different from the goals of personal health care and this has implications for any requirements of consent. Despite these differences, a common theme of respect for persons underlies both consent to individual health care and the involvement of individuals in public health decisions. Finally, that public health surveillance and interventions cross national borders may have implications for understanding how the mission of public health may be furthered or hindered by surveillance.

7.2 Public Health, Communities, and Populations

Public health practice and expectations have long been associated with community as a focal point (e.g. Goodman et al. 2014; MacQueen et al. 2001). Over the past half century an important theme in public health has been the cultivation of cooperation with communities in conducting surveillance (Public Health Leadership Society 2002). But there is not a great deal of agreement within the public health sphere on a single preferred account of what “community” means. There are also important differences between understandings of public health, community health, and population health (Bresnick 2017). Sorting out these differences is a critical first step to understanding the roles consent might play in surveillance.

7.2.1 Public Health

In the public health literature, one primary use of the term “public health” refers to the activities of organized public health agencies. As we explained at the beginning of this volume, surveillance conducted by these agencies—or others delegated authority by them—is the initial primary subject of this volume. “Public health agencies” in this sense are defined by grants of political authority. There are local health departments, state health departments, and national health departments. Pan-national organizations are devoted to public health such as the Pan American Health Organization or the European Centre for Disease Prevention and Control. The authority of these entities may be defined by treaties or conventions such as the Maastricht Treaty establishing the European Union or the Pan American Sanitary Code and Additional Protocols. At the global level is the World Health Organization, currently with 194 member states. Members of the United Nations may join the WHO by formal notification to the UN secretary-general that they accept the WHO constitution; non-members of the UN are admitted to the WHO by majority vote of the World Health Assembly, the decision-making body of the WHO. These various agencies engage professionally in public health research and practice. The “publics” that they serve are defined by their reach of recognized authority, from the local to the nearly global.
Public health as thus defined jurisdictionally is different from either community health or population health (e.g. Faden and Shebaya 2016). There may be many communities within a single public health authority and there may also be communities that transcend single authorities and require coordination among them. Depending on how “populations” are defined, they, too, may transcend or exist within the jurisdictional scope of public health authorities.

### 7.2.2 Communities of Geography and Communities of Interest

Public health has long sought to engage the communities they serve in participatory programs and research. Community-based participatory research (CBPR) has become a favored methodology especially for research aimed at community health improvement. In this literature, community may be conceptualized as everyone living within a given local jurisdiction (e.g. Stoto et al. 1996). Or, “community” may be understood to refer to groups within and perhaps overlapping a jurisdiction’s political boundaries but nonetheless sharing important features that may need to be recognized for successful engagement (e.g. Israel et al. 2013). Recognizing that “community” was given different meanings in CBPR, MacQueen and colleagues sought to understand empirically what participants in this research themselves regarded as characteristics of a community. Based on their findings, MacQueen and colleagues proposed this core definition of community: “a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings.” (MacQueen et al. 2001, p. 1936). These researchers note, however, that different elements of this definition may prove more salient depending on the context; shared social ties may be far more important in some communities than diverse characteristics, for example. Rajan (2019, p. xiv) similarly defines community in the global economic perspective as unconstrained by size but bound by locality: “a community is a social group of any size whose members reside in a specific locality, share government, and often have a common cultural and historical heritage.” Rajan thus explicitly rejects the use of the term “community” to describe virtual communities or national religious communities in favor of the idea of a community as a group whose members live in proximity to one another and share government and heritage.

But there are challenges to this understanding of community as spatially bounded. In an age of global communication and movement, people who share an identity, an interest, or a health condition with people living some distance away may have less in common with their proximate neighbors and more in common with people who share the identity but live hundreds of miles away. Contemporary technology vastly augments and compounds this ability to share identities across distance. Identities such as “gay” or “feminist” or “vegan” may achieve far greater salience than
identities such as “New Yorker” or “Parisian” or “southern.” Language such as “the black community” or “the disability community” or “the gay community” is common. If these are identities that achieve salience—even if only through the Internet—this might seem to establish their claims to being communities beyond the limits of geographical space. On the other hand, people within a given geographical space may have very little in common, especially if borders are fluid and people frequently move in and out. Illustrating how geography may not establish commonality, MacQueen and colleagues observed that their finding that “diversity” was part of how their research participants understood community may have been influenced by the fact that their subjects were gay men in San Francisco, an international meeting ground for gay men (MacQueen et al. 2001, p. 1935).

In the practice of public health surveillance, a shared identity locally grounded may take precedence over the shared preferences of people at a distance. A critical reason why geographically defined community matters in public health surveillance is the role played by the exercise of powers by local governments. In the U.S., this power to act for the general welfare is termed the “police power” and it belongs to the states or local entities as their delegates, not to the federal government. Public health has long relied on local governmental authorities to require notification of listed communicable diseases and to enable early reporting of new communicable health threats. The potential integration of social and political dimensions of local life only strengthens the appeal of geographically defined community as a basis for public health surveillance. Public health may be able to work through local spatially defined communities to gather information that might otherwise not come to light. Understanding the impact of local cultural or religious practices and preferences for matters such as bodily integrity or diet can play major roles in the ability of public health to encourage immunization or to achieve behavioral changes to address NCDs such as diabetes. Conversely, local attitudes towards behavior judged to depart from local practice, such as sexual practices judged at variance from local values, may suppress information or access to medical care and erect barriers to public health interventions. In these ways, geographically defined community can serve as a building block for or a roadblock to surveillance and other public health activities.

Public health agencies need local communities to respond to their efforts. Ideally communities should be cooperative and attentive in encouraging their members to share personal health data as well as being attentive to reasonable advice given to the community by public health authorities. But ideals of responsiveness may be questioned for their efficacy and their justification. Is there any reason, for example, to assume that communities, however defined, will or should respond in a cooperative fashion to public health? Or, are communities likely to respond in ways that are deeply distrustful and disengaged from collaborating with public health authorities? What if the community in question lacks identity, or if whatever identity is claimed for it arises outside the “community” as an identity imposed or attributed to a set of people but not clearly shared by them? Even shared identities do not mean that the
willingness of individuals to be helpful may be shaped by a local leadership (be it political, economic, religious or social) that recognizes and accepts public health competence and authority and enjoys the confidence of the local community. Answering these questions will require working through complex interrelationships between community as defined by local geographical space, community as defined by shared identity, and the reaches of public health authorities.

Moreover, community cohesion may be sustained, strengthened, or weakened by the nature of individuals’ relationships to the community. Individuals may find themselves in communities where they have lived since birth. They may be regarded by others as community members. Or, they may enter communities by affirmative acts such as immigration, taking up an occupation or a job, or signing up for a group such as a disease-related social media site. Such acts may be sustained or atrophied by the depth of commitment on the part of community membership more generally. Further affecting community cohesion is that people may be members of multiple communities, especially when communities are defined by identity rather than geographical space. Mobile populations may be members of more than one geographical community, too; this characterization could apply to migratory farm workers, workers in seasonal resorts, or wealthy owners of second homes.

Often important as well to community cohesion are the attitudes of the larger population to the community. Members of the community may be limited in various ways from participation in the life of the larger state or nation as a whole. Exclusion may strengthen community members’ own resolve to define themselves against the larger, external population. But the external population may also celebrate the community, which in turn may reinforce its value to the people who make up the community. For public health, what matters is how the cohesion of a community may facilitate or obstruct sharing information or engaging in other activities.

Geographically defined communities may or may not have identifiable leaders other than the leaders of the political jurisdictions in which they are located. If most community members share a common religion, the faith community may have a recognized leadership structure. Elected officials from a cultural or ethnic background that is common in the community may be seen as spokesmen or women for community members sharing that background. Business leaders or others who have achieved success or fame may also be turned to for advice or consultation about the community. However, while these leaders may speak for the views of many in the community, they may not speak for all. Nor do they have the status of recognized political authority or head of an organized group that can claim as members all who live within a spatially defined community.

Three different approaches to community may thus be distinguished for considering the roles of consent:

- community as everyone living within a local political jurisdiction (drawn from Stoto).
- community as one or more groups of people within a geographical area that are linked by social ties, share common perspectives, engage in joint action in these
geographical locations or settings, and that may or may not be diverse in other ways (drawn from MacQueen)
– community as based in common interests or identity (drawn from references to possible identity communities such as “the black community” or “the disability community” or “the Deaf community”).

### 7.2.3 Populations

Populations may be distinguished from communities in any of these senses. A population is a set of people possessing a given characteristic that singles them out for public health attention. For example, all U.S. citizens, all people living today, or all people of German ancestry are potential populations. Studies of population health examine patterns of health outcomes or factors affecting health among the defined population or population subgroups (e.g. Hertzman and Siddiqi 2009). For purposes of surveillance, populations are often defined by health risks such as obesity that are inclusion criteria independent of local administrative or geographical boundaries (e.g. Chunara et al. 2013). Everyone at risk of HIV is a population in this sense, as is everyone at risk of diabetes from obesity. Populations thus identified by risk susceptibility may have shared characteristics that give rise to the risks but may not have much else in common with one other. Collecting data about such populations may face different challenges than collecting data from a geographically defined or identity defined community. Whether the focus of surveillance should be population in contrast to community is determined in part by which takes priority: the disease of interest; the community of geography, identity, or interest; or some mix of these.

In some ways, in today’s world there may be closer relationships between populations, interest- or identity-based communities, and geographically defined communities than in the past. Shared risks may overlap with identities or with geographies. Features of identity such as race, ethnicity, religion, gender, or sexual orientation may map onto geographical communities in some cases or transcend these communities in other cases. Any of these may also map onto or transcend the jurisdictions of established public health authorities. The conventional expectation in public health practice is that local governments, in the U.S. often at the county level, serve as community leaders during public health threats and have ongoing administrative responsibilities for many aspects of the public health mission. These political definitions of community often are linked to social, cultural or other values that prevail within but also transcend local political boundaries.

Public health agencies may seek to delineate communities or populations depending on what is of interest to their goals of promoting health. However, these delineations may not fit well with the individuals composing the groups thus delineated. Public health officials may seek to argue that populations or communities should be defined by a given set of characteristics such as sexual preference,
religious commitment, racial or ethnic identification determined by legislatively determined census categories, age cohort, or generation, but whether they can do so persuasively is another question.

7.3 The Changing Landscape of Groups: Cooperation and Volunteerism

Organized groups may be further distinguished from communities and populations. Groups must be organized in some way, with an identified means for entering and leaving the group but within this characterization, there is a range of possibilities. Groups may be organized around a service, an activity, a health issue, or any other shared concern. Groups may be longstanding, as with many social clubs, fraternities, or religious organizations. Today, groups may be organized to accomplish a short-term goal and facilitated by social media postings. Groups and their members may be present in communities or in populations of interest to public health investigations. The value of groups for public health is that they can be a ready source to facilitate information gathering, communication, and conversations about health issues. Groups may also have leadership structures that be helpful sources for consultation. Groups may, however, also be sources of resistance to public health or of behaviors that may prove troubling, such as resistance to vaccination.

The United States in the nineteenth century and the first decades of the twentieth century was a landscape of towns and villages. Groups of many kinds flourished within this landscape. This multiplicity of organizations was observed by Tocqueville in 1835 (2006 ed.) as the distinctive feature of American society. Small town residents joined in or organized formal organizations such as clubs and fraternal associations (Wuthnow 2013). These organizations combined charitable endeavors, served as forums for community leadership, and acted as advocates for policy change. Notably, some of these groups were founded by women and addressed issues of importance to women such as suffrage. These organizations played extensive roles in the advancement of public health initiatives such as temperance or the campaigns against STIs during the Progressive era described in Chapter 3. Overall, a good number of men and women in the U.S. spent their time when they were not at work or with their families in the membership clubs and organizations found in every moderately-sized town.

In many ways, the voices of American communities were to be found in such service clubs, fraternal organizations such as the Masons, politically minded advocacy organizations such as the Grange, or the trade union movement. Perhaps one of the most successful of all of these was devoted to public health, the Woman’s Christian Temperance Union, formed with the political goal of banning consumption of alcohol. The WCTU at its height had four hundred thousand members; today, its membership numbers fewer than twenty thousand. Weekly meetings of many of these organizations were forums where public health authorities could report to communities on health conditions and seek support for public health campaigns.
The respective memberships of such organizations were largely separated by race, ethnicity, gender, and religious affiliation until relatively recently. This darker side of the presence of groups in American society cannot be forgotten. The WCTU did not admit Jews or Catholics for decades. And at its height the racist Ku Klux Klan had as many as five million members and engaged in a wide range of charitable activities (Rothman 2016). The challenge for public health institutions in working with groups is to balance this darker side while recognizing that groups may have useful streams of information. Public health may want to establish ongoing relationships with groups to pursue public health goals, while at the same time the groups have goals that contradict public health values or even goals intended to do harm to other communities and populations locally or nationally.

Political theorists reflecting on this role of groups emphasize the important of non-state actors in both supplementing and balancing the state. For example, von Gierke (1939) argued that a good society was composed of fellowships such as guilds that played a regulatory role in the economy and in maintaining social well-being. He lamented the growth of state institutional actors at the expense of non-state actors or organizations described as fellowships in reducing the role of voluntary organizations that were independent of the state. The Canadian theorist Will Kymlicka defends the role of groups such as tribes in a liberal political society; his view is that so long as people may leave, groups may depart internally from the more general values of the liberal state with respect to health practices (Kymlicka 1996).

A special case of groups is that of indigenous groups having a level of political authority in addition to their organized structure and claims to cultural rights. Under the International Covenant on Economic, Social and Cultural Rights (to which the U.S. is a signatory but not a state party), states parties recognize the “right of everyone to the enjoyment of the highest attainable standard of physical and mental health.” (UN 1967, Art. 12 §1). The 2007 UN Declaration on the Rights of Indigenous Peoples recognizes the right of indigenous people “to be actively involved in developing and determining health … programmes affecting them and, as far as possible, to administer such programs through their own institutions (UN 2007, Art. 23). The Declaration also recognizes rights the highest attainable standard of physical and mental health and to the maintenance of traditional medicines and health practices (UN 2007, Art. 24), as well as to the right to intellectual property over cultural heritage and traditional knowledge (Art. 31, §1). How these provisions apply to surveillance is not specified. In the United States, CDC works with tribes for surveillance of environmental exposures, infectious diseases such as tick-borne Rocky Mountain spotted fever, and even in some cases behavioral risks. These efforts take place in collaboration with tribes. CDC also links with the Indian Health Service to improve the quality of national surveillance data and the extent to which it is representative of tribal populations (CDC 2017, p. 21).

In sum, the contemporary organizational landscape in the U.S. is populated with organizations that in many respects are influential from the local to the global. These organizations vary considerably in structure and relationships to state and quasi-state entities. Voluntary membership organizations have in recent decades
contracted in membership and in their attributed leadership role. Some such locally or nationally based organizations that seek a voice in public health-related initiatives do remain, however. For example, the Sierra Club claims a million members and is active in public health anti-pollution campaigns.

Broadly described as non-profits, a million and half voluntary organizations exist in the United States today. Since the 1990s and more so in recent decades, loose confederations of groups have arisen with greater ease to respond to non-communicable as well as communicable threats to health and wellbeing such as natural disasters, gun violence, compromised water supplies, opioid addiction, or coerced sexual relations. These issue-based organizations capture considerable public attention from social media and traditional media alike. Their creation has generated loosely formed groups that can span the county and mobilize large numbers of volunteers to help those in need and to support political intervention to accomplish specific goals. Black Lives Matter and the MeToo movement are prime example of this phenomenon. Such formation of short broad coalitions built around the power of an immediate shared concern is enabled by social media. The recognition that one quarter of the American population will volunteer for a wide range of services to others (Bureau of Labor Statistics 2016) has reduced traditional constraints to action.

That we live in age of non-state actors is particularly evident in the expanding world of public health (WHO Director General 2019). In the arena of public health, many organizations, some more organized and some less loosely organized, are of value in disseminating information about public health-related challenges. Perhaps in the expanding remit of public health, Greg Consalves is a 2018 MacArthur “Genius” awardee who has developed research tools in academia to draw creative and unusual connections between research and social interventions. His efforts have long been directed at establishing productive relationships between public health research and activists to address ongoing rates of HIV infection, links between violence against women and lack of access to indoor sanitation, and the failure of mining companies and the South African government to compensate families for occupationally-related disease.

Following Robert Putnam’s image in Bowling Alone (2000), a lively literature has called attention to the declining membership of organized clubs and societies. What appears to have happened is the rise of nonprofits that blur relationships to the state, the community and to the force of contemporary social media. In short, Von Gierke might have been more prescient to map out the complex relationships among non-profits, the state, and volunteerism that shape to an impressive extent public health initiatives today.

For community involvement in sustaining the public health mission, the identification of leadership is complex but critical. Using leadership of local organizations is one strategy of consulting and securing support for public health surveillance. Local leadership communities may not coincide with local governments and, even when they do coincide, may not reflect the preferences of the local population. If the goal for public health is a more nuanced account of the contours of opinion, then sorting out leaders who capture the range of concerns in the population is core to likely success. If the need to undertake a public health program is so urgent that
consultation cannot be obtained in the time frame available, as with rapid spread of infection in a community where vaccination rates have plummeted far below herd immunity, community leaders can be consulted as a substitute. As we just discussed, however, it is neither clear who these leaders might be nor clear as to the authenticity of their ability in the addressing the health concerns of the identified population. This does suggest that consultation is important but with whom and under what conditions is from time to time elusive.

### 7.4 Consent: Public Health and Individuals

Any discussion of consent and public health must start with the recognition that public health is not the same as individual health care. This chapter began with the observation from the Bloomberg School that clinicians treat one patient at a time while public health prevents disease or improves health in populations. Nevertheless, the public and the individual cannot be fully separated, just as the public sphere and the private sphere abut, overlap, and intertwine. Addressing an epidemic threatening the public may require treating individuals who are the sources or likely locations of spread. Case identification and contact tracing has remained essential in the fight against COVID-19. At the same time, community factors clearly matter, too, such as safe workplaces. Protecting the health of the individual may be impossible or impracticable without addressing the health of those in the surrounding area or community. Nor can consent to personal health care be entirely teased apart from consent in the context of public health. Public health authorities stress the importance of individual consent in building trust among the population served while at the same time stressing the limits of consent in addressing needs for surveillance and protection.

Also in the background of the discussion of consent and public health is the unlikely prospect of insulating individuals who might decline to be surveilled or to accept the terms of a public health community-based response to prevent disease spread. Any view of the role of consent must take into account this observation that individuals cannot be isolated as unique health islands but must be in some way subject to the processes of public health. Individuals are interconnected most obviously for contagion. But as we saw in Chapter 6 about the new public health, they may be interconnected at least for information about other dimensions of health as well. That no one is a health island poses an immediate challenge for insistence on individual consent to public health. Insistence on unanimous individual consent has the potential to erect insurmountable barriers to any successful public health effort.

Political scientists refer to this ability of an individual to block effective collective action as the “Polish veto” or “liberum veto” after a practice in the Polish-Lithuanian Commonwealth that enabled debate to be suspended and legislation nullified on the request of any envoy to Parliament. In eighteenth century Polish-Lithuania, the veto was instituted to safeguard the liberties of nobles against an absolutist monarchy and maintained as the “apple of liberty’s eye” (Lukowski 2012,
The risk of legislative paralysis was avoided as long as there was effective consensus about restraints on use of the veto. The solution to eventual legislative breakdown, according to Polish historian Jerzy Lukowski, was to address the mistrust that had arisen between the monarch and the aristocracy by enacting constitutional reforms that enshrined protections for liberty. In the end, Lukowski writes, “Unanimity supposedly continued to hold sway, no matter how improbable this must have been in assemblies numbering dozens or even hundreds of participants. Unanimity remained the ideal actively pursued by szlachta [noble] society: to attain it, safeguards were more important than efficiency or effectiveness” (2012, p. 96–97).

Such political experience with the individual veto is instructive for understanding the role of individual consent to public health activities. On the one hand, making individual consent necessary for any public health activity risks great public harm. Even if consensus were possible to negotiate, it takes time; in contexts of public health emergencies, timely information and action may be essential. Mistrust is endemic when people are afraid of the spread of deadly disease from one another or from sources unknown. Addressing mistrust is at the heart of sustaining surveillance in these circumstances, just as it was in the Polish legislature of the eighteenth century. Consent, or consent-like strategies, may be part of solutions to resistance to public health efforts.

### 7.5 Individual Informed Consent: Models from Bioethics

This is an age of ubiquitous consent on both sides of the Atlantic. Insistence on consent is ever-present in discussions of private affairs from sexual relations to marriage and the creation of families. The ease with which consent can be given and the consequences that may result remain contested, however. Notice and consent substitute for regulation to protect individuals from risky products or activities, from sharing information over the Internet to hang gliding. Consent also creates contracts and absolves manufacturers from liability. Consent may occur almost without people realizing it, with a click of an “I agree” button to share content over the Internet or an eager unwrapping of a shrinkwrapped package without reading the notices it contains. Consent may occur apparently quite readily even when important rights are involved, as when an employee signs a contract of employment without reading that she has ceded her right to go to court rather than be subject to arbitration if a dispute arises about her job. In some jurisdictions the reaction has been to significantly tighten some consent requirements, as in the European Union’s Data Protection Regulation or the development of consensual relationship policies on US college campuses. Autonomy has grown steadily within and outside the family and in other autonomous or partially autonomous groups consent has become the common expectation of the day.

Chapter 3 described the development of individual informed consent in bioethics and its impact on testing for HIV. This autonomy-based paradigm locates the
process of consent in separate individuals; assumes they are aware of their values, conditions, and options; and arms them with the knowledge, time, and skills to assess which course of action will best serve their values. Through support for confidentiality and control of information, the paradigm of individual consent is extended to information as well as it was for testing for HIV.

Informed consent is not a panacea for protecting individuals, however. The paradigm admittedly idealizes, in well-recognized but problematic ways (e.g. Faden and Beauchamp 1986; Kim 2019). Many decisions about personal health care are made within asymmetries of knowledge, resources, power, and dependency. Patients may be in pain, in fear of suffering, or faced with death. Decisions may need to be made quickly without time for calm or careful reflection. Patients without direct experience may find it very difficult to imagine what life would be like in an altered condition; people notoriously express different views about what they believe would be their quality of life with hypothesized disabilities than they do about their lives with actual experience of the disability.

Recognition of individual embeddedness in relationships and communities presents resources for addressing the inadequacies of informed consent in enabling individuals to seek to realize their values in receiving personal health care. Patients’ family or friends may play mitigating roles in reducing the flaws that plague effective consent. Relational theorists have pointed out that individuals exist in interrelationships with others that are constitutive of their identities and theories of their good. Individuals also may not make decisions fully on their own but with support and participation from others.

In addition to families and friends, support groups, either real or virtual, provide forums for sharing information and experiences, hopes and sorrows, and strategies and resources. The popularity of Facebook groups for parents of children with birth injuries or PatientsLikeMe for individuals with comparatively rare conditions illustrate how decisions about health may become embedded in interpersonal contexts. It should not pass without notice that support groups or Facebook groups may be groups or possibly even communities of at least some of the types delineated above. Groups and communities potentially offer resources to address at least some of the asymmetries of individual informed consent. The possibility also should at least be open to discussion that public health may have resources, including trusted experts or leaders, to counter asymmetries in individual consent. Whether groups, communities, or even state public health agencies function supportively or repressively, and give information or disinformation, is of course open to question. The only point at this juncture of the argument is that informed consent has insufficiencies that resources beyond the individual may be helpful in addressing.

Writers about informed consent have increasingly sounded the theme that it should be regarded as a process rather than an event. “Shared” decision-making under which physicians and patients develop mutual understandings and knowledge and work together to achieve care plans that reflect the patient’s values is a common description of this process. Here, too, there may be insights for individual consent from public health. Decision-making processes involve not only working together but also adjustment and compromise, trial and error, and revision and re-revision.
Sometimes, what matters more is the acceptance, thoroughness, and fairness of the process—not the result. Seen in this way, the process of individual informed consent is not the excavation of a “right” choice for a given patient. Rather, it is achievement of a plan that has come about in a good way. The decision may not be final, either, but subject to evaluation, re-evaluation, revision, and re-revision.

The informational function of informed consent is relevant here, too. Informed consent is about enabling people to have the knowledge they need to make the decisions they face. It thus requires judgments about what information is needed and how that information can be shared to improve understanding. Judgments about information and how it may be shared are themselves complex and contested; as Chapter 2 described, even scientific judgments are not univocal or settled. The process of subjecting recommendations to transparency, examination to avoid conflicts of interest, and assessment and reassessment is not simply individual. Of course, decisions about relevant information may be politically motivated and problematic; state legislatures in the U.S. have enacted legislation notoriously requiring physicians to read discredited information to women seeking abortions, such as that abortion causes depression or increases risks of cancer. Once again, the point here is not that public intervention is always or even usually benign, but that it may have insights and resources to contribute to the process of individual consent.

In individual health care, one asymmetry remains on the patient’s side, at least for the most part in many societies: the right to say “no.” To be sure, as a practical matter this right may be differently achieved, honored in the breach, or ignored for patients with different vulnerabilities and resources. But common law jurisdictions recognize imposing health care on people without any consent as the tort of battery (Schloendorff 1914), at least absent special justifications such as emergencies or imprisonment. Vaccination, too, has been long recognized as an exception in many jurisdictions, although the requirement remains controversial. In Jacobson v. Massachusetts (1905), the U.S. Supreme Court opined over a century ago that “The police power of a State must be held to embrace, at least, such reasonable regulations established directly by legislative enactment as will protect the public health and the public safety (p. 25).” Moreover, the Court reasoned,

…and surely it was appropriate for the legislature to refer that question [of what should be done in a health emergency], in the first instance, to a Board of Health, composed of persons residing in the locality affected and appointed, presumably, because of their fitness to determine such questions. To invest such a body with authority over such matters was not an unusual nor an unreasonable or arbitrary requirement. Upon the principle of self-defense, of paramount necessity, a community has the right to protect itself against an epidemic of disease which threatens the safety of its members (p. 27).

That this decision was later infamously applied to permit eugenic sterilization of those believed to be intellectually disabled (Buck 1927) has raised continuing questions about the scope of such public health authority but not about its underlying constitutional authority to act for the overall public welfare.

Libertarian theorists, however, urge that the asymmetric ability to say “no” should remain on the part of members of the public for to the extent possible in public health. Except in the clearest cases of self-defense on the part of the public,
these theorists argue, people should be able to opt out of public health activities. This position has been urged especially for interventions in support of the concerns of the new public health, as discussed in Chapter 6. But it has also been extended to gathering information needed for surveillance, at least to the requirement that people should be permitted to “opt out” of any requirements to share information about themselves.

Jessica Flanigan (2013, 2017), for example, argues that exactly the same commitments that justify anti-paternalism in bioethics extend to anti-paternalism in public health and to regulation of pharmaceuticals. People who are entitled to make unwise judgments as patients, she says, should surely also be entitled to make these same unwise judgments as consumers. After all, “consumers and patients are the same people” (2013, p. 173). “Because it is wrong for a physician to substitute his judgment for a single patient’s, it is even more wrong for a policy maker to substitute his judgment for an entire population’s” (2013, p. 175). Flanigan does limit her argument to coercive interferences; she supports the view that governments may act to ensure that people have access to adequate information and may also engage in nudging to counteract known cognitive biases. Otherwise, she contends, people may not be made to act for their own good, even when that good involves sharing information about themselves. That the authority intervening is democratically legitimated does not solve the underlying justificatory problem for Flanigan: if physicians may not impose health care on patients or reveal their health records without their consent, that the legislature has authorized them to do so should not make a difference. Both public and private power, she contends, must answer to the underlying rights of individuals, rights which take precedence unless the balance of moral reasons counts in favor of coercion.

As pointed out in Chapter 6, however, information poses a problem for this analysis, if information about some is needed for others. There are strong non-paternalistic reasons for surveillance. Defenders of individual control over information reply that depending on the circumstances some may be able to opt out of sharing “their” information without compromising the information available to others. According to this analysis, information is analogous to herd immunity: society does not need universal vaccination in order to be protected against the spread of infection, nor does it need universal information to protect the public against dangers to health. To be sure, both vaccination and information requirements to protect the public vary with the circumstances. Depending on the contagiousness of a disease, the percentage of the population needing to be vaccinated to create herd immunity will vary; for measles, 90–95% of the population must be vaccinated, but for polio the number is lower, for example (e.g. Silverman 2019). Similarly, depending on what is needed for data to be sufficiently representative of the population, the percentages that can opt out without compromising the analysis will vary. The distribution of opting out percentages matters, too; if a high proportion of people from a particular group decline to share, the data will be compromised for that group, just as herd immunity may not be created in a closely-knit population subgroup. Moreover, just as there are situations in which particular individuals must be vaccinated—for example, family members of an index case or travelers leaving an
infected area—so there may be situations in which information about particular individuals is necessary, for example to determine the significance of a genetic variant in a relative or to trace the transmission of an infection.

Thus, opt out strategies may not always be available without compromising public health. Rigid insistence on individual informed consent as a necessary condition for public health surveillance is not an acceptable position, as Onora O’Neill has argued (Manson and O’Neill 2007; O’Neill 2003) along with many other scholars (e.g. Berg 2012). Nonetheless, important insights are to be gained from the idea of informed consent and the underlying values of respect that it was designed to capture. People should be informed. They should be involved in decisions not merely as objects but as participants in the process. They are not—as Kantian autonomy captures—mere means only; they are ends deserving of respect. These points are not merely instrumental, although public health is likely to be met with resistance when people become suspicious that information is being withheld or that they are being used for the benefit of others. Instead, they are core ethical values that reflect why resistance may not only occur but also be warranted. They are values to be realized in the context of non-paternalistic justifications for public health surveillance.

The discussion that follows takes up how these elements of respect—information, participation, and subjectivity—can be reflected in surveillance decisions made by governmental units or decisions involving groups, communities, or populations. These processes are consent-like in some ways, but they are not the individualistic informed consent paradigm of bioethics. Nor are they the adoption of an opt in or an opt out framework for individual participation. The expectation is broadly accepted that consent matters in health care particularly when personal data are shared, and that data sharing is more likely to be successful if the population served believes it can trust public health authorities. The challenge for public health is how to acknowledge the concerns of a community without accepting a commitment to seek individual consent or agreement to gather and share personal data. Recognition is critical of some kind of community responsibility for the data collected and the consequences of its distribution for the individuals concerned (Lee et al. 2012).

In what follows, we develop how each of the different ideas of community sketched above may—or may not—instantiate elements of respect through sharing information, encouraging participation, and recognizing the subjectivity of members as people with their own values. The different ideas of community considered are:

- the political legitimacy of established public health authority
- group membership
- geographically defined community
- interest or identity-defined community
- population as defined by risk or some other characterization of interest.
7.6 Public Health Authorities: Democratic Practice, Political Participation, and the “Consent of the Governed”

Public health functions as an agency of government. One possible strategy for respecting individuals in surveillance is reliance on existing political institutions. Democratic forms of government are generally viewed to present the closest analogy to individual consent, as reflecting “the consent of the governed,” so we consider them as the best case here.

The “consent of the governed” has over the past two and half centuries been widely regarded as necessary to establishing a democracy and sustaining its existence. Yet how the requirement for consent of the governed is to be met has never been entirely clear. What consent means in institutional practice has been even less clear. As is regularly pointed out, consent as the right to vote did not extend in any obvious way to the great majority of people living in the British colonies at the time of the Declaration of Independence. Consent as the right to vote was gradually extended to greater numbers of people with the elimination of property qualifications and conditions of servitude, the grant of women’s suffrage, and reduction of the voting age to 18. But consent as the right to vote is not universal; depending on the jurisdiction, it may not extend to those who are underage, who have been convicted of certain crimes, who have been declared mentally incapacitated, or who are not residents or citizens.

The relationship between the right to vote and consent is a different matter, however. On one end of the spectrum is the view that voting in an election suffices for actual consent. The act of voting serves as an endorsement of the process and so arguably of consent to its outcomes. Conversely, someone who does not vote might be presumed not to endorse the process but to prefer a different system and hence not to consent. If only a few people vote, the more general conclusion might be drawn that people have taken the initial steps to seek new institutional arrangements for how they are to be governed. Equating voting with consent and not voting with not consenting, however, would be premature. The failure to vote also could be construed as a measure of satisfaction that the existing system is working well and so there is no reason to go to the polls. Or, it might reflect ignorance; political philosopher Jason Brennan (2016) questions allowing irrational or ignorant voters to have any kind of say in political decisions that affect others. Similarly, voting could be construed as an expression of the need for change. The meaning of voting is ambiguous, thus putting into question the relationship between voting and consent.

On the other side of the spectrum is the libertarian view that voting can never replace requirements for individual consent. Jessica Flanigan, whose opposition to the new public health was discussed in the preceding chapter, argues further that the fact that a democratically elected government institutes a coercive policy does not change whether the policy is justified in the first place (Flanigan 2013). If consent is required for someone to undergo a medical procedure, as she claims that it is, democratic authorization for patients to undergo the procedure without their consent does not constitute authorizing them to undergo the procedure without consent. On
Flanigan’s libertarian view, it is only permissible for a democracy to coerce when it would be permissible for an individual to do so, and it is only permissible for individuals to coerce when it would prevent them from being harmed by others (2013, p. 176). That the individual has accepted the benefits of living together in society or has in some way agreed to the decision process does not change this underlying limit on when the use of coercion can be justified. Instead, Flanigan thinks, the individual must have consented to the benefits or the process with the coercion as a condition, in order to be considered to have consented to the coercion too.

Libertarian positions about democratic legitimacy such as Flanigan’s may be criticized on many grounds. Most importantly for public health, such libertarianism holds a very narrow view about the extent to which individuals’ actions affect only themselves and not others. On such libertarian views, someone’s diabetes affects only herself whereas someone’s measles might affect others. If, to the contrary, we think that someone’s diabetes does affect others—or take the more far-reaching structural position that someone’s diabetes and whatever effects it might have on others are embedded in a common social framework—then we have grounds for rejecting the line between self and others that underlies the insistence that individual consent is necessary to legitimate any coercive public health measures that extend beyond preventing contagion.

Rejecting libertarianism does not, of course, mean accepting the view at the other end of the spectrum that voting constitutes consent. A more moderate view might be that, in a democracy, legislative oversight reflects the concerns about respect for persons that motivate consent requirements. If in the jurisdiction in question the legislature assigns responsibility for decisions to administrative agencies, then the question would be whether a structure of legislative assignments regarding surveillance to public health sufficiently respects individuals who are involved in the surveillance. In practice, a good deal of surveillance has been conducted at the local government level and local governments perhaps present the most compelling case for effective democratic oversight of surveillance. Oversight allows accountability of elected leaders to their constituents rather than agreement in real time of every constituent to every decision. Nonetheless, even with this level of oversight there are gaps in achieving respect.

One limitation of democratic oversight is that it yields at best a patchwork quilt of yeas and nays to majority decisions accepting the terms of surveillance. People who are persistently in the minority may mistrust and reject participation in surveillance; resistance may be especially significant if these are people who are in the minority on many issues or are from disadvantaged groups. On the other hand, adequate surveillance may be exactly what is needed to reveal disadvantage, as the publication of the disparate impact of COVID-19 has done. Timing is another difficulty, as decisions may need to be made quickly about issues that may have been difficult to predict in advance such as a novel pandemic; consultation risks obstructing these decisions. These limitations might be addressed by regarding public health surveillance as a collective commitment that is ratified by policy makers on behalf of the governed to be performed by agents of the public health department. That is, authorization occurs beforehand at the policy level. Afterwards, failures to object take the place of consultation at the moment.
Whether authorization and apparent later acquiescence are meaningful for people in the jurisdiction is questionable, however. Problems of minority exclusion may remain. In addition, members of the political community at one point in time may be quite different than members at a later point in time. Members of a later political community may not even be aware of—much less have been consulted about—earlier decisions about surveillance policies. Another problem is that some or many members of the political community may be poorly informed at any point in time; unless efforts to communicate are assiduous, surveillance may come as a surprise to some.

Two decisions by the New York City health authorities—one about limiting the size of cups of soda and the other about diabetes surveillance—illustrate how these gaps may emerge and become significant even when decisions can be made without time pressures for immediate action. In 2013, as discussed in Chapter 6, New York City health authorities decided to implement a cap on the size of sweetened beverages. Because neither the city council nor the state legislature had been able to agree on an approach to reducing consumption of sugary beverages, and city public health officials considered these drinks to be a significant public health threat, the Board of Health adopted a regulation prohibiting specified establishments from selling drinks in cups larger than 16 ounces. A successful court challenge determined that the Board’s action exceeded its regulatory authority—that is, that the Board had acted on its own rather than under the umbrella of the required legislative action. The court challenge intervened to block what was widely regarded as action by the Board without appropriate democratic oversight.

The decisions about diabetes surveillance, however, illustrate insufficiencies in legislative authorization. Several years before the soda size regulation controversy, the Board had taken a set of highly controversial surveillance actions regarding tests for a measure of diabetes control. It created a hemoglobin A1c registry and required reporting of test results to the registry. It also implemented a pilot study in the South Bronx, an area with particularly high diabetes rates. Under the pilot as originally proposed, patients would be informed of their test results and significance and physicians would be given quarterly summaries of their patients’ levels of diabetes control (Chamany et al. 2009). (After opposition surfaced, the pilot was designed to allow patients to opt out, although critics claimed that the opt out process was too difficult for many to use.) These actions were met by extensive ethical criticism for violating privacy, imposing an intrusive form of paternalism, interfering with physician-patient relationships, and discriminating against largely minority residents of the South Bronx. Notably however, while critics cited disanalogies between tracking diabetes as an “epidemic” and listing contagious diseases for surveillance (e.g. Barnes et al. 2007), whether the action was within the legislative grant of authority to public health was not challenged. Instead, the controversies about the registry proposal were all about the conflicts between privacy and public health presented by the registry. Privacy advocate Janlori Goldman (2008) and her

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1 New York Statewide Coalition of Hispanic Chambers of Commerce v. New York City Department of Health and Mental Hygiene, 16 N.E. 3d 538 (N.Y. 2014).
coauthors argued that the registry lacked adequate privacy safeguards, threatened the integrity of the physician-patient relationship and would backfire as patients avoided seeking care. Law professor Harold Krent et al. (2008), in a thorough legal analysis of the registry, pointed out its many legal risks to patients but did not ask whether the registry overstepped the authority of the public health agency.

Public comment had been solicited before establishment of the program (Chamany et al. 2009), so there was at least some transparency and opportunity for the public to be heard. However, Fairchild and colleagues describe the process of public consultation as limited and not at all systematic (Fairchild et al. 2007a, b; Fairchild 2006). Major city hospitals and clinicians were consulted, but local and state medical associations were not. The American Diabetes Association was consulted and agreed to support the registry only if patients gave informed consent to participation. During the development of the registry proposal, privacy advocates were not involved, according to Fairchild (2006). Citizen advocates pressed privacy concerns at a hearing, but few public comments were submitted. There is no report of efforts to engage local groups in the South Bronx despite the area’s history of community organizing; one study several years later of the South Bronx after the recession reports that the area had significant “bridging social capital among …different cultural and historical worlds” (Parés et al. 2017). Pushback against the registry was the result, and subsequent efforts to extend the registry model to HIV were met with stiff opposition. Even though the registry did not draw the challenge of overstepping public health’s administrative authority that was later wielded successfully against the soda size regulation, it can be viewed as a failure of democratic oversight. Respect for those governed by surveillance requires more than a general legislative grant of authority and public notice if it is to be sustainable.

### 7.7 Involving Groups and Communities

Earlier in this chapter, we identified groups, communities bound by geography, and communities of identity or interest as potentially distinct sources for community engagement. Here, we consider whether—and how—each of these might be involved in surveillance in ways that help to generate the forms of respect that underlie claims for informed consent: information, participation, and recognition of subjectivity.

#### 7.7.1 Groups

Groups have the advantages for consultation of recognized leadership and membership structures. Some groups may also have governmental authority—Indian tribes are the best example in the United States. With the advent of social media, groups have become far more fluid, although some with quite extensive structures remain.
Groups may have established methods for communicating with members that enable ready dissemination of information. Groups may also have structures that encourage members to voice their concerns by coming to meetings, commenting through social media, or even talking with other group members. If groups have identified values, religious or otherwise, people holding group leadership positions may be able to give effective voice to these values. This is not the same as “speaking for” the group, which would suggest that the group leader is acting in a representative capacity. Rather, it is giving voice to values that are likely to be shared among group members. Communication here may also be more than one way, if group leaders and group members discuss shared concerns and how values might be articulated in light of these concerns.

An example of involving groups in these ways is provided by recent vaccination controversies in Orthodox Jewish communities in New York. These communities have high rates of vaccine refusal. When they were beset by a measles epidemic in 2019, the response of the City health department was to mandate vaccination within four of the most affected ZIP codes. The result was controversy and resistance. Cantor (2019) urges instead that there should be support for efforts to address the vaccination refusals through groups respected by the community. The Orthodox Jewish Nurses Association (OJNA) is a group founded quite recently—in 2008—to provide a network of support for Orthodox nurses. Membership requires dues; the organization maintains a website, publishes a journal, has local chapters sponsoring social and educational events, and maintains an active social network presence on Facebook (OJNA 2019). In response to the misinformation campaign that had encouraged vaccine refusals in the New York Orthodox communities, OJNA published a booklet explaining vaccine science and OJNA members met with small groups in the Orthodox community, especially mothers who had received antivaccination appeals (Cantor 2019). Community religious leaders also spoke out in favor of vaccination (LaMotte 2019). More so than top-down public health requirements, these efforts have the potential to engage group members in addressing their concerns and countering other communication strategies that are also directed at group members.

7.7.2 Geographically Defined Communities

The vaccination controversy is unusual in the extent to which it affected a particularly tight-knit group. Surveillance, as well as other public health activities, may also involve geographically defined communities. As described above, these communities may share some or all of cultural or religious ties, histories, perspectives, or interactions. They are geographically bounded but not necessarily coincident with political jurisdictions.

The movement for community engaged participatory research (CBPR) has generated a considerable literature about involving geographical communities in research (e.g. Coughlin et al. 2017; Dolgon et al. 2017). CBPR is research, and thus
emphasizes consent by both individuals and on behalf of the community, but the literature contains a wealth of materials about engagement. Establishing community partnerships is core to the methodology of CBPR. According to one standard text about the methodology as it is used in health research, nine principles guide CBPR partnerships:

- communities are to be acknowledged as units of identity
- research must build on community strengths and resources to identify concerns
- partnerships must share power equitably in a manner that recognizes existing social inequalities, for decisions at all stages of the research process
- processes must be reciprocal and involve learning on all sides
- there must be a balance between knowledge generation and intervention for the mutual benefit of all community partners
- focus must be on the local relevance of health problems and emphasize an ecological approach
- systems development must be addressed through a cyclical and iterative process
- results must be disseminated to all partners and partners must be involved in the wider dissemination of any research results
- the process must be long term and involve commitments to sustainability (Israel et al. eds. 2013).

Several themes in these principles are particularly relevant. CBPR is to be relevant to community concerns; similarly, surveillance might attend to issues of particular salience in the community. Power and learning should be shared and reciprocal; surveillance decisions should not be top down only. Benefits should be shared, too. Ongoing communication is critical, especially about what is being learned and how that information is being shared. And surveillance is an evolving and ongoing process.

These principles describe what partnerships with communities should generally be like but do not themselves describe how communities should be approached to achieve these goals or how particular partners should be identified. Addressing these issues, the text suggests that partners may be identified in many ways, but a common starting point must be how residents of the geographical area define their identities. To get to know communities, researchers are urged to contact all the organizations that might give voice to people within the community, from parent-teacher associations and schools, to community safety or housing groups, to environmental justice coalitions (Israel et al. eds. 2013, p. 48). They are also urged to identify community “movers and shakers” through these groups (p. 54). A recognized ongoing challenge for CBPR, however, is to reach beyond service professionals and other policymakers to other community members who may lack time or resources to attend meetings. Providing meals and childcare may help but barriers such as work schedules may still impede community participation. Another challenge is to develop structures for ongoing collaboration, all along guided by overarching
principles such as equity and reciprocity. These challenges are also faced by public health as it seeks to involve its community in surveillance.

Fundamental to CBPR is the idea that the community itself has interests and concerns beyond the coinciding interests of individuals making up the community. Whether and how to identify these community-level factors is not easy, however. A literature review of discussions of ethics in CBPR identified community considerations as community self-determination, protection of community values, respect for culture, dissemination of results to the community, equity within the community, and consideration of community needs over individual liberty (Mikesell et al. 2013). In a 2011 review, Shore and colleagues assessed how community concerns are addressed in the process of reviewing the ethics of CBPR research by institutional review boards and concluded that community-level considerations typically are not included in the reviews (Shore et al. 2011). This study surveyed community groups involved in CBPR partnerships involving research with human subjects and found that just over a third did not have processes for deciding whether the community should participate in research. They also concluded that many communities most affected by inequities did not have the resources to create effective review processes. A noted—and notable—limitation of the research was that it did not ask how survey participants themselves defined “community” (Shore et al. 2011, p. S363).

A 2017 report of the Committee on Community-Based Solutions to Promote Health Equity in the United States of the National Academy of Medicine attempted to tackle the problem of involving communities in addressing health inequities. The definition of “community” used for this report was sufficiently broad to include both spatially defined communities and communities of interest: “Any configuration of individuals, families, and groups whose values, characteristics, interests, geography, and/or social relations unite them in some way.” (Weinstein et al. eds 2017, p. xxiii). The report describes how community assets can be built, leveraged, and modified and can create a context in which to foster health equity” (p. 9) by developing concrete examples of community-based solutions to health inequities. In selected case studies, the report describes these strategies for engaging communities: getting recommendations for stakeholders and partners from the mayor and city council, consulting local health care centers, consulting neighborhood community organizing centers, consulting local charitable organizations such as United Way or a nonprofit Children’s Bureau, engaging local schools, linking faith communities such as Protestant churches and the local Catholic diocese, working with an organization devoted to food security, working with an organization pursuing environmental justice, and contacting local social service agencies, among others. This variety suggests that successful methods for engaging communities will vary with the individual circumstances of communities. Challenges include communication, the time and energy needed for participation in longer-term projects, and changes in political administrations (Weinstein et al. eds 2017, p. 315). Essential to addressing these challenges are shared visions, hope for a better quality of life, trust, and community agency, according to the report. Without sufficiently charismatic
leaders, community engagement often failed. Community partnerships also required “very specific governing practices and structures that were tailored to the needs and makeup of the community being engaged” (p. 319). This analysis suggests that the more structure and leadership exists within the community, the better may be the prospects for sustained engagement of the community in surveillance that is acceptable to them.

7.7.3 Communities of Interest, Communities of Identity, and Populations

Communities of interests or identity may lack geographical cohesion or any recognized leadership or structure. A group bound by an interest—in protesting genetically modified foods, achieving a cure for a devastating disease, or accessing expensive drugs for their condition—may be bound by little else than the interest that brought them together. No community values or ties may extend beyond the interest that is mutually shared. Individuals may be willing to share data to address that interest, especially if the interest is highly salient to them, but addressing other forms of surveillance with communities of interest may be more difficult. Once data use goes beyond the interest that brought these individuals together, cohesion may be difficult to sustain. Without any structure other than the shared interest, it will be more difficult to establish inclusive political channels sufficient to sustain information exchange or participatory engagement.

On the other hand, some communities of interest may have established communication networks, especially through the internet. Facebook pages or other social networking sites may be useful for sharing information about surveillance and its results. Email lists and lists of followers on sites such as Twitter can serve as a way for getting out information about surveillance and its results. Social media can also be a means for inviting participation. Polling, qualitative research strategies, or online focus groups may be possibilities for gauging attitudes of those involved in communities of interest and attempting to respond to them.

Communities of identity such as “the Black community” or “the disability community” may present further difficulties. Communities singled out by an identity characteristic may not be linked in any other way. There may be no established channels of communication to transmit information about surveillance, its results, or other important health information. Public health may rely on media that it believes are more likely to appeal to people who share the interests in question. For example, the Centers for Disease Control and Prevention tried to educate Blacks about HIV/AIDS testing by advertising on radio stations believed to have high rates of listeners who are Black (Hall et al. 2010). This method of communication is imperfect at best, however. There may be no structures other than existing political institutions to encourage participation. A further challenge is that an identity characteristic used to delineate a supposed community of interest may—but may not—be accepted by all
those who are considered as within the community (Jewkes and Murcott 1996). Imposition of an identity characteristic may be met with surprise and displeasure by those who believe they have been mischaracterized or who do not wish to be associated with a community of identity. Communications aimed at people that presume membership in an identity community may backfire as a result. On the other hand, relying on people to self-identify as members of an identity community—as does the census for categories such as black/African American—may be both under- and over-inclusive, especially if people have multiple or mixed identities.

Whether individuals are singled out as members of a community of identity or as a population subgroup may also be unclear. Populations are defined by questions of interest for public health, such as risks. These may or may not coincide with communities of identity such as Blacks in the U.S., residents in the US, or everyone living in areas of high rates of a particular disease such as HIV/AIDS. If a public health official states the importance of working with the Black community on a public health issue such as HIV, that official may mean all Americans who indicate they are Black on a census form, or a set of Black individuals living in a specific geographic space, or perhaps more ambitiously the Black population (however identified) of the nation as a whole. The official also may think of a nationally dispersed set of localities, each one a community that in turn has much in common with other communities. In this example, individuals may share an identity, they may or may not have chosen the identity, and others may have designated the identity for them externally.

Efforts by the CDC to address rates of HIV in the U.S. illustrate how communities of interest, communities of identity, and populations may become blurred. Rates of HIV and rates of new diagnoses of HIV among people who self-identify as coming within the census category black/African American are significantly higher than rates among other racial or ethnic groups (CDC 2019). In reporting this data, the CDC refers to black/African Americans, whites, and Hispanic/Latinx as subpopulations. It also refers to the challenge that “some African American communities have higher rates of some sexually transmitted diseases (STDs) than other racial/ethnic communities,” using the language of community rather than subpopulation but here as referring to what might be geographically located communities of Blacks rather than communities of identity. The federal government website HIV.gov describes its informational sheets concerning HIV rates among blacks/African Americans nationwide as “HIV’s Impact in the African American Community” (HIV.gov 2019)—here, using the language of a community of interest to refer to the population subgroup of black/African Americans rather than to communities with shared ties. These differences matter. Given the growing knowledge about HIV transmission within groups that share social interactions, blurring the lines between communities defined through geographical linkages, communities of identity, and subpopulations may prove troubling in developing strategies for addressing disease spread (Morgan et al. 2018; Sullivan et al. 2018). But it is also troubling about building trust in surveillance, as strategies for communicating with groups and local communities may be quite different from strategies for addressing subpopulations.
7.8 Movement: Surveillance Crossing International Boundaries

A still further problem for communicating about and engaging people in surveillance is that people move. When they move, disease travels with them. This has been true at least since the early great empires. The Roman Empire in many respects was a success. Once the Romans conquered a kingdom, the new province gained access to trading markets from England to the Nile and as far as India. Roman engineers built new water systems that supplied public baths and running water, put on public spectacles and good theatre, trained a very effective army, built straight roads, protected shipping lanes, and expanded citizenship. Ironically, however, the historical evidence suggests that people living in Roman areas were shorter and had weaker bones than people before or after the Roman Empire—likely because the presence of disease impaired nutrition (Harper 2017). The ease of movement throughout the Empire brought not only better trade but the plague as well that killed far more Romans than the ever-ongoing battles to expand and sustain the Empire. Roman engineers did not successfully address sewage discharge and Roman medicine had not discovered the germ theory of disease. Great plagues would continue to bring sobering numbers of deaths through the middle ages. The aristocracy and the poor both died in great numbers, but as Boccaccio points out in the *Decameron* leaving plague infested areas may have helped the more privileged to survive (Tuchman 1978).

Movement remains an important force in the spread of disease today. The scale of human movement is considerable: from tourists and owners of second homes to traveling salesmen, concertgoers and attendees at international sporting tournaments, migrant laborers and refugees, hundreds of millions of people are on the road. Movement may mock borders as boundaries to restrict the spread of disease. This is especially true for diseases with longer incubation periods such as influenza (up to 4 days), measles (10–12 days), COVID-19 (up to 14 days), or Ebola (up to 21 days), as people may complete their travels before they realize that they are becoming ill.

Each year, seasonal influenza strains emerge from southern areas of Asia and spread across the globe, infecting an estimated billion people (WHO 2019). The predominant strains of seasonal influenza vary somewhat from year to year and health officials seek to predict them sufficiently in advance to enable manufacture of appropriate vaccines. Pandemic influenza occurs when a novel strain emerges to which a significant proportion of the population has no immunity. Fears are that a contemporary pandemic would spread even more quickly and be particularly lethal in areas of the world with inadequate access to health care for prevention or support (WHO 2019, p. 5). We are seeing these fears materialize today with COVID-19 spread.

The influenza virus is particularly unstable and subject to rapid mutation through genome re-assortment from various strains (Shao et al. 2017). Proximity can be harmful in exchanging different viral strains, as occurs in areas of Asia. Air transit moving people rapidly across the globe can then spread novel strains far afield.
To illustrate, the European Centre for Disease Prevention and Control estimates the scope of potential for influenza transmission by air, given that over 900 million airplane passengers travel within Europe every year: “The transmission of influenza viruses, for example, is facilitated in closed/semi-closed settings through direct person-to-person contact or from contaminated surfaces. At the beginning of the influenza A(H1N1) pandemic in 2009, air travel was the cause of the introduction of this new virus into countries not primarily affected, and aeroplanes are likely to be a major vector when the next pandemic occurs” (ECDC 2017). Indeed, disease transmission is a significant concern within the heart of the European Union with its relatively open land borders and free movement of goods and services within the Union. The EU may implement public health measures restricting travel on the part of people arriving by ship or plane from foreign destinations. At the height of the COVID-19 pandemic, borders were closed within the EU. But the scale of travel within the EU is of such a proportion that maintaining such a strict public health regime is challenging. The estimate is that 90 million intra-EU visits take place to France in any given year while another 80 million visits occur to Spain. Fortunately for the EU, the broad health of people living in Europe is superior to that in many parts of the globe, which suggests that the quality of personal health care systems should be seen in tandem with public health surveillance.

On a global scale, the World Health Organization tracks influenza and its spread. The WHO strategy for influenza during the decade from 2020 to 2030 follows the International Health Regulations (IHR) by seeking to build strong national capacities for influenza preparedness and response. Under the IHR, the state performs the primary and necessary role in the enterprise of legislation regarding health policy (WHO 2005, Art. 3 §4). The influenza strategy recognizes the primary role of states in developing health infrastructures and ensuring universal access to health care (WHO 2019, p. 6). By 2030, the desired outcome is for every country to have an evidence-based influenza plan, optimized to fit its needs (p. 9). This structure recognizes states as autonomous actors in governing their respective populations.

The IHR structure also commits states parties to obligations regarding the risk of disease spread beyond borders. Through becoming a state party to the WHO, states agree to developing and maintaining adequate surveillance capacities (WHO 2005, Art. 5) and to notifying WHO of events that may constitute public health emergencies of international concern (Art 6).

A major challenge to this regime is the problem of equity that we discussed in Chapter 4. Although states share the obligations to surveille and report threats equally, they may be far from equal in their commitment to collaborate with the WHO in addressing threats or in their ability to devote resources to surveillance. The IHR permit WHO to offer states collaboration in the effort to assess the potential for international spread through travel and, if states decline the offer of collaboration, to share the information with other states depending on the magnitude of the risk (Art. 10, §§3, 4). But the IHR do not give WHO authority to compel collaboration by states parties that are unwilling to collaborate. States also may be far from equal in their surveillance capabilities or their ability to address emergent health care needs. The IHR permit WHO to offer assistance to states in developing and
maintaining their capacities (Art 5, §3). They also urge states to undertake to collaborate with each other, including through mobilization of financial resources, but this is a recommendation not a requirement (Art. 44).

An important provision in the IHR allows non-state actors to report possible health emergencies of international concern (Art 9). Receipt of information from non-state actors may lead WHO to start an investigation, even if the relevant state party has not notified WHO of concerns. Non-state actors may be engaged across borders in ways that states cannot be, along with other advantages and disadvantages. They may have greater capacities and access to information that states do not. Their inclusion may reflect concerns about willingness of states to cooperate with WHO. WHO has developed a framework of engagement with non-state actors in response to the recognition of the increasing role they are playing in global health (WHO 2016). However, participation of non-state actors in surveillance may have mixed results. WHO singles out concerns for transparency, undue influence, conflicts of interests, and potential risks to its credibility raised by partnerships with non-state actors. WHO is also concerned that through the support they are given non-state actors may acquire competitive advantages, pursue their own interests, and whitewash their images. The WHO Director-General reports annually on the status of engagement with non-state actors. The possibility of reporting may also be risky for non-state actors; Médecins Sans Frontières was forced to close treatment centers due to attacks during the 2019 Ebola outbreak in the Congo.

The ease by which influenza and other infectious diseases cross boundaries with mobile populations has led to increasing resistance to migrants such as asylum seekers and refugees. At this juncture, security policy and public health policy may seem to converge. Defending the city, the state and the nation against invading armies may become an obvious parallel with the image of an epidemic moving toward the city threatening illness and death. But engaging the enemy in a theater of war distant from the borders of a home state is not at all parallel to addressing contagious disease transmission. People coming from abroad may be seen as dangerous threats, but they are also desperate refugees. Demands to close borders may become insistent—regardless of their likely efficacy. On the other side, those living in areas where disease have emerged may face grim choices between isolation, flight, or the possible hope of inoculation or effective treatment.

States’ obligations as parties to the IHR also involve expectations about how they are to respond to these perceived threats. These include limitations on the health documents that can be required of travelers who are not seeking temporary or permanent residence (Art. 35). They also include limitations on the health examinations of travelers that may be carried out without their informed consent (Art. 23, §3). Additional health measures are permitted on a case by case basis, provided that they are the least intrusive and invasive possible to achieve the objective of preventing the international spread of disease (Art. 23, §2). States are also permitted to collect information about destinations so that they may follow up if there is need to contact travelers (Art 23, §1). Travelers who refuse may be denied entry and states
may take further action to prevent disease spread, including quarantine according to state law (Art 31, §2). In implementing any of these measures, the IHR require states to treat travelers in accord with respect for dignity, human rights, and fundamental freedoms (Art. 32). States must take gender, cultural, and ethnic or religious concerns into account and must arrange for food and water, appropriate accommodations and clothing, appropriate medical treatment, and protection of possessions (Art. 32). Summarized, these provisions allow states to protect public health but require them to minimize harm to individuals affected.

Reactions in the U.S. to Ebola illustrate the tensions that may affect how states actually perceive and respond to apparent threats from abroad. The West African Ebola outbreak in 2014–2016 presented no systemic threat to the U.S. homeland but was met with great fear and at least some stigmatization of people from the region as potential sources of infection. The only way Ebola could affect people within the U.S. who had not traveled to areas where they might be exposed was by coming into direct contact with infected bodily fluids from someone who had become infected abroad and returned to the US, yet misinformation about modes of Ebola transmission circulated widely. The failure to recognize a case of Ebola in a patient who had traveled from Liberia, and subsequent infection of health care workers in an underprepared facility, contributed to public perceptions that CDC had gravely underestimated the threat. A good deal of popular support was expressed by political leaders at local, state and federal levels for denying entry or re-entry of people who came from African nations experiencing the outbreak and for quarantine of people suspected of potential exposure. These calls extended to doctors and nurses who had served in charitable roles in countries associated with the Ebola outbreak. Health communication scholars Shaunak Sastry and Alessandro Lovari (2017) argue that CDC messaging about Ebola through social media reaffirmed western anxieties about infections emerging abroad. The image of President Obama deploying troops abroad to fight the epidemic may have contributed to this perception of foreign threat to be fought elsewhere. Other communication scholars note the prevalence of stories on social media about risks of infection in the U.S. in contrast to stories about the epidemic in West Africa or the science of Ebola spread (Roberts et al. 2017). A later critical review of the U.S. response to Ebola indicated the importance of involving local health departments in developing guidance, providing healthcare facilities and other potentially involved personnel such as EMS workers with appropriate guidance about infection control, communicating about risk to address popular misconceptions, and most importantly striving to avoid disconnections between these popular misconceptions and decisions made by political leaders (Dwyer et al. 2017).

In the wake of the West African Ebola epidemic, the CDC engaged in a rulemaking process to amend its authority to over quarantine of interstate travelers and travelers from abroad (HHS 2016). The proposed regulation expanded CDC’s authority to monitor threats including through electronic means. It established requirements for commercial passenger flights to report death or illness to CDC and
allowed CDC to implement travel restrictions on people moving among states who are reasonably believed to be infected with a quarantinable disease. Comments on the proposed rule were extensive and the final rule incorporated some protections in line with the IHR requirements for treatment of people under detention as potential threats to public health (HHS 2017). For example, under the final rule individuals being detained must be provided with adequate food and water, appropriate medical treatment and accommodation, and means of necessary communication. Individuals must also be informed that health examinations will be conducted by licensed health care workers with their informed consent. Critics argue, however, that the final rule is insufficiently protective in the extent to which it gives CDC discretionary authority to act quickly before administrative processes can occur (e.g. Edwards et al. 2017). In a notice of proposed rulemaking in July 2020, the administration of President Trump used pandemic threats as justification for emergency powers to reject asylum seekers to the U.S.

Nonetheless, people may be motivated to try to escape infection through movement, just as those who were able did in the Renaissance times of Boccaccio. Individuals behave rationally when they weigh the costs of leaving—moving away from families, jobs, or established networks—against the potential safety of flight. Movers may face the barriers of quarantine on arrival if domestic fears are sufficiently elevated. The IHR seek to mitigate the crueler aspects of this choice through protections for basic human dignity, and they may be well advised to do so. For diseases may travel very quickly with people who seek to hide concerns about their health. US reactions to the Ebola threat may prove instructive about the importance of protecting potential victims for achieving public health goals. One study indicates that of travelers to New York City being monitored for potential Ebola by the health department, a small but significant percentage gave misinformation about their temperatures or their whereabouts (Tate et al. 2017). Reported reasons included the stress of being monitored, discrimination at work, and avoidance by people they knew. Support during the monitoring, including information they could give to people about the protections monitoring could provide, was perceived as particularly helpful by people in complying with their surveillance. These findings support the need for addressing risks of harm to those under surveillance, when public health takes justified protective measures, to the ultimate success of protective measures, as Mark Rothstein (2015) argues the U.S. failed to do in reacting to Ebola.

In responding to movement, public health seeks to stabilize transmission by encouraging people to stay in place in times of a communicable disease crisis. To do so, it must calibrate responses carefully, providing accurate information about surveillance activities and what they are revealing, while not evoking irrational fear. Efforts to inform and to engage local entities, from health departments to members of multiple communities, are critical in countering flows of misinformation. Failures to respect people under the watching eyes of public health surveillance may backfire into sequestration or flight. The mobility of populations and diseases they carry underscore these ethical imperatives.
7.9 Summary

The impetus to insist on informed consent rests on important aspects of respect for individuals. Individuals should be able to understand what is happening to them and participate in decisions that affect them. Individuals should be treated as sources of their own good. These aspects of respect matter even when justifications for surveillance rely on non-paternalistic considerations such as prevention of harm to others or achievement of health equity. This chapter has explored how these aspects of respect can be achieved without reliance on individual consent when surveillance affects individuals, groups, or communities, and even when it crosses international borders.

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