ABSTRACT: Surveillance plays a crucial role in public health and for obvious reasons conflicts with individual privacy. This article argues that the predominant approach to the conflict—relying on a conceptual distinction between research and practice—is problematic and then offers an alternative. It outlines a basic interests approach to public health measures and an unreasonable exercise argument, which sets forth conditions under which individuals may justifiably exercise individual privacy claims that conflict with public health goals. The view articulated is compatible with a broad range of conceptions of the value of health.

INTRODUCTION

Surveillance plays an integral role in public health. Information is gathered to detect and track disease outbreaks and monitor myriad aspects of health, including (among other things) tuberculosis (TB), occupational safety and health, cancer rates, immunization, and HIV/AIDS (Stroup, Zack, and Wharton, 1994; Thacker 1994; Gostin 2008). The importance of surveillance is reflected in express public health exceptions in statutes and regulations that otherwise protect health information. Yet there is a substantial and growing body of evidence that people are deeply concerned about privacy in their health information. Reconciling the need for information-gathering to protect public health with individuals’ claims to privacy is therefore an important task.

However, determining when public health goals may supersede persons’ interests in privacy and justify surveillance is difficult. My task in this article is to provide an account of when it is justifiable to collect individually identified information for the purpose of promoting public health. I begin by providing background regarding the state of public health surveillance and privacy. I next outline the tension between privacy rights and health
surveillance and argue that the predominant approach to justifying public health surveillance, one based on a conceptual distinction between research and practice, is inadequate.

I offer an alternative view, which centers on the unreasonable exercise argument. The view begins with what I call the basic interests approach, which maintains that public health activities (including surveillance) are justified insofar as they focus on persons’ basic interests but denies that aggregate benefit is sufficient to justify interventions. Within the context of this approach, I advance the unreasonable exercise argument, according to which public health actors may subordinate individuals’ nonbasic interests when exercising claims to such interests unreasonably threatens others’ basic interests. However, when a person’s exercise of a claim based on a deep personal interest does not impose such a threat, there is a pro tanto reason not to restrict exercise of that claim. I further specify the basic interests approach and the unreasonable exercise argument by sketching how they can be applied in different cases.

BACKGROUND

Public Health Surveillance

Public health surveillance is “the ongoing systematic collection, analysis, and dissemination of health data to those who need to know” (Thacker, Stroup, and Dicker 2003, p. 224). Its scope is wide, both in its purposes and its methods. Information gathered in public health surveillance is used “to assess public health status, to define public health priorities, to evaluate programs, and to conduct research” (Thacker 1994, p. 8). Surveillance is used in detecting epidemics, understanding the natural history of diseases, determining the magnitude and geographic distribution of problems, evaluating control and prevention efforts, planning and priority setting, detecting changes to health practices, and stimulating research (Thacker, Stroup, and Dicker 2003, pp. 8–14; Thacker 1994, pp. 8–24; CDC 2011a).

Surveillance systems collect information in numerous ways. They may use mundane sources such as vital statistics (e.g., birth and death records), surveys, and environmental data regarding risk factors (e.g., air-monitoring data gathered under the Clean Air Act and hazardous materials spills reported to the federal Department of Transportation) (Thacker, Stroup, and Dicker 2003, p. 231). There are also sentinel surveillance programs, which monitor key health events. For example, occupational health conditions are monitored in the United States by key health care providers participating in the Sentinel Event Notification System for Occupational
Risks (SENSOR) (Stroup, Zack, and Wharton 1994, pp. 45–46). The recognition that behavior is a crucial aspect of health has led public health agencies to gather information regarding the use of alcohol, cigarettes, and drugs, the use of safety devices such as seatbelts and bicycle helmets, and persons’ eating, exercise, and sexual habits (Gostin 2008, p. 292). A relatively novel approach, which may prove useful for early detection of outbreaks or bioterrorism, is syndromic surveillance. This involves “collecting and analyzing statistical data on health trends—such as symptoms reported by people seeking care in emergency rooms or other health care settings—or even sales of flu medicines” (Stoto, Schonlau, and Mariano 2004).

Another surveillance method is mandatory reporting of specific diseases. In the United States, states require that health care providers and laboratories report certain diseases. These reports are in turn voluntarily submitted to the Centers for Disease Control and Prevention (CDC). Registries of health information are another important facet of health surveillance. These are records that contain information collected from multiple sources and that are linked to particular people over time (Stroup, Zack, and Wharton 1994, p. 51). For example, immunization information systems collect vaccination data about children within a geographic area to help ensure high vaccination coverage (CDC 2011b). Disease registries exist in the United States for a variety of conditions, including cancer, TB, HIV/AIDS, birth defects, and occupational diseases. Researchers have also proposed registries of pregnant women in an effort to better understand the effects of pharmaceuticals on developing fetuses (French et al. 2008). Of particular note is a recent, controversial initiative for surveillance of diabetes in New York City. Because diabetes is a large and growing problem, the New York City Board of Health mandated laboratory reporting of A1C (blood glucose) tests and created a registry to track control of blood sugar levels of people with diabetes (NYCDHMH 2005). The move has generated substantial controversy, in part because there is no provision for patients to opt out of reporting and in part because the benefits of the initiative are unclear. I discuss the initiative more fully below.

Privacy

Despite the central role that surveillance takes in public health systems, there is ample evidence that people value privacy in health information. Sixty-eight percent of respondents to a California HealthCare Foundation poll said that they were concerned about medical record privacy. The
same poll found that one in eight people engaged in “privacy-protecting behavior,” by, for example avoiding seeing health care providers, asking doctors to fudge diagnoses, paying out-of-pocket to avoid making an insurance claim, lying to health care providers, and skipping tests (California HealthCare Foundation 2010, p. 20). The Johns Hopkins University Genetics and Public Policy Center has held focus groups in several cities to examine public opinion regarding genetic and health research. It determined that the key burden for getting people to participate in large cohort studies was concern about privacy (Williams et al. 2009; Krane 2007).

Not only is there strong evidence that people care deeply about medical privacy, but legal rights to medical privacy have also been recognized both legislatively and judicially. For example, the Health Insurance Portability and Accountability Act (HIPAA) privacy rule restricts the conditions under which health information may be used or disclosed (45 CFR 160, subpart A, and 164 subpart E). The United States recently enacted the Genetic Information Nondiscrimination Act, which protects persons’ privacy insofar as it prohibits insurers and employers from making decisions about coverage and employment based on results of genetic tests (PL 110-233, 122 Stat. 26). In Whalen v. Roe, the United States Supreme Court determined that there is a right to privacy in medical information, though it concluded that the state has a sufficient interest in controlling drugs to maintain a prescription database (429 US 529 [1977]).

Such concerns about health privacy conflict with the extensive role that surveillance plays in public health. Indeed, disputes about privacy have been central to political debates regarding surveillance programs. There has been significant opposition to immunization registries, HIV/AIDS registries, syphilis reporting, and occupational disease reporting on privacy grounds (Fairchild, Bayer, and Colgrove 2007). New York’s diabetes initiative has likewise been the center of privacy debates. Various groups raised objections to the initiative during public meetings. Some expressed concern over what they considered a private matter being turned into a public matter, and others thought that the decrease in privacy was unjustified on the grounds that diabetes does not pose a threat to others.

RESEARCH AND PRACTICE

The primary way of resolving the tension between public health surveillance and privacy concerns is by distinguishing between public health research and public health practice. Protection of human subjects in research in the United States is guided by the Belmont report, as well as by
international guidelines set forth in the Nuremberg Code, the Declaration of Helsinki, and the Council of International Organizations of Medical Sciences’ Ethical Guidelines for Biomedical Research and Epidemiological Studies (NCPHS 1979; Council for War Crimes 1947; World Medical Association 2008; CIOMS 2002). Each of these places important restrictions on research in order to protect the interests of research subjects against any claims made on the basis of widespread benefits to communities (Gostin 2008, p. 310).

These guidelines are codified for human subjects research conducted with federal support, which is generally regulated by the federal policy for the protection of human subjects, or “Common Rule” (45 CFR 46). Under the Common Rule, federally supported research on human subjects must be reviewed and approved by an institutional review board (IRB) and the subjects must give their informed consent. With respect to privacy, the Common Rule requires that IRBs ensure adequate protection for subject privacy “when appropriate” and that researchers inform subjects of the degree to which identifying information about the subject will be kept confidential (45 CFR 46.111[a][7]; 45 CFR 46.116[a][5]). Thus, there is some recognition of, and legal protection for, privacy in research conducted under federal auspices.

However, a great deal of information collection in the public health sphere is conducted by state and local entities, independently of the Common Rule. And although principles outlined in the Belmont report and elsewhere are meant to apply regardless of who funds research, many think that some public health information-gathering is important enough that it ought not be constrained as research under the Common Rule. Lawrence Gostin describes the situation as follows:

State and local health departments routinely engage in a broad range of activities, including surveillance (e.g., reporting, disease registries, and sentinel networks), epidemiological investigations (e.g., outbreak investigations and emergency response), and evaluation and monitoring (e.g., program evaluation and oversight). Scholars have been wrestling with the problem of when these routine practices become a form of population-based research. This is a vexing and important problem, because if routine public health practices were classified as “research,” health departments would have to submit this activity for review by institutional review boards (IRBs) and obtain informed consent from participants. Classification of practice as research, therefore, could impede rapid and effective responses to community health threats. (2008, p. 309)
This problem has led to significant efforts to distinguish public health research from public health practice. The CDC has issued guidelines on the matter, focusing on intent. Research is intended to “generate generalizable knowledge to improve public health practice,” and practice is intended to “identify and control a health problem or improve a public health program or service; intended benefits of the project are primarily or exclusively for the participants (or clients).” Moreover, knowledge generated in public health practice “does not extend beyond the scope of the activities” (CDC 1999).

It is certainly plausible that there are important differences between activities characterized as public health practice and those characterized as research. However, there are deep problems with the approach. One is the difficulty of drawing the distinction. In their analysis of attempts to distinguish research from practice, Amy Fairchild and Ronald Bayer found that how an activity is characterized depends on the entity performing it. While state public health authorities might collect information as part of practice, other entities collecting the same information for the same purpose could be interpreted as conducting research. Thus, the “same initiative might be designated research at the federal level and require IRB review and practice at the state level, requiring no ethical review” (Fairchild and Bayer 2004, p. 632). Even at the federal level alone, officials are inconsistent in how they distinguish research from practice (Fairchild and Bayer 2004).

This kind of inconsistency is surely a mark against an approach to a problem in practical ethics, though the difficulty of making the distinction is not fatal to the approach. After all, many distinctions important to moral analysis are difficult to make: alive versus dead, act versus omission, treatment versus enhancement, and so forth. The deeper problem is that whether an activity is research or practice tells us nothing whatever about what actions are justified as part of that activity. That is, the distinction between research and practice has no independent moral importance. And the mere fact that something is categorized as practice rather than research fails to provide a reason why the activity should be exempt from IRB oversight and privacy protections such as those afforded under the Common Rule.

The research/practice distinction in the public health context derives from the distinction between research and practice in the clinical context (Mariner 2007, p. 373). The distinction makes sense in the clinical context as a way of avoiding the problem of physicians subordinating the individual
interests of patients to common goods derived from medical research. A health care provider has a fiduciary responsibility to the individual patient that she treats. In clinical research, though, the provider’s responsibilities are divided between care for the patient and commitment to research. This contrasts with the public health context, including public health practice, which necessarily focuses on common goods. The characteristic of clinical practice that justifies treating it differently from research—the fact that the physician has a duty of care to the individual, for the sake of the individual—undermines its analogy with public health.

The Council of State and Territorial Epidemiologists has proposed guidelines for distinguishing between research and practice, and a model state public health privacy act has been created that focuses on several factors that distinguish research from practice. One might argue that even if the difference between research and practice does not have independent moral significance, it could be a useful demarcation if each criteria on which it is based track morally salient consideration. Unfortunately they don’t. The guidelines and model act distinguish between research and practice based on the following criteria: (a) whether there is a law authorizing an agency to conduct the activity, (b) whether the intent of the activity is ameliorating health threats within a community or seeking generalizable knowledge, (c) whether the activity benefits the community or seeks instead to benefit society more broadly through greater knowledge, and (d) whether the activity is characterized by standard interventions (practice) or by experimental design (research) (Gostin, Hodge, and Valdiserri 2001; Hodge 2005; Gostin 2008, pp. 312–13; Snider and Stroup 1997).

The first criterion, whether there is a law authorizing an agency to conduct the activity, does indeed support fewer protections, as we often legitimately give up certain goods when those goods become burdensome and undermine common goods. However, the other criteria are less helpful. It is unclear why the fact (if it is a fact) that an activity is intended to ameliorate health threats within a community rather than to garner generalizable knowledge matters to whether the activity itself is justified. More important is whether the activity actually does (or could be reasonably anticipated to) ameliorate health threats rather than garner generalizable knowledge. Further, there is something of a false dichotomy in this approach. Surely health threats may be ameliorated by generalizable knowledge; many investigators pursue generalizable knowledge in order that health threats be ameliorated, and
ameliorating health threats may lead to generalizable knowledge. Note also that the more generalizable one’s findings, the more they are likely to contribute to prevention and injury, health improvement, and efficiency.

The third criterion, whether an activity benefits the community or seeks instead to benefit society more broadly through greater knowledge, is especially problematic. It is certainly the case that an activity focused on a direct benefit to a particular community looks much more like a clinical practice than an activity that is spread more widely and based on gaining knowledge. But concluding that more narrowly focused activities should generally be interpreted as practice, and therefore subject to fewer protections, implies that activities with a narrower range of benefits should have fewer restrictions (per Common Rule protections) than activities with broader scope. This seems to get things backward. If the activity stands to benefit a greater swath of people, there is better reason for foregoing protections, all else being equal. Further, although an activity benefiting the community seems closer to clinical practice than research, it is unlike clinical practice in that there is no person or entity responsible for the interests of individuals. Thus, it is unclear why community benefit favors interpreting an action as practice.5

The final criterion for determining if an activity is research or practice is whether the activity is characterized by standard interventions or by experimental design. Here it is important to distinguish between interventional research and observational research. Either can be characterized by good study design. The criterion makes a certain amount of sense in the case of interventions, as it seems to juxtapose standard interventions with cases in which some people receive standard interventions and others do not. In such cases, worries about subordinating the interests of research subjects would apply. In the case of observational research, rigorous study design might be indicative of research (e.g., by assuring representative sampling). That, however, would seem to be a mark in its favor, and it is hard to see how it provides a reason for greater subject protections.

So, the idea that the need for Common Rule–type protections is mitigated in the case of an activity that constitutes practice rather than research is misguided. The distinction has no independent moral salience, is difficult to make, and is often erroneously based upon the entity performing the action. Further, the criteria for making the distinction do not track morally salient considerations. Wendy Mariner has reached a similar conclusion, arguing that much of what is characterized as public health practice is in fact research and that protections afforded human subjects
under the Common Rule should be extended to people participating in
public health endeavors (Mariner 2007, p. 374). Yet the mere fact that an
activity constitutes research does not tell us whether diminishing persons’
privacy via public health surveillance is justified. The focus should instead
be on the values underlying the information gathering and the interests
justifying privacy protections, to which I turn in the following section.

THE BASIC INTERESTS APPROACH

Although the research/practice distinction fails to provide an adequate
guide for resolving conflicts between public health surveillance and pri-
vacy, another approach, which takes the proper scope of public health
into account, may be more promising. Just how to understand the term
“public health” is the subject of significant debate. For instance, there is
a question as to whether factors that affect health—such as education,
homelessness, and human rights—are constitutive of public health (Roth-
stein 2002). Nonetheless, for the purposes of this article, it is promising to
begin with the traditional view that public health should be understood
as population health. The Institute of Medicine states that public health is
what a society does “collectively to assure the conditions for people to be
healthy” (Committee for the Study of the Future of Public Health 1988,
p. 19; Rothstein 2002, p. 145). A full articulation of this kind of view
comes in a recent book by Wendy Parmet. Parmet offers an account of
public health that centers on what she calls the “population perspective.”
According to this view, health is understood from a social or community
perspective, and the “health of populations qua populations is an impor-

Parmet provides some important guidance in applying this perspective
to assessing the health of populations when she compares and contrasts
the population perspective with utilitarianism. In her view, utilitarianism
provides some support for the population perspective insofar as it is a
maximizing theory. The difference between the two is that the good to be
maximized on the population perspective is much narrower—health within
a defined group instead of utility among all individuals (2009, p. 15).

However, the view that the population perspective, and hence public
health generally, “seeks to maximize group health” (Parmet 2009, p. 16)
is problematic. The comparison with utilitarianism shows why. Utilitarian-
ism is a moral theory that is consequentialist, welfarist, and sum-ranking:
it is concerned with the consequences of actions (rather than with, for
example, virtues or respect for autonomy), the consequence that matters
is individual welfare, and the best state of affairs is the one in which the aggregate welfare of all relevant individuals is maximized. The population perspective mimics utilitarianism insofar as it is consequentialist and sum-ranking (i.e., maximizing) and differs only in that the consequence that matters is health within a population (presumably measured in terms of quality-adjusted life years, disability-adjusted life years, or the like). The problem comes in using the population perspective to determine policy. It is true that public health interventions can at times be justified insofar as they can maximize health within a population in cases in which individuals acting alone or along with health care providers would fail—consider the efficacy of public sanitation measures relative to individual efforts to drink clean water absent such measures. But if our guiding principle is health maximization, interventions at the individual level will be justified if they do in fact increase aggregate health. The state of affairs with such an individual intervention will rank ahead of the state of affairs without it. In other words, a sum-ranking view fails to distinguish individual and population health and therefore is liable to opt for individual health interventions on the grounds that they increase population health, independently of whether they comport with individuals’ own senses of good.

A related problem is that a consequentialist view that maximizes the particular good of health within a population will necessarily subordinate nonhealth interests. Some individual behaviors decrease aggregate health only insofar as the decision-maker’s health decreases (e.g., avoiding doctors, being sedentary, not flossing). Surely, though, some efforts to change those behaviors would be unwarranted on the grounds that people are within their rights to engage in them. Thus, coercive measures to increase aggregate health require at least some justification to override individual autonomy. That justification might be the negative effects of individual behaviors on others’ health, sufficient risk to individual health to warrant strongly paternalistic actions, or something else altogether, but simple appeal to marginal increase in aggregate health would not suffice.

Fortunately, there is a better way to interpret public health from the population perspective and using it to guide action, which I refer to as the basic interests approach, following a framework developed by Alex London (2003). Even though one natural interpretation of population health—the one Parmet explicitly makes and which Mark Rothstein argues is implicit in other accounts—is aggregative and sum-ranking, it need not be (Rothstein 2002, pp. 145–46; Parmet 2009, p. 16). A different approach is to see public health as securing a set of interests that is public in the sense
that the interests are shared by all members of a society, just in virtue of the fact that they are reasonable, rational persons. To see why, it is useful to consider John Rawls’s understanding of primary goods.

People in a modern, liberal democracy have widely diverging interests and projects. Some people will want opportunities for certain types of athletic recreation, others will seek intensive religious experiences, still others will look to intellectual or artistic projects, and many will order their lives around interest or social groups. Often these will conflict. For example, creating the opportunity for people to play baseball on a new field might undermine others’ opportunity to hunt in the location where the field would be placed, and vice versa. That is exactly as we would expect in a pluralistic society. These interests are personal interests.

However, the existence of such a society requires social cooperation, which on Rawls’s view demands that citizens in the society be able to exercise two moral powers: the ability to form and revise a conception of the good (i.e., to be rational) and the ability to form a sense of justice and what is right and hence the ability to abide by fair terms of cooperation (i.e., to be reasonable) (1996, pp. 301–2). Based on this conception of a citizen, Rawls posits that each citizen has a number of fundamental interests (or primary goods) regardless of his or her particular conception of the good and personal interests. Among these are basic rights, liberties, and opportunities, and social bases for self-respect. They also include certain “natural goods,” among them health, which are only partly a function of the basic structure of society (1999, p. 54).

The important point here is the idea that there are basic interests that every person in a society would want more of, and those interests must be treated as basic in a liberal, pluralistic society. Being deprived of the basic goods undermines persons’ ability to form their own conceptions of the good and to be reasonable such that they can abide fair terms of social cooperation. Moreover, restriction of a person’s basic interests (e.g., deprivation of basic rights and liberties, curtailment of opportunities, imperilment of health) gives rise to a claim on the rest of society to ameliorate these restrictions.

Public health can be understood along the lines of Parmet’s population perspective in the sense of fostering basic interests that all members of society have rather than in terms of maximizing health within a population. There are some advantages to this view. One is that it avoids the problems associated with sum-ranking. Rather than having to interpret any increase in health within a population as an improved state of affairs,
we are instead able to distinguish fair opportunity for individual health gains from coercive health gains that sacrifice other basic interests. Such a view also allows us to think about fairness, health disparities, and the relative burdens of health measures; a maximizing scheme might prioritize increased health of already healthy members of the population, if such gains are easier to attain. Another advantage is that this is a political conception. It is compatible with the broadest range of substantive conceptions of the good. Because basic interests are those that are shared by any member of a pluralistic society, people with widely divergent personal interests can agree to a public health scheme that fosters basic interests among the whole population.

Finally, note that this view of population health leaves open the issue of what kind of assistance is required when persons’ basic interests are threatened. This is important for a couple of reasons. On a maximizing view, the way to deal with health threats is whatever way leads to the greatest aggregate health within the relevant population. The view here allows for the possibility that persons have claims to assistance in reaching some minimum necessary to ensure basic interests. Moreover, on some views, certain public goods that benefit each person in a society create a duty for each person to provide an in-kind contribution toward that good. For example, G. Owen Schaefer et al. (2009) maintain that because all individuals in a society have benefited from biomedical research, all individuals have a duty to participate as subjects in biomedical research. On the view presented here, the impingement of an individual’s basic interest merely creates some claim to assistance and leaves open just how that claim may be fulfilled.

THE UNREASONABLE EXERCISE ARGUMENT

The basic interests approach provides a view of population health that explains and justifies interventions without resorting to simple aggregation and without automatically justifying interventions based on aggregate benefits. But as yet it does not provide an account of what types of interventions are permissible. The goal of the unreasonable exercise argument is to help answer that question. The first part of the argument is as follows.

(1) Claims to privacy in health information with respect to state agencies are based on deep personal interests.

(2) Subordinating a claim based on a deep personal interest is justified where the individual’s exercise of that claim unreasonably threatens a basic interest of others within a community.
(3) If exercising a claim based on a deep personal interest is likely to cause others serious injury, illness, or death, then exercising that claim unreasonably threatens a basic interest of others within a community.

(4) Hence, where a person’s exercising a claim to privacy in health information with respect to state agencies is likely to cause others serious injury, illness, or death, then it is justified to subordinate that claim.

Let me explicate this a bit.

With respect to the first premise, there is little question that people have some claims to privacy in health information. Otherwise, it would be utterly unproblematic for one to divulge any sort of health information freely, for state actors to gather pell-mell all kinds of health information about individuals, and for state agencies to publish that information for all to consume. At the very least, privacy in health information is underwritten by widely held personal interests.

There is, however, a question as to whether privacy is an important enough good that it is a basic interest. In some contexts it may be. Privacy is best understood as a three-part relation between a person, some domain of information, and some other person, persons, or entity. Any discussion of interests in, claims regarding, or rights to privacy should therefore specify who the privacy holder is, what information is at issue, and who the other parties are that can learn that information (Rubel 2011). Privacy in some information with respect to some entities would very likely rise to the level of a basic interest. Consider privacy regarding how one votes with respect to the state, privacy regarding one’s intellectual habits with respect to the state, and privacy regarding sexual orientation, genetic predispositions, aspirations and fears, and one’s naked body with respect to the general public. In the public health context, the privacy at issue is generally privacy regarding one’s medical information with respect to certain government actors. If we assume that no information conveyed will be disclosed to other agencies and to entities not already involved in a person’s health care, it is difficult to see a basic interest at work. At least this is true in most cases; below I address some particular contexts in which medical privacy may rise to the level of a basic interest.

But the first premise states that claims to privacy in health information are based on deep personal interests. By this I mean that they are based on interests that are more weighty than (mere) personal interests but not sufficiently weighty to be considered basic. One reason is that health information privacy is important to many persons’ conceptions of the good. As I have already noted, the desire for health information privacy is strong,
widespread, and resilient. Moreover, there is no reason to think such a desire is based on a misplaced fear or a mistake about facts. Many people are concerned about receiving ill treatment or being discriminated against on the basis of health information. The possibility of having their health information disclosed may lead people to avoid care, which is generally detrimental to their health and hence interests regardless of their particular conceptions of the good. Health privacy also implicates autonomy and dignitary interests, regardless of whether there is a chance of ill treatment, discrimination, or care avoidance (Bloustein 1964; Reiman 1976; Benn 1971; DeCew 1997). Some people may wish not to have their identities shaped by information about their health and so may want to control who views them in terms of their health conditions and who views them without such information.12

A further reason that claims to health privacy are based on deep interests has to do with a sense of fair terms of social cooperation. Given the widespread desire for privacy generally and health information privacy in particular, any mandatory diminution of that privacy by state actors should be justifiable in terms that the subject of the information gathering could agree to as fair in light of others’ reasonable conceptions of the good. Certainly some information collection is justifiable in this way: keeping track of motor vehicles and drivers’ licenses in order to assure only qualified drivers are on the roads and that they are using nonstolen vehicles is surely justified in such a way. But not all health information collection can be so justified. Where collection of health information does not redound to the benefit of the subject of the information, and where any health benefits to others are tenuous, small, or attainable in other ways, it would be difficult to justify the collection as fair to the persons whose conception of the good includes (or relies on) health information privacy.13

Finally, there is an important liberty interest at stake in health information privacy. Boudewijn de Bruin has recently made the case that privacy losses both limit persons’ freedom to act in certain ways and decrease those same persons’ knowledge about their freedom. If others have information about a person, they may use that information in a way that affects that person’s ability to act. So, a data breach might give a bank officer information that would lead her to reject a person’s loan application on the ground that she’s receiving, say, cancer treatment (2010). Moreover, de Bruin points out that the value of freedom stems from knowing that we possess it: uncertainty about the effects of information breaches undermines a person’s ability to act. Relatedly, there is an autonomy interest in
understanding such effects, since information collected for public health can often be used to delimit a person’s opportunities. Information about tuberculosis may be used to quarantine or isolate people; information about HIV status is used to punish people who have sex without disclosing their status; information about HIV affects persons’ ability to travel and immigrate; information about vaccination affects whether people can enroll in schools; information about body weight has been proposed as a basis for an insurance surcharge for diabetics (Lacey 2011); and so forth. More importantly, the effects of the information may not be known at the time it is collected. We do not know how information will be used in the future.

For these reasons health privacy with respect to state actors is best understood as a deep, personal (and nonbasic) interest. It is worth emphasizing that at this point I am outlining a condition for justifying surveillance and arguing that it is justified to restrict a claim based on a deep personal interest where exercising that claim unreasonably threatens basic interests. A fortiori, it would be justified to restrict a claim based on a nondeep personal interest.

Now, in some cases privacy regarding one’s health with respect to state actors may implicate basic interests. As noted, TB (especially TB that is multidrug resistant or extensively drug resistant) may be grounds for quarantine or isolation (42 USC 264; 42 CFR 70, 71). Freedom of movement would seem to be a basic interest. So, at least in some cases, privacy with respect to state actors, in conjunction with laws enabling further actions based on that surveillance, implicates basic interests. In such cases, we are not confronted with conflicts between the basic interests of some individuals and the less weighty personal interests of others but with conflicts between basic interests. Subordinating some basic interests for the sake of other basic interests can be justified by appeal to the number or magnitude of basic interests at stake, such that if enough others’ interest in not contracting a disease that is likely to cause serious illness or death is strongly enough implicated, it can be justified to surveil others and to quarantine or isolate some. That does not entail that only aggregated interests matter, just that some degree of aggregation of basic interests can provide sufficient justification for subordinating of basic interests of others.14

The second premise simply says that one justification for restricting a claim that is based on a deep personal interest is the fact (if it is a fact) that the exercise of that claim unreasonably threatens a basic interest. Certainly
it is not the case that any exercise of a claim based on a personal interest that threatens a basic interest justifies a restriction. After all, the threat may be trivial. Eva’s personal interest in genealogy might turn up information that undermines other people’s opportunities—for example, by showing that they are related to a disreputable ancestor—but that is not enough reason to restrict anyone’s ability to do genealogy. Further, it cannot be the case that restricting claims based on deep personal interests is unjustified despite unreasonably threatening basic interests. Reasonable exercise of a claim demands that one’s exercise of a claim be based on reasons that other members of a society can endorse. Yet others cannot be expected to endorse withholding information about one’s health where doing so poses a great risk to their basic interests. That kind of risk is precisely what the second premise picks out: a risk so great that others cannot be expected to endorse it for the sake of others’ deep personal interests.

The third premise sets forth a condition under which a threat to one basic interest—health—resulting from exercise of a claim based on a deep personal interest is unreasonable. Specifically, it is unreasonable when the exercise of that claim is likely to cause others serious injury, illness, or death. Another possibility is that this requirement be less stringent. That is, we might consider exercise of a claim to be unreasonable if it is possible, though unlikely, to cause serious injury, illness, or death. But that seems implausible and unduly restrictive. Randy’s interest in raising chickens in his backyard might trivially increase the possibility of avian flu spreading and causing serious illness or death, should it reach this country in the first place. But that would not be an adequate reason to ban backyard chicken coops tout court. In contrast, one might argue that mere likelihood of causing serious injury, illness, or death is not a sufficient justification for restricting exercise of claims based on deep personal interests; rather, perhaps near certainty is required. That seems implausible insofar as we restrict deep interests for modest gains in safety and health often enough: consider restrictions on the exercise of First Amendment rights by time, place, and manner for the sake of safety or restrictions on selling foods that many would value on the grounds of some increased likelihood of food-borne illnesses. More importantly, “likely” can be interpreted widely enough to accommodate a variety of views about where to draw lines regarding increases in risk.

From these premises, the conclusion follows: in cases in which a person’s exercising a claim to privacy in health information with respect to state agencies is likely to cause others serious injury, illness, or death, it is justi-
fied to restrict that claim. This is the basic condition of the permissibility of mandatory collection of personal information, or the positive case. The second part of the unreasonable exercise argument is the negative case, which sets forth a condition under which restricting a persons’ ability to exercise a privacy claim is impermissible. This part of the argument starts with the first premise that claims to privacy in health information are based on deep personal interests and adds another premise and conclusion:

(5) If exercising a claim based on a deep personal interest would not impose an unreasonable burden on others within a community, there is a pro tanto reason not to restrict exercise of that claim.

(6) Thus, where exercising a claim to privacy in health information would not impose an unreasonable burden on others within a community, there is a pro tanto reason not to restrict exercise of that privacy claim.

The added premise is based on the respect for individual interests that is the foundation of political liberalism. It is grounded in the same kind of reasons that underwrite premises 2 and 3. Legitimacy in a liberal, pluralistic society demands that justifications for policies be made in terms that are acceptable to reasonable persons prepared to cooperate in governing. Where justifications fall short—for example, where the deep personal interests of some are subordinated despite there being no unreasonable burden on others to justify this subordination—there is a threat to fair terms of social cooperation. Those whose interests are subordinated cannot be expected to abide policies that impose substantial burdens on deep personal interests absent a strong reason—for example, likelihood of causing serious illness, injury, or death.

Conclusion 6 follows, providing that where exercising privacy claims in health information would not impose unreasonable burdens, there is a pro tanto reason not to restrict that exercise. The pro tanto reason, of course, can be overridden by other reasons. One of these would be evidence that persons’ whose privacy is affected would actually consent to the information gathering. Another is an offsetting benefit that would make the effect on deep personal interests less burdensome; still another would be persons’ practical ability to avoid the effects of the policy on one’s interests. There might be such dramatic returns of benefits to the population as a whole that subordinating even deep personal interests could be worth it, or potential harms to individuals might be sufficiently large to warrant paternalism. I return to these issues in the discussion in the following section.
In the previous section I set out a structure for justifying public health surveillance. The foundation for the view is the basic interests approach, which is fleshed out using the unreasonable exercise argument. My task in this section is to further specify the idea of unreasonable exercise by demonstrating how it could be deployed with respect to different types of surveillance.

**Tuberculosis**

Consider first tuberculosis (TB), a paradigm case of named disease reporting. TB is infectious, transmitted from person to person through the air, and infection can be latent. Most TB infections are treatable, though there is a growing problem of drug-resistant strains of TB; if not successfully treated, TB is serious and can be fatal; people with compromised immune systems are especially vulnerable. Historically, TB has been a particularly lethal disease. It began to decline in the United States in the mid-to late 1800s. That decline reversed for a period in the late twentieth century, and multiple drug-resistant forms of TB have emerged, leading to greater public health interventions (Fairchild and Oppenheimer 1998, p. 1105; Selgelid 2008, p. 10). TB surveillance was introduced in various states and municipalities in the late nineteenth century with the primary goal of intervention and prevention of transmission, both among family members and to other members of the community (Fairchild, Bayer, and Colgrove 2007, pp. 33–40). It is currently subject to named reporting across the United States (and across the globe), and information gathered in the states is transmitted and compiled by the CDC. There is a debate about the degree to which public health measures are responsible for TB’s decline. Famously, Thomas McKeown has argued that the primary cause of the decline is increasing material wealth and nutrition rather than interventions (McKeown 1988). Nonetheless, the reversal of TB’s decline for a period in the 1980s and 1990s and the rise of multiple-drug resistant forms makes public health interventions, including surveillance, particularly salient.

Clearly, TB implicates persons’ basic interests. More importantly, TB implicates not merely the basic interests of persons who have TB; because TB is infectious, serious, and transmitted from person to person, persons’ basic interests are involved independently of whether they actually have TB at the moment. That’s not surprising insofar as TB is a paradigm public health issue. But the fact that TB does not implicate the basic interests of
the population solely in terms of the individual health effects of the disease does not alone tell us what measures are justified in addressing it. That’s the function of the unreasonable exercise argument.

There’s no question that privacy regarding whether one has TB is a deep personal interest. That is not only true today but was also historically the case. Historically, having TB was seen as particularly loathsome, evidence of uncleanliness, and used to explain class stratification. Currently, it may be stigmatizing and obligate one to a course of drugs, or (if one fails to adhere to treatment regimens) it may be the basis of quarantine or isolation. Hence, according to the argument I have outlined, restricting persons’ claims to privacy would require that their exercise of that claim—which is to say, keeping information regarding whether they have TB private with respect to public health actors—would unreasonably threaten some basic interests of others within the community. McKeown’s view that living conditions rather than interventions are responsible for TB’s decline notwithstanding, the problem of multiple-drug resistant strains provides a strong reason for surveillance in the United States, and its persistence worldwide provides strong reason for surveillance anywhere.

Assessing the legitimacy of TB surveillance (which is to say, assessing named reporting of TB) under the unreasonable exercise argument, though, depends on the underlying reasons for that surveillance and more importantly on the connection between the surveillance and others’ likelihood of contracting the disease and becoming seriously ill or dying, as per premise 3. Surveillance that takes place at the state and local levels serves the purposes of direct disease control and prevention as well as program planning and evaluation (Birkhead and Maylahn 2000, p. 257). Likewise, an important purpose of TB surveillance generally is intervention for the sake of treatment, education, and possible quarantine or isolation, which depends directly on individual identification. In its recent *Global Tuberculosis Control*, the World Health Organization places such actions at the centerpiece of its “Stop TB” strategy (2011, p. 28). The CDC recommends mandatory reporting of suspected or confirmed TB cases within two working days of identification in order to ensure prompt action by public health actors (CDC 1993). Timely identification and reporting of patients is important in avoiding “ongoing transmission, secondary cases, and TB outbreaks” (Silin et al. 2010, p. E9).

Hence, named reporting of TB is important for control of TB because it limits the opportunity for the individual reported to infect others, making it less likely that others will contract the disease and become seriously ill
or die. Assuming that such measures are effective, exercising a privacy claim regarding one’s having TB would appear to make it likely that others would become seriously ill or die. On the account offered here, such an exercise is unreasonable, and public health officials are justified in subordinating individuals’ privacy interests and mandating named reporting. To the extent that named reporting of TB prevents infected persons from causing others to become seriously ill or die, we do not need to appeal to the second part of the unreasonable exercise argument.

The use of TB surveillance is not, however, limited to preventing individuals identified with TB from infecting others. It is also used as a tool for assessment. Surveillance data is useful in measuring disease burden and for planning and targeting interventions (Castro 2007; World Health Organization 2011; D’Ambrosio et al. 2010). This raises the question of whether such programmatic goals can alone justify subordinating individuals’ deep personal interests in privacy regarding having TB. On the account offered here, whether information gathering in order to assess and plan is enough to justify reporting does not depend on the function of the surveillance (i.e., informing for planning reasons versus preventing individuals from infecting others), but on the likelihood of a person’s exercise of a privacy claim causing another’s serious illness, injury, or death. If the assessment and programmatic goals are so undermined by individuals’ exercise of privacy claims, and failure to report those cases is likely to cause serious illness, injury, or death, then exercising privacy claims would indeed be unreasonable. And on the account offered here, such surveillance could be justified.

But that’s a tall order. For named reporting of disease aimed at assessing disease prevalence, program evaluation, or the like to be justified under the unreasonable exercise argument, several things must be true. First, the information garnered must be useful enough that failure to collect it would likely cause others serious injury, illness, or death. Second, and relatedly, it must be that alternative methods that do not subordinate deep personal interests would not allow for sufficiently accurate assessment and similarly effective programs. Most importantly, individuals’ exercise of privacy claims—namely, preventing their information from being gathered—must be likely to cause others serious injury, illness, or death. The focus here is on mandatory reporting, not consensual information gathering, and if reporting can be effective for assessment purposes where subjects have adequate opportunity to forego participation, then their exercise of that opportunity will not be the cause of harms to others’ basic interest.
Put another way, in cases in which the cause of others’ disease, injury, or death would be some person P having infected them, and mandatory reporting of P’s condition would prevent such infection, justifying the reporting under the unreasonable exercise argument is straightforward. However, when the connection between exercising a privacy claim and others’ disease, injury, or death is more attenuated, it is less likely that a person’s exercising a privacy claim will be the cause of others’ serious injury, illness, or death. That connection is attenuated if disease assessment and program evaluation can be done without mandatory reporting. Hence, named reporting for of TB appears justified insofar as it prevents others from becoming infected by the person reported. And it is possible that assessment and programmatic goals could justify mandatory reporting but only if failure to report would actually cause others to get TB.

Diabetes

Diabetes surveillance is in a sense at the frontier of disease reporting. New York City’s initiative is the first major effort in mandatory diabetes reporting, and the fact that diabetes is a chronic condition distinguishes it from archetypical reporting efforts, which have focused on communicable disease. This, along with the fact that the members of the department that implemented the program have published a lengthy explanation of the program and its justifications, make it particularly useful to examine diabetes reporting to help further specify the approach to surveillance set forth here.

As noted, diabetes is a significant and growing health problem. The problem is acute in New York City, where 8.7 percent of people over the age of twenty have been diagnosed with diabetes, and 2.8 percent of people are believed to have undiagnosed diabetes. The rates are particularly high in households with annual income less than $20,000, among minorities and among older people (Thorpe et al. 2009, p. 58). The true scope of the problem is unclear, as approximately 23.5 percent of people in the city may have elevated glucose levels that indicate a prediabetic condition (Thorpe et al. 2009, p. 59). Moreover, the problem remains obscure to people with diabetes and elevated glucose levels, as many are unaware of their blood sugar levels. The city health department reports that although 31 percent of diabetic patients in commercial managed care and 42 percent of diabetic patients in Medicaid managed care in New York state have A1C (blood glucose) test levels that indicate poor control, only 10 percent of diabetics are aware of their A1C test levels (NYCDHMH 2005).
It is against this background that the city decided to implement its diabetes surveillance initiative, requiring all laboratories using electronic reporting to report the results of all A1C tests. The proposal was adopted unanimously by the New York City Board of Health in December 2005 and was implemented in January 2006. Since 15 January 2006, New York City labs have been required to report all A1C test results to the department of health. There is no provision allowing either physicians or patients to opt out of the reporting requirement; that is, surveillance is mandatory (New York City Health Code 13.04 (2006); Goldman et al. 2008, p. 809).

Because of its particularly high incidence of diabetes, the South Bronx is initially targeted by the intervention part of the initiative. When a laboratory reports an A1C test result of greater than 9 percent to the health department, the patient will receive a letter in the mail from his or her health care provider reporting the high level and may receive further information regarding diabetes care and control (Goldman et al. 2008, p. 809; NYCDHMH 2009). Patients may opt out of this aspect of the program by submitting a “do not contact” request. The opt-out provision appears on the health department’s website, and it does not appear that the patient would have a meaningful opportunity to opt out prior to receiving a communication regarding his or her A1C results (Goldman et al. 2008, p. 809). The intent is for the program to extend to the other boroughs and for the city to develop its ability to help patients learn to manage their condition (Fairchild and Alkon 2007, p. 570).

There is no question that diabetes affects persons’ basic interests, though as we have seen that alone is not enough to determine what measures are justified in protecting those interests. That turns on persons’ claims and the degree to which exercise of those claims poses a threat to others’ basic interests. Here is where the unreasonable exercise argument has some bite. Regardless of whether diabetes affects persons’ basic interests, it is difficult to see how persons’ exercising claims to privacy regarding their A1C test results would unreasonably threaten others’ basic interests. It would seem unlikely that exercising such a claim would cause others serious injury, illness, or death; hence, it is not justified to restrict claims to privacy on those grounds. For the same reason, there is a pro tanto reason to not restrict persons’ abilities to exercise privacy claims in this case. Nonetheless, it is worth delving deeper into the initiative and its justifications in order to determine whether it comports with the unreasonable exercise argument.

In response to a variety of criticisms of the initiative, members of the department implementing the program have written an article explicating
the rationale for the registry. They offer several arguments in support of the program. One is based on the magnitude of the threat of diabetes and the potential of a registry to improve the health outcomes of the people monitored. They note that diabetes threatens longevity and quality of life for one in eight adults in New York City, and state that such a threat “warrants an urgent public health response,” and that the department’s experience using registries makes their use in this case appropriate (Chamany et al. 2009, p. 559). Moreover, they argue that early indications suggest “that the benefits will outweigh the potential harms” (Chamany et al. 2009, p. 548). This appears to be a straightforward use of aggregative conception of public health. It takes a threat to the overall health of people in a population to justify an intervention likely to decrease that threat, without regard for whether the mechanism of the threat is that people suffering the disease threaten the health of others in the population and without regard for the nature of the interests subordinated for the sake of the health improvement. Of course, the intervention may in the end be justified, but the basic interests approach and unreasonable exercise argument provide a mechanism to avoid rote aggregation and account for other important interests.

A second line of argument that the department offers in support of the program specifically concerns the lack of a provision to opt out of the registry, which entails that anyone having an A1C test performed will lose privacy in this respect regardless of whether they consent to it (or would consent, if asked). It maintains that requiring consent would lead to incomplete reporting and keep some patients out of the program, despite their desire to be in it (Chamany et al. 2009, p. 559). Accordingly, the department concludes that the “program’s potential benefit and reach outweigh the potential harm to individuals” (Chamany et al. 2009, p. 559). Again, this looks to be an example of the aggregative view. But more importantly, unless it is likely that the incomplete reporting will harm others’ basic interests, it would not provide adequate justification for mandatory reporting on the view offered here. Similarly, if consent procedures keep some people who wish to be enrolled out of the program, that would seem to be a reason to change consent procedures, not to preclude people from exercising a privacy claim.

Here it is worth revisiting the points I have outlined regarding public health surveillance undertaken to determine disease prevalence and program assessment. As noted, such goals can justify mandatory reporting on the view advanced here. For mandatory reporting to be justified, indi-
individuals’ opting out must likely cause others to suffer serious illness, injury, or death. There are a number of reasons to think that is not the case for the New York City initiative. One is that it is entirely unclear whether large numbers of people would opt out of reporting if given the option. Another is that there may be alternative information gathering programs that could offer good enough information for assessing disease prevalence. Further, the department justifies the lack of an opt-out provision in terms of its inability to follow up on people affected, not in terms of the necessity of each person’s information in understanding the disease sufficiently to create effective programs in the future (Chamany et al. 2009, p. 559). The broader point, though, concerns the kinds of reasons that suffice for mandating the surveillance; individuals’ exercise of privacy claims must be likely to cause others to suffer serious illness, injury, or death. Without such a connection, the initiative fails to meet the unreasonable exercise requirement. With such a connection, it meets the requirement.

A third line of argument is particularly useful in demonstrating the potential usefulness of the unreasonable exercise argument. The department compares diabetes to other conditions for which there is mandatory reporting and maintains that “requiring consent for reporting could set a hazardous precedent for other notifiable disease reporting, severely hindering the control of communicable disease outbreaks and the detection of environmental exposures” (Chamany et al. 2009, pp. 559–60). The unreasonable exercise argument provides a means of distinguishing diabetes reporting from outbreaks and environmental exposures. Where outbreaks and exposures are such that specific information is necessary to understand the underlying threat and prevent or respond to others being affected, and where the outbreak or exposure is likely to cause others serious injury, illness or death, then mandatory reporting without patient consent is justified precisely because failure to consent (i.e., exercising a claim to privacy) would unreasonably threaten others’ basic interests. This does not appear to be the case with respect to diabetes.

As for the similarity between diabetes and other noncommunicable diseases for which New York mandates reporting, the unreasonable exercise argument again provides appropriate analytic tools. The department notes that there is already mandatory reporting for a number of noncommunicable conditions, including birth defects, cancer, occupational disease, and lead poisoning. The department is certainly correct to point out that mandatory reporting of noncommunicable diseases can be justified. However, the mere fact that some noncommunicable diseases are subject to
mandatory reporting does not provide a justification for a new reporting requirement for diabetes. That requires an argument based on the proper role of reporting, which I've tried to supply. In some cases, a justification for reporting may be based on reasons incorporated into the unreasonable exercise argument. So, for example, reporting occupational disease may be crucial in identifying patterns and hence preventing others from being harmed. That is, exercising a claim to privacy may unreasonably threaten others' basic interests by likely causing others serious injury, illness, or death.

In other cases, reporting may be justified by reasons that override the \textit{pro tanto} reason not to restrict exercise of a claim to privacy. New York's lead poisoning program, for example, requires the blood-lead levels of all children to be reported (Chamany et al. 2009, p. 561). As noted, one potential reason for restricting exercise of privacy claims is justified paternalism. Although determining when and whether paternalism is justified is a controversial endeavor, there is no question that it is much easier to justify it for children, and that could provide sufficient justification in the case of blood-lead reporting.

The point here is not to argue that, all things considered, mandatory reporting of A1C results is unjustified. Perhaps what we have here a case of justified paternalism (which implies that more stringent regulation of behavior could also be justified), or perhaps exercising privacy claims regarding blood glucose levels is likely to cause others serious injury, illness, or death. Rather, the point is that diabetes surveillance and the arguments marshaled by the department in favor of New York's program help illustrate the basic interests approach and the unreasonable exercise argument. If the arguments and the approach proffered here are right, they present a problem for the surveillance initiative.

CONCLUSION

There are, of course, limitations to the view. One is that the conclusion of the unreasonable exercise argument is that where exercising a privacy claim in health information would not impose an unreasonable burden, there is a \textit{pro tanto} reason not to restrict exercise of that privacy claim. But that means that there may be other reasons sufficient to justify restricting exercise of the privacy claim. Maybe paternalism is justified in some cases. Perhaps we can democratically consent to collection of information and conditions for consent obtain. A further limitation is that the view articulated here tells us nothing about distribution: how to allocate
resources to protect basic interests, and how to determine the extent of claims generated by threats to basic interests is a topic beyond the scope of this article. Still another limitation concerns the tools at the disposal of public health actors. Surveillance is something public health actors have long used, and no doubt it is effective in many areas. But the tools needed to address, for example, diabetes may be beyond the purview of public health entities.

Nonetheless, the approach outlined here provides a way to adjudicate between certain kinds of interests in the context of public health measures generally and public health surveillance specifically. My task has been to address the tension between public health surveillance and individual privacy while avoiding the research/practice distinction that I argue is misguided. To do so I have argued for the basic interests approach and deployed the unreasonable exercise argument. I think that the approach has some important advantages. For one, it avoids justifying surveillance based on whether disease is infectious. Infectiousness matters for justifying surveillance not for its own sake but because of the way infectious diseases affect the interests of those who do not have a disease and because of the efficacy of surveillance. Moreover, it provides ample justification for reporting of noninfectious disease, based on how reporting is likely to affect others’ interests. So, where tumor registries, occupational disease reporting, immunization records, and so forth allow public health agents to identify problems and intervene to prevent serious injury, illness, or death, reporting can be justified even though the conditions are not communicable. A final advantage of the view offered is that it avoids the problems of aggregating views.

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NOTES

2. The Council of State and Territorial Epidemiologists (CSTE) makes recommendations for notifiable diseases, but states have the responsibility of mandating reporting. Thus, notifiable diseases vary by state but with substantial overlap (Thacker 1994, p. 5; CSTE); see also CDC 2009.
3. Amy Fairchild, Ronald Bayer, and James Colgrove argue that privacy arguments have evolved substantially from the era of “paternalistic privacy” in the late nineteenth and early twentieth centuries to “democratic privacy” in recent decades. Nonetheless, they document that privacy concerns have figured prominently in debates about public health surveillance for over a hundred years, even if the tenor of and parties making the arguments have changed.

4. Fairchild quotes two commentators from a meeting held in August 2005. One stated that “to me diabetes is a very private matter that would become a public matter.” Another articulated a “desire as a private citizen to keep my personal medical information private between my physician and myself and nobody else” (2006, p. 175). See also Fairchild and Alkon 2007, p. 571.

5. One might argue that the thrust of the third criterion is really the means by which the benefits are to be achieved, such that benefits achieved merely through greater knowledge are disfavored. That is, action that directly benefits the community tends to be practice, whereas activity that benefits society more broadly through generalizable knowledge tends to be research. In that case, the third criteria would be redundant with the second criteria and problematic for the same reasons.

6. This is a crude version of utilitarianism, and the proper understanding of utilitarianism is of course a matter of much debate and raises questions about the proper locus of judgment (acts, rules), how to measure welfare, who counts, and so forth. Those debates do not bear on this project.

7. Obviously not all such efforts would be impermissible. Providing free floss would clearly not impinge on anyone’s right to not floss. On the other hand, the mere fact (if it is a fact) that fines or bathroom sink cameras would best increase floss rates, and hence aggregate health, would not justify imposing fines or installing cameras.

8. My starting point here—distinguishing between personal and basic interests and focusing on basic interests as Rawlsian primary goods in order to explicate the good of a population—follows closely the approach to the “common good” set forth by London (2003). London develops this view further in “Reasonable Risks in Clinical Research” (2006, p. 2878) and “Two Dogmas of Research Ethics and the Integrative Approach to Human-Subjects Research” (2007, pp. 109–110), where he analyzes clinical research rather than public health measures.

9. Note that the task here comports with various conceptions of the importance and role of health and health care generally. It says nothing about principles of allocation and distribution, about the precise foundation for claims to
health and health care, and the relationship between health, health care, and social justice. (See, for example, Buchanan 2008, Ruger 2010, and Powers and Faden 2006.) Rather, it is a way of separating and adjudicating among different interests in a public health context.

10. Notice that this will not provide a full account of the scope of public health of the sort that Rothstein (2002) seeks to provide, for it remains open the ways in which public health might seek to address health matters and what entities might be considered part of a public health system. Instead it serves to place one limit on the domain of public health.

11. It is worth noting that the New York City health department maintains that because the A1C results reported in the diabetes initiative will be subject to stringent protections, there is no privacy loss. It would be more accurate to say that there may be no privacy loss beyond that lost regarding A1C results with respect to the public health agency (Chamany et al. 2009, p. 560).

12. A well-articulated example of this is Barbara Ehrenreich’s 2001 essay, which describes a breast cancer survivor identity that many people embrace: one of strength in the face of the disease, of sisterhood with other survivors, and of taking action to raise awareness of the disease and money for research and treatment. Although diagnosed and treated for breast cancer, Ehrenreich explicitly resists incorporating breast cancer survival into her identity.

13. Rawls identifies three considerations in determining what constitutes a basic liberty: (1) persons’ determinate conceptions of the good, (2) persons’ capacity to for a conception of the good, and (3) persons’ capacity to honor fair terms of agreement (1996, pp. 310–11). On the conception outlined here, privacy in health information would appear to implicate (1) and (3), only, thus making it a weighty liberty but not plausibly a basic one.

14. Thanks to a reviewer at Kennedy Institute of Ethics Journal for making this point. Note here that even though privacy can implicate basic interests, it nonetheless seems that privacy is best construed as a personal interest for several reasons. First, for the greatest part, surveillance does not have quarantine, isolation, or other basic interest restriction as a consequence. Second, surveillance only implicates the basic interest in freedom of movement in conjunction with other state actions, such as statutes providing for quarantine or isolation. It is more parsimonious to understand the relevant conflict as between a basic interest of not contracting TB with the basic interest of not being quarantined or isolated. There is a separate conflict between the basic interest of not contracting TB and the deep, personal interest of privacy, which is a deep, personal interest in part due to its connection to different basic interests. Third, relatedly, personal interests can be related to basic interests.
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without actually rising to the level of basic interests. For the purposes of this article, we can just as well construe privacy as solely a personal interest or as generally a personal interest, even though there might be a few cases in which it is actually a basic interest (e.g., when quarantine or isolation may result).

15. It is worth noting that there may be cases in which information about P’s illness is important in preventing serious illness, injury, or death not because P is likely to infect others, but because so little is known about the illness that information about P is particularly helpful. This could be the case during acute outbreaks, where the sparseness of existing information makes each bit of knowledge more valuable.

REFERENCES


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