JUSTIFYING PUBLIC HEALTH SURVEILLANCE: BASIC INTERESTS, UNREASONABLE EXERCISE, AND PRIVACY

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Abstract: Surveillance plays a crucial role in public health, and for obvious reasons conflicts with individual privacy. This paper argues that the predominant approach to the conflict is problematic, and then offers an alternative. It outlines a *Basic Interests Approach* to public health measures, and the *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 conceptions of the value of health.

1. 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 (N. Stroup, Zack, and Wharton, 1994; Thacker 1994; Gostin 2008). The importance of public health surveillance is reflected in express public health exceptions in statutes and regulations that otherwise protect health information.[1] 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, it remains controversial when public health goals may supersede persons' interests in privacy and justify surveillance. My task in this paper 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 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*, according to which public health activities (including surveillance) are justified insofar as they focus on persons' basic interests, but aggregate benefit is not sufficient to justify interventions. Within the context of this approach, I advance the *Unreasonable Exercise Argument*, according to which (a) public health actors may subordinate individuals' non-basic interests where exercising claims to such interests unreasonably threatens others' basic interests. However, (b) where 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 it can be applied in different cases.

2. BACKGROUND

A. PUBLIC HEALTH SURVEILLANCE

Public health surveillance is "the ongoing systematic collection, analysis, and dissemination of health data to those who need to know" (Thacker, N. 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, N. Stroup, and Dicker 2003, pp. 8-14; Thacker 1994, pp. 8-24; CDC(c)).

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, N. 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 U.S. by key healthcare

providers participating in the Sentinel Event Notification System for Occupational Risks (SENSOR) (N. 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 use of alcohol, cigarettes, and drugs, use of safety devices such as seatbelts and bicycle helmets, and persons' eating, exercise, and sexual habits (Gostin 2008, pp. 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 U.S., states require that health care providers and laboratories report certain diseases.[2] These reports are in turn voluntarily reported 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 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 (b)). Disease registries exist in the U.S. 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 will discuss the initiative more fully below.

B. 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 Health 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," 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 privacy (Williams et al. 2009; Krane 2007).

In addition to evidence that people care deeply about medical privacy, legal rights to medical privacy have 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 C.F.R. Parts 160 and 164, Subparts A and 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 (Pub. L. No. 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 U.S. 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).[3] New York's diabetes initiative has likewise been the center of privacy debates. Various groups raised objections to the initiative during public meetings. Some objected to having what they considered a private matter becoming 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.[4]

3. Research and Practice

The primary way of resolving the tension between public health surveillance and privacy concerns is distinguishing between public health *research* and public health *practice*. Protection of human subjects in research in the U.S. 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 (National Commission 1979; Anon. 1947; World Medical Association 2008;

CIOMS 2002). Each of these places important restrictions on research in order to protect the interests of research subjects over 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 C.F.R. §§ 46.101-404). 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 C.F.R. § 46.111(a)(7); 45 C.F.R. § 46.116(a)(5)). Thus, there is some recognition of, and legal protection for, privacy in research conducted under federal auspices.

However, much information collection in the public health sphere is conducted by state and local entities, independent 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 (Gostin 2008, p. 309).

This problem has led to significant efforts to distinguish public health research and public health practice. The CDC has issued guidelines on the issue 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) or the participants." 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 many activities characterized as public health practice and those characterized as research. As Steven Coughlin points out, "[m]any public health practice activities (for example, outbreak investigations and emergency responses) cannot be effectively carried out in a timely manner if they are subjected to the administrative burdens of IRB review …" (Coughlin 1997, pp. 15-16). 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 would 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 considering federal actions only, officials are inconsistent in how they distinguish research and 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, and gets its rhetorical force, 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 for the sake of common goods derived from medical research. Where one receives treatment from a physician or other provider, that provider has a fiduciary responsibility to the individual patient. In clinical research, though, the provider's responsibilities are divided between care for the patient and fidelity to the 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 which focuses on several factors for distinguishing between research and practice. One might argue that even if the difference between research and practice is not of independent moral significance, it could be a useful demarcation if each of the criteria on which it is based track morally salient consideration. Unfortunately they don't. The guidelines and model act distinguish 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 if the activity seeks 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. 312-313; Snider and D. 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 warrants fewer protections. The intentions of the people endeavoring the activity are not relevant 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 if it seeks 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. That appears backwards. 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 whether 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, avoiding Common Rule type protections on the grounds that an activity constitutes practice rather than research appears misguided. The distinction has no independent moral salience, is difficult to make, and is often 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 should occur with the human subjects protections afforded under the Common Rule (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.

4. The Basic Interests Approach

Although the research / practice distinction fails to provide an adequate guide for resolving conflicts between public health surveillance and privacy, another approach based on the proper scope of public health may be more promising. Just how to understand 'public health' is the subject

of significant debate. For example, there is a question as to whether factors that affect health—such as education, homelessness, and human rights—are constitutive of public health (Rothstein 2002). Nonetheless, for the purposes of this paper 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" (Institute of Medicine 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 important goal of social life"(Parmet 2009, p. 14).

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 contrast 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 (Parmet 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. Utilitarianism is a moral theory that is consequentialist, welfarist, and sum-ranking. That is to say, it is concerned with the consequences of actions (rather than, 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.[6] 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 where individuals acting alone or along with healthcare 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 will fail 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 a particular good, in this case health within a population, will subordinate non-health 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.[7] Rather, at least coercive measures to increase aggregate health require some justification to override individual autonomy interests. 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 will refer to as the *Basic Interests Approach*, following a framework developed in (London 2003).[8] 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. 145-146; 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.[9] 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 the right, and hence the ability to abide by fair terms of cooperation (i.e., to be reasonable) (Rawls 1996, pp. 301-302). 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 (Rawls 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 that those interests are basic as a precondition for 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.

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 maximizing health within a population.[10] There are some advantages to this view. One is that it avoids the problems associated with sum-ranking. Rather than interpreting any increase in health within a population as an improved state of affairs, it allows us to distinguish fair opportunity for individual health gains from coercive health gains that sacrifice other basic interests. It 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, Schaefer et al., maintain that because all individuals in a society have benefitted from biomedical research, all individuals have a duty to participate as subjects in biomedical research (Schaefer, Emanuel, and Wertheimer 2009). 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.

5. 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 that argument is as follows.

(A1) Claims to privacy in health information with respect to state agencies are based on deep personal interests.

(A2) 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.

(A3) 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.

(A4) 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.

I will 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 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, and any discussion of interests in, claims regarding, or rights to privacy should 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 any information conveyed will not be disclosed to other agencies and to entities not already involved in a person's healthcare, it is difficult to see a basic interest at work.[11] At least in most cases; below I address some particular contexts in which it may rise to 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. The desire for health information privacy is strong, widespread, and resilient, as discussed above. 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 ill-treatment or discrimination on the basis of health information. The possibility of having their health information disclosed may lead to people avoiding 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. (DeCew 1997; Benn 1971; Bloustein 1964; Reiman 1976). Some people may wish not to have their identities shaped by information about their health, in essence making the case that they wish 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 in non-stolen 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 information collection as fair to the persons whose conception of the good includes (or relies upon) 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 in addition to limiting persons' freedom to act in certain ways, privacy losses decrease those same persons' *knowledge about* their freedom. Where others have information about a person, they may use that information in a way that affects the first 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 (de Bruin 2010). Moreover, de Bruin points out that the value of freedom stems from knowledge about that freedom: uncertainty about the effects of information loss undermines a person's ability to act. A related point is that there is an autonomy interest in understanding such effect. Information collected for the purpose of public health is often information that can be used to delimit a person's freedoms and 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 non-basic) 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 non-deep personal interest.

Now, in some cases privacy regarding one's health with respect to state actors may implicate basic interests. As noted, TB (especially multi-drug resistant or extensively drug resistant TB) may be grounds for quarantine or isolation (42 U.S.C. § 264; 42 C.F.R. parts 70 and 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 basic interests of some and 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 appeals to numbers or degree of basic interests, 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 surveill others, quarantining or isolating 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]

A2 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 some 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 of information about one's health where doing so imposes a great risk to their basic interests. *That* kind of risk is precisely what A2 picks out: a risk so great that others cannot be expected to endorse the reasons for creating it.

Premise A3 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 expressive activity 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, conclusion A4 follows: 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 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.

(A1) Claims to privacy in health information are based on deep personal interests.

(A5) 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.

(A6) 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.

This part of the argument starts with premise A1 from above. It adds in premise A5 that we ought not restrict a person's ability to exercise a claim based on a deep personal interest unless exercise of the claim would either impose an unreasonable burden on others within a community, or there is some other good weighty enough to override the first claim. This is a premise 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 A2 and A3 above. 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 deep personal interests of some are subordinated despite there being no unreasonable burden on others—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 A6 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 outweighed, or potential harms to individuals might be sufficiently large to warrant paternalism. I will return to these issues in the discussion in the following section.

6. Surveillance and the Unreasonable Exercise Argument

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 contrasting 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 U.S. in the mid- to late 1800s. That decline reversed for a period in the late 20th 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 19th 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 U.S. (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 90s and the rise 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, transmitted from person to person, and serious, 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 as discussed above, the fact that TB implicates the basic interests of the population beyond 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, both now and historically. Historically, having TB was seen as particularly loathsome, evidence of uncleanliness, and used to explain class stratification. Currently, it may be stigmatizing, obligate one to a course of drugs, or (if one fails to adhere to treatment regimens) be the basis of quarantine or isolation. Hence, according to the argument outlined above, 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 aside, the problem of multiple-drug resistant strains provides a strong reason for surveillance in the U.S., and its persistence worldwide provides strong reason for surveillance anywhere.

Assessing 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 A3. 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, tracking others potentially infected, and possible quarantine or isolation, which depends directly on individual identification. In its 2011 report Global Tuberculosis Control, the World Health Organization places such actions at the centerpiece of its Stop TB strategy (World Health Organization 2011, p. 28). The CDC recommends mandatory reporting of suspected or confirmed TB cases within 2 working days of identification in order to ensure prompt action by public health

actors (Centers for Disease Control and Prevention 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 will become seriously ill or die. On the account offered here, such an exercise is unreasonable, and public health officials are justified in subordinating the privacy interest and mandate named reporting. To the extent that named reporting of TB prevents infected persons from causing others to become seriously ill or die, we need not reach 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 those goals are so effective in preventing others' serious illness, injury, or death, that failure to report those cases is likely to cause serious illness, injury, or death, then exercising the 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 the information would likely cause others serious injury, illness, or death. Second, and related, is that alternative methods that do not subordinate deep personal interests would not allow for accurate enough assessment and similarly effective programs. Most importantly,

individuals' exercise of privacy claims—i.e., 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, where the cause of others' disease, injury, or death is some person P's infecting them, and mandatory reporting of P's condition prevents such infection, justifying the reporting under the Unreasonable Exercise argument is straightforward. However, where 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 where disease assessment and program evaluation can be done without mandatory reporting.[15] 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 where failure to report actually causes 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 in section 2, diabetes is a significant and growing health problem. The problem is acute in New York City, where 8.7 percent of people over 20 citywide 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 for 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 January 15, 2006, New York City labs have been required to report to the department of health all A1C test results. 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, 809).

Because of its particularly high incidence of diabetes, the intervention part of the initiative initially targets the South Bronx. 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, 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 of opting out prior to receiving a communication regarding his or her A1C results (e.g., a provider informing the patient of the opportunity) (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, state that such a threat "warrants an urgent public health response," and 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 discussed in section 4. 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 wanting 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 preclude people from exercising a privacy claim.

Here it is worth revisiting the points outlined above 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. To do so, individuals' opting out must likely cause others to suffer serious illness, injury, or death. If it is the case that diabetes surveillance is

like this, then mandatory reporting could be justified. 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, 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 would fail 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. 559-560). The Unreasonable Exercise Argument provides a means of distinguishing diabetes reporting from outbreaks and environmental exposures and linking that distinction to justifications for mandatory reporting. 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. That, however, does not appear to be true with respect to diabetes.

As for the similarity between diabetes and other non-communicable 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 non-communicable conditions, including birth defects, cancer, occupational disease, and lead poisoning. The department is certainly correct to point out that mandatory reporting of non-communicable diseases can be justified. However, the mere fact that some non-communicable 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, 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 pro tanto reason not to restrict exercise of a claim to privacy. New York's lead poisoning program, for example, requires blood-lead levels for all children to be reported (Chamany et al. 2009, p. 561). As noted above, one potential reason for restricting exercise of privacy claims is justified paternalism. Although it is controversial when paternalism is justified, 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 it is 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.

7. Conclusion, Limitations

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 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 distributions: how to allocate resources to protect basic interests and the extent of claims generated by threats to basic interests is a rich topic beyond the scope of this paper. 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 is effective in many

areas. But the tools needed to address, e.g., 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 in this paper 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 Unreasonable Exercise Argument. I think that the approach has some important advantages. For one, it avoids justification of 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 non-infectious 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. Another advantage of the view offered is that it avoids the problems of aggregating views.

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[1] See, for example, Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, 45 C.F.R. §§ 164.512-514; American Recovery and Restoration Act of 2009, Public Law 111-5, Section 13405(d).

[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(a)).

[3] Fairchild et al argue that privacy arguments have evolved substantially from the era of "paternalistic privacy" in the late 19th and early 20th Centuries, to "democratic privacy" in recent decades. Nonetheless, they document that privacy concerns have figured prominently in debates about public health surveillance for over 100 years, even if the tenor and parties making the arguments have changed.

[4] Fairchild quotes two commentators from a meeting held in August 2005. One stated that "[t]o 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." (Fairchild 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 redundant with the second criteria and problematic for the same reasons.

[6] This is a crude version of utilitarianism, and there is of course much to be specified and debated about the proper understanding of utilitarianism, including the proper locus of judgment (acts, rules), how to measure welfare, who counts, and so forth. Those debates do not bear upon this project.

[7] Obviously not all such efforts would be impermissible. Providing free floss would clearly not impinge 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 implementing them.

[8] My starting point here—distinguishing 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 'common good' set forth by (London 2003) London develops this view further in (2006, p. 2878) and (2007, pp. 109-110). London develops his account in order to analyze clinical research rather than public health measures, but a similar approach can be used here.

[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; 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. Rather it serves to place one limit on the domain of public health.

[11] It is worth noting that the NYC health department maintains that because the A1C results reported in the diabetes initiative will be subject to stringent protections, there is no privacy loss. More accurate would be 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 discussion of breast cancer in her essay (Ehrenreich 2001) She describes a breast cancer survivor identity that many people embrace. Roughly that identity is one of strength in the face of the disease, sisterhood with other survivors, and being active 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 (Rawls 1996, pp. 310-11). On the conception outlined here privacy in health information would appear to implicate (1) and (3), only, thus making it weighty but not plausibly a basic liberty

[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, and related, is that personal interests can be related to basic interests without actually rising to the level of basic interests. For the purposes of this paper, we can just as well construe privacy as solely a personal interest or as generally a personal interest, with a few cases where it's a basic interest (e.g., when quarantine or isolation may result).

[15] It is worth noting that there may be cases where the link between one person's information, knowledge of disease, and others' likelihood of incurring serious illness, injury, or death is not based on the first person infecting others, but on the importance of that person's information. Such could be the case during acute outbreaks, where information is sparse such that information about any affected individual is particularly important.