

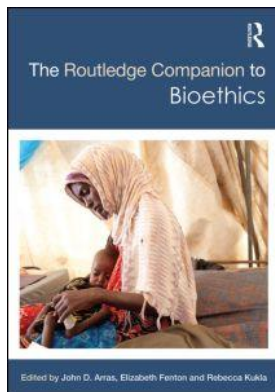
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John D. Arras, Elizabeth Fenton, Rebecca Kukla

### **Privacy, Surveillance, And Autonomy**

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Alan Rubel

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## PRIVACY, SURVEILLANCE, AND AUTONOMY

*Alan Rubel*

### Introduction

We all like at least some privacy, and there isn't much dispute that privacy in health and medical information matters. This is for a variety of reasons. One is that support for privacy protections is strong; public opinion research consistently indicates that persons care deeply about health privacy. Another is that health privacy has significant historical roots, dating back to the provisions for physician–patient confidentiality in the Hippocratic Oath. The popular appeal and historical protections for health privacy make sense because privacy implicates important interests. Information about a person's health can be used to deny that person employment, financial, or other opportunities; and learning about a person's medical condition may lead others to define or view that person disproportionately in light of that condition. Accordingly, there are a variety of legal protections for health information privacy. In the U.S., these include the *Health Insurance Portability and Accountability Act*, the *Genetic Information Nondiscrimination Act*, and the *Common Rule* covering certain human subjects research.

But the sheer usefulness of health information creates enormous pressure for access. Information about disease incidence aids in protecting public health; information about the behavior of patients is useful in providing care; information about drug prescribing and use can help in enforcing drugs laws; and many kinds of health information can serve as data for research. Health information can also be important for democratic governance: Health information may be relevant in determining candidates' fitness for public office, and government transparency may require that people have access to information about government-provided health services, even where that information contains individually identifiable information.

The importance of health privacy and the usefulness of individual health information give rise to a variety of conflicts about the extent to which it is justifiable to collect and disseminate health information. In order to make sense of these conflicts, it will be useful to first examine what privacy is and why it is valuable (*if* and *when* it is valuable).

### *What Is Privacy?*

There are a number of different accounts of the nature of privacy. One important divide in the literature is whether privacy is primarily about others' access to one's personal information or whether it is primarily about one's control over personal information. On

access views, a person has privacy with respect to one's information just in case others are unable to learn of, physically obtain, or otherwise have that information (Allen 1988: 15; Gavison 1984: 347). There is a dispute about what the nature of that access is. Is another person's physical access to information enough for there to be a privacy loss, such that a person who can physically examine another's personal information, but doesn't, diminishes the privacy of those persons with information in the database? Or is it instead that *cognitive* access is required, such that one must actually learn information about the individuals (Powers 1996)? Must another person know some *fact* about another for her to lose privacy, or is it enough that she have a reasonable belief about her (Parent 1983; Rubel 2011: 280–4)? Regardless, the key to any of these access views is that privacy turns on what other persons are able to do with one's information, and not on one's own power to act.

In contrast, control accounts emphasize one's ability to make decisions about one's information. On these views, one has privacy only if she can actually exercise power over her information, for example by granting or denying others access (Westin 1967: 7; Inness 1992: 41–55; Fried 1970: 140–1). To see the difference, consider the case of a person leaving a version of his medical record on the seat of a city bus. On control views, he has lost privacy with respect to that record regardless of whether anyone actually picks up the record and examines it. On access views, that loss of control does not entail that his privacy is diminished.

Whether or not one controls information will on most accounts matter morally; we often care about protections for personal information because we want the power to choose who can access it. This points to a different divide regarding the nature of privacy: Morally neutral (descriptive) accounts and normative accounts. In her influential book, Judith DeCew maintains that privacy pertains to information that “is not generally—that is, according to a reasonable person under normal circumstances . . . a legitimate concern of others” (DeCew 1997: 58). This view builds in the idea of *legitimate* concern into privacy, and hence privacy is by definition morally weighty. Morally neutral accounts allow that one can have privacy even in information that is mundane, such as one's location when he walks down a public street, or that is the legitimate concern of others, such as whether one committed a crime. On these views, the moral question comes in determining what sort of information one has a claim or legitimate interest in keeping private (Moore 2010: 26–7).

For our purposes here, it is useful to navigate these conflicting accounts by stipulating several things. First, privacy concerns access to information. Second, only some information is weighty enough that one could have a legitimate claim to prevent others from having access to it. And control of one's information, or control over that information that one has a legitimate interest in keeping others from accessing, is at least *prima facie* morally important. This leaves open the question of what information one can legitimately prevent others from accessing. To answer that question requires looking at underlying moral justifications for privacy and specifically health privacy.

### ***Why Health Privacy?***

Why should we protect privacy in health information at all? That is, why should we consider the ability to restrict others' access to individuals' health information morally important? To begin, it's at least intuitively plausible that persons have a claim to limit others' access to their health information; otherwise, it would be utterly unproblematic

for physicians, insurers, records managers, researchers, and so forth to share indiscriminately all of one's test results, records of doctor visits, prescription information, and so forth. But to make the case that privacy protections are justified, we will need a fuller explanation.

One possibility is that privacy protections are justified by the potential negative effects of information disclosure on persons' welfare. For example, a lack of privacy may undermine persons' healthcare: Where individuals worry about privacy regarding their medical information, they are likely to engage in "privacy protective" behaviors, such as lying to their care providers, seeing multiple providers, using different pharmacies, not participating in research, and paying in cash rather than using insurance (Goldman 1998: 49; California Healthcare Foundation 2010: 20). Likewise, privacy may increase or protect one's opportunities. Information about a person's health status, medical history, or genetic attributes may undermine her employment prospects, insurance eligibility, financial backing, promotion potential, or opportunities for positions of responsibility. Privacy may also protect people from stigma. Some may believe that aspects of a person's health and medical status reflect negatively on that person (for example, sexually transmitted infections, mental illnesses, some chronic diseases). Hence, where others learn that one has such a condition, she may lose some degree of social esteem.

Although the possibility of negative effects on persons' welfare provides a plausible ground for protecting health privacy, it has important limitations. The fact that people engage in privacy protective behaviors when they worry about health privacy is a reason to protect privacy only on the assumption that doing so will engender trust among patients and lead them to optimize care decisions. Trust, however, is based on *beliefs* about information privacy and security. Suppose that instead of working to secure persons' health information, we sought merely to deceive them about potential negative consequences of disclosing their health information and convincing them that their information is far more secure than it actually is. By doing so we might achieve the result of people optimizing their care and therefore having better results. Surely, though, it is wrong to mislead people about such important matters. The wrongness cannot be attributed to the negative effects on persons' welfare—the effects of the deceit are actually beneficial to persons' welfare.

Rather, the wrongness is based on deceit, which is an affront to their *autonomy*. Autonomy is a complex concept, and there are a number of controversies about its nature, scope, and moral weight, as discussed in several chapters in this volume (see "Related Topics" at the end of this chapter). Nonetheless, autonomy at least includes the ability to govern oneself and make important decisions according to one's own reasons and values, to the extent that one sees fit. Deceit is an affront to autonomy because it short-circuits a person's decision-making capability and her ability to act according to her own reasons. Thus, deceiving persons regarding the status of their health information might have beneficial consequences for their welfare but be morally unjustifiable because it impinges their autonomy.

Consider next the possibility that persons could lose some opportunity or suffer some material harm by disclosure of health information. Certainly that would be a negative effect from the standpoint of the person whose information is disclosed, but it is not clear that such consequences could justify privacy protections as a general matter. Richard Posner has famously argued that insofar as individuals seek to protect from disclosure only "discrediting" information (that is, people tend to advertise information favorable to their prospects and conceal information that is unfavorable), it is likely

more efficient from the standpoint of social welfare to not protect individual privacy in most cases (Posner 1984). Posner's argument turns on the difference between consequences for an individual—perhaps loss of some opportunity—and overall consequences for society. It could be the case that if employers, financiers, insurers, and so forth had more information that was disadvantageous to some individuals, they could make better decisions, and aggregate social welfare would increase through better employment decisions, sounder financing schemes, lower insurance premiums, and the like (though at the expense of those persons who lose out on opportunities).

One might doubt whether this would actually come to pass—decision-makers might give undue weight to medical information. Alternatively, one might doubt that the proper measure for determining whether privacy protections are justified is aggregate social welfare. Perhaps instead the right question to ask is whether denying persons opportunities on the basis of health information is *unfair* or *discriminatory*. Such an argument based on unfairness or discrimination can be understood as an appeal to autonomy. The ability to self-govern includes the ability to exercise a degree of choice over important aspects of one's life and to navigate one's life according to values that are one's own. Whether one can secure employment, financial backing, insurance, or positions of responsibility are important in modern society, and it is exceedingly difficult to participate as a full member of society if one is precluded from these opportunities. Having one's ability to participate as a full member of society restricted for reasons that are largely out of her control—for example because of information regarding her health—therefore imposes an important limit on one's ability to exercise choice over her life and to navigate her life according to her values. As such, it is a limitation on a person's autonomy. There remain questions about whether it is the responsibility of employers, financiers, and others to ensure availability of opportunities. Nonetheless, if privacy is to be justified on the grounds of preserving opportunities, it is at least partially a matter of autonomy rather than overall welfare.

So, while appealing to welfare can provide some grounds for privacy protections, welfare-based protections are buoyed by the value of individual autonomy. Privacy protections may also be justified by direct appeal to individual autonomy, either insofar as privacy is an important object of autonomous choice or insofar as privacy is an important condition for exercising autonomy. These views are sometimes referred to as “personhood” or “personal dignity” accounts of privacy's value (Allen 1988: 43).

Privacy is an object of autonomous choice to the extent that individuals value privacy and conceive of their goals and projects as being their own, and not for others' observation. Persons are capable of choosing for themselves what is of value in their lives. In many cases what people value will include existing, acting, and making decisions privately, without the scrutiny of others. That valuation provides a reason for respecting privacy, at least with respect to self-regarding actions. Moreover, others' knowledge of important facts about a person affects the nature and meaning of the choices she makes (Benn 1984: 228–9). That is, whether one engages in an action might have a different meaning to her depending on whether she believes it is done without others' knowledge or with others' knowledge. In other words, privacy is important to individuals and is a constituent part of the actions and projects they choose. Note that the way privacy is incorporated into one's values is independent of any harms or negative effects that might result from information disclosure. One might want her medical records to remain private with respect to her employers, business investors, or the general public even if the information in those records were *beneficial*—for example if her records showed her to be the very picture of good health. Where one values having privacy, and where privacy

is an important element of the life one wishes to lead, privacy is valuable not because it increases one's welfare—perhaps it does, perhaps it doesn't. Rather, it is valuable because it is a constituent part of the sort of life that she considers valuable (see Raz 1988: 200–1 for an account of constitutive value). Failure to give weight to that value results in a failure to give weight to autonomy.

There is ample reason to think people place this sort of value on health information privacy. As noted, there is evidence that people engage in privacy-protective behavior when they worry about disclosure of health information. Focus group research conducted in numerous cities has revealed that concerns about privacy form an important barrier in getting people to participate in large cohort medical research (Krane 2007; Williams et al. 2009). A study conducted by the Gallup Organization (2000) found that almost 80 percent of its respondents were concerned about their medical information privacy, and over 90 percent thought that genetic research was particularly important from the standpoint of privacy. And public opinion surveys regarding biobank research indicate that a majority of respondents would participate in biobank research, but 90 percent would have concerns about their privacy (Kaufman et al. 2009).

A different way that privacy is relevant to autonomy is that privacy can be a *condition* for autonomy. Others' scrutiny of one's opinions, aspirations, and feelings can have a leveling or homogenizing effect, such that important decisions are less the product of one's own values and deliberations. Implicitly incorporating others' views into one's important, self-regarding choices diminishes the extent to which those choices are the agent's own (Bloustein 1964: 187–8; see also Reiman 1976). More important in this regard is that privacy protections create the conditions necessary to exercise autonomy in human relationships. People maintain many, highly varied relations, ranging from deeply intimate friendly and familial relationships to arm's length business relationships. Appropriate information disclosure is important to each (Fried 1970: 140–4; Rachels 1975: 326). For example, part of what it means to be a close friend is choosing to share important information; it would be difficult to say that a person is a close friend if one never shared anything important and personal with that person. In contrast, keeping the appropriate distance in business relationships involves limiting disclosures of personal but irrelevant information.

The inability to choose what information to share with friends or choose the information available to business relations makes one less able to steer those relationships. Moreover, the relationships individuals enter and how they decide to navigate those relationships are among the most important ways we use our values, goals, and projects to steer the course of our lives. Selective disclosure of information in the context of relationships is vital to exercising autonomy. And where one cannot selectively choose to disclose important information in entering many and varied relationships, autonomy is circumscribed. Hence, privacy protections for important information, which allow individuals to decide when, how, and with whom to share information, are thus important in their exercising autonomy over a fundamental aspect of life. Privacy with respect to health information is crucial here, as it is often the case that sharing or not sharing health information is part of what defines one's relationships.

### *Health Privacy Disputes*

The tensions between desire for privacy, underlying justifications for privacy protections, and usefulness of health information become clearer when we examine health information and privacy in several controversial contexts.

## Public Health Surveillance: Overriding Autonomy Interests for General Welfare

One conflict concerns health information in which individuals have an autonomy interest, but which is particularly important for social welfare. Consider public health surveillance.

Surveillance is central to efforts of public health organizations in assessing the status of public health, establishing priorities, detecting epidemics, monitoring disease, and assessing programs (Thacker et al. 2003). Some data collected for the sake of public health, such as vital statistics and environmental data, do not have serious health privacy implications. But public health surveillance also includes mandatory, named reporting of various diseases and development of disease registries that track individuals with certain conditions over time. In the U.S., individual states require care providers and laboratories to report cases of (among other things) infectious diseases such as tuberculosis (TB), HIV/AIDS, and syphilis. In addition, there are registries for non-infectious diseases, including cancer, occupational disease, and lead poisoning in children (Fairchild et al. 2007; Chamany et al. 2009: 561). A particularly controversial case is New York City's recent mandate that city laboratories report by name results of A1C (blood glucose) tests in an effort to address the growing diabetes problem. The reporting is coupled with a pilot program in which residents of certain areas with particularly high rates of diabetes will have their providers notified when test results are elevated (Fairchild and Alkon 2007; Goldman et al. 2008).

Mandatory, named reporting of diseases to public health entities clearly conflicts with individual privacy regarding health information. Surely, though, at least some types of public health surveillance are morally justified. Consider TB, which is infectious, largely treatable with antibiotics, serious and potentially fatal without treatment, and historically lethal. If mandatory reporting of TB (including multiple-drug resistant strains, which are particularly worrisome from the standpoint of public health) is an effective part of efforts to prevent others from becoming infected (and preventing some from dying), it is hard to see how persons' autonomy interests in privacy could provide a compelling case against reporting. The difficulty comes in determining how to resolve cases that are less clear cut. The approach currently employed by the U.S. Centers for Disease Control and Prevention and by state and local health departments is to distinguish between public health research, for which there should be privacy protections such as those required for all health research, and public health practice, which warrants less privacy protection (Gostin 2008: 309). This approach is problematic for several reasons, including the difficulty of distinguishing research and practice and the distinction's failure to track anything of independent moral importance (Fairchild and Bayer 2004; Mariner 2007: 374; Rubel 2012: 6).

Another possibility is to turn to moral principles underwriting public health surveillance and protections for individual medical privacy. Public health entities are centrally concerned with health issues at the population level, in contrast to clinicians who have responsibilities to individual patients and researchers who have responsibilities to protocols and the scientific enterprise (Rothstein 2002: 145; Institute of Medicine 1988: 19). Public health surveillance may therefore be understood as a mechanism of protecting overall health and welfare (see Parmet 2009), and surveillance efforts will be justified to the extent that they lead to greater, aggregated health of the members of a population.

But how should we justify privacy protections—should *any* increase in aggregate welfare warrant surveillance efforts? Consider first the view that privacy protections should be based on consequences for persons' welfare. Where individuals are likely to engage in the sorts of privacy-protective behaviors discussed above, surveillance efforts might have deleterious effects on their health and in the case of infectious disease, the health of others. For example, in the early days of HIV/AIDS testing in the U.S., many activists and public health officials opposed mandatory reporting of the names of infected individuals to confidential state registries for fear that it might dramatically reduce voluntary testing and counseling, and hence would increase infection rates (Bayer 1991). Those effects, however, fit easily within the view that public health should promote aggregate health within the population. That is, if the effects are large, and lots of people avoid care, then they would undermine the very rationale justifying the surveillance in the first instance.

A different welfare argument for protecting privacy is that if others were to learn the identities of persons with reportable diseases, it could harm their employment, social, financial, and other prospects. Protecting individuals from harms to opportunities can be addressed within the context of public health surveillance by placing restrictions on those who can access information in disease registries. This seems to be the strategy employed by the New York City public health department in its diabetes surveillance initiative. In defending the initiative, department members have pointed out that information collected is more difficult to access than information collected for other disease registries (Chamany et al. 2009: 560).

But neither of these rationales accounts for persons' autonomy interests in privacy regarding health information. A different approach is to take seriously the idea that persons have important autonomy interests in privacy and then consider the conditions under which it is justifiable for a society to subordinate that autonomy interest. One possible dividing line is where a person's maintaining privacy in her health information unreasonably threatens others' health, for example by making it likely that they will become seriously ill or die (Rubel 2012). On this view, mandatory reporting of serious infectious diseases would be justified because keeping private the fact that one has such a disease makes it likely that others will contract the disease and become seriously ill or die. Likewise, reporting of diseases could be justified if the knowledge obtained is necessary for controlling the disease. However, where the reporting primarily redounds to the benefit of the person whose information is reported, it is more difficult to see how it can be justifiable to subordinate persons' autonomy interests in keeping the information private. Of course, the information could be collected *voluntarily*, for that would be a means of allowing persons to make the reporting decisions according to their own reasons and values.

### **Whole Genome Sequencing: Autonomy and the Ability to Share**

Respect for autonomy does not always weigh in favor of greater privacy protections. As discussed, privacy protections are either buoyed by autonomy, the object of autonomous choices, or a condition of autonomous choice. But because autonomy includes the ability to act according to one's reasons and values as one sees fit, one may choose to diminish one's own privacy by sharing information. Prohibiting outright persons from sharing their health information would likewise restrict persons' autonomy by preventing them from sharing information where doing so comports with their values and reasons.



Consider the case of whole genome sequencing in the context of medical research and in clinical practice. Since the human genome was first sequenced in the early 2000s, there have been substantial advances in genomic research. One such advance is the capacity to sequence individuals' entire genomes. It is projected that sequencing a single person's entire genome will soon cost as little as \$1000 (PCSBI 2012: 22). The ability to store entire genomes, correlate them with health conditions, and compare the genomes of a growing number of people promises significant advances for medical research and clinical practice. Whole genome sequencing has already aided care providers in identifying and treating rare diseases, and the hope is that it will lead to greater personalization of medicine (e.g., by identifying promising interventions based on individuals' genomes) and identification of genetic variants that correlate with specific diseases (PCSBI 2012: 19–20). For example, discoveries of genetic variants that make one more susceptible to diseases like diabetes, Alzheimer's disease, cancer, and heart disease may lead to better clinical outcomes.

However, as the predictive value of whole genome sequencing rises—that is, as the number of conditions known to correlate to particular gene variants grows—there is greater potential harm to individuals who have their genomes sequenced. If others have access to an individual's genomic information, they may be able to make inferences about that person's health prospects. This has important implications for persons' welfare, for the reasons discussed above. It is also important insofar as there is the potential for persons to experience psychological harms should they learn that they have variants associated with diseases that will become manifest in the future (Powers 2008).

It would seem that protecting genomic information as a general matter is important for preventing such potential harms. Doing so would also give persons the opportunity to disclose their own information selectively, according to their values as they see fit. In light of vast and growing amount of information shared via social networks, and the widespread appeal of participating in such networks, it is plausible that many people will value the opportunity to share genomic information. That is, they could exercise autonomy in deciding to share their information as part of the research enterprise, to aid clinicians in their care, and potentially with others sharing similar conditions in order to build community. But the case for autonomy-based sharing is not clear cut. For one, the degree to which persons' decisions to share information would be autonomous is unclear. The potential of whole genome sequencing is largely unrealized, and we cannot anticipate just what research will reveal (PCSBI 2012: 18). This uncertainty undermines the degree to which consent to information sharing is informed, and hence the degree to which it is autonomous.

Moreover, there are cases where it is justifiable to limit persons' exercise of autonomy for paternalistic reasons. Anita Allen has argued that if privacy is important enough, it is justifiable to paternalistically protect privacy, which could include preventing certain types of information disclosures (Allen 2011). Note, too, that there may be negative consequences should people extensively exercise choice regarding use of their information. For example, if people can control what types of research to which they will contribute information, or if they can withhold information from endeavors that benefit from large datasets, they could undermine research results and hinder public benefits (Gostin 2009).

Exercising autonomy by sharing genetic information carries different sorts of risks than participating in other sorts of research. By sharing genetic information, one also shares information about one's family members. Hence, the risks of stigma, discrimination, and

psychological stress extend to others. A related issue has to do with discrete groups of people who share genetic traits. One famous example regards DNA samples collected from members of the Havasupai Tribe in the Southwest U.S. for the purpose of diabetes research (see Chapter 17 in this volume). These samples were subsequently used without further consent for different research, including studies on schizophrenia, historic migration patterns, and inbreeding (Lee et al. 2009). Because such research bears upon all members of the group, the decision to share information implicated the interests of many persons other than those who agreed to share information. Note that determining what consent procedures are appropriate in such circumstances is particularly difficult.

In the final analysis, it may be that persons should be able to choose to share their genomic information. That is the conclusion of the Presidential Commission for the Study of Bioethical Issues, which has recommended that persons have the opportunity to share their information, though noting that such sharing should occur only with robust consent procedures and against a background of strong privacy protections (PCSB 2012: 74, 91). Nonetheless, because knowledge of what genomic research will uncover is limited and because decisions to disclose directly implicate others, the autonomy issues surrounding privacy in genomic information are not clear cut.

### Privacy and Democratic Principles

Privacy protections for health information can also conflict with democratic principles, which are on many accounts justified by autonomy. For example, health information may be relevant to electoral decisions. It may also be part of government records to which the public should have access.

Suppose that a candidate for public office has been diagnosed with a terminal disease, and it is likely that she will not survive her first year in office. A different candidate has a family history of heart disease, but is himself in good health. It would seem unfair and distracting to make the second candidate's medical record (including his family history) available to the public and hence a campaign issue. However, it also seems reasonable that the health information about the first candidate is relevant and important for voters to know. But is that correct? Why should candidate health information matter at all, and why should voters have access to any information? Addressing the issue will pit candidates' autonomy interests in health privacy against voter autonomy interests based in democratic principles.

Democratic theory relies on individual autonomy in the practice of political representation and in the right to vote, which are essential to any plausible conception of democracy. There are competing views of why liberal democracy is a justified form of government. Some accounts maintain states are legitimate, and can command authority, only insofar as they enjoy the consent (either explicit or tacit) of the governed (Locke 2009; Estlund 2008). Others locate the legitimacy and authority of democratic, representative government in its consequences; such a government leads to better outcomes for persons living under it (Mill 1859; Raz 1988). But in either case, exercising the right to vote is important insofar as it allows persons to exercise their wills in political processes, and this requires persons do so autonomously (Schauer 2000: 307–8). After all, coerced and purchased votes are under no plausible view legitimate. And adequate information is required to ensure that votes are actually cast autonomously. Without good information, an electoral choice may not be based on a person's own values and reasons, much as a person's consent to a medical procedure is inadequate where she is not provided important, relevant information.

The question here is when, and to what degree, persons' health and medical information should be disclosed based on liberal, democratic principles. In at least a few cases, it would appear that some medical information about candidates for elected office is important in order to ensure that votes for that candidate are based on sufficient information that they are cast autonomously. Consider that several U.S. presidential candidates, including John F. Kennedy, have had health risks that they have kept secret from voters; in some cases those risks have been serious enough that there was a substantial risk that they would be unable to fulfill the tasks of office. This possibility raises several questions. First, do candidates for office have some duty to disclose serious medical conditions to the electorate? Streiffer et al. (2006) argued that there *is* such a duty for presidential candidates where the condition is likely to undermine the candidate's ability to complete the "core functions" of office. That duty is based on persons' rights in a liberal democracy to be governed with their consent.

A further question is whether laws can be justified requiring candidates to disclose serious medical conditions to voters or representatives upon seeking office. This is a more difficult question. Such a requirement might undermine its very purpose by deterring good candidates from seeking care for health issues, thereby jeopardizing their ability to fulfill the responsibilities of office (Annas 1995: 948). Also problematic is that disclosure requirements could serve to derail campaigns, causing them to focus on claims about candidates' health rather than on more substantive issues (Annas 1995: 948). But what, if any, health information is actually relevant to persons' decisions about voting? Frederick Schauer argues that people in a democracy have not only the right to make electoral decisions autonomously, but also the right to decide what information is a relevant basis for that choice (Schauer 2000: 303–6). This would appear to imply that any health information about any candidate could be relevant. Surely, though, some medical information is either unrelated to the ability to perform the functions of office (prior minor illnesses, ancestry) or important only in light of unreasonable prejudices (sexual history, minor mental health issues) such that disclosure is not warranted by autonomy interests. Finally, if there is a duty to disclose, and if it is justifiable to require disclosure, there remains a question as to how broadly that requirement ought apply. The President of the United States, for example, is in many ways a special case due to the scope of presidential power. The extent to which disclosure and disclosure laws are appropriate for that office need not apply to positions where the consequences for health problems are not as great.

A different health privacy issue concerns the democratic principle of open government, or the idea that governments ought to be transparent about their policies and workings. Transparency is encoded in a variety of laws requiring that government bodies meet in public, that information collected and held by state actors be accessible to the public, and that members of the public have the right to speak freely about government information. This principle of publicity can be justified both on consequentialist grounds (publicity helps ensure good government) and on autonomy grounds (publicity of government policies and information is necessary to secure either tacit or explicit consent) (Gutmann and Thompson 1996: 97–101).

This creates a conflict when state actors provide key medical services. Consider, for example, state coordination and provision of emergency medical services. In the U.S. and elsewhere, emergency medical services (along with other emergencies, such as police and fire protection) originate with calls to a centralized number (9-1-1 in the U.S.). Dispatchers collect information from a caller and relay it to others who respond

to the emergency. Calls to 9-1-1 are generally recorded, and in most states these recordings are public records. Hence, they are available to the public by request. Because such calls often contain personal health information—names, addresses, symptoms, history, and so forth—there is a conflict between interests in open government and interests in health information privacy. It is easy to see why such information would be important from the standpoint of transparency. People may wish to know how responsive emergency services are to different locations and different conditions, or to hear how personnel respond to particular, important cases. Investigating such issues is surely part of exercising one's autonomy within a democratic society. But whether that interest suffices to override persons' privacy interests, also grounded in autonomy, is unclear.

### Conclusion

Regardless of the particular conception of privacy, the moral importance of health information privacy depends on autonomy, either in support of welfare-based justifications for privacy, as an object of autonomous values, or as a condition for autonomy. But that only goes so far in determining what privacy protections are justified. Privacy in health information may conflict with others' welfare, as illustrated by the public health surveillance issue. The choice to share information may be important enough or implicate others' interests sufficiently that we might consider constraints on sharing, as illustrated by the whole genome sequencing case. And privacy protections, themselves based on autonomy interests, may frustrate others' autonomy in a democratic state. There are myriad other health privacy issues out there, such as the moral basis for physician-patient confidentiality, the relation between privacy regarding information and privacy of health decision-making, and the testing of students, athletes, and employees for drug use. Nonetheless, these issues often track the same conflicts—between others' welfare and individuals' autonomy interests, between an individual's autonomy interest and her own welfare interest, and between one's autonomy interest in privacy and others' autonomy interest in information.

### Related Topics

Chapter 17, "Ethical Issues in Genetic Research," Dena S. Davis

Chapter 21, "Autonomy," Catriona Mackenzie

Chapter 25, "Public Health and Civil Liberties: Resolving Conflicts," James F. Childress

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