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Privacy, Public Health, and Controlling Medical Information

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Abstract This paper argues that individuals do, in a sense, own or have exclusive claims to control their personal information and body parts. It begins by sketching several arguments that support presumptive claims to informational privacy, turning then to consider cases which illustrate when and how privacy may be overridden by public health concerns.

Keywords Privacy · Public health · Control of medical information

In Orchomenos Greece, as many as one in four people carry the gene that causes sickle-shaped red blood cells. The problem is when two parents both carry the gene their offspring may develop sickle-cell anemia. In an effort to prevent this disease researchers tested everyone in the village so that marriages between gene carriers could be avoided.

> A group of researchers tested the villagers at Orchomenos, assuming that carriers would behave rationally and would pair with non-carriers in order to mix the genes safely and protect the community's children. The non-carriers, however, refused to cooperate. Even though the gene is harmless on its own, carriers became stigmatized and non-carriers refused to marry them. In the end, the carriers became a shunned subclass who were forced to marry among themselves, making the situation even worse that before (Platt 1997, p. 200).

While the researcher's goals were noble, they obviously failed to foresee the ramifications of disclosing this kind of personal information. Highlighted in this sort

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of example are the tensions between individual privacy rights, public health, and control of information. Those who take privacy rights seriously may argue that there should be general prohibitions against disclosing information of this sort—no matter what the gains in social utility. In reply, defenders of public health might claim that such disclosures are a necessary part of protecting the common good.

I will argue that individuals do, in a sense, own or have exclusive claims to control their personal information and body parts. In the first part of this article, I will sketch several arguments that support presumptive claims to informational privacy. In the second section, I will consider several cases which illustrate when and how privacy may be overridden by public health concerns.

Establishing a Presumption in Favor of Privacy[1]

I favor what has been called a "control" based definition of privacy rights.[2] A privacy right is an access control right over oneself and to information about oneself. Privacy rights also include a use or control feature—that is, privacy rights allow me exclusive use and control over personal information and specific bodies or locations.

To get a sense of the importance of privacy and separation it is helpful to consider similar interests shared by many non-human animals. While privacy rights may entail obligations and claims against others—obligations and claims that are beyond the capacities of most non-human animals—a case can still be offered in support of the claim that separation is valuable for animals. Even though privacy may be linked to free will, the need for separation provides an evolutionary first step. Alan Westin in *Privacy and Freedom* notes,

> One basic finding of animal studies is that virtually all animals seek periods of individual seclusion of small-group intimacy. This is usually described as the tendency toward territoriality, in which an organism lays private claim to an area of land, water, or air and defends it against intrusion by members of its own species (1968, p. 8).

More important are the ecological studies demonstrating that a lack of private space, due to overpopulation and the like, will threaten survival. In such conditions, animals may kill each other or engage in suicidal reductions of the population. Lemmings may march into the sea or there may be what is called a "biochemical die-off". Calhoun notes that experiments with rats and spacing in cages show that a

[1] Parts of this section are based on material published in Moore (2003, 2008a). For a lengthier treatment and justification of privacy rights see Moore (2008b, 2009).

[2] This account is similar to Anita Allen and Ruth Gavison's "inaccessibility" view of privacy and Ernest Van Den Haag and Richard Parker's "control" theory. See Allen (2003), Gavison (1983, pp. 113–134), Fried (1970, chapter 9), Wasserstrom (1979, p. 148), Gross (1971, p. 170), van Den Haag (1971, p. 147), Parker (1974, p. 280). For a critique of control based accounts of privacy see Judith Jarvis Thomson (1975, p. 295).

certain level of separation is necessary for the species.[3] Moreover these results hold across a wide range of species supporting the contention that separation, like food and water, is a necessity of life (see e.g., Allee 1938; Deevey 1962; Gilliard 1963; Snyder 1961; Wynne-Edwards 1962).

If it is plausible to maintain that humans evolved from non-human animals, then it is also plausible that we may retain many of the same traits. In 1969 Edward Hall noted a link between a lack of privacy and psychological and physical disorders in humans and non-human animals.[4] Lewis Mumford notes similarities between rat overcrowding and human overcrowding. "No small part of this ugly urban barbarization has been due to sheer physical congestion: a diagnosis now partly confirmed by scientific experiments with rats—for when they are placed in equally congested quarters, they exhibit the same symptoms of stress, alienation, hostility, sexual perversion, parental incompetence, and rabid violence that we now find in Megapolis" (Mumford 1961, p. 210 cited in Fuller et al. 1996, p. 267).[5] These results are supported by numerous more recent studies (see, e.g., Baum and Koman 1976; Clauson-Kaas et al. 1996; Edwards and Both 1977; Fuller et al. 1996; Morgan 1972; Farrington and Nuttal 1980; Paulus et al. 1978; Ruback and Carr 1984). Overcrowding in prisons has been linked to violence (Megargee 1977; Porporino and Dudley 1984), depression (Cox et al. 1984), suicide (McCain et al. 1980 psychological disorders (Paulus et al. 1978), and recidivism (Farrington and Nuttal 1980).

Moreover, cultural universals—like rituals of association and disassociation—have been found in every society that has been systematically studied (see Murdock 1955). Based on the Human Relations Area Files at Yale University, Westin argues that there are aspects of privacy found in every society—privacy *is* a cultural universal.[6]

While privacy may be a cultural universal necessary for the proper functioning of human beings, its form—the actual rules of association and disengagement—is

[3] The lack of separation leads to the disruption of social relationships and increases of disease, high blood pressure, and heart failure. Calhoun allowed Norway rats, which were amply fed, to breed freely in a quarter-acre pen. Their number stabilized at 150 and never exceeded 200. Paraphrased from Hall (1968, p. 86), Calhoun (1950, pp. 113–122).

[4] "The disorders of Calhoun's overcrowded rats bear a striking resemblance to… Americans who live in densely packed urban conditions… Chombart de Lauwe has gathered data on French worker's families and has demonstrated a statistical relationship between crowded living conditions and physical and social pathology. In Manhattan Srole et al. showed that only 18% of the representative sample were free of emotional disorders while 23% were seriously disturbed or incapacitated" (Hall 1968, p. 86).

[5] This view is echoed by Desmond Morris who writes, "Each kind of animal has evolved to exist in a certain amount of living space. In both the animal zoo and the human zoo [when] this space is severely curtailed… the consequences can be serious" (Morris 1969, p. 39).

[6] This view is supported by John Roberts and Thomas Gregor: "… privacy as a set of rules against intrusion and surveillance focused on the household occupied by a nuclear family is a conception which is not to be found universally in all societies. *Societies stemming from quite different cultural traditions such as the Mehinacu and the Zuni do not lack rules and barriers restricting the flow of information within the community, but the management and the functions of privacy may be quite different*" (Roberts and Gregor 1971, p. 225, italics mine).

Barry Schwartz, in an important article dealing with the social psychology of privacy, provides interesting clues as to why privacy is universal. According to Schwartz privacy is group preserving, maintains status divisions, allows for deviation, and sustains social establishments. As such, privacy may be woven into the fabric of human evolution (Schwartz 1968).

culturally dependent (Spiro 1971, 121–148). The kinds of privacy rules found in different cultures will be dependent on a host of variables including climate, religion, technological advancement, and political arrangements. As with the necessities of food, shelter, and education we should not jump to the conclusion that because the forms of privacy are culturally dependent that privacy is subjective "all the way down." The forms of privacy are culturally relational while the need is an objective necessity.

Given all of this, one can, with great confidence claim that privacy is valuable for beings like us. The ability to regulate access to our bodies, capacities, and powers and to sensitive personal information is an essential part of human flourishing or well-being.

Toward Informational Privacy Rights

While it might be admitted that privacy, broadly defined as a right to control access to and uses of bodies and information, is morally valuable it has not been established that individuals have moral claims to control personal information. One way to begin is by asking how claims to control intangible objects, like facts about someone, are generated. In the argument that follows I will employ a version of John Locke's proviso on acquisition. "For this labor being the unquestionable property of the laborer, no man but he can have a right to what that is once joined to, at least where there is *enough and as good left for others*" (1689, § 27). Locke claims that so long as the proviso that enough and as good is satisfied, an acquisition does not prejudice anyone. Viewed as a kind of "no harm, no foul" rule, actions that pass this standard leave little room for rational complaint—I will call this version of Locke's proviso a "Pareto-based proviso."[7] Consider the following argument.

P1 The value of privacy related to human well-being grounds a weak presumptive claim to use and control personal information

P2 Respect for persons, possession, self-creation and project pursuit grounds a weak presumptive claim to use and control personal information

P3 If no one is worsened by such use, then the weak presumptive claims generated by the value of privacy and respect for persons are undefeated—actions that pass a Pareto-based proviso are permitted (no harm, no foul)

P4 It is typically the case that others are not worsened by some individual's use and possession of their own personal information

C4 Thus, the weak presumptive claims to use and control such information are, in many cases, undefeated and moral claims (perhaps rights) emerge

[7] The "Pareto" condition is named after Vilfredo Pareto (1848–1923) an Italian economist and sociologist. One state of the world, S1, is Pareto superior to another, S2, if and only if no one is worse-off in S1 than in S2, and at least one person is better-off in S_1 than in S_2. S_1 is *strongly* Pareto-superior to S2 if everyone is better-off in S1 than in S2, and *weakly* Pareto-superior if at least one person is better-off and no one is worse-off. State S1 is Pareto optimal if no state is Pareto superior to S1: it is *strongly* Pareto optimal if no state is *weakly* Pareto superior to it, and *weakly* Pareto optimal if no state is *strongly* Pareto superior to it. Throughout this essay I will use "Pareto" as a "super-weak" condition—i.e., no one is worsened. (Adapted from Cohen 1995, p. 160.)

The importance of privacy for human well-being along with a concession that the promotion of certain fundamental values is a moral requirement may provide adequate support for the first premise. Only a pure deontologist would deny that good and bad consequences, especially related to basic needs, do not generate weak presumptive claims.

Support for the second premise builds on the notion of respect for persons as moral agents. Without justification, it would be wrong to take personal information and leave the original possessor without it—as it would be to wrest an apple from someone's hand who just plucked it from an unowned tree. Developing one's capacities, intellectual effort, and engaging in lifelong project pursuit are generally voluntary activities that can be unpleasant, exhilarating, and everything in-between. That we voluntarily do these things as sovereign moral agents may be enough to warrant presumptive non-interference claims against others. In doing these things, we create the facts of our lives—acknowledging weak presumptive claims to use and control personal information about these activities might be grounded in respect for persons and moral desert. Given that the first two premises establish the same point—they are redundant—if either is correct, then the argument goes forward.

Providing support for the third premise requires a clarification and defense of a Pareto-based proviso. In terms of clarification we must adopt an account of value—so that moral bettering and worsening can be determined. An individual could be worsened in terms of subjective preference satisfaction, wealth, happiness, freedoms, opportunities, etcetera. Which of these count in determining bettering and worsening? Second, once the terms of being worsened have been resolved, which two situations are we going to compare to determine if someone has been worsened. Is the question one of how others are now, after my appropriation, compared to how they would have been were I absent, or if I had not appropriated, or some other state? Here we are trying to answer the question "Worsened relevant to what?" This is known as the baseline problem.

In principle, the model of informational privacy being sketched is consistent with a wide range of value theories.[8] So long as the preferred value theory has the resources to determine bettering and worsening with reference to the use and control of personal information, then Pareto-superior moves can be made and justified. For now, assume an Aristotelian eudaimonist account of value exhibited by the following theses is correct.

1. Human well-being or flourishing is the sole standard of intrinsic value.
2. Human persons are rational project pursuers, and well-being or flourishing is attained through the setting, pursuing, and completion of life goals and projects.[9]
3. The control of physical and intangible objects is valuable. At a specific time each individual has a certain set of things she can freely use and other things she owns, but she also has certain opportunities to use and appropriate things. This

[8] It has been argued that subjective preference satisfaction theories fail to give an adequate account of bettering and worsening. See Hubin and Lambeth (1989, p. 489) and Moore (2004).

[9] For similar views see: Rawls (1971, Chap. VII); Aristotle, *Nicomachean Ethics*, bks. I and X; Kant, *The Fundamental Principles of The Metaphysics of Morals*; Sidgwick (1907), Perry (1926) and Lomasky (1987).

complex set of opportunities along with what she can now freely use or has rights over constitutes her position materially—this set constitutes her level of material well-being.

While it is certainly the case that there is more to bettering and worsening than an individual's level of material well being including opportunity costs, I will not pursue this matter further at present. Needless to say, the view sketched earlier regarding the value of privacy fits well with a eudaimonist account. Whatever value theory that is ultimately correct, if it has the ability to determine bettering and worsening with reference to the use and control of personal information, then a non-worsening standard can be used to determine when weak presumptive claims to use and control are undefeated.

Turning to the baseline problem—or what two situations do we compare to determine moral bettering and worsening—I believe that we should affirm the following base point. We compare how someone is after an action to the moment before. Consider a common case dealing with worsening: the face puncher case. When Crusoe punches Friday in the face we say that Friday has been worsened compared to the moment before the punch. We do not compare Friday's state of pain after the punching to his condition a month before when—let us suppose—he was in great pain due to falling into a fire. Since an individual's level of material well-being changes over time, the baseline of comparison should also change.[10]

A Pareto-based proviso indicates when others may have legitimate complaints against an established weak presumptive claim of use and possession. If in possessing and using your own personal information no one is worsened relative to the appropriate base point, then no one could have a compelling claim that would override the weak presumptive claims already in place. Put another way, an objection to appropriation, which is a unilateral changing of the moral landscape, would focus on the impact of the appropriation on others. But if this unilateral changing of the moral landscape makes no one worse off, there is little room for rational criticism.[11]

The truth of the fourth premise seems fairly obvious in light of my characterization of a Pareto-based proviso. When an individual uses and controls

[10] Suppose we compare how Friday is when he gets to use and control some value V to his condition where he does not get to use or control V. On this account, whenever anyone exclusively uses and controls V they worsen others. Assuming that water is valuable, Crusoe worsens Friday when Crusoe takes a drink—alas, Friday would be better if he got to drink the water in question *even if they are both standing by an endless stream of perfectly good drinking water*. Such baselines are indefensible because they produce over-broad accounts of moral bettering and worsening. For more about the difficulties in determining a baseline (see Hubin and Lambeth 1989, p. 489; Kagan 1989, chap. 3).

[11] To adopt a less stringent principle would permit individuals, in bettering themselves, to worsen others. Such provisos on acquisition are troubling because they may open the door to predatory activity. To require individuals, in bettering themselves, to better others is to require them to give others free rides. Both of these standards are open to rational complaint. See Nozick's Robinson Crusoe case in *Anarchy, State, And Utopia* (1974, p. 185).

Several other points can be offered in support of a Pareto-based proviso as well. A "no harm, no foul" principle leaves "moral room" for individuals to live their lives as they see fit. While consequences matter, there is no maximization requirement—no required trade-offs of someone's lifelong goals and projects for mere incremental increases in social utility. In this way a Pareto-based proviso accords with our considered convictions regarding respect for persons and at the same time accommodates consequentialist views linking theories of the good and theories of the right.

their own personal information it will generally be the case that others are not necessarily worsened. Consider some health-related fact that Crusoe comes to know about himself. To consider if Friday has been worsened we compare how he is prior to Crusoe's coming to know the fact in question to Friday's situation after Crusoe's discovery. In either case, Friday is unaware and is not worsened by Crusoe's use and control. On the other hand, suppose that Crusoe knows that he is a violent sleep walker and Friday is planning to sleep nearby. In this case, it seems that Friday has been (or will be) worsened by Crusoe's non-disclosure—foisting un-consented to risks on others constitutes a morally relevant worsening.

If the argument so far has been compelling, then it will be conceded that individuals have moral claims to use and control their own personal information. But since information is non-rivalrous it is not clear that using and controlling personal information about others worsens them. In seeking to use and possess information about Fred, Ginger does not *necessarily* worsen Fred. Suppose that upon seeing him, Gingers notes that Fred has green eyes. Surely Ginger's mere possession of such information does not worsen Fred relative to how he would be in her absence or had the acquisition not occurred. But when Ginger offers information about Fred up for public consumption—suppose that she shares this information with a much wider audience than Fred could have ever reached via daily public activity—she does worsen him in terms of increased risk, commercial exploitation, and the like.

The Risk Argument

Central to the risk argument is the claim that in connected societies where information trading is both efficient and nearly costless, disclosure of personal information opens individuals up to certain risks—for example, being controlled by entities with their own agendas. Typically, such control comes in two flavors. First, governments use such information to retain domination and expand power.[12] Second, corporations may use personal information to overwhelm individuals in a sea of solicitations and promotional advertisements or to control their employees. Sharing personal information about someone else with a third party—say a home address and religious affiliation—may have serious consequences. German Jews in the 1940s, and more recently, American Muslims know this all too well—or consider the Orchomenos Greece case once again.

Without video, audio, and other kinds of robust surveillance, when Fred steps out on a public street he both creates certain facts about himself and relinquishes exclusive control of this information to those who share the public domain. The

[12] The following quote from a Chinese military newspaper applies a number of these issues to information war. "After the Gulf War, when everyone was looking forward to eternal peace, a new military revolution emerged. This revolution is essentially a transformation from the mechanized warfare of the industrial age to the information warfare of the information age. Information warfare is a war of decisions and control, a war of knowledge, and a war of intellect. The aim of information warfare will be gradually changed from 'preserving oneself and wiping out the enemy' to 'preserving oneself and controlling the opponent.' Information warfare includes electronic warfare, tactical deception, strategic deterrence, propaganda warfare, psychological warfare, network warfare, and structural sabotage" (*Jiefangjun Bao,* Chinese Army Newspaper, cited in Carlin 1997).

information captured by others is held in non-permanent mediums like memory and is acquired by a relatively small number of people. In such cases, Fred incurs few risks and the sharing of such information by second and third parties poses little threat. Please note that Fred could disguise himself or go out at night to further limit public access to personal information. Hinting at the property rights argument to come, Fred could use his property to justifiably limit access to personal information.

But when such information is captured digitally via video and audio surveillance or with some other more permanent medium, Fred is subjected to increased risks. Such information may lie unused for decades and then be resurrected by those in power or with commercial agendas. Societies where personal information trading or data mining is facilitated through the use of technology, like digital environments, the use and control of personal information opens individuals up to risks and losses. If so, the disclosure of such information will worsen Fred relative to the base point of prior to disclosure and a step toward informational privacy will have been established.[13]

Two further considerations, suggested by Helen Nissenbaum, deserve mention at this point. Nissenbaum notes that data shifting—using information gathered for one purpose in some new way—violates what she calls "contextual integrity." "In the public surveillance currently practiced, information is routinely shifted from one sphere to another, as when, for example, information about your supermarket purchases is sold to a list service for magazine subscriptions" (1998, p. 585). An admittedly extreme case of data shifting occurred when a stalker of actress Rebecca Shaefer secured her home address from certain state licensing records and murdered her. Moreover, the digitization of information coupled with the expansion of computer networks has allowed information aggregation of a sort not seen before. Information that may be freely given in different contexts for various purposes is collected in digital profiles that are then sold. Data shifting and aggregation open up individuals to unforeseen and un-consented to risks.[14]

The Bodily Access and Property Rights Argument

Suppose that Fred creates and wears an anti-disclosure suit that shields him in public spaces entirely. All that his fellows know is that someone is present—they do not know if Fred is old or young, male or female, tall or short, etc. In simply wearing his anti-disclosure suit Fred does nothing wrong—he does not necessarily worsen anyone. In this example, to discover much about Fred would require violating his

[13] A serious objection to this argument is that maybe the risks imposed on individuals through the manipulation of personal information are counterbalanced by other values such as increased opportunities or security. I would counter that the iterated nature of the risks along with the fact that such burdens (and benefits) are imposed, not freely chosen, constitutes a morally relevant worsening.

[14] These considerations provide a compelling answer to what might be called the consent argument *against* informational privacy. On this view, individuals have no privacy rights because they have—by stepping into the public domain or by sharing information—agreed that others may own and control this information. But even if consent, however thin it might be, is given for the initial disclosure of disparate bits of information, it does not follow that consent has also been given for data shifting and aggregation of this information. The notion of consent implied in this argument against informational privacy may also be challenged. Appearing in public is a necessity for most of us.

property rights or liberty rights. Alas, the suit and what it shields is his to control. While odd and probably perverse, if Fred where to reveal nothing about himself to anyone at any time it would be perfectly appropriate.[15] Another way to put the point is that Fred's rights to control access to his body, capacities, and powers—what might be called physical privacy rights—coupled with property rights will afford him near complete control over the information that he creates through daily activity.

To summarize the bodily control and property rights argument in support of informational privacy we begin with four plausible propositions. First, individuals have use and possession claims concerning information about themselves. Second, individuals have access control rights over their body, capacities, and powers. Third, individuals may acquire physical and intellectual property that will aid in restricting access to personal information. Finally, individuals have a general moral and legal right to make contracts. Taken together, these rights, claims, and liberties provide the foundation for informational privacy.

If all of this is correct, then we have a fairly compelling case in support of the view that individuals have moral claims to control access to and uses of specific places, things, and certain kinds of information—i.e., we have established a presumption in favor of privacy.

Cases and Illustrations: Revisiting Orchomenos and Infectious Disease Transmission

Orchomenos and Sickle-Cell

Returning to the case introduced at the start of this article and assuming presumptions in favor of privacy have been established, we are now in a position to offer a better analysis and perhaps more compelling solutions. In the Orchomenos Greece case the primary tension is between individual privacy rights and public health concerns. While I have not argued for this claim, let us assume that the occurrence and frequency of sickle-cell anemia is a public health issue worthy of government action. Researchers in this case sought to promote public health by publishing the names of those who had the sickly-cell trait so that carriers could avoid becoming involved with each other.

Sickle-cell anemia is a blood disorder which causes various complications and a shortened life span. Those with the disease live on average between 42 and 48 years and many suffer with various levels of pain and fatigue on a daily basis (www.sicklecellsociety.org/index.htm). If both parents have the trait, there is a one in four (25%) chance that their child would be born with sickle-cell anemia. There is also a one in four (25%) chance that their child would be unaffected and not have the sickle-cell trait. There is a one in two (50%) chance that their child would be born with the sickle-cell trait. If only one parent has the sickle-cell trait and the other does not carry the sickle hemoglobin at all, then there is a one in two (50%) chance

[15] Assuming of course that Fred is not shielding immoral *and* criminal activity.

that their child would be born with the trait and a one in two (50%) chance that the child would be unaffected. If one parent has the sickle-cell disease and the other is a carrier of the trait, there is a one in two (50%) chance that their child will have sickle-cell anemia and a one in two (50%) chance that they will have the trait. If one parent has sickle-cell anemia and the other is free of the sickle hemoglobin, then their children will carry the trait. If both parents have the disease, then their children will have the disease.

In order to avoid the possibility of children being born with sickle-cell anemia researchers tried to ensure that trait carriers or those who have the disease were paired with non-carriers. The result of publishing this personal information was that those who had the disease or carried the trait were viewed as defective and forced to marry among themselves—ultimately worsening the problem.

In cases such as this, my inclination is to search for a policy that promotes both privacy and public health. For example, before having children all parents should get tested and be given the appropriate sorts of counseling. When sickle-cell risks are involved—when both carry the trait, one has the disease and the other the trait, or when both have the disease—the prospective parents should be made aware of this along with various options. While context may limit the possibilities, these prospective parents could adopt or obtain an egg or sperm donor. They could also choose to "roll the dice," not have kids, or to separate.[16] In any event and before any information is offered, each would commit to a legally binding non-disclosure agreement regarding medical information about the other. In this way, the values of privacy and public health can both be promoted.

STD Transmission

The tensions between protecting public health and respecting individual rights to privacy found in the Orchomenos Greece case are also found in sexually transmitted disease (STD) cases.

> More than 15 million sexually transmitted diseases (STDs) occur annually in the United States. Rates of curable STDs in the United States, the highest in the developed world, are higher than in some developing countries. STDs account for 87% of the diseases most frequently reported to public health authorities in the United States; of the 10 most frequently reported diseases, 5 are STDs. The direct and indirect costs of STDs are also substantial. In 1994 dollars, the total cost for common STDs and their sequelae is estimated to be $10 billion annually (St. Lawrence et al. 2002, pp. 1784–1788, citations omitted).

If a sexually active individual tests positive for an STD we may wonder if public health concerns should override the presumption in favor of informational privacy

[16] If both prospective parents have the sickle-cell disease—i.e., there is no "dice rolling," the child will have sickle-cell anemia—they should be strongly encouraged to adopt or obtain a donor. I hesitate in saying that they should be prohibited from having kids, because I would hesitate in claiming that a life with sickle-cell anemia would not be worth living and that a proper function of government is to prevent such lives.

established earlier. While acknowledging the vast literature on this subject, I argue that the best policy position would be to protect both privacy and public health—and in cases where one of these values must be sacrificed, minimal violation should be preferred.

STDs, both viral and bacterial, can profoundly affect those infected. Some STDs are easily cured (syphilis, gonorrhea, etc.) while others remain resistant to cures (HIV, AIDS, herpes, etc.). In many cases, individuals who have contracted an STD may remain asymptomatic. Some of these diseases affect fertility and morbidity.[17]

Over the years there have been numerous policies adopted in response to the spread of STDs (Cowan et al. 1996; Hogben 2007). Given that I am inclined to support privacy rights and individual ownership of personal information but do not think that these rights or presumptions are absolute, I would favor a modified Swedish model.[18] Patients who test positive for an STD are given a number (made anonymous) and are legally required to disclose the names of their sexual partners. The names of these sexual partners are also made anonymous and are contacted by the patient or a health care professional (perhaps a system of double entry could be used with the links between patient identities and fake names controlled by health care professionals). If contacted by a health care professional, the name of the source shall not be disclosed—although admittedly, if the contact has only one sexual partner the identity of the source will be apparent.[19] Once contacted those at risk should be tested—if these contacts fail to get tested they may be legally required to do so. If someone knowingly has an STD and continues to have unprotected sex with an unknowing partner, the infected party should be held criminally liable.[20]

There are several rationales for such a policy. First, this sort of policy attempts to balance privacy with public health—neither value is held as absolute and neither trumps the other in every case. Privacy is protected by anonymizing the names and perhaps the kind of STDs of patients. Public health is protected by limiting the spread of STDs. Those who champion strong privacy rights—and I put myself in this group—would never argue that privacy should be allowed to shield domestic abuse. Given that many STDs may be asymptomatic yet still cause damage and some are life threatening, one could view knowingly engaging in unprotected sex as a form of assault. In one way, it is like playing Russian roulette with someone who does not know they are playing. Morally and legally requiring disclosure may be painful and embarrassing—it may even cause the end of some relationships—but

[17] "STDs can result in irreparable lifetime damage, including blindness, bone deformities, mental retardation, and death for infants infected by their mothers during gestation or birth. In women, STDs can lead to pelvic inflammatory disease (PID), infertility, potentially fatal ectopic pregnancies, and cancer of the reproductive tract" National Prevention Information Network CDC, http://www.cdcnpin.org/scripts/std/std.asp (last visited 3/10/2009).

[18] The economic cost of such a policy is not my present concern.

[19] Anonymous e-cards have been used to contact those at risk with some success. See http://www.isis-inc.org/in-print/PLoS_Report_200810.php (last visited 3/10/2009).

[20] Surprisingly many couples continue to have unprotected sex even after one of them has contracted HIV. In a "European Study of heterosexual transmission of HIV infection around half of the 245 couples taking part continued to have unprotected sexual intercourse despite repeated counseling" (Cowan et al. 1996, p. 249).

these are minor compared to the costs that may be imposed on others. Moreover, individuals who complain have little ground to stand on—by engaging in unprotected sex and likely lying about it, these individuals have chosen to treat their partners with a profound level of contempt or lack of respect. By engaging in such behavior we may argue—along good Kantian lines—that the very privacy rights at issue have been waived.

A second rationale for the STD policy sketched above is that it will advantage those who are at risk. Pregnant women can be tested and minimize STD transmission during pregnancy. Those who are asymptomatic can be tested—and in some cases cured—perhaps avoiding irreparable damage that may occur. Those who are innocently infected can obtain treatment and move beyond the sorts of behavior or individuals that caused the infection.

Finally, it seems clear that the US policy regarding STD transmission and infection rates is not working compared to Canada or other European states. The reported rate of curable STDs in the US is more than 5 times the rate in other western democracies. For example, in the US there are almost 150 reported cases of gonorrhea per 100,000 persons each year compared to 3 for Sweden (Eng 1997, Chap. 2).[21] Moreover, many of these states have stronger privacy protections in place than the US.[22]

Influenza Transmission

As I write this section the United States has just declared a health emergency related to the transmission of swine flu. Numerous individuals have died in Mexico City and there have been reports of infection in Spain, Canada, the United States, and New Zealand. As with other highly infectious diseases such as drug resistant tuberculosis, we may wonder about the appropriate balance between individual privacy, liberty, and public health. As with sickle-cell case and STDs, I argue that policy should protect privacy and public health whenever possible. In cases where individuals have drug resistant tuberculosis or a new strain of deadly influenza it would seem perfectly appropriate to quarantine these individuals and at the same time restrict general access to personal information—who they are, where they work, etc. If we are going to restrict the liberty of these individuals, it would seem the least we could do is insist on respecting individual privacy rights.

As we move from mild outbreaks with low mortality rates to severe pandemics which threaten millions, privacy and liberty would appropriately give way. We may need to know who is infected and the source of the infection to determine if we are at risk—especially during early stages of transmission when outbreaks may be contained. I should note, however, that this sort of information sharing would likely be ineffective in pandemic scenarios where containment is not an issue. In a situation where hundreds of millions are infected and millions are dying information access channels would be overwhelmed. I also recognize that free speech concerns

[21] Admittedly there may be many causal factors that impact these numbers – e.g., perhaps there are better systems of sex education in Canada and Europe.

[22] For example see European Data Protection Law http://www.dataprotection.eu/ (last visited 3/10/2009).

arise at this point and have dealt with these issues elsewhere (Moore 2010, Chap. 7). To be brief, I argue that there is a host of publically relevant information surrounding these sorts of events that should be made available—e.g., how many individuals are infected, mortality rates, locations of outbreaks, and what policies are being implemented to protect public health. In a nightmare scenario where containment is impossible and mortality rates high publishing the names and addresses of those infected would hardly be worthwhile—moreover in these sorts of cases we may be beyond the circumstances of justice and morality (see Hume 1751, pp. 494–496; Hubin 1979).

Conclusion

If the arguments offered earlier are correct, then a presumption in favor of individual privacy has been established. Individuals have moral claims to control access to and uses of their own personal information. These claims are not absolute however. In cases where there is a compelling risk to public health we may justifiably insist on limiting privacy and liberty. In many instances—perhaps most—there are perfectly reasonable methods for protecting both privacy and public health.

I am well aware that no precise policy recommendations have been defended in the preceding analysis. In closing I would like to suggest the following. Assume that privacy is morally important along with public health such that in some cases privacy considerations will be dominant and in other cases public health will win. Also assume that there are many instances where neither is implicated or there is a method for securing both. In determining the correct balance between public health and informational privacy John Rawls's notion of placing individuals behind a veil of ignorance may be of some service (1971, pp. 136–142). Behind this veil of ignorance individuals do not know their age, race, gender, political affiliation, life goals, profession, subjective desires, and the like—they do not know if they are a public health official, an infected individual, or someone at risk of being infected. What individuals do know, however, is that privacy and public health are valuable and important for stable democratic institutions and human flourishing. From this vantage point we can ask two important questions. What information is necessary to protect public health and how can this information be obtained and disseminated while protecting individual privacy?

In some cases, we may determine that privacy should trump public health. For example, few would agree that we should adopt a policy of publishing the personal information of kids who have lice. In other cases, we may insist that public health should override liberty rights. Consider the case of someone infected with drug resistant tuberculosis and who continues to attend large public gatherings in spite of being warned. Viewing this case from an unbiased position along with the risks involved, arguably everyone would agree that this individual should be legally restrained from traveling where they will—they may be quarantined. Note, however, from behind the veil of ignorance we would likely refrain from adopting policies that sanction widespread access to this individual's name, address, and picture. In this way, public health and privacy may be respected. Cases of STD

partner notification may impact privacy—especially if the partner is monogamous—but privacy can be maintained as well. We don't need to disclose this information beyond a very short list of people—certainly there would be no compelling reason to broadcast this information to family members or to the general public. Finally, perhaps in a very few cases it may be necessary to override privacy in favor of public health. Consider the case of patient zero who is knowingly infecting others with a deadly disease. In this example, it would be perfectly appropriate to widely broadcast this individual's name, picture, and the like as is similarly done in "man-hunt" cases for violent criminals.

In closing, I would like to caution against sweeping aside privacy protections in times of national emergency. In such cases—as with the balance between liberty and security struck after 9/11—individuals get caught up in overly passionate responses and typically trade away too much of one value for an unknown amount of another. My view is that there may be situations where privacy should be sacrificed for public health—but these times are rare indeed—and in most cases, if we think imaginatively, we can secure both privacy and public health.

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