

**THE USE OF PERSONAL INFORMATION
IN BIOMEDICAL RESEARCH:
SOME PHILOSOPHICAL ISSUES**

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Biomedical science is not purely laboratory-based. Much of it involves extensive statistical analyses of data pertaining to human subjects. Vast quantities of data are collected and analyzed in order to establish hypotheses, to confirm or to reject them, and to test new drugs and new medical procedures. Data can be collected in the course of conducting research, or they can be retrieved from records and data bases. The data that can be interpreted are meaningful and once interpreted become information. Those data pertaining to human subjects can yield information about persons. As such they are personal data and the information they yield is personal information. With sufficient personal information, a person can be identified and various aspects of him or her can be known. Such knowledge can be used in ways that affect a person. Any conduct that affects others falls within the ambit of ethics. It follows that the use of personal information in biomedical research has ethical implications. Wherever there are ethical implications, there are ethical issues and concerns. In what follows three clusters of issues and concerns will be discussed: (1) Privacy and Confidentiality; (2) The Right to Privacy; (3) Right to Privacy Versus Obligations to Community.

1. Privacy and Confidentiality

1.1 Privacy

Privacy is essentially a situation in which a person finds himself or herself, vis-à-vis others in the world. This bare description does not show that it is something of value, or something to which we can claim a right, or something over which we should have control. Arguments have to be advanced to demonstrate that privacy does have these

latter characteristics. What kind of situation is privacy and why does it have these characteristics?

According to Ruth Gavison (Gavison 1995), a person's privacy is a situation constituted by the extent to which other persons have access to him or her. Privacy varies inversely with access. Access can be either informational or physical. To have informational access to someone is to possess information about that person, and to have physical access to someone is to have the means to gain physical proximity to that person. Informational access can facilitate physical access and conversely. At one extreme, access is nil and privacy is complete, and at the other access is unlimited and privacy is completely lacking. Both extremes are only theoretical, as no one is in a situation of complete privacy where he or she is totally cut off from the world, and no one is in a situation of zero privacy where he or she is fully transparent and physically accessible to the world. Real privacy is a matter of degree, well inside these two theoretical extremes.

Since privacy is understood in terms of access, it is possible for someone to lose privacy when the information to which others have access is vague, or inaccurate, or even false. Loss of privacy is not just a matter of how much is known about a person, which in turn depends on how much accurate or true information can be accessed. Vague, inaccurate or false information about someone does not make him or her better *known* but can still cause a loss of privacy if it draws others' attention to that person. Celebrities often lose their privacy because false rumors are circulated about them. Indeed, one of the main worries about privacy, as we shall see, is that inaccurate or false information is circulated, particularly when the affected person is unable to correct it.

We typically value our privacy. But why is privacy a thing of value? A number of arguments can be advanced to show that it is. Firstly, privacy is needed to protect and to advance certain personal interests. James Rachels (Rachels 1975) has identified many different interests that privacy helps to protect or advance, such as: (1) Interest in not being placed in a competitive disadvantage, which would be the case if one's competitors had access to one's strategies and plans, (2) Interest in not being placed in

embarrassing situations, which would be the case if others had access to embarrassing information about oneself, (3) Interest in protecting one's marriage, one's job, etc., which could be harmed if others (one's spouse, one's employer, etc.) had access to personal information, such as medical records, and (4) Interest in being assessed fairly in seeking insurance, credit, etc., which might be harmed if irrelevant personal information were available to insurers, credit providers, etc. It is important to note, something that Rachels does not do, that under this heading (and to some extent under (2) and (3)), false or inaccurate information may cause greater harms. Rachels goes on to say that these interests arise in unusual situations, in which personal information may be used against a person, and as such they do not highlight what is significant in privacy, namely its value in normal or ordinary situations, in which a person is not threatened with harm. In the latter situations, there is an interest in maintaining social relationships with others, which would be impossible if we cannot control who can have access to us. For instance, friendship depends, among other things, on being able to share certain personal information (and physical space) with a friend and to exclude others from it, information that need not be embarrassing or damaging.

Rachels is right in emphasizing the role of privacy in forming and maintaining social relationships. However, it would be wrong to downplay the significance of privacy in safeguarding those other interests that he mentions, particularly when it comes to biomedical information. Given the recent and anticipated advances in computer and information technology, the proliferation of sophisticated data bases, the vast quantities of biomedical data being collected, and the fact that personal biomedical information has the potential to be used to someone's disadvantage, the situations in which these interests may be adversely affected are much less "unusual," or much more "normal" or "ordinary" than Rachels believes.

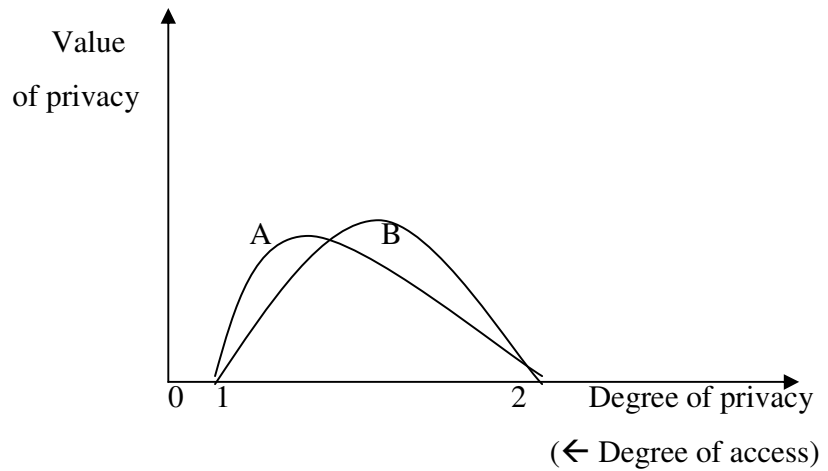
In addition to promoting the interests identified by Rachels, privacy plays an indispensable role in promoting many other personal values. Ruth Gavison (Gavison 1995) mentions creativity, personal growth, mental health, autonomy and liberty. For instance, in the case of autonomy, privacy is necessary if we are to make decisions without undue influences or pressures. Through the promotion of these values, further values will be enhanced. Important among them are collective values such as

democracy, which will be promoted with greater autonomy and liberty, and commerce, the success of which depends on there being trust, and trust depends partly on the confidence we have that access to personal information is not indiscriminate.

Finally, privacy in itself has a value, independently of other values and interests with which it is necessarily linked. It gives a person a “breathing space,” a sense of solitude, a kind of inner peace that comes with the knowledge that one is not under the prying eyes of others. Indeed, it might be said that the degree of privacy a person has chosen to have is partly what defines his or her own individuality. Each one of us is who he or she is by virtue of, among other things, the private space in which we are enclosed.

If we accept that privacy is to be understood in terms of others’ access to us, we have to accept that the value of privacy does not correlate with the degree of privacy over the entire range from zero privacy to complete privacy. Since “no man is an island,” others’ access to us, or our accessibility to others, to some extent, is important and valuable. Complete privacy, or being completely cut off from others, even if it is possible, is not a good thing, any more than complete loss of privacy. The relationship between privacy/access and the value of privacy can be understood in terms of the following diagram (Figure 1). The value of privacy is measured along the vertical axis, and the degree of privacy along the horizontal axis from left to right (and the degree of others’ access to us from right to left). Curves A and B begin at Point 1 rather than Point 0 because complete lack of privacy, or total access, (Point 0) is impossible. The curves begin to rise after Point 1, indicating that the value of privacy increases as one has more privacy (or is less accessible to others), reaches a peak and then starts to decline as one becomes less and less accessible to others. At Point 2, well before complete privacy, or total inaccessibility, the curves touch the horizontal line, indicating that the value of privacy has reached zero. Whether the curve skews to the left (Curve A) or to the right (Curve B) depends on personal circumstances: a person who deals a lot with others, such as a politician, or a movie star, or someone serving the community such as a priest, may need to trade off some privacy for more public accessibility, and his or her value curve will be more like Curve A rather than Curve B. On the other hand, an ordinary “private citizen” may have a value curve more like Curve B than Curve A.

Figure 1



1.2 Confidentiality

Given that privacy is a thing of value, there is a need to protect it, and given the inverse relationship between privacy and access as shown above, the way to protect privacy is to control access. More specifically, since privacy is of high value only within a certain range (which varies from person to person, see Figure 1), it would be good if we could control access in such a way as to maintain privacy within that range. In the case of physical access, we could do so by adapting our lifestyles to suit our individual circumstances, and also relying on laws that regulate physical access such as laws against trespassing, stalking, unauthorized surveillance and so on. In the case of informational access, control of access depends on the extent to which personal information can be gathered, and the extent to which gathered information can be kept confidential.

Literally, the confidentiality of information is the trust placed on the person to whom the information is given (the “authorized” person) that he or she does not pass it on to others (the “unauthorized” persons). This literal sense comes from the etymology of the word “confidentiality” (*con* – together, mutual and *fidere* – to trust). Confidentiality is expressed in the confidence, or the trust, we have in the authorized person that he or she does not allow others to have access to the information. In many cases, confidentiality can be maintained through a system of trust. The context in which the information is

generated or given is sometimes sufficient to indicate the confidentiality of the information, such as personal information revealed to a friend. In professional contexts, confidentiality is protected by ethical rules of professional conduct. However, it is often the case that those in possession of personal information are not clear what should be treated confidentially and how seriously confidentiality should be taken. The law may have to be resorted to for its protection, as failure to protect it will result in the loss of trust, or loss of confidence, which in turn damages the value of privacy.

Confidentiality is a matter of degree. Information can be highly confidential, or moderately confidential. The degree here is not the degree of trust, or confidence, which should be as high as possible. Rather it is the degree of access. Highly confidential information is highly inaccessible and moderately confidential information is moderately accessible. Since the degree of confidentiality varies with the degree of access, as does the degree of privacy, confidentiality is also a measure of privacy. Furthermore, since confidentiality can be objectively specified and monitored – there are standard ways of determining whether confidentiality is breached – it is through the control of confidentiality that we control privacy in its informational aspect (and indirectly, privacy in its physical aspect). Thus, the protection of privacy (in its informational aspect) can be accomplished through the protection of confidentiality, that is, restricting access to information only to authorized persons or authorities.

2. The Right to Privacy

2.1 Justifying the Right to Privacy

Just because something is of value, it does not follow that anyone has the right to it. We do take for granted that there is a right to privacy, but the basis for this right has to be established. There are a few ways of doing so.

On one line of reasoning, the right to privacy may be thought of as a property right. J.J. Thomson (Thomson 1975) claims that the right to privacy is a cluster of rights that intersect with the clusters of property rights (or right of ownership) and the rights over person (which are for her a kind of property right). If someone gains unauthorized access to my belongings, whatever they may be, and for whatever purpose, he or she

has violated my right to privacy, insofar as I have the right to my belongings, a right based on my ownership of them and one that entitles me to decide who shall have access to them. If someone obtains information pertaining to me as a person without authorization, he or she has violated my right to privacy by violating my right over my person, a right that gives me control over my person. In a great number of cases, Thomson's account explains well enough why we think they are cases of invasion of privacy. However, the account seems inadequate when it comes to personal information of the biomedical kind. For instance, it is not clear whether a patient can claim ownership over the medical records kept by his or her physician, nor is it clear whether the physician's medical notes have anything to do with the patient's right over his or her person; yet it is clear that the indiscriminate dissemination of medical records is a case of violation of the right to privacy.

On a somewhat more promising line of reasoning, we can think of the right to privacy as derivative of the rights a person has to protect certain interests, such as those mentioned by Rachels above. Since interests may be harmed by certain kinds of informational and physical access, those that constitute invasion of privacy, the right not to be harmed translates into the right to privacy. However, as Rachels has pointed out, the value of privacy goes beyond the value of the interests that privacy helps to protect. Privacy has value even when a person's interests are not under threat. The question is whether there is a right to privacy as a thing of value when no threat to a person's interests exists. Here, it may be suggested that there is a natural right to privacy. The idea of natural rights derives from the idea of natural laws. Religious thinkers, such as St. Thomas Aquinas, think of natural laws as the laws laid down by God to regulate human conduct. Non religious thinkers take them to be the laws that enable human beings to live well, given their natural tendencies. For instance, the prohibition against murder may be said to have its basis in a divine law against murder ("Thou shall not kill"), or a natural law based on the fact that human beings cannot live well unless they refrain from murdering each other. Given that there are natural laws (e.g. against murder), there are natural rights (e.g. the right not to be murdered). Insofar as privacy is required for a person to live well – it is necessary for a person to form relationships such as friendship, as noted before -- we can speak of a natural right to

privacy. This claim is strengthened by the fact that, again as pointed out earlier, a certain degree of privacy is required for a person to live as an individual person, to see himself or herself as a person.

Unfortunately, the idea of natural laws/rights is controversial, particularly when it makes the transition from a legal doctrine to an ethical doctrine. Many influential thinkers, such as Bentham, have rejected it. One objection is that we cannot ground the ethical, or what ought to be the case, on the natural, or what is the case. So grounded, natural rights cannot be overridden (particularly if they are based on divine laws). This seems to be a serious objection when it comes to the right to privacy. As we have seen, the value of privacy is a balance between privacy and access. For an individual, there is always some trade-off between privacy and accessibility, a certain degree of the latter a person must allow, for his or her own good as a member of the society. Furthermore, as we shall see, accessibility also has a value from the community's point of view. Making the right to privacy a natural right that cannot be overridden does not allow for the balancing of privacy and access from both the individual and the communal points of view. However, this objection can be deflected by giving the natural rights idea a communitarian twist. John Rawls (Rawls 1971) has argued that certain rights can be justified on the grounds that they would be the rights that we would insist on having, if we were in the "original position" of coming together to form a society and acting behind the "veil of ignorance," that is, not knowing about how well we would be doing in the society. He argues that under these conditions we would insist on the rights to "basic liberties," such as political liberty, freedom of thought and speech, freedom from arbitrary arrest and so on. These are the basic rights that we would not want to trade off for any other advantage. In addition to them, we would also insist on a host of other rights that would make life better, although we would be willing to trade them off for the benefit of all, particularly those who are worst-off. It follows that if there is a natural basis for the right to privacy, that is, if privacy is what we need in order to have a good life, then we can built it into a Rawlsian framework, and argue that there is a right to it on the basis that we would insist on it in the original position. However, since the freedom to live in privacy would not be part of the "basic liberties," the right to privacy can be traded off in ways that make life better for all, particularly the worst-off.

2.2 The Right to Privacy and Consent

As noted above, the protection of privacy can be accomplished by protecting the confidentiality of personal information. Given that there is a right to privacy, we can now speak of the right to confidentiality. Again as noted above, we can maintain confidentiality by restricting the collection and handling of personal information to those who are authorized to collect and handle such information. The right to confidentiality means that the person to whom the information pertains, or belongs, has the right to authorize access, that is, to give consent to the collection and use of such information. Given the relationship between privacy, access and confidentiality, and given the fact that the protection of any right is through duties, or obligations, ethical as well as legal, the protection of the right to privacy is through a set of obligations which ensure that information can only be collected and used with the consent of the person to whom the information pertains, or belongs. As a general rule, then, to collect, to obtain, or to use information about a person without his or her consent, is to violate that person's right to privacy, and again as a general rule, to violate someone's right is to fail to respect that person. However, there are circumstances in which consent is not necessary, as implied by Figure 1.

Figure 1 shows that a person may allow a certain degree of accessibility by others so as to enhance the value of his or her privacy. We need to allow others access if the society is to function to our advantage. For instance, service providers need to gain access to provide services. It would be too cumbersome to seek consent every time access is required. In the medical context, patients' medical record may be accessed in the course of their treatment. Thus, in many situations, we accept that consent is either not necessary, or can be taken as having been implicitly given. In the case of informational access, certain kinds of information may be collected or used in certain ways without explicit consent, and the collection or use of such information in such ways does not constitute a breach of confidentiality, or a violation of the right to privacy. The trader who keeps a list of names and contact details of clients does not violate their right to privacy even if they are not aware of it (which does not mean that such details cannot be used in ways that do constitute invasion of privacy). Indeed, in certain situations, such as when there is a need to ensure security in a place of work,

personal information may have to be publicly displayed. The Rawlsian justification of the right to privacy and confidentiality allows for, indeed requires, trade-offs to be made. Thus, the right to privacy is the right to that particular level of privacy that yields the most value. Likewise, not everything that is personal has to be confidential: the level of confidentiality has to be calibrated to yield the most value. To be sure, as noted earlier, legislation may be necessary in certain situations to clarify the legal obligations of confidentiality and the need to obtain consent.

One clear implication of the argument above is that consent is not necessary when personal information enters the public domain. Since the obligation to seek consent derives from the right to privacy, if privacy is not affected, the need to seek consent does not arise. Also, there are situations in which personal information, once consented to be used, becomes depersonalized and hence non-confidential. In these situations, information may be used, or re-used, for any good reason without seeking consent. For instance, biomedical data, which have been collected for a specific research project with the consent of the participants and have been anonymized, may be re-used for another research project without the need for another consent. It may be said that since the source of the information is still the research participants who gave the original consent, any further use of the information, even if depersonalized, amounts to exploitation. However, writing in the *British Medical Journal*, Mary Warnock (Warnock 1998: 1002) dismisses this concern, arguing that it is an “exaggeration” to refer to the use of “anonymous data, collected for a particular study, [for] a further, previously unthought of, study” as “exploitation.”

2.3 Balancing Rights

We have seen that in considering what is private, there is already a balancing between privacy and access, as Figure 1 shows. The need for balance also exists from the community’s point of view. Just as an individual finds that he or she will benefit most by allowing a balance of privacy and accessibility, the community will function best by balancing the need to respect members’ right to privacy with the need to gain access to them. Indeed, the latter can be elevated to the level of a right, the community’s right of access, if we argue along the Rawlsian line that it would be what we would, in the

“original” position, grant to the community. Such right of access should be thought of as an individual’s right to be exercised through the community, rather than something over and above individuals, insofar as it is necessary for the protection of the health, welfare and security of individual members of the community. For instance, personal information, including medical record, may be made available to the authorities without consent to control communicable diseases, or to protect by-standers from bodily harm.

It may be asked whether the logic of the Rawlsian argument extends beyond the protection of the health, welfare and security of all members of the community to the *enhancement* thereof. If it were extended in this way then, in the case of biomedical research, personal information could be obtained and used without consent in research that would yield health benefits to the community as a whole. Unfortunately, such extension of the Rawlsian argument cannot be justified. For one thing, balancing rights in this way sets the community on a dangerous slippery slope towards curtailing the right to privacy for minor benefits. For another, the Rawlsian argument, as typical of an argument for rights, is aimed that the protection of the individual against others and the state. As such, it does not apply to cases where the individual’s interest is not directly at stake, as compared with cases where the health, welfare and security of members of the community are at risk and need to be protected. It is not directly at stake in the enhancement cases, even though there is a chance that certain individuals will benefit from such enhancement.

The conclusion so far is that given the right to privacy, personal information may not be collected and used without consent, unless for the protection of the health, welfare and security of all members of the community. Against this conclusion, it may be said that when members of the community are reluctant to give consent, or more generally to participate in biomedical research, substantial benefits that such research can yield will be foregone. It may be said that it is unreasonable for the community to forgo substantial benefits, and so we need to balance the value of consent against the benefits of the research conducted without it. However, such view undermines the value of privacy noted above. More importantly, it assumes that we, as individuals, do not take into account community benefits when we balance privacy against access to determine the value of privacy as shown in Figure 1. It may be that members of the public will be

much more willing to give consent to personal information being collected and used in research, or to become research participants, if they are informed about the benefits of research. In any case, it is possible to convince ourselves that we should take community benefits into account when we decide how much privacy we should have, or whether we should participate in biomedical research. There are a number of ways of doing so, which will be explored in what follows.

3. Right to Privacy versus Obligations to Community

It has been argued that since we are now the beneficiaries of past research efforts, which would not have been successful without the participation of members of the public who volunteered to be research participants, we have the duty to reciprocate by volunteering to be research participants, or at least consenting to our personal information being collected and used in research. In order to discharge this duty, we will have to be less concerned about the right to privacy, or more willing to allow access to us. In terms of Figure 1, our privacy value curves will have to skew a little more to the left. However, Hans Jonas (Jonas 1991) has rejected this line of reasoning. Jonas argues that being beneficiaries of past research, if we owe past participants anything, it is a debt of gratitude, not an obligation to participate in current research. Past participation was voluntary and past participants may be praised for having been altruistic, but this does not impose an obligation on us. On the other hand, making participation into a duty of reciprocating could well put an unfair moral and social pressure on the current generation.

Jonas' dismissal of the duty to reciprocate is rather too quick. To begin with, to acknowledge that we do *owe* a debt of gratitude is already to acknowledge that we are under some kind of an obligation, that there is something we *ought* to do. (It is interesting to note that in Old English, "ought" is the past tense of "to owe.") It is true that what we ought to do to discharge a debt of gratitude is not necessarily to repay in kind (to become research participants ourselves). However, this is true, arguably, only when the relationship between the giver and the receiver is asymmetrical, such as between the rich and the poor, where the receiver (the poor) is in no position to repay in kind. When the relationship is symmetrical, we typically expect the debt to be repaid in

kind. Naturally, it is open to Jonas to insist that we owe nothing to past participants. In any case, there is nothing we can do now to benefit past participants in return, and we certainly do not owe any debt to future generations (for the scientific benefits we now enjoy). The case for reciprocity in biomedical research remains to be established.

According to Knoppers and Chadwick (Knoppers and Chadwick 2005), in the last decade of the twentieth century, new trends have emerged in the ethical debate surrounding human genetic research. These authors claim that there has been a “move away from autonomy as the ultimate arbiter” in bioethical debates towards the ideas of “reciprocity,” “mutuality,” “solidarity,” “citizenry” and “universality” (Knoppers and Chadwick 2005: 75 & *passim*). If they are right, a new context may well be emerging in which there is a greater acceptance of the idea that the right to privacy needs to be balanced against the duty of making ourselves more accessible for research purposes. However, trends cannot be accepted just because they are trends: they will have to be justified. Knoppers and Chadwick do not offer any justification for the ethical trends they observe. More importantly, any “move away from autonomy” is inherently dangerous. What we need to do is to reconfigure the idea of autonomy, taking it out of its traditional individualistic context and put it in a communitarian context.

In the Western philosophical tradition, the idea of autonomy goes hand in hand with the idea of a person as an individual independent of and apart from the society, who chooses to live in the society, accepting social restrictions and assuming social responsibilities so as to further the individual’s own interests. Hobbes’ justification of obedience to social rules and Rousseau’s notion of the social contract are based on such conception of a person. As we have seen, the idea of “rights” is typically understood as individual rights, posited to protect the individual from the undue intrusions into the individual’s life by the society and by other individuals in the society. Even Rawls’ communitarian theory of justice presupposes this conception of a person. Given this conception, reciprocity is at best a virtue, like gratitude, or humanity. It is difficult to elevate it to the level of a duty, or obligation. However, a different conception of a person has existed just as long as that found in thinkers such as Hobbes and Rousseau. It is the dominant conception in the East, particularly in Confucianism, though not entirely unknown in the West (Nuyen 2006).

According to Julia Ching (Ching 1998: 72), “the Chinese view of the human being tends to see the person in the context of a social network rather than as an individual.” For Roger Ames (Ames 1993: 151), Confucianism takes a person as “a social product, defined not as some essential locus of potential or rights claims but in the pattern and roles of social discourse” and thus “the Confucian notion of personal realization is irreducibly social.” In the Confucian tradition, a person is constituted of the social relationships in which he or she stands. Social relationships, in turn, are characterized by social positions, or roles. More importantly, social positions are defined in terms of obligations, or duties. To each position is attached a set of obligations, and to be in a position is to be under a set of obligations. Given this conception of a person, various duties are built into the being of each individual person. It is not difficult to argue that among such duties is the duty to reciprocate. Thus, it may be said that science is just one the networks of social relationships, binding scientists, researchers and all other members of the society, each having a role to play. If science is seen as a social, or collective, activity then the role of an ordinary member of the society is to assist in the advancement of science, either by volunteering to become a research subject, or to allow personal information to be used in research. Given this understanding of what it is to be a person, the notion of a duty to participate in research does not put undue social or moral pressure on a person as Jonas claims, because to be a person just is to be under such pressure. Neither does it represent a “move away from autonomy” because it takes an autonomous person to recognize the duties and obligations that constitute himself or herself as a person and to act accordingly.

To be sure, this way of understanding persons and society also puts pressure on scientists and researchers, who accordingly are not individual persons independent of society, pursuing their scientific goals with the help of other members of the society: rather, they occupy specific positions in the scientific node of the network of social relationships, pursuing common scientific goals *together with* other members of the society. As such, there are specific duties and obligations, which dictate the kinds of research that may be pursued, and the manner in which the research is conducted. In relation to the latter, we can specifically stipulate the duty to respect the right to privacy, which entails obligations to seek consent, to treat personal information with

confidentiality and so on. Just because a person is understood in terms of a network of social relationships, it does not follow that privacy is no longer, or less, relevant. If anything, it is even more relevant insofar as, as argued above, privacy is necessary in forming and maintaining social relationships.

By way of conclusion, it may be observed that, in identifying new trends in the bioethical debate, Knoppers and Chadwick come from the scientific side, attributing the new trends to the nature of contemporary biomedical science. Thus, they note that biomedical scientists can no longer confine their research to homogeneous or isolated populations, but have to study heterogeneous populations; that a great deal of research findings affect not specific individuals but genetically related groups; that there are common human vulnerabilities requiring the pooling of research data into data bases; that collective identity is often implicated in biomedical research and that ultimately the human genome is shared by all and all should have an interest in research on it. Knoppers and Chadwick seem to imply that the nature of modern biomedical science necessitates new ways of thinking in biomedical ethics. However, whether these new ways signal a “move away from autonomy” is debatable. What is true is that modern biomedical science can no longer be conducted in the a conceptual framework in which a person is understood as an individual independent of others, and a society is a collection of such individuals, the latter existing for the sole purpose of furthering the interests of individuals. Arguably, a conceptual framework in which persons and society define each other is much more congenial to modern biological science. This conceptual framework puts a premium on the value of privacy, allowing its role in forming and fostering social relationships to come to the fore, and thus secures the right to privacy and through it the respect for personal autonomy. At the same time, it highlights the fact that the value of privacy, for the individual as well as for the society, is a balance between distance and accessibility vis-à-vis others, that confidentiality is a balance between privacy and communal interests, and that respect for personal autonomy is respect for a person, scientist, researcher or otherwise, as an individual standing in a network of social relationships, which encompass all the sciences, especially the new biomedical science, given its nature.

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