Changing Ethical Frameworks: From Individual Rights to the Common Good?

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Introduction

Whereas in the 1970s early bioethicists believed that bioethics is an arena for the application of philosophical theories of utilitarianism, deontology, and natural law thinking, contemporary policy-oriented bioethicists seem rather to be keen on framing ethical issues through political ideologies. Bioethicists today are often labeled ''liberal'' or ''communitarian,'' referring to their different understandings of the relationship between the individual and society. Liberal individualism, with its conceptual base of autonomy, dignity, and privacy, enjoyed a long period of dominance in bioethics, but it has increasingly come under attack from ideologies promoting a more salient role for concepts of solidarity, community, and public interest.

In the context of research ethics, it has been argued that principles of individual autonomy, informed consent, and privacy can seriously hamper medical research that aims to further the common good.[1] Although technologies for the gathering and analysis of information have evolved rapidly, strict regulations protecting individual rights have obstructed the use of that information. For example, it has been pointed out that epidemiological research has been impeded by the impossibility of collecting statistical data without a subject's informed consent.[2] In relation to biobanks, it is widely believed that restrictions requiring new informed consent for the re-use of biological samples and data severely limit research for the common good or public interest.[3]

The rethinking of ethical frameworks is best reflected in the several restrictions to which the concept of informed consent has since been subjected: the concept has either been modified (e.g., open or broad consent in biobank research) or, in some areas of application (e.g., in e-health projects), abandoned altogether. We will see that although in genomic research an attempt is still made to balance individual rights and the common good, in the fields of public health, people are more reluctant to allow paternalistic interferences in individual autonomy. All of

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these examples and their heterogeneity point to the need for more contextualized ethics.

In this article I show that although many communitarian-minded critics do not reject individual rights, suggesting instead that rights should be balanced with considerations of the common good, it is not clear how this balance should be achieved. As can be seen through an analysis of the proposed ethical frameworks of genetic and healthcare record databases, the common good or public interest is often set in opposition to the participants' right to autonomy, and in the end it becomes an either-or issue. This polarization may have occurred because of overly narrow notions of autonomy and the common good, which make it difficult to see their close relationship. My suggestion is to seek inspiration from Aristotle's political philosophy, in which a clear, cogent, and persuasive effort is made to bind together the common good and autonomy. As Aristotle neither champions nor represents the liberal nor the communitarian, this fact alone should contribute to bridging liberal and communitarian bioethics.

Changing Ethical Frameworks

Traditional medical ethics of the Hippocratic tradition was developed in a virtue-based framework of professional ethics, stressing the physician's duties of beneficence and confidentiality. The relationship between doctor and patient was based on the patient's trust and acknowledgment of the physician's authority.

In the late 1960s and early 1970s, an era of liberation in many fields of life, this paternalistic approach fell under attack. Medical ethics was caught up in rights movements and took the position that patients needed to be empowered against paternalistic doctors and an intimidating technology that threatened to de-humanize patients.[4] The shift toward the autonomy model can also be explained as a reaction to the oppressive history of eugenics and coercion of human subjects in the name of so-called public interest (Nazi doctors' experiments on prisoners of war, the Tuskegee case in the United States, etc.). Thus bioethics promised to pay the highest respect to the autonomy, privacy, and equality of each person. The principle of informed consent was codified in various international documents that argued that respect toward individual interests and choices was paramount, and that social interests or the paternalistic impulses of the medical community would never be allowed to override individual interests in medicine.

Since the 1990s, it has increasingly been argued that bioethics has made a big mistake by making individual autonomy a basic ethical principle at the cost of other important principles. Several critics have advocated for new ethical frameworks focusing on more collective values, such as reciprocity, mutuality, solidarity, citizenry, and universality.[5] Daniel Callahan has summarized the main concerns of communitarian critics as follows:

> As a field bioethics has displayed two serious deficiencies: . . . it has failed to pursue with sufficient imagination the idea of the common good, or public interest, on the one hand, and that of personal responsibility, or the moral uses of individual choice, on the other. By its tendency to reduce the problem of the common good to justice, and the individual moral life to the gaining of autonomy, it has left a moral void.[6]

Communitarian ethicists also remind us that human beings are social animals, and that "our nature is distorted if we think of ourselves only as co-existing social

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atoms.''[7] Because genetics has demonstrated our profound connectedness to our siblings, parents, other humans and even animals, drawing a strict line between what is mine and what belongs to another indeed seems to be questionable.

I agree that bioethics has suffered from one-sidedness, absolutizing the freedom and choices of the individual, and relegating responsibility, solidarity, and equity to the background. Unfortunately the communitarians have not been able to convince their opponents that there really is such a thing as a public in the sense of an all-inclusive category, and that the members of this public may have common interests. Although communitarian critics may be differentiated by their use of the terminology, alternating between the common good and the public interest,[8] they have nevertheless not succeeded in demonstrating in what cases and circumstances it is justified to make the common good a transcendent value. Mainline bioethics continues to hold the line of privileging the interests and well-being of the individual over the interests of science and society, and of reinforcing this privilege in ethical regulations. Following the line of the WMA Helsinki Declaration and the Oviedo Convention, a recent international document, the UNESCO Declaration on Bioethics and Human Rights (2005) declares, ''The interests and the welfare of the individual should have priority over the sole interest of science or society.''[9]

The question, however, is how we understand the ''interest of society.'' The main target of the UNESCO declaration seems to be the protection of the individual against the power of the majority. Thus ''society'' seems to refer to a summation of individual choices or personal preferences. By implication the ''interest of society'' will very likely turn out to be tantamount to the interest of the majority and to conflict with the interests of the few. Alternatively, the public interest might refer to something different that is objectively more beneficial to us. One could imagine a definition that would make the public refer to all of the members of a given society, thus approaching the connotation of ''common.'' Our assessment of public interest might be revised in just such a direction, one that can most fruitfully be accomplished by bringing its definition into greater alignment with the use of the concept of the common good in antiquity.

Balancing Autonomy and the Common Good

In the ancient Greek polis, the goal of the state was to promote the well-being of society. The collective benefits—peace, order, prosperity, justice, and community—pertained to all members of the society, and their existence depended on their reciprocity. The assumption was that in normal situations the common good and the good of the individual would coincide. In case of conflict, the common good would be treated as the higher good. The ground of Aristotle's political philosophy is his belief that ''the state is by nature clearly prior to the family and to the individual, since the whole is of necessity prior to the part''[10] but neither stands independently of the other. The good of the republic is imbricated with the good of each citizen, and the citizens experience the goodness of their republic in their everyday lives. For Aristotle the common good refers to ''a good proper to, and attainable only by the community, yet individually shared by its members.''[11] It is important that for Aristotle the common good is at once communal and individual. It does not coincide with the sum of individual goods, but rather transcends the

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goals and purposes pursued by people in their interpersonal and social relationships.

Aristotle recognizes the conditions of the common good in both the virtuous character of the citizens and the institutional arrangements in the republic. Because the common good requires a shared life devoted to cooperative activities, it requires citizens to be just.[12] Unfortunately most human beings are not just; they are perpetually engaged in competition for such external goods as honor, money, or power. As there is always a scarcity of external goods, their bad disposition leads to intense competition and continuous conflicts. Consequently the main condition for arriving at the common good is the moral reorientation of the citizens, which implies education toward virtue. However, there are other obstacles standing in the way of attaining the common good, such as reconciling our differences in interests, capacities, and occupations.

Whereas in *Nicomachean Ethics* Aristotle teaches us that the common good cannot be achieved without cultivation of the citizens' virtue of justice, in *Politics* he shows that it is essential to ensure constitutional arrangements that tie the good of the individual citizens to the good of the republic. Likewise it is imperative to involve all citizens in political deliberation concerning that good, which is attainable by the community yet individually shared by its members. Deliberation about our collective ends requires practical reason (*phronēsis*), which is developed through self-governance in one's household affairs and through participation in political deliberation.[13] Aristotle reminds us that at the heart of politics lies "a quest to protect the integrity and political autonomy of each citizen in a political cosmos."[14]

I think that there are good reasons to believe that, as members of society, we do have several common interests, and that society is more than a conglomerate of separate individuals competing among themselves for limited resources. Society's role does not consist solely in enabling individuals to fulfill their individual conceptions of the good life. The problem is how to define the common good in a way that truly evokes and encompasses the interests we all have in common.

In what follows I show how scientific knowledge and public health have been identified as public goods that need to be set above individual interests. I will comparatively examine two cases: population-based human genetic database projects and e-health initiatives. On this basis I then try to elucidate whether modifications in informed consent procedures based on appeals to the common good or public interest necessarily lead to restrictions of patients' or research participants' right to autonomy. I am particularly interested in the justifications that have been proposed for reneging on informed consent—in the first instance, for replacing it with open consent and, in the second, for actually renouncing it. What interests me is whether the arguments offered in these contexts are strong enough to refute the basic tenet of the ethical regulations that maintain that public interest should never override individual interests.

Human Genetic Databases as Global Public Goods

In 2002 the Human Genome Organisation (HUGO) Ethics Committee[15] stated that human genomic databases are global public goods; that individuals, families, communities, commercial entities, institutions, and governments should foster the public good; and that humanity as a whole should be the beneficiary of

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these public resources.[16] What does this mean? Bartha Maria Knoppers explains the meaning of the concept of public goods by referring to two criteria: first, their benefits are "nonrivalrous in consumption (i.e., one person or group's use does not preclude another person or group's use of a public good)," and second, they are "nonexcludable (i.e., no one can be excluded from benefiting from a public good)."[17] The adjective "global" stresses that the beneficiary of global public goods must be humanity as a whole.

It is hoped that human genomic databases will serve to identify susceptibility genes for common diseases and improve the medical care and health of the populations involved. Related areas of research such as pharmacogenetics and nutrigenetics are considered to have an extremely promising future in furthering health and well-being. Based on these high hopes associated with the construction of population-based human genetic databases, several enthusiastic ethicists have claimed that genetic databases constitute an immense public resource, and that due to their population focus, they require "a vetting of current ethical principles and relinquishment of the focus on individual autonomy."[18]

Thus instead of emphasizing the individual's rights (to refuse to participate in research, to withdraw samples or data from the database), these communitarian ethicists believe that one should see it as one's "duty to facilitate research progress and to provide knowledge that could be crucial to the health of others."[19] This sense of duty is grounded in principles of solidarity and equity, which should promote participation in research for the common good and sharing of the benefits of this research with others.

It has also come to be believed—quite widely, in fact—that the case of population-based human genetic databases renders fully informed consent impossible, and that instead one should only speak of open or broad consent. Open consent[20] means that participants agree that their biological samples and data will be stored in the database and used for any future scientific research as approved by the relevant ethics committee. This committee then acts on behalf of the participants' best interests. Although there is ongoing debate as to whether the case of genetic databases makes broad consent qualify as genuine consent, the dominant view favors broad consent as the most efficient and economic approach.

The following arguments have been used to justify the use of open or broad consent rather than informed consent. The first is the utilitarian argument of maximizing happiness; given minimal risk to the participants, public interest (keeping the samples for unlimited time and using them for different research projects) outweighs the participants' right to autonomy and privacy. Second, it has been claimed that it is impossible to obtain fully informed consent, because at the time of collection one does not know what kind of research may be done on the samples in the future. This argument, unfortunately, is a circular one. Indeed, one might ask why we should permit gathering of such data at all, if it is to be used for unknown purposes—prior ethical justification should already have been provided in the first place. Although this is not stated directly, open consent is here also justified by an appeal to the public interest.

However, some critics oppose both of these options, insisting that there exists a third way between the current solicitation of informed consent from research subjects and obtaining open consent, which ultimately leaves the decision about permission for future use of data to the ethics committees. These critics believe that open consent should be allowed only when it is combined with opt-out

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consent for secondary research use,[21] or in cases in which participants' permission or authorization for data use is sought specifically and in advance.[22] Such critics also point out that open consent obtained from the participants at the time of becoming a gene donor does not automatically constitute consent for subsequent research; it merely constitutes consent for the inclusion of DNA samples and personal information in a population-genetic database. Consent for future research can only be obtained when information is made available about the aims, methods, sources of funding, institutional affiliation of the researchers, and other points mentioned in the Helsinki Declaration.[23] Those who argue for giving participants the positive right to authorize the use of their data, or the negative right to use the opt-out possibility if they do not agree with the concrete research proposal, stress the moral importance of consent in facilitating scientific citizenship and maintaining trust in science. This basic moral meaning of informed consent is to protect research subjects from deception and coercion.[24] Thus informed consent should be understood as a process of communication, which implies not only giving but also receiving of information and facilitation of mutual understanding. In keeping with this view, consent procedures should be designed to give patients and others control over the amount of information they receive and the right to opt out of research they do not agree with.[25]

Time will tell whether these reconsiderations of informed consent will lead to changes in protocols of informed consent. So far, population-genetic databases have operated on the basis of open consent, which restricts participants' autonomy and relies on their blind trust.

Electronic Health Records and Waived Informed Consent

A similar question—whether informed consent is deemed mandatory for the inclusion of data in population-based databases—has recently arisen in the context of e-health. E-health is an emerging field of medical informatics and refers to the organization and delivery of health services and information using the Internet and related technologies. My main focus is the electronic health record project, because here we can observe a clear move from open consent to no consent. I am interested in finding out what arguments are used to justify that the public interest in better (more efficient and cost-effective) healthcare has to override participants' individual interest with respect to autonomy and privacy.

A range of different terms is actually used to refer to e-health technologies (e-health, e-healthcare, electronic patient record, electronic health record). The electronic health record has been defined as "a digital, longitudinal record of a patient's health and health care that can be shared by different healthcare providers."[26] Electronic health records are being introduced in Australia, Canada, Denmark, England, Estonia, France, Scotland, the United States, and elsewhere with the hope that the introduction of Information Communication Technology (ICT) systems within healthcare will substantially reduce costs, improve efficiency, and reduce the number of patients who are inadvertently harmed by medical errors and violations.[27] Approaches to the structural setup, software applications, and ethical frameworks of electronic health records vary greatly. I have chosen to focus here on one example—the Estonian Electronic Health Record; a comparative account of models utilized in projects elsewhere is outside the scope of the current article.

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The Estonian Electronic Health Record[28] is a unique health information system that—together with three other e-health projects: Digital Images, Digital Registration, and Digital Prescription—will be linked with other public information systems and registers and will be implemented from 2008 to 2013 with funding from the EU Structural Funds. The Electronic Health Record (EHR) will include the most important personal data, medical records, records of visits to healthcare providers, and other health-related information of patients from all over the country.

When speaking about benefits of the EHR, one should distinguish between benefits to patients, doctors, hospitals, and the healthcare sector in general. Patients are promised benefits in terms of health, convenience, efficiency, and increased control over their data. First, doctors will have a better overview of the patient's medical history, which will potentially enhance treatment quality. Convenience is served by the fact that patients no longer have to run around carrying their medical papers from one doctor's office to another; instead, any doctor involved in a patient's treatment will have access to an overview of his or her medical history and test results. A corollary to convenience is efficiency: the electronic availability of all information will potentially reduce the number of repeat tests or analyses. Finally, patients will have increased control over their data through the patient's portal, where they can check who has accessed their medical records and when; in case of doubt, the patient can request that these be submitted to review. Thus we might venture the claim that to some extent, EHR even increases patient autonomy. Besides providing the patient with a comprehensive overview of the use of their personal medical information, the patient's portal offers further choices, such as declarations as to whether one wishes to be resuscitated in case of brain death, or to donate organs for transplantation.

If the system works as planned, doctors should have, in plain view and at their fingertips, a full overview of a patient's medical history, operations, and medicines prescribed and results of tests and analyses, as well as diagnoses made by various other doctors. This should improve diagnosis and treatment: accessibility of the big picture will raise efficiency, as well as speeding up information exchange between medical professionals. Dialogue and cooperation may in turn facilitate consideration of second opinions. Hospitals and clinics will also benefit from the EHR project. Digitalization of data will cut administrative bureaucracy, reduce paperwork, and improve the archiving system. The electronic system of booking appointments will alleviate the labor-intensiveness of registration procedures.

EHR also offers benefits to the healthcare sector in general, such as the improvement of quality control, better management and planning of future healthcare policies, and provision of data for national statistics and biomedical research. In fact, experts have claimed that when correlated with its various social uses (the use of health data for scientific and statistical purposes and for the auditing, planning, and management of healthcare services), the benefits of EHR outweigh the benefits to individual patients. The same argument has been used in favor of offering participants the chance to opt out of the later disclosure of medical information, and to refuse consent at the point of entry, when the patient's information is first recorded in the system.

Based on the preceding rationale, Estonian lawmakers decided that the Estonian EHR system should favor an opt-out rather than an opt-in approach.[29] The participants are not given a choice about the recording and storing of their data, but they are guaranteed a choice about sharing their data (in case of

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nondisclosure the data will be contained within a ''sealed envelope,'' which can be opened subsequently by the patient or by a physician, if the patient is in a life-critical situation). The initiators of the project obviously considered three different options—to obtain explicit informed consent, to presume the participants' consent and offer them the chance to opt out (soft paternalism), or to waive consent entirely, leaving no choice at all (strong paternalism).

Explicit informed consent, that is, the opt-in model, draws on the lessons learned from the history of medical ethics—that efforts to promote the common good must be constrained by liberty and informed consent, that those affected have the right to accept or reject the program, and that patients have a legitimate interest in privacy and preventing third parties from gaining access to sensitive data. The opt-out policy of data sharing (whereby an individual still has the right to prevent disclosure to treating physicians) limits individual autonomy but in effect implicitly guarantees that the data of the majority of the population will be available for administrative and statistical purposes, as well as contributing to a sound research base. To sum up, because the benefits of electronic health record databases have primarily been couched in terms of their various social uses (the exploitation of health data for scientific purposes and statistics and for the auditing, planning, and management of healthcare services), the public interest argument has dominated over considerations of personal uses (better health).

What arguments were proffered in the legal decisionmaking situation in favor of implementing an opt-out policy? Here we should distinguish between legal and ethical arguments. The legal argument stresses that the EHR does not create a new legal situation but only reinforces the one that already exists. We read from the commentary of the law:

> At the present time the processing of patients' personal information without the patient's explicit consent already takes place in the information systems of health care providers, and in the forwarding of data to third parties (such as other health care providers), as well as to various registries (such as the tuberculosis registry). Given that at the present point in time such autonomy of the patient does not exist, there is no question of depriving the patient of his or her autonomy.[30]

The three ethical arguments stated for not obtaining explicit informed consent and instead offering an opt-out policy are as follows. First, obtaining informed consent is too costly—in terms of both money and time; in effect this is a utilitarian argument. Second, the public interest argument claims that for better healthcare and security, it is necessary to have everybody's data in the database; only then will we have reliable data for statistics, management of the healthcare system, and biomedical research. Third, the paternalistic argument states that people may not be conscious of their real values or interests and may prioritize their privacy over their health. Given free choice, they might have withheld their consent from joining the database. This decision might, however, cause potential harm to these same people, either immediately or down the road. Because such behavior shows that not all people are rational, we should thus protect them from themselves. Clearly, among the justifications of opting out we can discern some that ultimately derive from paternalistic impulses.

When certain communitarian or collective values (efficient healthcare, solidarity, and security) are prioritized over the individual values of liberty, privacy,

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autonomy, and self-determination, there is a resultant turn from rights-based discourse to common good–based discourse. However, we cannot really say that the common good is being set in opposition to the right to autonomy and privacy. To be fair, we should recognize that an attempt is being made to balance individual and collective interests by promoting public health and preserving a certain degree of freedom of choice.

There is, however, another problematic aspect: if no informed consent is solicited, patients may not even be aware of their rights to declare their will. They may not be inclined or motivated to request corrections in their data, or to check who has accessed it or sequestered some of it in the "sealed envelope." It is essential that patients understand the consequences of preventing disclosure to their doctors. According to the Estonian law, in cases in which disclosure of some medical information is prevented, legal responsibility for treatment outcome shifts from the doctor to the patient.

It follows from the preceding discussion that autonomy remains an important concern even if we have prioritized public health over the individual interests of the patients. Practical implementation of autonomy is a demanding task; it requires educating people (on topics ranging from use of the ICTs to understanding of the complexities of the procedures), allowing time to ensure that they are appropriately informed, and building trust between doctors and patients. Even if one of the reasons for waiving informed consent was the need to save money, clearly the process of informing people about their rights cannot be waived, and this may still be costly and time consuming. Deliberative democracy is never cheap, but if we want to treat people as subjects and not objects of somebody else's will, we must create the conditions for the exercise of individual autonomy.

It has been interesting to see how electronic health record database initiatives (which are in many ways similar to genetic databases in that both are generated without individual informed consent) have not led to any particular ethical debate. One possible reason is that e-health fits naturally in a public health context; it is deemed logical, if not self-evident, that people's individual freedom should be limited in order to promote some kind of public good (public health measures must be compulsory if they are to be effective).

A Call for Contextualized Ethics

Onora O'Neill has recently argued that "informed consent procedures are inapplicable whenever the goods or benefits to be provided are public goods."[31] By making this claim, she means that up until very recently, medical ethics has taken clinical medicine and the treatment of individual patients as its point of departure, with an ultimate focus on the provision of individual medical services. Such a focus understandably entails primary consideration for individual interests, wishes, and choices. However, O'Neill continues, this approach cannot be extended as such to the provision of public health, in which the establishment of public goods means that the good must be offered to all, not merely to those who give their consent. Public health, which is concerned with promoting and protecting the health of populations, has thus emerged as a major challenge to medical ethics.[32] Angus Dawson has recently shown how bioethics may benefit from looking toward public health ethics as a new source of inspiration and direction.[33]

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These concerns and reservations all point to the need for a more contextualized ethics. Perhaps it is simply not possible to apply the same ethical principles to public health, clinical trials, treatment-oriented medical practice, and the acquisition, possession, and use of personal information, including genetic and medical information. Nowadays more and more attention is being directed to the differences among these contexts, not to speak of internal differences within them. The so-called rules of informed consent have been formulated in the context of invasive biomedical research involving humans and are not necessarily transferable to other contexts, such as public health or population-based genetic databases.

However, some critics are afraid of setting a dangerous precedent. They are afraid that if we relax the rules of ethics to facilitate research on human genetic databases, this may entail changes in other fields of research and in the end may leave research subjects without protection.[34]

Communitarian-minded critics clearly do not want to leave individual research subjects without protection against potential harm.[35] Ruth Chadwick and Kåre Berg are careful to stress in their programmatic article that they do not advocate a comprehensive shift toward community: "Individuals need to be protected and respected, and there needs to be adequate data protection to safeguard against misuse, discrimination and stigmatization. It is arguably neither morally nor practically feasible to expect individuals to show solidarity in the absence of such protections."[36] The main question thus remains where and how individual autonomy fits into the communitarian framework of bioethics. In my view the common good or public interest is often rejected because it is believed that affirming it will turn the clock back and return us to the paternalistic model of ethics, in which someone in authority will decide what is good for us. It therefore has to be shown that setting the public interest higher than individual interests can take place without the cost of violating individual autonomy.[37] Some people are skeptical about the common good, because they think that under the guise of the common good, power groups such as businesspeople, scientists, and politicians may promote their private or sectarian interests. Given the number of different interests engaged in initiatives such as population-based genetic databases or electronic health records, we should indeed be carefully analyzing whose "community" defines the common good or public interest. But this is exactly where autonomy comes in. It is essential that it is "we" who define what is in the public interest and not just a group of people who arrogate to themselves the authority to speak in the name of all.

If we understand "public interest" as synonymous with "common good" in Aristotle's sense, we will understand that what is expected from us is not simple devotion to the common good but a reasoned deliberation on the conditions and limits of the common good. Participatory self-rule is essential to a life of dignity; it is the "highest political good in itself."[38] It is through participation in a reasoned, deliberative politics that we settle our differences and develop agreement about collective ends.

Conclusions

In this article I have stated my agreement with the communitarian critics who say that we need a new ethical framework for handling the provision of public goods

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such as public health, scientific knowledge, or security. At the outset I asked whether, in cases in which the purpose is the provision of public good, public interest might override individual interests. I then showed that although communitarian critics have made an attempt to balance individual rights and the common good, it is still not very clear how this should happen. Shifting the focus toward community often leads to the abandonment or restriction of respect for individual autonomy and overemphasis on the common good. More significantly, despite the welter of discussions in which the common good is privileged over individual rights, the complex notion of common good has as yet been insufficiently elaborated. Formulating cogent and convincing as well as workable concepts of the common good indeed constitutes a real challenge for ethicists. I have suggested that the dichotomy of autonomy and the common good may be overcome through understanding their relationship in the spirit of Aristotle, whose articulation of the conditions of the common good speaks to both liberals and communitarians.

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29. The Estonian e-health project is regulated by the Act to Amend the Health Services Organisation Act and Other Related Acts (E-health Act) adopted by the Estonian Parliament on 12 December 2008; available at http://www.riigikogu.ee/?page=pub_ooc_file&op=emsplain&content_type=text/html&u=20080115122317&file_id=214114 (last accessed 31 May 2011).
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35. Conditions that are to be fulfilled before autonomy sacrifices can be justified are described in the following article: Hoedemaekers R, Gordijn B, Pijnenburg M. Solidarity and justice as guiding principles in genomic research. *Bioethics* 2007;21(6):342–50.
36. See note 19, Chadwick, Berg 2001:321.
37. Several critics have convincingly shown that the major mistake of liberal bioethics has been too narrow an understanding of merely individual liberty or self-determination. By making the idea of personal choice the highest value, liberal bioethicists have followed the Millian individualistic understanding of autonomy, which differs from the Kantian non-individualistic notion of autonomy. For Kant autonomy is founded on the rational nature of human beings, the humanity of persons. The principle of humanity requires that the rational capacity of persons be treated with respect, and never be used merely as a means for others. A return to the Kantian reading of moral autonomy as respect for the rational will of the person would allow us to understand that the principle of autonomy does not have to be restricted or abandoned in favor of the common good or public interest. See Rehbock T in this issue of the journal.
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