

Privacy, the Individual and Bioinformatics: A Buddhist Perspective¹

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Introduction

Bioinformatics is a new field of study in which the power of computer technology is harnessed to process biological information; thus the field is an interesting one where the two major technological trends of the early twenty-first century, namely biotechnology and information technology, are fused together. The application of computers and information technology in biological science has been necessary because biological information is exploding at an exponential rate, and there are many applications that the utilization of computer technology could lead to breakthroughs. One clear area of the application is of course the use of computers to sequence the human genome, which would not have been even conceivable if not for the use of a large amount of raw computing power to crunch through all the information that is available. Moreover, as of now

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sequencings of many more animals and plants are being completed at a very fast rate³.

Applications of these attempts at sequencing the genetic structure of organisms are rich and varied. Chief among them, of course, is the potential of using the information available in medicine. As many diseases can trace their origins to the genetic structure of the body, knowing what these structures are like is a very important first step toward successfully combating them. Once the gene for a particular disease is found, it is thought that the gene can be manipulated in such a way that the disease is prevented, at least within a population. Another area of development is pharmacogenetics, which is the use of the available information to create new drugs that would zoom in only on certain types of individuals who are susceptible to certain kinds of disease.

A central concern among these new developments around the use of biological information and its manipulation by computers is on the individual and her relations to society around her. Bioinformatics has raised several ethical questions, and the discipline is a very interesting case that points to a possibility of an eventual merger of bioethics and computer/information ethics⁴. Since genetic data is obtained from an individual, or a group of individuals, there is the question of who possesses the information in question⁵. Another issue concerns pharmacogenetics—the development and use of tailor-made drugs geared specifically on certain type of individuals according to their genetic predispositions, which has raised concerns about discrimination and others. Another, no less important issue, is centered around the information pertaining to an individual. Privacy is rightly a serious issue in both information ethics and in bioethics. In the former, there is a concern whether the privacy of an individual is compromised when, for example,

³ National Center for Genetic Engineering and Biotechnology (BIOTEC). 2001. *Bioinformatics and Computational Biology in Thailand: Outlook of Research and Infrastructure*. Available at http://knowledge.biotec.or.th/doc_upload/20041717159.doc and <http://www1.stkc.go.th/stportalDetail.php?id=1560>, [Accessed 24 July 2006].

⁴ See, for example, S. Hongladarom. "Ethics of Bioinformatics: A Convergence between Bioethics and Computer Ethics." *Asian Biotechnology and Development Review* 2006; 9.1: 37-44.

⁵ G. Palsson & P. Rabinow., "The Icelandic Genome Debate" *Trends in Biotechnol* 2001; 19.5: 166-171, p. 167.



the individual shares her personal information in a database, or when some information about herself or communicated by her is appropriated without her consent or knowledge. In bioethics, the concern is on the individual's biological data, and as computers have taken a more visible role in processing biological information, we are now seeing a convergence in information ethics and bioethics, as regards to the protection of the individual's biological information. It is a central concern of this paper to address this issue of privacy in the bioinformatic era.

Much work has been done on the topic of privacy in information ethics through cultural perspectives⁶. What I intend to do in this paper, however, is to present a group of questions that need to be addressed in order for one even to get off the ground in tackling the conceptual and normative questions surrounding privacy in bioinformatics. One of the most basic questions concern the status of the individual herself. Bioinformatics has indeed raised a very important metaphysical issue concerning the status of the individual. As it appears that the individual person is being reduced to a collection of bits of genetic information that could be stored and manipulated as any other type of data⁷, there is the question of what an individual person is constituted by. Is it the case that the individual is constituted by the set of genetic and other type of information that uniquely identifies him or her?

Considering that privacy is almost always taken to imply, more or less, protection of information *about* a person or an individual from prying eyes of the public or the authority, there is naturally

⁶ See, for example, Ess, C., 2005, "Lost in translation? Intercultural dialogues on privacy and information ethics", in Charles Ess (ed), *Ethics and Information Technology*, 7, 1, 1-6; Capurro, R., 2005, "Privacy. An Intercultural Perspective", *Ethics and Inf. Technol.*, 7, 1, 37-47; Hongladarom, S. Forthcoming, "Analysis and Justification of Privacy from a Buddhist perspective", forthcoming from *Information Technology Ethics: Cultural Perspectives*, Hongladarom, S., ed., Hershey, PA: Idea Group; Moor, J., 2002, "Toward a Theory of Privacy in the Information Age" in *Cyberethics: Social & Moral Issues in the Computer Age*, Baird, R. M., Ramsower, R. & Rosenbaum, S. E., eds. Amherst, NY: Prometheus Books: 200-212; Moore, A. D., "Privacy: Its Meaning and Value", *Am Philos Q*, 2003, 40(3): 215-227; and Kitiyadisai, K., "Privacy Rights and Protection: Foreign Values in Modern Thai Context", *Ethics Inf Technol*, 2005, 7: 17-26.

⁷ See, for example, Dougherty, S., "On Genetic Programs and Feedback Networks", *Configurations*, 2004, 12: 263-285; Thacker, E., "Bioinformatics and Bio-Logics", Postmodern Culture, 2003, 13.2. Available at <http://muse.jhu.edu/journals/pmc/toc/pmc13.2.html> [Accessed 21 July 2006]; Wilson, J. C., "(Re)writing the Genetic Body-Text: Disability, Textuality and the Human Genome Project", *Cultural Critique*, 2002, 50: 23-39.

a question concerning what kind of information and how much should information should be allowed. This is related to the metaphysical question concerning the status of the individual, which needs to be adequately addressed, and which is a subject matter of the rest of this paper. Moreover, I will address this topic through a perspective of Buddhism, which has a very interesting and potentially useful theory concerning the individual and her ontological status. Basically, I shall point out that, according to the Buddhist theory of Non-Self⁸, the individual is more accurately understood to be a construct, and not something existing in and of itself. And there is an important sense in which the individual is constructed out of the whose set of information that uniquely identifies her. Hence there is an intricate interconnection among the individual, information and privacy, and I shall address this issue through a perspective on the Thailand SNP Project, which is an attempt by the country to join the bioinformatics bandwagon.

Privacy and The Core Set of Genetic Information

How much genetic information should be allowed in the bioinformatic database in order that privacy of the individual is respected? In other words, in the attempt to gain the advantages that come with retrieving and storing genetic information of individuals in a computer generated database while maintaining the principle of privacy rights, how much information pertaining to a specific individual, or to a group of individuals in a community, should be allowed? On the one hand, there seems to be a motivation behind an idea that *all* and *any* such information should be allowed, in order to make full use of the advantages, such as the potentials in biomedicine or biotechnology that would presumably benefit humankind as a whole. There might be an argument to the effect that *how much* information should not be the issue; what is the issue should instead be whether there are any mechanisms in place which allow only authorized people to have an access to the information⁹. There does not seem to be anything related to how much information should be allowed.

⁸ Buddhist scholars will recognize that this is the *anatman* theory, and usually in literature on Buddhist studies such references to Sanskrit terms will often be made. However, I opted not to mention any Sanskrit terms in this paper, since this is not strictly speaking a Buddhist studies paper.

⁹ J. Moor, *op. cit.* note 3.



However, there is a concern that such full allowance might lead to unscrupulous use of information, and the authority might find it tempting to use the information to their advantages, such as in genetic profiling and other discriminatory practices, or to seek political gains. If there were a core set of information that constitutes the heart of the individual, then such information should be handled with much care and sensitivity, for it is conceivable that this core information is nothing other than the very identity of the individual herself. Moreover, in case of groups of individuals, the issue is also a parallel one, for a particular group might have its own identity, some set of information that defines the group as a unique one. For such a group, then, the core information is that which is shared by its members and whose possession entitles an individual to belong to the group. In certain socio-cultural cases, the core information that defines a group could well be much more important and politically sensitive than that of an individual alone. And it is here that bioinformatics, as an attempt to deal with genetic information of groups of individuals, comes to the fore as a potentially politically explosive enterprise.

The point is that, if such core set of information does exist, then care needs to be taken when information is obtained from individuals or groups of individuals in order that their privacy is maintained. It seems, moreover, that there is at least a case for the existence of such core information. Perhaps a core set of information for a group might be easier to define than that of an individual. One has to bear in mind that a core set of information is the set of information that defines an individual or a group of individuals to be that particular individual or that particular group alone and none other.

Thailand SNP Research Project

Starting in 2003, a team of researchers from the Ramathibodi Hospital, Mahidol University, initiated the “Thailand SNP Discovery Project” (<http://thaisnp.biotec.or.th: 8080/ thaisnp>). The aim was to search for single nucleotide polymorphisms (SNP) in 64 selected general members of the Thai population (the number was then reduced to 32), in order to form a database on which other spin-off projects can be based, such as ones on pharmacogenetics,

anthropological studies, genetic susceptibility to certain diseases, and so on. According to the words of the Term of Reference of the Project:

An SNP database will be completed of all genes identified in the whole human genome and their regulatory regions with allele frequency and LD block patterns in Thai and other (French, Japanese and African) populations. This database will also contain other information including genomic sequences, genomic structure, primer sequences, functional genomics etc¹⁰.

The database of the Thai population would be part of an international effort in creating like databases among the world's population, which could spawn many further research works, both for clinical applications and for basic science, as well as further international collaborations.

In order to collect the blood samples for analysis, 32 'normal and healthy' Thai people were selected from around 6,000 volunteers. The selected underwent interviews of family history, health records, had some of their blood taken out, and the DNA from the blood samples were analyzed in a bioinformatics lab which was set up for the first time in Thailand as a part of this Project. It was hoped that some correlation might be found between the genetic structure available in the database and susceptibility to certain diseases, such as Thalassemia, which Thai people suffer more than the global population on average. There was also an interest in finding out "who the Thais really were" through physical anthropological research. Some of the samples were sent to France, which acted as the hub for the global SNP Project.

Essentially, the role of a SNP is to function as a marker for genetic disposition of a certain individual or groups thereof. A spin-off project of the Thailand SNP Project, as mentioned, is to find out whether there is a correlation between susceptibility to malaria and Thai people's genetic structure. According to the team:

¹⁰ National Center for Genetic Engineering and Biotechnology (BIOTEC), *Bioinformatics and Computational Biology in Thailand: Outlook of Research and Infrastructure*, op. cit. note 1.



[The] project aims to search for genes involved in genetic susceptibility to clinical malaria through genome screening linkage analysis. The study is based on a population from Suanpung village, Ratchaburi province, located near the Thai-Myanmar border. Its size is around 6,000, with 2,800 individuals having been followed up by the Faculty of Tropical Medicine, Mahidol University since 1994 for parameters related to clinical malaria and other confounding factors. Family structures were established. The familial cases in the population studied have allowed us to perform a genome screening linkage analysis (<http://thaisnp.biotec.or.th:8080/thaisnp/project>).

It is clear that there are ethical considerations in these endeavors. Firstly, the genetic profiling of the individuals in question need to be protected. In fact the research team has made sure that participants in their projects understood and signed their consent forms. However, there is another dimension regarding the amount of information that could be taken and stored that does not violate the principle of privacy. In this case, it is the aim of the project that provides a limit of the nature and the extent of information belonging to an individual that is obtained and processed. In the case of the malaria project, only the information pertaining to the individual's susceptibility to the diseases is relevant, and it would seem unethical to use the information in some other ways. However, since the individuals who participated in the project donated their tissue sample which naturally contains all the information about herself or himself, there is no natural barrier against the use of such information in some other ways. This perhaps explained why there are so many spin-off projects from the original SNP Discovery Project and this demonstrates the tremendous power of genetic information and computational biology. Ethical guidelines need to be in place in this matter, and they should be unambiguously enforced.

Now the question is: to what extent does the privacy of the individual is threatened when she participates such a project like this one and donated her tissue sample? Is only the information that specifically related to genetic susceptibility to malaria relevant?

Of course not, because there are many other diseases, and the genetic informational structure of the individual could point to other developments, such as a potential in developing tailor-made drugs, and so on. In most cases there is a delinking of the individual's social identity (her name, for example) and the genetic information belonging uniquely to her. But even though the information in question still is information *about* her, it uniquely identifies who she is. The information that uniquely identifies who she is as well as her identity is there. And in case of a group, the argument is similar. There should be a delinking of the identity of a group and the genetic information that identifies that particular group. For example, it is generally agreed nowadays that racial discrimination is ethically objectionable. However, genetic database might facilitate such discrimination through a system that links an ethnic group with certain genetic structure that belongs to individuals in the group. This linking is certainly not absolutely certain; it is always performed through statistical calculations—for example, this trait could identify this ethnic group if members of the group show a higher concentration of the genetic trait than an average population.

In what follows I shall argue that any information that uniquely identifies an individual or a group of individuals is the 'core' information of that individual or that group, and as such the information needs to be protected if the individual's privacy rights, or the rights of the group, are to be respected. I will also present a brief Buddhist perspective and also a metaphysical analysis of the matter too.

The Core Information and the Metaphysics of the Individual

A formal definition of the core information of a person, *p*, might be given as follows:

A set of information, *S*, represents the *core* set of information regarding a person, *p*, just in case *S* uniquely identifies *p*.

Correspondingly, here is the definition for a group.



A set of information, S^* , represents the *core* set of information regarding a group of persons, G , just in case S^* uniquely identifies G .

Philosophers will immediately recognize this to be very similar to describing an essential property of an object or a group of objects. An essential property is just the property that uniquely identifies the identity of the object having it. The idea is as old as Aristotle. In the contemporary context of bioinformatics, the idea about essential properties could become that of the genetic information possessed by an individual. The very idea of being able to link genetic information to the identity of an individual at all is based on the notion that genetic property is an essential property. It uniquely identifies an individual and more than that it seems to indicate who he or she really is. According to Eugene Thacker, “[b]ioinformatics is both a suggestive trope and a material practice which provides an example of the ways in which the scientific body is currently being reconfigured and reorganized, largely through an intersection of developments in biotechnology and the Web.”¹¹ What is reconfiguring and reorganizing the scientific bodies of human beings are precisely the tools enabled by bioinformatics, which utilize computer technology to manipulate bodily data. In this case, there is an intriguing interconnection between the individual and her set of information, so much as, as I shall argue later, that the very putative self of the individual can be found in the information itself.

This is what is potentially very sensitive and controversial about genetic information. The idea behind the Thailand SNP Project, for example, very clearly shows this belief in genetic properties as essential properties. The SNP Project people would like to find a genetic trait of the Thai population that serves to identify the population as Thai and not, say, Burmese or Vietnamese or Japanese. Genetic information determines the very ethnic identity of a population.

¹¹ E. Thacker, *op. cit.* note 4.

Buddhism and the Individual

The distinction between essential and non-essential properties, or in the parlance of this paper, the core and the non-core set of information, has become suspect in recent days. Many philosophers, for example, have become disenchanted with the idea of essentialism and proposed arguments such that such a distinction is not based on objective facts at all, but instead on our own convenience in distinguishing things for our own purposes. Hence the distinction between what is essential and what is not depends more on whether we regard something as very important and indispensable (to our own context-bound agenda), or not. In this case, genetic structure that determines the identity of an individual thus is regarded more like something that serves the purpose of sorting individuals out based on genetic criteria, and not as a property that exists in perpetuity. The sorting is performed in a pragmatic and piecemeal fashion rather than in any sort of way that reflects objective reality.

This view is well in accord with that of Buddhism. A basic idea of Buddhism is that things in objective reality are ‘empty of their inherent existence.’ What is means is that there is no essence to anything. What a thing is, what separates it from other things, is just a result of human being’s convenient designation through concepts and language. According to the Buddhists, there is just no real distinction between essential and non-essential properties and thus between the core and the non-core set of information that we have talked about. This, as I shall show, has a profound implication on what we should take privacy to mean and on any system of justification of privacy.

There being no essential property beyond convenient designation points to an interesting conclusion that justification of privacy is based, not on the traditional mode of metaphysics of the individual, in which an individual is an atomic autonomous unit to be accorded with a group of rights, including the right to privacy, but on a ‘convenient designation’ based on the realization that a society that respects privacy of the individuals is somehow a ‘better’ place to



live than the one that is not¹². In this case the distinction between the core and the non-core sets of information remains. It is only how the distinction is understood and justified that is changed. And my view is that, understanding the core/non-core distinction in this way might serve better to formulate concrete policies or guidelines regarding privacy and data protection than with the traditional conception. And here the Buddhist contribution is a clear one.

According to Buddhism, what is understood to be the self is a result of causes and effects and the conception of self arises out of a kind of grasping onto these disparate and juxtaposed episodes of causes and effects, resulting in an illusion that the self actually exists while in fact it does not. This point, known as the Doctrine of Non-Self, is unique to Buddhism among all the religions in the world. A passage from the *Guide to the Bodhisattva's Way of Life*, one of the most celebrated texts in the Buddhist world, has it as follows:

First, with your own intellect, peel off this sheath of skin, and with the knife of wisdom loosen the flesh from the skeleton.

Breaking the bones, look inside at the marrow and examine for yourself, "Where is the essence here?"¹³

The idea here is that the essence of a person, or his or her individual self, is nowhere to be found. According to the passage, it is clear that the self, if it existed, is not something that can be directly perceived. In this case the self is clearly not identical with the body, but it is not identical with the mind either, for it is very difficult to pinpoint what exactly in the mind, which consists in series of mental episodes one occurring after another, that corresponds exactly with the self. Furthermore, in the *Fundamental Wisdom of the Middle Way*, another well known text, there is a passage describing how what is understood to be the self is analyzed:

¹² Hongladarom, S., 2005, "Electronic Surveillance in the Workplace: A Buddhist Perspective", in *Electronic Monitoring in the Workplace: Controversies and Solutions*, Weckert, J., ed., Hershey, PA: Idea Group: 208 - 225.

¹³ Santideva, 1997, *A Guide to the Bodhisattva Way of Life*, Translated by Vesna A. Wallace and B. Alan Wallace, V: 62-63.

If the self were the aggregates,
It would have arising and ceasing (as properties).
If it were different from the aggregates,
It would not have the characteristics of the aggregates¹⁴.

Briefly, what this verse means is that, if the self were the same as the aggregates that all together constitute what is normally taken to be the self (one might understand the aggregates roughly to be the body and the mental episodes that make up a conception of a self), then the self would be subject to arising and ceasing.

However, this cannot be the case because one's own self does not just come to be and ceases to be very rapidly, unlike what is in fact taking place in our bodies. When one understands the body to be one's own self, when one is pointing toward it, for example, what is being pointed to is then analyzed, and then a series of questions is asked. Is what is pointed to, which is understood to be the self, identical with the body? The answer is no because the body changes and replenishes itself in a relatively short period of time, whereas the self is taken to be constant. Then there is the question whether the self is identical with the mind, and the answer is again no because our mental episodes change even more rapidly than our own bodies. We think one thing a moment and then another thing in another moment, and it is characteristic of the mind in that it takes upon the characteristics of the things it thinks about. However, if one were to think that the self were different from the aggregates, one would also be laid in another dilemma because what is normally taken to be the self, what it actually is, is always in terms of body and mind, in other words in terms of the aggregates. Hence to understand the self to be separate from the aggregates is unacceptable either. Nagarjuna's conclusion is that the self does not actually exist, it only appears to exist due to our own grasping on to things. In any case, the Buddhist's conclusion is that what is understood to be the self is only a result of an illusion, not unlike the illusion one has when one sees a reflection on hot sand to be a pool of water.

¹⁴ Nagarjuna, 1995, *The Fundamental Wisdom of the Middle Way: Nagarjuna's Mulamadhyamakakrika*, Garfield, Jay., trans., New York: Oxford University Press: XVIII: 1.



Buddhism and Bioinformatics

Now, what relevance does this teaching have on the attempt to analyze and justifies privacy and data protection in bioinformatics? The idea of privacy is based on the notion that there is a self and that the self is constituted through a system of information about it which needs to be protected from prying eyes. However, if Buddhism teaches that the self does not inherently exists, then there seems to be a problem of how Buddhism could have a theory of privacy. Nonetheless, the idea that the self does not inherently exist does not imply that it does not exist at all. We can certainly refer to our own selves, only that in deeper analysis we find that such a self is merely a result of causes and effects and does not exist on its own. Nonetheless, that does not preclude there being such a self as a referent to normal use of language and normal understanding.

If this is the case, then for Buddhism there needs to be a system where the concept of privacy is analyzed and justified¹⁵. The idea is that there is a theory of privacy in Buddhism which is a pragmatic one. Privacy is justified through its role in furthering and fulfilling certain sets of goals that human communities find important. One of these goals, for example is that individuals in a society should be protected as regards to the set of information which they find dear to themselves and which they do not want to divulge to the public. This is a matter of respect for individuals. The same also applies to groups sharing more or less the same genetic traits; they need to be respected too. The question then is how such respect is justified, and in Buddhism this is justified through the fact that the respect in question plays a large role in enabling certain kinds of things that communities find enriching and satisfactory. Guaranteeing the privacy rights of the individual is part and parcel of a kind of society that respects individual integrity, where the authority is not given absolute power to do anything they please. And since these are now considered to be desired goals, and since it is a fact of the matter that privacy is necessary for furthering these goals, privacy is then justified according to Buddhism.

¹⁵ S. Hongladarom, *op. cit.* note 3.

In other words, Buddhism teaches that the individual self is a construct, which does not mean that the self does not exist at all. Since it is a construct it is so constructed out of certain type of material, and here the role of information in constituting an individual is very important. Individuals are constructed out of information, and if this is the case, then the attempts in bioinformatics to manipulate genetic information of an individual or groups of them would risk endangering their very selves and identities. Even though the individual self does not, strictly speaking, exist, there does clearly exist the information pertaining to an individual, and since some kind of information could be regarded as the core for a particular individual, this information needs to be protected. Hence the need for privacy in bioinformatics according to Buddhism. The problem then is, for Buddhist societies at least, how to protect the privacy of personal information while not necessarily compromising the need for scientific progress and development.

Information as Part of the (Conventional) Self

This need to find a balance between scientific progress and ethical, regulative requirements is as old as bioethics itself. Opponents to bioethics have pointed out that bioethics has raised false alarms, that they tend to cry out too loud when there is not so much danger, and so on. In the case of privacy, there is an obvious need to formulate clear guidelines and regulations on this issue, and it has been my purpose here to point that Buddhism has a role to play too. As the 'core' set of information is not, objectively speaking, out there (because since the individual is herself a construct, any differentiation of individual-constitutive information as 'core' or 'non-core' is a construct too), it exists nonetheless in the practical fashion out of the need to protect privacy. There seems to be a need to distinguish between what kind of information should or should not be allowed. And since it is ultimately the goals shared by members of a society that provide the final say, any such attempt should refer to these goals. More specifically, the Buddhist viewpoint is such that the individuals in question, whose genetic information is to be obtained and stored in a computerized database, should have a clear role to play in any kind of decision making on how such information is to be manipulated.



This point underscores the need for more democratization in decision making in bioinformatics. This is more than allowing the research participants the ability to ‘recall’ their own genetic information from the database as stipulated in some informed consent forms. Often this is not possible unless the scientists maintain a linking system that could link up bits of genetic information to their owner. In many cases decisions in scientific enterprises such as a research project involving bioinformatics are made by the investigators without even bothering to consult the individuals whose tissue samples were taken for information. It is indeed true that there is a requirement for these individuals to read and sign informed consent forms, whose idea is based on the notion of fully functioning, autonomous individual. This idea, however, is being criticized by many, especially those coming from cultures which do not have such a tradition¹⁶. According to the Buddhist perspective, although the individual self cannot be objectively found to be essentially there, this does not preclude the fact that such a self does indeed exist. There is an important distinction in Buddhist teaching between the ‘ultimate truth’ and ‘conventional truth’; the former is the kind of truth at the level of immediate perception of reality without the distorting medium of conceptualization; the latter, on the other hand, is the kind of truth which is familiar and based on linguistic categories. For Nagarjuna, the two truths point to one and the same basic reality, and it is a mistake to take one to be more prior or more basic than the other¹⁷. What this implies in our case here is that there is indeed a self, conventionally speaking, and as a consequence such a self needs to be treated with respect. This is in accordance with another part of teaching of Buddhism, one that it shares with other religious traditions, on the dignity of the individual or the person. Since the information being manipulated in the bioinformatic database is part and parcel, indeed part of the very self of the individual whose

¹⁶ See, for example, Klitzman, R., “Complications of Culture in Obtaining Informed Consent”, *Am J Bioeth*, 2006, 6.1: 2-21; Macpherson, C. C., “*Research Ethics Committees: A Regional Approach*”, *Theor Med Bioeth*, 1999, 20: 161-179; London, L., “*Ethical Oversight of Public Health Research: Can Rules and IRBs Make a Difference in Developing Countries*”, *Am J Public Health*, 2002, 92.7: 1079-1084; Turner, Leigh., “*From the Local to the Global: Bioethics and the Concept of Culture*”, *J Med Philos*, 2005, 30.3: 305-320; and Walter, P., “The Doctrine of Informed Consent, A Tale of Two Cultures and Two Legal Traditions”, *Issues Law Med*, 1999, 14.4: 357-375.

¹⁷ Nagarjuna, op. cit. note 10, XXIV: 8.

tissue samples have been taken in the first place, it can be regarded that the information in the database consists of none other than the parts of the selves of these individuals. But if this is so, then the principle of respecting the individual self implies that this information needs to be respected, since it is the selves of the individuals, then they should have some roles to play in saying how these parts of themselves are to be processed and manipulated.

Putting the point differently, this implies that decision making regarding how genetic information is to be used should be more democratized. There should be a mechanism, beyond the traditional informed consent form, by which individuals who in some substantial way do exist as genetic information stored in the database are respected. What this means for privacy is also clear. If the selves of the individuals do exist in the database as information, then their privacy needs to be respected too. And as there is no hard and fast distinction between the ‘core’ and the ‘non-core’ set of information (because such a distinction would entail that the individual is an inherently existing substance), the distinction is then based on practical terms and the principle of democratization described above implies that it should be the individuals themselves who by and large decide on what is the core or the non-core set of their own information.

Conclusion

To conclude, the Buddhist teaching on the identitylessness of the individual points to the fact that, although the individual does not possess her own individual essence or substance, she is still entitled to privacy rights regarding her genetic information in the bioinformatic database because part of her being is constituted by the very information that is stored there. Moreover, the Buddhist viewpoint is such that this conclusion is strengthened; the reason is that even though there is no objective, substantial essence to the individual, her empirical, conventional self is still there and there being no objective, substantial self means that she can be constituted by a set of information. When there is no essence to be found, she can lay claim to the information in the database more forcefully because it is ultimately speaking the convention that determines the extent of her identity, and since values and norms are judged



in Buddhism more in reference to pragmatic goals rather than to objective, transcendent rules, there is a clear way to show that the information is part of her own being. A consequence is, of course, that her privacy should be protected accordingly.¹⁸

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