Review

Looking back, looking beyond: revisiting the ethics of genome generation

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This paper will explore some of the ethical imperatives that have shaped strategic and policy frameworks for the use of new genetic technologies and how these play a role in shaping the nature of research and changing attitudes; with an attempt to conceptualize some theories of genetic determinism. I analyse why there is a need to put bioethical principles within a theoretical framework in the context of new technologies, and how, by doing so, their practical applications for agriculture, environment medicine and health care can be legitimized.

There are several theories in favour of and against the use of genetic technologies that focus on genes and their role in our existence. In particular the theory of geneticisation is commonly debated. It highlights the conflicting interests of science, society and industry in harnessing genetic knowledge when the use of such knowledge could challenge ethical principles. Critics call it a 'reductionist' approach, based on arguments that are narrowed down to genes, often ignoring other factors including biological, social and moral ones. A parallel theory is that there is something special about genes, and it is this "genetic exceptionalism" that creates hopes and myths. Either way, the challenging task is to develop a common ground for understanding the importance of ethical sensitivities.

As research agendas become more complex, ethical paradigms will need to be more influential. New principles are needed to answer the complexities of ethical issues as complex technologies develop. This paper reflects on global ethical principles and the tensions between ethical principles in legitimizing genetic technologies at the social and governance level.

[Bhardwaj M 2006 Looking back, looking beyond: revisiting the ethics of genome generation; *J. Biosci*. **31** 167–176]

1. Introduction

Products of scientific endeavors in many branches of science have challenged us with problems of great moral importance. Nuclear physics, for example, gave us the capability to destroy the world, perhaps the ultimate moral dilemma. But genetics has created more subtle and interesting dilemmas for life. It challenges us with dilemmas of responsibilities to ourselves, nature and also to future generations. Historians of science have identified beginning of a new era with Mendel's explanation of how certain traits are inherited. The elucidation of the structure of DNA more than fifty years ago has influenced the direction of research in biology, medicine and health care. Since then, genetics has seen several developments from determining the structure of genes to sequencing entire genome discovering disease-linked genes, and providing genetic attributes to physical and behavioural characteristics. In particular the last two decades of the 20th century saw remarkable developments in information technology as applied to genetics.

Technological developments inevitably give rise to ethical questions. As our understanding of genetics, and the development of new technologies related to health and the environment progresses, opportunities and potential uses of those technologies at a wider scale increase and it also holds true for genetics. Developments in the new technologies that bear on genetics have created a kind of '*genosphere*' in the minds of ordinary public in which our thinking and actions are focused on the role of genes in our lives. This has led to a growing uncertainty about issues related to health and the environment.

Keywords. Genomics; geneticisation; ethics; governance.

This paper discusses, albeit selectively the ethical imperatives of these developments in genetic technologies and their "value impact" on society (Bosshard 2004).

2. Recognizing the potential of genes

The year 2003 marked the 50th anniversary of Watson and Crick's discovery of the double helical structure of DNA, the molecule of life. It was also the year in which the initial draft of the Human Genome Project was completed. We know now that there are three billion chemical letters that make up our DNA and human beings probably have 20,000-plus protein-encoding genes. Let us consider some examples of what some hope to find with knowledge of the entire map of the human genome (UK White Paper 2003).

- Predisposition to certain diseases and how some genes can protect us from some diseases
- Identification of relationship, if any, between human races and genes.
- Our life style choices, and interaction between external environment and our genes.
- Genetic responses to drugs, leading to a 'pharmacogenomics' in which drugs are targeted based on individual needs.
- Nutrigenomics, how we can introduce drugs through food.

Biotechnology has also influenced agriculture and the environment. It has provided options to tackle malnutrition, hunger and environmental pollution. The debate over genetically modified food and plants has already wrapped trade and industry, environment management and health.

It is said that there are over 800 million hungry people in the world, mostly in the poor regions (FAO 2000). Over 80% of the countries of the world are said to be 'developing' or 'underdeveloped'. It is argued that genetic modification can help to reduce and eliminate malnutrition in the world. Genetically modified food has been debated now for over a decade since the introduction of first commercially genetically modified *Flavr Savr* tomato, a whole genetically modified food produced by US biotech company *Calgene*. Since then genetic engineering has been used in agriculture for several purposes, including:

- Salt tolerant crops (Riddle 2002).
- Herbicide resistant crops (FAO 2001).
- Insect resistance (FAO 2001).
- Increased nutritional content (UNDP 2001).
- Food and vegetables with longer shelf-life (UNDP 2001).
- Livestock production (FAO 2001).
- High protein meat (FAO 2001).
- Environmental clean up (UNDP 2001).

These are some examples of our growing reliance on genetic engineering and increasing use of genetic technologies. It can be said that the impact of new technologies and their dependency on genetic knowledge has led to an attitude where entire biological and medical research agendas and their outcomes are narrowly based on roles ascribed to genes. This view-point is popularly known as determinism in genetics.

3. Geneticisation and genetic determinism

Lippman (1991) used the term geneticisation to mean "tendencies to make distinctions between people on the basis of what one believes are genetic differences, to view most disorders, behaviours and physiological variations as determined (wholly or in part) by genes. It comprises ways of both thinking and doing, applying genetic technologies to diagnose, treat and categorize conditions previously identified in other ways". Since then the term has been broadened and debated. The debate has concerned both the interpretation of 'gene' as a material part of the organism and also as a coding mechanism controlling and expressing phenotypic and behavioural characteristics.

The history of genetic testing tells us that the study of supposedly single gene disorders has been around for 150 years (Holm 1999). Predictive screening is commonly carried out in several countries for some single gene disorders including Huntington's disease and cystic fibrosis. It can be said that these conditions are rare, and hence linking them to their genetic component was an easier attempt than carrying out a similar exercise on multifactorial conditions in which a combination of genetic factors and environmental factors like diet and lifestyle are believed to play a significant role in causing a condition. It is claimed that the outcomes and information from such research will help us in understanding the interaction between genes, diseases and external factors. The hope is that the knowledge so gained will help people to make choices to modify their lifestyles and allow those with certain genetic profiles to avoid certain foods, chemicals and environmental factors (such as smoking) that might be particularly risky.

The focus on deterministic attitudes of genetics has also been commonly seen in modern agriculture, especially in plant genomics. The introduction of genetically modified food, plants and other organisms has been advocated as a response to deteriorating environmental conditions and climate change. It is claimed that the worsening of environmental conditions, particularly for agriculture, may be in part because of the green revolution that was based on the intensive use of pesticides and synthetic insecticides (FAO 2003) It is argued that genetically modified foods promise to provide enormous benefits, boost prosperity in developing countries, and provide more choices for the consumers. Golden rice with the daffodil gene producing beta-carotene to stop vitamin A deficiency, Bt genes in plants to produce natural insecticide, or Roundup ready soybeans resistant to herbicides can be considered as optimistic examples of the genetic determinism attitude. These promises and hopes of finding solutions in genes to the problems of hunger, diseases, inherited genetic conditions and environment problems are a distinctive feature of present-day scientific research.

4. Predictability of technology

Technological prediction is extremely difficult, particularly when we talk about events that may lie a generation or two away. But we can still construct some scenarios for possible future that suggest a range of outcomes. Some of these are likely, even happening today, others may never materialize (Fukuyama 2002). It is important to remember that the biotechnology revolution is broader in its scope than genetic engineering. It is not limited to our ability to decode and manipulate DNA, but it involves entire biology. This is so because advances in genetics eventually affect a number of other related fields including molecular biology, population genetics, medical genetics, behaviour genetics, anthropology etc. The prospects of the biotechnology revolution are difficult to predict, but its consequences will have major implications for the world. As Marshall Nirenberg said, “We are apt to learn to move genes around long before we can know it is safe to do so” (Nirenberg 1967). The ‘safety’ aspect concerns not only biology, but also sociology and ethics. It is already affecting trade and politics at a global level, as well as the lives of individuals and changes in the environment. The international negotiations on agricultural products, especially on genetically modified (GM) food and plants, provide an example of how the biotechnology revolution can impinge on questions concerning the environment, health safety, property rights, legal systems, ethical concerns, cultural issues, other social and economic issues, industry and governance structures.

Aldous Huxley’s *Brave New World* of 1932 envisaged the revolution about to take place in biotechnology. ‘Bokanovskification’, commonly understood as hatching of people outside the wombs, is an extension of *in vitro* fertilisation; and the drug soma, which gave people instant happiness could well be an example of what biotechnology has in store. Seventy-plus years after the publication of *Brave New World*, we can see that while the technological predictions appear plausible if not startlingly accurate, the ethical implications of the technologies remain to be explored. Today biotechnology has moved on and we now talk of cloning, stem cell research, nanotechnology, pharmacogenomics, and nutrigenomics and even growing “testicular eggs” (*Nature* 2005). We can mix two species to create chimeras, genetically modified organisms with desired characteristics. Designer babies are being talked about; and we can also save and store our genes for future use by freezing. The prediction of technology is an open-ended question dependent on state of the technology.

5. Conceptualizing genetic determinism

The sequencing of the human genome led to a resurgence of the idea of genes as the powerful master molecules directing our characteristics, growth and behaviour. The dominance of “gene talk” in popular discourse has tended to obscure other causes of biological and social problems (Nelkin and Lindee 1996).

Deterministic views of genes did not emerge from the decoding of DNA sequences or from the predictions of what we can do with DNA. The history of medicine shows several examples of studies in which “heritable factors” were associated with certain diseases. But the decoding of the human genome and various other genomes of plants and other organisms, the notion that “It is all in the genes” usually stands for one of two things. Either it is assumed that DNA is the controlling agent and we do what genes order us, to do puppet-like determinism or, that we can take charge of DNA, so to speak, with our knowledge and technology and use it to make our future better (“promethean determinism”) (Peters 1997). We are either victims of our genes or can take charge of our genes. The concepts of nature and nurture have been shifted to biological extremes. These are limiting views and raise fundamental questions for other fields of scientific enquiry that may not support deterministic assumptions.

Historians of biology have pointed out that the term heredity referred to both transmissions of potentialities during reproduction and the development of these potentialities give rise to specific traits. With the development of statistical methodology for analysing the transmission of hereditary traits, the attribution of causal powers to genes elicited a positive response from the research community (although it can be argued that the scientific community did not favour the term genetic determinism). However, the belief that it is essential for research and health purposes to understand how genes influence our biological fate has led to the notion of genetic essentialism. This is based on the belief that understanding can be gained by reducing an object of knowledge to its ‘essence’. In biological sciences, it could be related to the reductionist approach of explaining everything in terms of genetics.

The outcomes of new research in medical technology are constantly challenged by the way in which potentially critical information is conveyed to lay people. The concept of genetic exceptionalism (Murray 1997) is a complicating factor. It is based on the belief that there is something special about genetics. Proponents of this belief argue that genetic information is unique because it is predictive, independent of time and shared with ‘blood’ relatives. Future medical research and healthcare policies will be influenced by this approach. The UK government’s White Paper *Our inheritance, our future* (DoH 2003) is aimed at recognizing the potential of genetics in the main healthcare stream and how patients can benefit from advances in genetics. However, it has been opposed and criticized, especially in medical research, as it ignores other kinds of medical data that might influence health and well-being. This has raised a debate on just what factors act as essential influences on our existence. What shapes our lives, moral values and choices?

6. Bioethics, biotechnology and genomics

The ethical assessment of technologies is challenging and problematic; and developments in technologies will inevitably give rise to new ethical challenges. New genetic technologies pose challenges for ethics, as they are not only developments in technologies but also in the potential uses of technologies and future opportunities. It is therefore not simply a matter of applying ready-made theories to the assessment of new technologies and their implementation, because the advances lead us to rethink our theories (Chadwick 2001).

The need for an ethical assessment of biotechnology and other genomic technologies has led to the development of a new field of inquiry, bioethics, which is devoted to the issues emerging from developments in the biological sciences during and since the 1970's. 'Bioethics' does not denote any particular field of human inquiry, but works as an intersection between ethics and life sciences, connecting medicine, biology and environmental sciences with social sciences like philosophy, religion, literature, law and public policies.

Contemporary bioethics includes both medical ethics and environmental ethics. Some of the technologies used in medicine were also applicable to the environment and natural systems that led to the inclusion of environmental ethics in bioethics. Bioethics is sometimes narrowed down to 'genetics', where it focuses on ethical issues raised by genomic technologies.

7. Principles of bioethics

Bioethical principles are based on several ethical theories and are similar to principles of biomedical ethics, as described by Beauchamp and Childress (1999).

(i) Beneficence describes the practice of good deeds. Doing good is beneficient. Beneficence is also related to benevolence that emphasizes intentions to do good. It focuses on obligations to prevent any harm (Churchill 1996).
(ii) Non maleficence emphasizes obligations not to inflict any harm. Harm in itself is a vague concept; it is difficult to measure harm and at times it is taken as a normative concept describing what is harmful. The prescription to do no harm sometimes has a relatively lower scope in law (Siefert 1996).
(iii) Autonomy is the guiding principle for recognition of human capacity for self-determination and independency in decision-making. The minimum content of the principle of respect for autonomy is that persons ought to have independence, be free from coercion and other interferences. It is often talked of in terms of rights and liberty (Miller and Gregory 1998).
(iv) Justice, the ethical principle of justice is based on the conception of fair treatment and equity through reasonable resolution of disputes. There are different types of justice, for example, libertarian justice, socialist justice, communitarian justice, and feminist justice, and these are based on different theories of virtue (Sterba 1996).

It has been argued that these principles do not necessarily provide answers to the ethical issues raised by genetic engineering, especially in the debate of genetically modified organisms and limited to the medicine. Debate on GMOs has been based on justice, rights and centrism in ethics, and principles of governance. As noted earlier, principles of ethics are continuously evolving with the progress in technology and new ethical principles evolve. New ethical concepts like solidarity and equity have emerged based on communitarian ethics; and are often used in contemporary ethical debates on research involving large populations, and particularly, groups in society.

8. Centrism in bioethics

Ethical principles are applied based on the views of direct and indirect implications of an action and its effect on living beings. The effect may or may not be directly involved with the incident. This concept can be termed as centrism. Centrism is based on whose view we emphasize and on whose interests we primarily focus. Commonly three kinds of centric views, biocentric, ecocentric and anthropocentric are used. They play a fundamental role in the way we analyse the benefits and risks arising out of new technologies, especially in the debate surrounding genetically modified organisms.

Biocentric thinking focuses on each individual organism. It may include the role played by each organism in the ecosystem. It emphasizes the value of each life equally in decision making or the consequences on an organism. Ecocentric thinking focuses on the whole ecosystem as a dynamic system with inter-relationships between different entities of the system. Ecocentric thinking does not identify one individual life separately but takes a holistic approach to the ecosystem, over and beyond the impact of one species on the whole system. Anthropocentric thinking focuses on human beings and their interaction with nature. It is sometimes criticized by environmentalists and animal rights activists as based on a 'self-love' approach which does not give equal and due importance to other living beings (Macer 1998).

Let us now consider a few examples of the ethical issues raised by the genetic modification of plants and use of new genetic technologies in health care.

9. Ethics of genetic modification

The appearance of genetically modified (GM) food in the market marked the beginning of a new level of public debate with a focus on technology, agriculture and economy (Eurobarometer 2002). The controversies surrounding GM food, which is one of the major types of "novel food", are debated widely for the reason that genetic engineering allows modifications in the genetic make up of crops, vegetables, fruits and animals, and also in the transfer of genes by artificial means, a transfer that disregards what appear initially to be natural boundaries.

Extrinsic concerns about genetic modification are based on doubts regarding the technology, its potentiality, newness and applicability to all life forms. Proponents of genetic modification argue that it provides a great opportunity for solving hunger, food insecurity, and malnutrition in the world since this technology provides options for agriculture in a wide range of environmental conditions and helps in increasing quantity and quality of food.

The applications of modern biotechnologies provide potentially unlimited possibilities of changing hereditary characters. Genetic engineering can be applied in all species and across kingdoms. For example, use of the Bt gene in plants to produce toxin to kill insects has been applied to many species (James 2002). These concerns led to a lack of trust in the technology and fears of transmission of alien genes into food; the consumption of such food leading to fears about the safety of the food and health risks. This has to be balanced against the fact that millions of people need food to survive.

GM food labelling has been a high point of controversy in global trade, especially trade between Europe and the USA. It is argued that labelling provides choice to consumers, fulfils their right to know what they eat. Public surveys in Europe have shown stiff resistance to GM food in Europe based on health, safety and other ethical concerns (Eurobarometer 2004). Labelling raises several issues. How much and what information should be on the labels, in what languages (for international markets), do people reading the information really understand what that information means, is that information trustworthy?. Another important issue for developing countries is that the majority of food trade depends on local markets where small farmers sell their produces; labelling their products is difficult not only because of a lack of knowledge but also because of the economic liabilities involved.

Many Non-Governmental Organisations (NGOs) in the world have raised the concern that growing genetically modified crops will be harmful for the environment and genetic modification will result in "superweeds, for example, herbicide resistance genes from canola could flow into weedy relatives to make them resistant to herbicides" (Brown 2003). It is said that GM crops are unsafe for other organisms that feed on them; for example, Bt toxin kills monarch butterfly larvae. Therefore genetically modified crops and foods will result in the loss of our biodiversity. Also, since the technology is new and needs high levels of investment, it would be unfair to small farmers in poor countries who thrive on subsistence farming and are not subsidized by governments, a luxury that is available to many farmers in the developed world.

Scientific studies on GM food have not been conclusive. The possibility of pleiotropic effects (side affects) can not be ignored, although theoretically the situation with transgenes is no different from traditional varietal hybridization and selection. As yet, there is no control over where in a plant's chromosomes the foreign gene will integrate and, conceivably, silence its own genes. There are other concerns about stability and resistance breakdown in GM plants. The risk assessment and risk management aspects of technology have not yet been resolved internationally. Further, poor communication on the subject of risks has led to public distrust.

Intrinsic concerns about genetic modification are based on how people view life, nature, religion, their personal emotions and values. There is a feeling that mixing up genes in the organisms for our use is "Playing God" and human beings should not intervene in God's realm. Crossing natural species boundaries is the creation of new life forms and inventing a new world through technology. Genetic engineering disrupts the beauty, integrity, balance of nature and harms sentient beings. However, at the same time we can say that high tech medicines involve playing with God and agriculture was started by disrupting nature. Hybrid plants and animals like mules are cross-species. It is also argued that people eating meat harm the life of sentient beings. Many supporters of GM food consider these concerns not valid and do not provide any solution to pragmatic issues like saving the environment and improving environmental conditions, solving hunger and malnutrition, preventing loss of biodiversity etc.

Ethical concerns have also been raised on the environmental impact of genetically modified plants. The majority of these concerns center on the welfare of present and future generations. It is our duty to leave nature as it is or in a better condition for our future generations. The rights to exploit environment in pursuit of livelihood, as against the rights of others to preserve environment as an amenity have also been argued, along with the rights of other living beings such as plants and animals. The concept of 'unnaturalness' also comes from the way we express our relationship with nature, and genetic modification has indeed prompted us to think and reflect how far, though gradually human intervention should be allowed. Such reflections have been an important contributor to the rise in the interest of organic farming.

The emphasis on organic agriculture is on using inputs (including knowledge) in a way which encourages the biological processes of available nutrients and defence against pests, i.e. the resource 'nature' is manipulated to encourage processes which can help to raise and maintain farm productivity (Wynen 1998). Organic food activists consider their food as a wholesome food without any, or only some detrimental effects on humans and the environment, because it is grown with natural resources used as "raw materials". They claim that it is sustainably acquired food. But questions have been raised about the human health safety aspect of the organic food. There is a view that organic food is becoming more and more responsible for the increase in the food-borne diseases, as it is more prone to bacterial and fungal contamination; and it is capable of getting rotten fairly quickly and thus has a high risk of pathogenicity.

10. DNA, medicine and ethics

Few subjects pose as many difficulties for rational discussion as the effect of genetic research on human health and human welfare. Genes and genetic research have been coupled with eruptive themes such as racism, loss of genetic diversity, genocide and religious debates on abortion and contraception. In the present health care systems, at least in the developed countries, use of new DNA technologies has been actively pursued for several purposes.

10.1 *Genetic testing and screening*

Prenatal and post natal genetic testing is carried out commonly in most developed countries. Genetic testing for heritable conditions like Alzheimer's disease, Parkinson's, Down syndrome, breast cancer, is routinely done, especially for the families who have a history of the condition. Predictive testing may have some health benefits for people at risk where future complications can be managed better if they are identified earlier. Counselling services are also provided for families to help them to choose possible options for their future and their risk of transferring the condition to future generations. Screening for genetic susceptibility for common and prevalent conditions like diabetes, hypertension, and dementia is also under research scrutiny.

Whilst the primary scientific motivation is to understand disease mechanisms and open new possibilities for therapy, there are strong ethical, professional and commercial pressures when it comes to genetic testing. Disability movement groups have argued that prenatal genetic diagnosis is a form of genetic cleansing from society and immoral as it degrades human dignity and rather pushes the notion of biological perfectionism, in a throw back to Eugenics movement of the past including in the Nazi era. There are also concerns raised about the information that is provided and the reliability of that information. Although non-directive genetic counselling is done, the ethical challenge lies in how it affects the autonomous decision-making and personal choice of patients. The escape through 'informed consent' has raised debate on the legal acceptance and moral acceptance of genetic testing.

Genetic information is intensely personal and affects not only biological existence but also social life; hence it must be treated with the greatest respect. However, it is not always possible or even expected (for example, among some Asian and African communities) to keep it confidential. Privacy and confidentiality are the key ethical concerns in genetic testing. There is also the question of balancing the autonomy of a person with a utilitarian perspective, in the sense that disclosure could protect a large number of people. Nevertheless, we cannot ignore the possible danger of genetic discrimination of people when it comes to in health care, insurance and place of work.

10.2 *Embryos, gene manipulation and gene selection*

An issue related to the genetic screening is the ability to choose what characteristics we want for our children and ourselves. This is a powerful notion and often debated as it touches on our concept of personhood and autonomy. The choice has become possible with our ability to freeze embryos and store DNA samples. Potential genetic uses of embryos include attempts for altering gene structures, preimplantation screening for chromosomal anomalies and genetic diseases, and preimplantation therapy and sex selection, and presently, stem cell research. Preimplantation Genetic Diagnosis, a technique that helps couples to choose (what they believe may be) almost perfect embryos to be implanted in prospective mothers with those that have a chance of developing a mutant phenotype in later life being discarded. This has been widely condemned; especially by disability groups. Proponents point out the economic costs of bearing a disabled child and the right of couples to choose. The utilitarian argument of wasting aborted and discarded embryos instead of their use for medically beneficial research is also put forward (Burley and Harris 2002). Should there be a limit to exercising choices, what are the areas where limits are required and can we really define the moral status of embryos?

An empirical version of the slippery slope argument says that if we accept we are more likely as a matter of fact to accept Y. This is commonly cited in connection with the changes and rapid developments in technology changing attitudes to assisted reproduction since the first "test tube" baby in 1978. Since then, developments have taken place in matters of surrogacy, genetic selection based on physical characteristics leading up to selling and buying of desirable eggs and sperms, creation of embryos for research for specific purposes.

The potential benefits of organismal cloning are discussed in two contexts – one, that of animal versus human cloning, and the second, that of reproduction versus research (for health). Animal cloning has not been as controversial as human cloning. Its votaries call attention to the fact that it is a kind of genetic engineering that has long been practiced, especially in agriculture. Pharmaceutical firms use germ line gene transfer in laboratory animals to produce animals with traits that are not found in nature. Genetic modification has been done in animals to produce insulin to treat diabetic mellitus, human growth hormone, blood clotting factors and for the treatment of cystic fibrosis.

The principal therapeutic benefits of human cloning (as claimed) include producing tissues and organs for therapies. It is argued that reproductive cloning provides a choice for the treatment of infertility. The debates do not necessarily focus on those who think that cloning should be permissible in some circumstances or those who think it should be completely banned. It is rather focused on a range of other values like medical benefits to parents and scientific freedom, especially applying to therapy. Reproductive cloning is not for the quest of knowledge; rather, it is motivated by the quest for children who will carry our genes in future. The compelling arguments against cloning have not only been based on the Playing God theory, but also on the possible harm to children, based on the argument that the science is not perfect so it is unreliable, and the danger of children with abnormalities is high (Jaenisch and Wilmut 2001). Fanciful as it may sound, concerns have also been raised regarding a possible clash between cloning and the values within a family, its implications for society, the misuse of cloning to raise an army or a 'superhuman'. The arguments invoke issues such as control over nature and loss of sense of human dignity based on human characteristics, its uniqueness and rationality, irreplicability; and other exogenous sources like God and nature.

10.3 *Beyond the Human Genome Project*

The completion of the Human Genome Project was heralded as a "biological moonshot". An impressive undertaking, it opened one gateway for looking at biology from a genetic perspective. The central thrust to the human genome project was from biomedical research. The sequencing of the entire genome has already had a profound impact on the wider spectrum of clinical research. Although labelled as the Human Genome Project, it expanded to the sequencing of other organism, both plants and animals. Having sensed the potential of knowing the genome, the competition to discover and unveil genes and create a monopoly over the knowledge is still on. The Human Genome Diversity Project (HGDP) was targeted "to find out who we are as a species" by understanding genetic differences between different ethnic and aboriginal populations. It raised ethical concerns and was criticized as dividing an already divided society into genetic groups. The Human Genome Project proved that we all share the same DNA, though not all the genes. The dangers of misuse of the knowledge produced led to several international guidelines on the ethics of human genome research. The development of the Human Genome Organization and its ethics committee has played a critical role in developing guidelines. The explanation of all human beings sharing more or less the same DNA led to the development of the concept of DNA as a natural heritage from which subsequent ethical arguments on rights and responsibilities, and ownerships and issues of commercialization have developed.

Although the HGDP was shelved after staunch ethical criticism, the ideology behind the research did not die. Now we have the International Hapmap Project and Genetic Database projects in several countries focusing on genetics, health and individual and population specificities. On the one hand, these projects focus on developing cures and medicines based on individual genetic characteristics and also try to search for common genetic characteristics of a population. Present day clinical research has moved to focus on the factors that influence the role of genes, and how genes function to produce proteins. The drive towards the individualization of health-care has led to the expansion of macrogenomics, therapies based on individual responses to drugs, and nutrigenomics, focusing on the associations between specific nutrients and genetically-influenced individual responses to diet (Chadwick 2004).

These new trends in medical research and the use of new technologies involve the participation of large populations, sometimes almost the entire population of a country, for example, the health sector database of Iceland. Large scale DNA sampling for health and medical research is thought of as desirable from the empirical research perspective. Also, it addresses the anxiety attached to the public perception of genetics which had earlier been prominent in issues related to food (Bhardwaj 2004). Ethical issues are usually presented from the perspective of individualism and choice, but they also need to be looked at from a broader perspective of the common good.

11. Economics and genetics

Commercialization of technologies is one aspect of globalization. Genomic knowledge is an expensive business and still largely a possession of the developed world. Most of the poor parts of the world still face fundamental issues of environment and health care, although technology transfer has been integrated as part of policy recommendations in biotechnology at the international level (FAO 1999). There are two aspects of economic issues related to genetics. The local aspect concerns issues that are internal to the advancement of technology and its priorities lie at the individual and state levels. The global version has to do with how the external (rich) world looks at opportunities of using technologies to solve fundamental problems.

Economic implications and benefits influence the choices we make at personal and broader levels. The survey done by Singer *et al* (2002) on the top ten biotechnologies needed for developing countries shows that GM food and stem cell research may not be the first priority for the majority of the developing world. However, there is a perception that although not a top priority, biotechnology provides a means of exploiting the benefits that may arise as byproducts of other technologies. The "10/90 gap" has been used to refer to the wide disparity in global spending on health research between developing and developed countries, a gap that is exacerbated by the genomic revolution. In developed countries, although genomics research was initially undertaken by the public sector and academia, private funding has become substantially higher. Research funding can determine research priorities and agendas as well as access to the products of research. The severe competition between the public and private sector, at least in the developed countries, has influenced the priorities of research at a global level. Research priorities are driven by market considerations and the profit motive and not by a desire to improve the availability of therapeutics and diagnostics for diseases prevalent in developing countries, although the developing countries are used sometimes as testing grounds (Bhardwaj 2001).

A recurrent issue in the ethical debate overlaps with economic issues of intellectual property rights (IPRs), patenting of genetic materials and their interpretation in the context of access to drugs, benefit sharing, international trade agreements and especially their impact on developing countries. In the international debates on commercialization of genetic technologies in plant genomics, the danger of overexploitation of genetic resources led to the developments of concepts of access and ownerships of genetic resources and benefit sharing. Genetic engineering has threatened traditional secrets of the production of best varieties and the risk of genetic drift has made it difficult and expensive for farmers to market their produce. The stern competition between small scale, subsistence farmers and the industrial agriculture with loss of markets and control over their varieties has served to ignite this issue in developing countries that are considered to be rich in biodiversity and genetic resources. Every country's genetic resources are considered as the property of that country, its conservation is important for biodiversity and unexpected natural disasters. Farmers and breeders should have an access to genetic resources for good productivity and choice of better varieties for sustainable agriculture and food security at the same time given rights to protect their own varieties. This access can be tangible; for example access to the good seeds, or intangible, in the form of information regarding the availability of the best seeds and varieties.

The issue of ownership of genetic resources starts from whether stakeholders have rights to ownership in agriculture. Many groups have claimed to have rights over genetic resources. They include farmers, cultural groups, rural communities, industry corporations, scientists, governments, and environmental groups. Sometimes issues like customary right and legal rights can obstruct the process of facilitating a successful biotechnology policy. Since genetic resources can move across borders, Intellectual Property Rights complicates the issue. A similar problem crops up when it comes to translating traditional knowledge into commercial application without a proper sharing of the benefits, as seen in the neem tree debate in India, and the using traditional knowledge of indigenous tribes (example, in South America) to create databases on genetic resources (Bhardwaj *et al* 2003).

Sound arguments have been made against the patenting of human DNA, although thousands of patents have been granted already for human DNA sequences, mutations, cloning vectors, proteins or parts of proteins etc. (Oldham 2004). An argument that has been made about the special status of human DNA is that the human genome is the common heritage of humanity, similar to any other shared natural resource, although the precise nature of the human genome as a common resource is harder to elucidate. Another ethical constraint against granting property rights on human genes is that each person has the right to self-ownership that brings an inalienable right to one's body and genes that should not be transferred to others. Nonetheless it is also debated that patents do not necessarily confer ownership of genes. The view of genes and genome as the common heritage of all humanity becomes complicated when it comes to deciding whether it should be considered as a discovery or an invention.

Present-day trends are towards the involvement of large populations in medical research, and new ethical principles need to be developed at the global level. Benefit sharing has been involved as a mandatory criterion in medical research in order to protect participants and communities from exploitation in the name of research. The HUGO ethics committee in its statement on benefit sharing elaborates that potential benefits of research participation should be part of the collaborative relationship between the researcher and the community (HUGO 1999). The principle of respect for communities, although a novel principle, is sought for the unique cultural values and social values that might be at stake as a participant in research.

12. Global ethics, governance of genetic research

This article has not attempted to cover all the ethical arguments surrounding genomics research in plant genomics, medical genetics and health care. But I hope I have succeeded in introducing a few ethical issues related to modern genetics.

New technologies inevitably affect the value systems that impinge on our ethical and moral choices. Technology influences traditional values, and old value systems can be translated into new ones with the use of new technologies (Bosshard 2004). There are also differences between the values of different cultures. Universal principles of justice, doing no harm, respect and beneficence exist in all cultures. But their philosophical foundations and applications are uniquely rooted in each culture. For example, in Asia family ties are closer and a communitarian spirit is accorded more importance than individual choice. So when implementing the principle of informed consent of an individual, the roles of family and community can not be ignored. In the West the concept of individual autonomy is stronger, hence the final decision may be based on the individual's choice irrespective of how the community feels. "Harmony does not mean identical"; there are differences in similarities (Qiu 2004). Another of this is something that example we can see in the global debates on genetic engineering, even within the ambit of western values. Habermas draws a distinction between the debates in Europe (notably Germany) and the US suggesting that in Germany the focus is on whether certain things should be done and in the US on how they should be done (Habermas 2003).

The World Commission on Culture and Development (1995) identified as common global ethics: (i) human rights and responsibility; (ii) free and fair periodical elections; (iii) elements of democracy and civic society such as freedom of speech and information, freedom of association, protection of minority rights; (iv) peaceful solution of conflicts and promise of fair transactions; and (v) equality between and within generations. The Institute for Global Ethics proposed "love, truthfulness, fairness, freedom, unity, tolerance, responsibility, and respect for life" as ethical principles valid the world over (Loges and Kidder 1997). These principles are enshrined in several international ethical guidelines relating to the governance of genomics. The work of international agencies is supposed to be based on strong ethical foundations. However, balancing the ideals so as to ensure that they are sensitive to cultural and social particularities is complicated. Sometimes seemingly insurmountable challenges are posed to the authority of established regulatory frameworks, pointing implicitly to their limitations. Also, international institutions face crucial questions of management of uncertainty; for example, with regard to the safety of novel biotechnologies like genetic modification. There is also the uncertainty perceived by scientists, public and policy makers. The lack of confidence in scientific findings can be grouped in two categories. First there is uncertainty about uncertainty. The public is puzzled by the debate within the scientific community between "act now" and "wait and see". This signals confusion and ignorance, thereby supporting a rationale for inaction. A second uncertainty lies in the interpretation of science. For the ordinary public many scientifically significant findings seem irrelevant or incomprehensible to the exigencies of everyday life (Bradshaw 2000).

The terminology of ethics may not be that conspicuous in international and national procedures. However, the principles are inherently applied at all stages. Ethical principles need to be applied on a daily basis, starting from the individual level to the international governing bodies. The ethics of biotechnology starts from the level of individual organism level and encompass the whole environment, society, and governance systems.

Acknowledgments

The support of the Economic and Social Research Council of UK is gratefully acknowledged. The work was part of the ESRC Centre for Economic and Social Aspects of Genomics (CESAGen).

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MS received 13 August 2004; accepted 19 November 2005

*e*Publication: 4 February 2006

Corresponding editor: Vidyanand Nanjundiah