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## **Bioethics and Human Population Genetics Research**

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# **I. Population Genetics**

## ***1.1 What is Population Genetics?***

Population genetics is a discipline studying genetic variation in defined populations, including relevant aspects of population structure and geographic variability of DNA sequences and their frequencies. Their changes in time and space are controlled by evolutionary factors, among which population geneticists recognise as most important: mutation, natural selection (i.e. differential mortality and fertility of genetic types), drift (stochastic fluctuation tied to the demographic size of populations) and migration. Population genetics deals with the characteristics of genes within a population as opposed to the description of the genes in a particular individual. In this report we refer to human population genetics, but the term "population genetics" also applies to all other living organisms.

The biological relationships of human population groups and the theory of evolution can be studied as questions of broad interest to the understanding of human history. Population studies are not new, and in fact large surveys have been conducted all over the world in the last eighty years. Classical studies of genetic diversity have been dealing with antigen, protein and enzyme polymorphisms, for example HLA or blood groups. Modern genetic studies are based on the molecular analysis of DNA polymorphism. Classical studies look at expressed sequences, which represent less than 10% of the genome, whereas molecular genome diversity studies are mainly concentrated in parts of the genome that are often not expressed at the phenotypic level.

## ***1.2 Main Trends in Population Genetics Research***

### **1.2.1 Genetic Epidemiology**

Isolated populations are the main source for observation of genetic forces acting in human evolution. While gene frequency across different populations varies for specific diseases, the total effect of genes on mortality appears similar. Pedigree information can be used to observe migration, to measure the mean-inbreeding coefficients, or to trace the linkage of disease. The method used to make a pedigree sheet, and the information sought, depends upon the objects of investigation, the quality and quantity of basic data, and their purposes. In some studies, additional clinical investigations on the hereditary diseases, or common diseases of polygenic inheritance, are included. These epidemiological surveys have been conducted at the ethnic, regional or transnational level, according to the disease studied (e.g. Tay-Sachs disease in Ashkenazic Jews, cystic fibrosis in Europe, North America and recently other countries).

Comparative studies can be made on the differences in the mortality and fertility as well as on anthropometric data between consanguineous and non-consanguineous groups. They can be used to test genetic susceptibility using polymorphic markers in different communities, which can also examine genetic susceptibility to environmental agents. This makes possible the prevention of certain multifactorial diseases by careful avoidance of exposure to environmental agents.

Consanguinity and large family size are very interesting for population genetic studies, but studies of consanguineous marriages of families have the potential to raise numerous ethical and social issues. There are opportunities for genetic epidemiological research in countries where consanguineous marriage is a long-standing tradition. Such research projects can use data from many sources, for example, birth and death records, family register books, or anthropological or medical surveys, and socio-economic data in order to test inbreeding effects.

### **1.2.2 Genetic Screening**

Population genetic studies are not new. What has evolved very quickly is the technology and level of analysis. The first genetic studies in populations came from surveys all over the world looking at frequencies of single gene diseases. This was followed by the

laboratory analysis of blood samples for the establishment of allele frequencies of blood groups, HLA proteins and enzymes all over the world. Some of these studies were done on banked blood samples that were anonymous in character. Others were conducted, however, on sampled individuals from target populations, some large and open such as the Europeans, or small and isolated, like the Basques - linguistically, culturally, religiously or geographically isolated.

Based on these studies, mass screening programs for particular disease genes were adopted as was the case in Cyprus for thalassemia, or in many countries for phenylketonuria (PKU) in new-borns. Genetic screening and genetic testing have been discussed in another report of the International Bioethics Committee of UNESCO (IBC), and by numerous other persons and organisations over the last twenty years (recent reviews include: Chadwick et al., 1993; Murray, 1993; McCarrick, 1993; Nuffield Council on Bioethics, 1993; Nielson & Nesper, 1994). Many of the issues in current genetic screening programmes are relevant to population genetics research, but some significant issue are different, such as the notion of group consent. Moreover, while at present we are focusing on research, we should also foresee the applications and benefits flowing from the Human Genome Project that could well apply to whole populations. Therefore the ethical considerations must be carefully treated, since whole groups of asymptomatic individuals are the targets rather than single individuals who come forward themselves.

### I.2.3 Spatial and Temporal Variation

More recently, molecular biology has enabled geneticists to work out the spatial and temporal variation of gene frequencies. Several projects have started independently in different countries, others, such as the Human Genome Diversity Project (HGDP), proceed as an international addition to the Human Genome Project (HGP). Some studies look at molecular variation among populations, whereas others analyse genetic diversity in the broader cultural context. Samples could be, and frequently are, analysed from all over the world. However, for genetic studies the more isolated homogeneous human groups are thought to be the most informative. Some of these studies focus also on ancient DNA, since links between present day human groups are presumably to be confirmed through ancestors of those human groups which are alive today.

*I.2.3.1 Multidisciplinary approaches.* Genetic diversity is increasingly being seen in a much broader context. In some cases, local geneticists have been interested in the study of human diversity of the indigenous inhabitants of their countries, understanding from the beginning that only an interdisciplinary, holistic approach to this issue is capable of providing a reasonable view along with a re-evaluation of cultural and genetic diversity of populations. In this report the word "indigenous" is used in a broad sense to mean a person that lives in a given part of the world, but not only meaning the original inhabitants (cf. UN Economic and Social Council, Commission on Human Rights, "Reports on Indigenous Peoples"). Research projects covering most disciplines, including anthropology, architecture, arts, bacteriology, dentistry, design, musicology, nursing, nutrition, philosophy, and medicine, as well as health care services, provide joint efforts to perceive all the peculiarities of isolated communities and give a much broader picture of, for example, the cultural and biological responses to environmental conditions and their understanding of health and disease, the natural laws that guide agriculture, settlement and architecture, and their cosmogonies.

This trend to involve broad multidisciplinary approaches in studies of populations, allowing for the participation of the community in the research, is exemplified by the "Expedición Humana" in Colombia, where the Human Genetics Institute from Javeriana University invited the whole University to join them. The aim of the "Expedición Humana" is to study the human diversity (cultural and biological) of a region of America which has been an important point in its populating and in its migrations from Asia to America. Teams of people from different disciplines travel to the communities. In each community that had previously been contacted and asked for consent, the investigators explain the different aspects they are interested in before once again asking for consent.

The information collected through all means (questionnaires, drawings, records, etc.) is then analysed some of which has already been published in a series of books. This information is given back to the community, in an attempt to provide useful analyses for the community itself. This approach to the study of the diversity of populations is less reductionist than just looking at their genes, and we would recommend such more humanistic ways of understanding the role of science and scientists. It creates, however, the expectation of follow up and continued intensive interest - essentially a complete medical service - which may be difficult to maintain unless special structures were created, which would be expensive. This is usually outside the power of individual researchers or research groups, and requires strong external financial interventions, most probably by governments.

*I.2.3.2 Human Genome Diversity Project.* One example of population genetics research is the HGDP described by L.L. Cavalli-Sforza as “*an international anthropology project that seeks to study the genetic richness of the entire human species*” (Cavalli-Sforza, 1994). The name comes from a proposal in 1991 in the journal *Genomics* to make a systematic study of the genetic diversity of human populations. However, like the HGP, it shares a much older origin in the work of population geneticists over many decades (Macer, 1991; Cavalli-Sforza et al., 1994; Cavalli-Sforza & Cavalli-Sforza, 1995). The Human Genome Organisation (HUGO) responded to the 1991 proposal in the journal *Genomics* by establishing an ad hoc Committee to develop the global project. In January 1994, the Council of HUGO approved HUGO's continuing oversight of the development of the HGDP (HGD Committee of HUGO, 1994; Kahn, 1994). The HGDP is being developed under the auspices of HUGO to promote global involvement and co-ordination.

The scientific aims of the HGDP stated in the 1994 HUGO Summary Document are:

- a) *“to investigate the variation occurring in the human genome by studying samples collected from populations that are representative of all of the world's peoples,”*
- b) *“and ultimately, to create a resource for the benefit of all humanity and for the scientific community world-wide. The resource will exist as a collection of biological samples that represents the genetic variation in human populations world-wide and also as an open, long-term, genetic and statistical database on variation in the human species that will accumulate as the biological samples are studied by scientists from around the world”.*

The main scientific value of the HGDP is:

- a) deepening our understanding of human history and identity;
- b) gaining knowledge about the environmental and genetic factors involved in predisposition and resistance to disease, so-called genetic epidemiology;
- c) encourage the development of local laboratories where the collection of genetic samples will be collected and analysed.

Even though to date there have been numerous studies on the development of culture, language and population genetics (e.g. Cavalli-Sforza et al., 1988, 1992; Sokal et al., 1992; Feldman & Zhivotovsky, 1992), and some consistency between genetic, cultural and linguistic observations has been found, a survey of more populations in a more systematic way will extend what we already know and test current theories.

Linguistic differences suggest there are about 5,000 population groups in the world. In the short term, the HGDP will attempt to study about 500 of these populations. Even if some populations refuse to enter the project, there are still many other populations that could be surveyed. It is expected, then, that the project will be able to obtain samples from a large number of willing populations. If funding does not permit such wide sampling there is still scientific merit in collecting data from a smaller number of populations (e.g. Cavalli-Sforza, 1995).

The HGDP initially planned to centralise the collection of samples from isolated populations, some of which are already under investigation in population genetics research. This led to fears among some members of indigenous groups that the knowledge could be used for further ostracisation (Lock, 1994). However, the HGDP is now moving away from both the idea of central control to regional control and from the focus on indigenous populations, to include all populations. Personal anonymity would be maintained by not having the names of individuals in the central repository, and by observance of established privacy rules.

The establishment of cell lines allows maintenance of a permanent record of the DNA of individuals of a population. At least two independent and physically separate collections in different countries should be kept, to maintain the resource. The HUGO HGDP Committee has said that access will be free, with some compensation for maintenance costs. Any data would be shared back into the main database, which would also include computer databases of genetic map and sequence data. There are also efforts to develop less expensive storage and micro-satellite marker techniques that can be used in local laboratories that have limited resources to ensure their fuller participation.

*1.2.3.3 Analysis of ancient DNA.* One of the recent trends in genetic studies is the analysis of ancient DNA samples, from fossils, preserved body remains, hair, or basically any body remains that contain DNA. There are scientific doubts about how much mutation occurs over the course of time the remains are kept in storage. However, these materials are providing an extra source of material for evolutionary studies. An example of the possible use of ancient DNA samples is the 7,000 year old frozen corpse found in the Austrian Alps has been used for analysis (Bahn & Everett, 1993). However, it may be impossible to find the appropriate persons to give consent. The question of consent is also related to the use of tissues from those who are recently deceased. In 1995, an urologist extracted sperm from a corpse in the New York city morgue at the request of the deceased man's widow. The sperm is in cryo-preservation awaiting the widow's entry to a local IVF clinic ("Sperm extracted from corpse is world first", *Guardian*, 21 January 1995, p. 12). Specific cultures may have very strong objections to these practices. DNA samples can be taken from the recently deceased and even sacred but archaeologically interesting sites such as tombs or battlefields. There could be no doubt that such samples would provide all sorts of interesting historical insights about the continuity of racial settlements and migration. Should however the anthropological interests outweigh the cultural and religious values about respect for the dead?

The ownership of these samples is sometimes claimed from those who believe the persons were their ancestors. In Israel there is a law requiring immediate reburial of all ancient body remains no matter which religious group they are thought to come from (Morell, 1995). In Australia there are laws to require return of tribal ancestors for tribal disposal rites. In both these cases scientists have been prevented from physical anthropology studies by such laws. This raises the question of group consent concern which will be discussed later. Peoples of most countries who have lost persons in war or disasters also call for the return of human remains. Can samples be taken?

## II. Ethical Issues of Population Genetics Research

### II.1 *Philosophical Basis*

The ethics of population genetics should be formulated with reference to the minimal agreed human values as expressed in international human rights law. These agreed human values are based upon recognition of the inherent dignity and of the equal and unalienable rights of all members of the human family. The rights of particular cultural groups to self-determination, including the safeguarding of cultural norms which are not in conflict with fundamental human rights, are then to be respected by research scientists. The Universal Declaration of Human Rights (1948) and the various treaties codifying human rights that have been developed from it are now all part of international law (Harris, 1991). Not only are all nations bound by human rights obligations in international law, so also are: international organisations, certain special entities such as the Vatican, special individuals such as diplomats, aliens, refugees, slaves, minorities, and persons, corporations and governments. Individuals are bound by the *ius gentium* in so far as human rights are at issue (Green, 1987).

Central to our human rights obligations is the promotion of “*respect for, and observance of, human rights and fundamental freedom for all without distinction as to race, sex, language, or religion*” (Charter of the United Nations, Article 55 (c)). The Universal Declaration of Human Rights is founded upon the notion that there are universally recognised human values and that these values are inherent in the human individual. In the Preamble, the Declaration states that “*the foundation of freedom, justice and peace in the world*” is the “*recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family*” (Fleming, 1995).

The equality with which “all members of the human family” are to be treated as far as human rights are concerned precludes all attempts to exclude from moral consideration human beings deemed to be non-persons. There is no philosophical agreement in the international community as to what constitutes personhood. Accordingly, Article 6 of the Universal Declaration on Human Rights and Article 16 of the International Covenant on Civil and Political Rights (1966) require that every member of the human family be treated as a person, that “*everyone has the right to recognition everywhere as a person before the law*”.

Respect for these fundamental human values, expressed as human rights, is the essential requirement of a civilised society, even though there are some cultural differences in the expression of this respect. It stands against the eugenic temptation to reduce the value of a human individual to the sum total of its genes. Human individuals have an “inherent dignity”. The human rights documents do not give a reason why human beings are to be seen as having unique value. They simply bear witness to the fact that the international community agrees that each human individual is to be counted as valuable as any other human individual. Jacques Maritain (1954), for example, noted the practical convergence on fundamental values despite profound disagreement on ideology. Despite all the difficulties it is possible, “*as the International Declaration of the Rights of Man published by the United Nations in 1948 showed very clearly, ... to establish a common formulation of such practical conclusions*”. When one asks the question as to why these rights or values ought to be accepted the debate over the religious and philosophical foundations for human rights begins. There are also some political disputes over how human rights are to be interpreted within the framework of international law.

The ethical framework within which scientific research is conducted should also be in accordance with the ethical norms current in the culture where the research is being conducted, recognising that the degree of importance accorded to communitarian values, varies between and within countries, populations and groups. This latter point has been well acknowledged by the recognition that “*minimum ethical principles must be formulated, recognising that, in the process of collecting, the human rights of people in participating populations should be respected and that these people are partners in work rather than merely subjects of it. Any particular region may have broader ethical concerns than those addressed here, which should only be considered as a minimum*” (HGDP, 1994).

## **II.2 Research Approach and Methodology**

### **II.2.1 Informed Consent**

The importance of obtaining consent from a study population is well recognised (even if not always practised). Population genetics studies should be conducted by personnel with the appropriate qualifications, but only after informed consent has been given for any general medical examinations, and removal of blood samples (generally under 20ml) or other bodily samples. Such samples are taken to the home laboratory or other laboratories, and the components separated for analysis. The analysis of the samples requires specific consent that should be sought and given before samples are obtained (Baird, 1995). By the term “specific” consent we mean it could include consent for complete genetic analysis of the DNA, or analysis for detailed purposes, but it should be clarified and informed.

The doctrine of informed consent is applied to both medical treatment and research. Before a person is asked to consent to any sampling or treatment they must be provided with certain information. This information includes at least the following, which must of course be presented in language the patient can understand:

- a) a description of the procedure - which is generally easy, and should be risk free if accepted medical procedures are used for sampling;
- b) a description of the risks and benefits of the resultant information.

It is worth noting that the need for consent to be "informed" may be objectively impossible to achieve. Even when correct information is carefully presented in culturally appropriate ways, it cannot be guaranteed that it has been understood. The ethical obligations that are achievable include accurate delivery of information together with the disclosure of relevant risks and benefits to the individuals and communities involved, in language that is accessible to the potential research subjects, and having regard to the legitimate cultural and religious needs and aspirations of particular communities, especially in the way in which consent is ultimately given. We should not speak so much, then, of "informed" consent as of an obligation or duty on the part of scientists to properly inform potential participants.

The application of the ethical principle of informed consent and respect for integrity is a more complex process at the level of populations. In order to ensure that that potential subjects understand the goals of research, the risks involved, the use to which research results could be put, and the rights of the groups and individuals under study, careful consideration is needed. The lines between genetic testing of individuals, genetic screening within one's own population, and population genetics research of other populations and groups, are not always clear. We do not ethically require group consent for most genetic testing, though society may draw the line at the freedom of choice to use genetic probes for non-therapeutic purposes (e.g. sex selection is banned in several countries). The fact that some recent population genetic studies may involve investigation of several hundred genes between single individual representatives of different populations makes the question of group consent extremely difficult.

There are various levels at which consent may need to be obtained for studies of population groups. High level governmental approval is in many countries mandatory for studies on specific populations of persons. Such official clearances need in every instance to be complimented by consent from the individuals and the local groups/communities selected for study - whether the consent is obtained directly or through formal/informal leadership, group representatives, or trusted intermediaries.

It is important to identify the most appropriate persons with whom to communicate, the persons from whom clearance should be obtained, and the appropriate content and media of communication. Research will need to take account of the group's social organisation, goals and aspirations, cultural values and mores, and laws (both statutory and customary). If the research methods involve the use of saliva, skin, hair, or blood samples, it is necessary to ensure that the collection of these body samples does not violate cultural norms and concepts relating to the human body and its functions.

The ways of approaching the communities must always take account of the particular social and cultural organisation and laws. Sometimes the leader or the individual chief of a family or familial group is the person who gives consent for the other members of the community to participate in the enquiries and biological sampling. These persons may be difficult to identify. Of course the most difficult group consent question is who can give group consent for the genome project itself - a question that no one has been able to answer (Macer, 1991).

Various groups of indigenous peoples have expressed their irritation with past population genetics research which they claim has been conducted without prior consultation and in a way where consent was obtained in terms inconsistent with their cultural norms. Practitioners of contemporary science do not always understand that the goals and aspirations of scientific projects may not always coincide with the goals and aspirations of particular cultures. It may not be ethically acceptable to some people to co-operate in the collection of saliva, skin, hair and blood samples, for the purpose of storage and the establishment of "transformed cell lines", samples which would be basically identical to the individual of origin which are then made available for study to scientists around the world. Therefore many representatives of indigenous peoples have expressed strong concerns about the HGDP.

An important outcome of this concern and the HGDP may be the more active participation of some individuals of the community in the research projects, as well as in the better formulation of precise questions that researchers try to answer through their observation or laboratory work. These concerns apply to sampling within any population genetics project. In order to bridge gaps between scientific goals and aspirations on the one hand, and cultural goals and aspirations on the other, it will be necessary for scientific information to be communicated to individuals and communities in terms that can be understood by those communities, and if they exist, by individuals acceptable to, and counted as trustworthy by, those communities.

It will not only be necessary to identify the correct person or persons to give scientific information, but also to identify to whom the information should first be given, and what cultural mechanisms apply to the giving of consent. This will involve taking account of the fact that individualised notions of obtaining consent which tend to dominate in liberal Western societies cannot be applied "carte blanche" to people of other cultures. In secular liberal societies consent is seen as an "informed" expression of an individual's self-will and autonomy. Consent is deemed to be informed if the subject is exposed to all relevant information, including risks. Other cultures of course may place greater emphasis on the advice of leaders who represent the continuity with traditional wisdom, or with the fate of family or group members. Relevant factors for moral decision-making in communitarian societies may derive from sources not as empirically accessible as medical data.

The moral and spiritual values which have profoundly shaped the cultures of different population groups may well result in deeply held convictions regarding bodily and familial integrity (Paulette, 1993). Information about genetic inheritance is loaded with emotional, historical, cultural, and religious significance, which may differ in different cultures and religions. The form in which the consent is given needs to be culturally appropriate as well. Not all communities are governed by bureaucratic paper consent forms and written signatures. The form in which consent is given will need to be discussed and agreed upon by each community.

### II.2.2 Selection and Participation

The participation of the study group in various stages of research is one good way of keeping open communication and of developing trust between researchers and research subjects. Such anticipation may take various forms depending on the situation. In international research projects, the involvement of the local scientists, if possible, and consultation with local groups, is an effective way of ensuring that communities or indigenous populations are treated with sensitivity, respect, and wisdom.

The style and norms that have governed international scientific research have changed over time. However, the values that express themselves in contemporary human rights documents are very ancient and have become the subject of international agreement in international law. Notions of informed consent are nearly fifty years old but depend in turn on those same human values, such as respect for human life, and which derive from the notion of the inherent dignity of the human person. Scientists must think and plan research projects well. Initially this can be done independently of the persons who might become involved. However, before seeking to implement those plans they need to refine their protocols where necessary to conform to established guidelines for research on human subjects. This has not always been done. It has been recently revealed that biomedical experiments were performed on more than 23,000 persons in about 1,400 different US Defence Department projects for over 30 years after the Second World War, and in which the requirements of informed consent were neither sought nor met. The selection of target populations included soldiers, prisoners, those considered to be mentally defective (both children and adults), hospital patients with terminal illnesses, and pregnant women. Despite the fact that these were all vulnerable persons whose involvement in research needed special ethical scrutiny, informed consent was generally not sought at all or not given (Estling, 1995). Scientists need to be particularly sensitive to projects involving human subject populations that have a history of facing discrimination, and need to consider not only the detailed planning of that research but also the human rights of the potential subjects, including the requirements of informed consent.



The planners of the HGDP got off to a bad start with misunderstandings and fears widely expressed among indigenous peoples. Because the HGDP was planning to collect blood samples, some groups called the HGDP the "Vampire project" (Lock, 1994), while other groups were angry because they believed that they were possible target populations even though no community representatives had been contacted about the Project. The Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples of June 1993 is a call for a halt to the HGDP until its impact has been discussed. Article 3.5 of the Declaration calls "*for an immediate halt to the on-going 'Human Genome Diversity Project' (HUGO) until its moral, ethical, socio-economic, physical and political implications have been thoroughly discussed, understood and approved by indigenous peoples*". The Declaration is actually not anti-science, and includes a call for involvement in scientific research: Recommendation 2.11 "*ensure current scientific environmental research is strengthened by increasing the knowledge of indigenous communities and of customary environmental knowledge*".

In fact the HGDP included all populations, not only indigenous populations. Since that time, the HGDP goals have shifted somewhat, but there has been a series of declarations directed against this project (Mead, 1995). The HUGO HGD Summary Document includes ethical guidelines which do address the question of participation, consent, and commercialisation (HGD, 1994). Nevertheless, the controversy continues. In February 1995, a forum of indigenous peoples in Asia issued a statement to the European Parliament in which they strongly opposed the HGDP and called for it to be stopped (ARCW, 1995). The Beijing Declaration of Indigenous Women formulated at the United Nations Fourth World Conference on Women (30 August - 8 September 1995) demanded "*that the Human Genetic Diversity Project be condemned and stopped*" and that their "*intellectual community rights*" be recognised.

However, on 6 July, 1995, the Science and Technology Committee of the House of Commons (United Kingdom, 1995) gave its support for the project in these terms: "*We consider that the Human Genome Diversity Project could indeed lead to greater understanding of events in human evolution. If differences between populations are not explored soon, the evidence will be lost. The Project should be pursued in its total context of diversity within as well as between populations if it is not to be misunderstood or misrepresented*". However, as the project guidelines themselves acknowledge, obtaining real informed consent from the cultural diversity of peoples who will need to participate if the Project is to be a success will be a challenge.

Therefore we would urge researchers to consider the history of the group that they plan to include in their research, taking into account matters not only of scientific interest, but also the ethical, social and ideological impact on the group, as a consequence of the research. The funding mechanism for the Human Genome Project in the European Community was delayed until a system for funding ethical, legal and social impact (ELSI) issues was established. In Canada up to 13% of the Human Genome Project has been spent on ELSI and educational issues, and in the United States of America 3-5% is allocated. We would also urge HUGO to continue its commitment to looking at these issues from an international perspective. Their ELSI Committee has met only twice: first in 1992, then in October 1995 to focus on population genetics, and plans to meet in 1996. The ELSI issues do not only relate to genome research, but to all of genetics and science.

## **II.3 Utilisation of Research Results**

### **II.3.1 Confidentiality**

As has already been well documented from the practice of genetic screening, the personal impact of genetic information is significant. These issues, related to individual privacy and possible abuse of genetic data by insurance companies and employers, have already been discussed in the IBC Report on Genetic Screening and Testing of 1994.

DNA collected from population groups would present analogous problems relating to the adequate protection of privacy (Annas, 1993); but the meaning of privacy could vary across cultures. Furthermore, it is important to note that in population genetics research confidentiality issues have to be considered at the community level as well as at the individual level.

One way of ensuring confidentiality for individuals would be not to collect or keep identifying information in the central repository. This would, however, limit the scope of research that could be done. Confidentiality for individuals in human population genetic research may be protected to a certain extent through coding and anonymity, with strong safeguards to protect the identifying information that is kept in the central repository. There may be cases where useful information for a person may be found, which may be released to individuals who should have been asked, when the information was collected, whether or not they want to know.

Confidentiality is more difficult to maintain at the level of communities. Although information regarding the identities of community samples may be restricted, in all probability, anyone who really wanted to identify communities may be able to do so. The difficulties involved in guaranteeing the maintenance of absolute confidentiality of communities and population groups should be discussed in the process of obtaining informed consent.

If all members of a community, or a population group, were found to have a gene that predisposes them to a common late onset disease, for example, could that information be protected? Health insurance companies could cancel or refuse health insurance to a population, in the same way that health insurance has been denied to individuals or members of a family in countries that do not prohibit genetic discrimination by law.

In several countries, these cases have led to legislation on genetic privacy. Although the principle of confidentiality is included in the "Outline of the UNESCO Declaration on the Protection of the Human Genome", further national efforts to protect against such abuses may be required. Nevertheless, it should be noted that in the future it is possible some genetic information about a particular minority could be exploited by States for political purposes, leading to further repression or to justify continued repression.

This also raises the question of who should be in control of the genetic information that has been collected. For example, if national governments want the repository to be in their country and subject to their control, should this be allowed? Although the keeping of genetic information on Third World populations in central repositories of the west may be politically objectionable, the idea of maintaining repositories in a country under a repressive regime is certainly not preferable. One of the main issues is whether the genetic information is predictive or identifying.

### II.3.2 Patents and Financial Benefits

Patenting has become an issue in population genetics primarily in relation to the patenting of products derived from the genetic material of indigenous peoples. In 1993, a patent filed by the United States government on the cell line of a 26 year old Guaymi Indian woman from Panama was opposed by the Guaymi General Congress, the World Council of Indigenous Peoples, the Rural Advancement Foundation International, and the World Council of Churches (*RAFI Communiqué*, Jan/Feb 1994). The patent claim was subsequently withdrawn, but on 14 March 1995, genetic material isolated from a man of the Hagahai people from Papua New Guinea's remote highlands was patented in the United States of America, and the decision maintained after challenge. Other patent claims are also being opposed (Butler, 1995).

These patent applications have served to cast deep suspicion on the motivation behind human population genetics research in general. Although the primary aim of most researchers is the pursuit of knowledge, and not commercial gain, and scientists with other motives may be excluded from particular projects as the HGDP maintains, nevertheless, the possibility is that products derived from genetic material collected in population genetics research could be patented for commercial purposes. Moreover, as in the case of *Moore vs. Regents of the*

University of California (1990) (Nuffield Council on Bioethics, 1995) where the Supreme Court of California ruled that John Moore does not have property rights in the cells taken from his body, the people who take part in population genetics research may stand to gain nothing from whatever patents that are granted on products derived from their genetic material.

At present, opposition to patenting of human genetic material is being mounted on two levels. On the first level is the opposition to any patenting of "life", which includes microbial, plant, animal and human life. The grounds for this may be religious, or cultural. Some indigenous groups have voiced their objections on this premise. Indeed, the patenting of naturally occurring life-forms is objectionable for many cultures. Since genetic material is seen as part of what constitutes life; as such, patenting transforms this material into a commodity that can be owned and traded in. There are a variety of arguments that are used to support this position, including lack of evidence that patents do stimulate invention, distinction between discovery and invention, need to allow access to the organisms, extended protection, the ideas of biotechnology were developed in the public, there is no special reason to privatise public goods, and a need for uniform utility patents (Busch, 1995).

On the second level, patenting is opposed on the grounds that people from whom genetic material is taken are not likely to receive any financial benefits from it. This opposition arises from past experience in which large corporations have collected genetic material and knowledge from the Third World and from indigenous populations, and then used these to develop and patent agricultural and pharmaceutical products without any benefits accruing to the original donors of the material or of the knowledge. When the International Board for Plant Genetic Resources was funded in the 1970s, for example, it created a public domain resource of 125,000 plant germ-plasm specimens. In fact, more than 90% of all the plant germ-plasm collected in the South in the last two decades has ended up in gene banks in Europe and North America (*RAFI Communiqué*, 1993a). This material has been the source for the development of products worth billions of dollars to farmers and agribusiness in the industrialised world as companies have subsequently obtained patents on hybrids. This is considered unjust by some Third World countries and NGOs because the generations of traditional farmers who had contributed to their identification, selection, and cultivation get neither financial benefit nor recognition. The same is true of pharmaceutical compounds; and, it is feared, may become true of human genetic material.

The Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples of June 1993 includes several recommendations to member states of the United Nations. Recommendation 2.7 states that "*commercialisation of any traditional plants and medicines of Indigenous Peoples must be managed by the indigenous peoples who have inherited such knowledge*", while Recommendation 2.8 demands that "*a moratorium on any further commercialisation of indigenous medicinal plants and human genetic materials must be declared until indigenous communities have developed appropriate protection mechanisms*". The Declaration also would like the promotion of a "*co-operative rather than competitive framework*", and an "*increase in the involvement of indigenous communities*" in "*research and training as well as education*", that would make them participants in the process of development of industrial goods from human genome research, and beneficiaries of possible commercial profits rather than being simply suppliers of samples that may eventually lead to significant therapeutic discoveries. The same concerns have also been expressed in the Asian Regional Consultation Workshop on the Protection and Conservation of Indigenous Knowledge meetings in 1995 (ARCW, 1995).

Besides these two levels of opposition, there is also debate about what exactly may and may not be patented under patent laws. One of the first declarations on gene patenting is the ICSU Statement on Gene Patenting in June 1992, which states: "*Information about nucleic acid sequences cannot be patented per se. Such sequences should be patentable solely within the context of their demonstrated significance and/or application and not of their potential products*". Furthermore, it was clearly explained that only inventions, whereby humans construct new elements that can be used, may be patented. Discoveries of natural laws, mechanisms, or elements are not patentable because no one has the right to monopolise a discovery. Identification of the genome and of the genes of which it is made up, and of the nucleotide sequences which describe the composition of these genes, constitute a discovery. As such, the human genome cannot be patented *per se*.

It is also argued that the human body (and its component parts) cannot be regarded as an asset, it cannot be marketed, and hence cannot be a source of financial gain (Pompidou, 1994). This is also discussed in the Draft European Convention of Bioethics, Article 11, which states: "*The human body and its parts shall not, as such, give rise to financial gain*". However, in note 90, it is stated that this does not apply to discarded tissues, such as hair and nails, "*the sale of which is not an affront to human dignity*". This is important to note because DNA can be obtained from discarded tissues. Nevertheless, we would like to point out that in some cultures, for example certain North American Indian cultures, this assumption is not true. Hair, even when cut, for example, has religious importance and is not regarded as discarded. The assumption that the sale of discarded tissues is not an affront to human dignity might not be valid for cultures other than those in Western societies.

Patenting has also been opposed on the grounds that it limits free and open scientific exchange, as well as access of researchers to genetic materials for research. Researchers require access to some major cell line collections, and one of the goals of population genetics research, such as the HGDP, is the creation of cell lines. Patents have already been granted on immortalised cell-lines and hybridomas which are useful in research or as monoclonal antibody sources for research and diagnosis. These cell lines are kept, reproduced and distributed by commercial companies, mainly the American Type Culture Collection (ATCC) in North America and the "Centre d'Etude du Polymorphisme Humain" (CEPH) in France, which charge for requested samples, as these services are expensive and laborious to maintain. In 1994, there was debate over the commercial access to DNA collected from 800 French families in the CEPH. The issue was divisive, as some founders wanted to ensure free access, while on the other hand, there were claims that exclusive commercial access would increase support (e.g. *Nature* 368 (1994), 175, 575). Eventually, the pressure led to the claim for exclusive commercial access being dropped.

Patents on these materials will require the payment of royalties which will in turn severely limit the access of scientists from poor countries to research carried out by scientists in the developed countries. This will exacerbate the gap that currently exists between North and South. The issue of patents is a primary concern of Third World scientists, who feel that their countries may end up being suppliers of genetic material for population genetics research, but they may end up having to pay for the products of these research outcomes.

This will be a barrier to Third World countries developing their own scientific strategies in the field of diagnosis and therapy based on publicly available gene sequences. And what if human genome patent claims are extrapolated to gene sequences of micro-organisms endemic in these countries? Would they also have to give up royalties for vaccines, designed by scientific teams from poorer countries against malaria, leishmania, chagas and other diseases, the micro-organism sequences of which are protected by an industrialised countries patent?

We note that public opinion in many parts of the world is against patenting of human DNA (Macer, 1994), although we recognise that the issue is complex and that there needs to be some protection of commercial investment in research. Most research funding is currently judged as an investment, and the trend is to become even more commercial. This trend is indeed a worrying one. By prioritising the objective of financial benefits, scientists are led by the possibility of commercialising research results rather than what many consider to be the nobler aim, the discovery of knowledge.

Accordingly, this working group recommends that patenting should be limited to new applications and processes which may be developed in the course of human population genetics research, and that conditions should be developed to ensure free access and use by researchers everywhere. In the event of the possibility of population genetic research material giving rise to patentable products, the principles of informed consent should be observed, and a mutually agreed upon mechanism should be worked out in ensuring that potential financial benefits flow back to the donors of the original genetic material.

This should not be on the basis of the sale of blood or other bodily tissue but on the basis of their co-operation in a scientific program which may bring large financial rewards to the companies involved, or those secondary companies which utilise the results. Care should

be taken to ensure who is the legitimate beneficiary of commercial benefits; that is, whether it should be the national government or some sort of trust fund for the population group. Benefits returning to Third World countries for example, may not necessarily benefit the indigenous populations from whom the samples were taken. We also note that no undue compensation should be offered to ensure participation in sampling (Knoppers et al. 1995), which may be extremely difficult to control given the one-sided power relationship in the poorer areas of the world. We see the return of financial benefits in terms of communities not individuals.

### II.3.3 Return of Research Results to Subjects of Research

It should be remembered that financial returns are not the only form of benefits of research results which could be returned to subjects of research. Perhaps a more important aspect is the return of information and research results to the communities from which data was collected. There are research projects, for example, which plan to write their research analyses and conclusions in popular form which are accessible to the communities so that they could be helpful to them in promoting concrete responses to particular problems.

The feedback of results to the communities concerned should also help to foster a greater sense of community identity in the face of aggressive cultural imperialism by industrial superpowers. But perhaps the most poignant problems of many populations involved in population genetics research is in the realm of public health. This, however, cannot be understood just as a diagnosis of symptoms and consequent medical treatment. In indigenous communities these problems are usually an intricate result of the breakdown of a traditional well-adapted cultural as well as biological relationship to the environment, due to economic and political pressures from the dominant society. At the individual level, the results of physical examinations and clinical diagnosis and options for treatment are sometimes communicated to each participant in the local languages through local health authorities and doctors as soon as possible. This is so as to utilise the health data collected for the improvement of community health, especially in the remote areas or areas with poor health services. The provision of health and medical care, however, should be appropriate to the cultural and social context of the community and should be sustained. In this, the principles of primary health care as contained in the Alma-Ata Declaration (WHO/UNICEF) of 1978 should serve as a good set of guidelines to follow.

At the community level, the health data could be utilised for the improvement of local community health. Thus, benefits should also flow back to the groups and communities in the form of contributing to the formulation and implementation of local and national health care policies that would enable communities to better their positions. These policies, as well as the health care services which are offered, should of course be decided upon by the communities.

Commercial benefits discussed in Section II.3.2 could be expressed in other ways. While there could also be provision for a one-time gift of cells or blood with no conditions, as is found in some tissue donation forms for blood and body tissues, can one individual sign away commercial rewards to future research knowledge for the population to which they belong? It may be technically possible to conduct population genetics research among students of an international university, with them giving their cells to science. It is a difficult ethical issue which we have not resolved, which while it has until now been ignored, we consider to be important.

### II.3.4 Implications of Knowledge from Population Genetics Research

Some challenging implications may arise from the better understanding of human history that population genetics research could provide. The new knowledge from such research could be used to educate people of indigenous groups that would help protect their interests. On the other hand, new knowledge of human group evolution and the relationships of particular groups to others may challenge existing world-views. Some population groups have strong beliefs in mythologies or cosmogonies which explain group origins and identity, and the return of data that challenges the accepted beliefs could be a delicate issue.

Population genetics research may also throw new light on the questions of who were the first inhabitants of regional areas, the historical relationships of populations to current national boundaries, and who has the right of government. Governments may fear that indigenous peoples will be able to use the claims of prior settlement to push land claims. Which inhabitants of which time period would we consider to be the legally entitled owners of land that had been successively colonised? Population genetics data may confirm or reject the information obtained from archaeology or history. In the West Pacific for example, recent population genetic studies show that settlement was from the West not from the Americas (Clegg, 1994).

Some would say that population genetics will not tell us anything within a time frame that could make valid legal claims under a common or civil law approach (Greely, 1995). We could also say that we already know much of human history, and indigenous peoples' claims to prior settlement may be ignored despite the clear knowledge that they were there. If ancient DNA samples are collected and markers used to trace the contemporary descendants, for example, this could be used to find the genetic descendants, but these may not be considered to be "legal heirs" to the land under most legal traditions. It is beyond the scope of the International Bioethics Committee to consider changing the legal system of ownership that tends to overlook European colonisation of the past few centuries, but we should note that there are recent legal rulings which support indigenous peoples' original titles to government lands in Australia and New Zealand.

### II.3.5 Other Issues Arising from the Use of Research Results

One fear that has been expressed about population genetics research is that access to and knowledge of a community's complete genetic make-up make it theoretically possible to devise cheap and targeted biological weapons trained solely on that community (*RAFI Communiqué*, 1993b). Given that greater genetic diversity exists within any particular population group than among population groups, it is highly unlikely that specific genetically-based genocidal weapons could be developed for specific population groups. Unfortunately, other methods of so-called "racial cleansing" are available. In this respect, restrictions on biological warfare which already exist in international law should be further strengthened.

The issues of discrimination, eugenics, stigmatisation and other ideological uses and abuses of genetic research on populations are discussed in the following section. Eventually the genetic data could be used for genetic therapy and intervention. Many of the ethical issues are summarised in the Report of the IBC on Gene Therapy of 1994. Although it appears unlikely, it is possible that in the future a population or society could agree to the general use of a genetic vector to provide a medical benefit, such as immunity to an infectious disease, or compensation for a common genetic disease among a particular genetic population. Such an issue is related to the extent that traditional vaccination programs are compulsory or voluntary, and we note that such programs are, and should be, generally voluntary although public information campaigns may encourage participation.

## **III. Public Understanding**

### ***III.1 Ideologies***

Public attitudes towards population genetics are often based on social ideologies, racism and eugenics, and can well lead to stigmatisation and genetic reductionism. The ideologies of racism and eugenics are human artefacts, socially and politically constructed, and may well prove impervious to scientific proofs. Indeed, such ideologies may improperly appropriate scientific findings to further advance and legitimise social and political programs. Research scientists need to be aware of their own assumptions and philosophical presuppositions as well as the assumptions and philosophical presuppositions of others, and to be prepared to work within a general framework of respect for human rights as expressed in international law. The pursuit of scientific enquiry as a means to legitimate ideologies is a temptation that should be resisted. Without paying attention to these issues, scientists themselves may sometimes find themselves unwittingly involved in unfair manipulations of their intentions or results, in the name of diverse ideologies.

Scientists themselves are not immune from the usual array of assumptions, dislikes, biases and prejudices, that beset the wider community. Unfortunately scientists have at various times in history believed themselves to be working in a value free domain, gathering the pure crystals of data and indeed trumping other human values and concerns in their pursuit of ever higher degrees of scientific knowledge. As Alasdair MacIntyre has observed (1982), it is a mistake, albeit "a pertinacious and long-lived one", to imagine that an "observer can confront a fact face-to-face without any theoretical interpretation interposing itself". But while philosophers of science may now be largely agreed that "this was an error", it is still a temptation for scientists to imagine that you can stare a fact in the face and view it just as a fact.

This is not to assert that there are no such things as facts but only interpretations. It is, however, a recognition that facts are observed by persons and that the reporting of facts may be distorted because they are interpreted by a particular individual with a particular mind-set, because of the frailties and limitations of the observer, and because the observer fails to see the fact in its overall context. It is in the recognition of this problem that scientists themselves may become better at and more cautious in interpreting the data before them, and more able to appreciate different interpretations of the same scientific data.

To standardise the way in which the scientific enterprise is best put in service of humankind, it is necessary for scientists to have regard to those human values upon which human beings are agreed, and which human beings agree need to be defended for the full flourishing of the human community. These agreed values may be found in the human rights documents of the United Nations, values which are in harmony with the world's deepest aspirations as to what it means to be human and living in solidarity with other human beings, and in harmony also with the moral insights of the religions and philosophies which have helped shaped the various human cultures. Since science itself has emerged from the traditions which favour the search for truth, for explanation of the natural world, then the scientific enterprise is at its best when it is pursued in harmony with the other values which also contribute to human flourishing.

### III.1.1 Racism

Population studies in the past have shown that most of the genetic diversity is to be found within every race or population, and if this is further confirmed to be true the typological classification of humans into different "races" is scientifically invalid. Nevertheless "racism" as an ideology and as an attitude is a human reality. Population geneticists point out that population genetics offers no scientific basis for the belief that certain races (however defined) are superior to other races. Indeed there is a greater diversity within populations than between populations. However, care needs to be taken in the way such an argument is formulated. Because of the potential for abuse of population genetics, we consider racism and eugenics as important issues of population genetics to consider, although some in the scientific community do not. Variation between individuals or groups could be (but not necessarily) associated with evaluative notions of "superiority" or "inferiority", and thus foster racism as some have suggested genetic counselling does.

Population studies in the past have shown that most of the diversity within the genes studied is to be found in every race or population and, if this is true, then this information could be used to combat racism. Since current population studies show that the typological classification of humans into different 'races' is scientifically invalid, we should avoid the use of the term "race". Population studies include linguistic and anthropological studies (Marks, 1995). Some such studies have been misused in the past, and today, and need to be treated with appropriate expertise and care by the investigators.

Historically, Third World people in general, indigenous people in particular, have been the objects of research by scientists from developed countries. The history of anthropology is based on the study of "exotic" races and anthropologists operated within the prejudices of their age. One example of this is the craniometry research that was done in the second half of the 19th century when Western scientists measured craniums and ranked races by their measurements. By their ranking, the white man is the most superior race, and the black man the most inferior, comparable to apes (Gould, 1981). We should also note that religious discrimination is often linked with ethnic discrimination.

The World Council of Indigenous Peoples was upset by the discussion that cells should be gathered from populations at risk of disappearing (Roberts, 1992; Pahr, 1994). At that time they mistakenly thought that the HGDP was aimed exclusively at sampling from endangered populations, which it should not be (Majumder, 1995). However, the HGDP does not contribute to the demise of the population groups it studies.

With the burden of this recent history, it should be no surprise that many Third World and indigenous people view Western research with suspicion. Researchers have responded to this by evolving research methods which involve their subjects in a more participatory fashion, or by developing research projects which not only aim to study, but also to share research findings, and whatever benefits which accrue from it, with their subjects.

Indigenous peoples' organisations now question the purpose behind research that is done on indigenous population groups. In certain parts of the world, indigenous peoples are facing cultural extinction. Where there is mass logging of tropical rain forests, for example, indigenous people who live there are depleted of food and water resources, and driven from their homes. They eventually join the ranks of waged labourers in logging camps and cash crop plantations. As their social fabric breaks up, they are in danger of losing their identity and culture. The struggle to survive as a people is a pressing concern of many groups. In this context, the call for researchers to collect genetic materials from indigenous populations, before they disappear as distinctive genetic groups, may appear to some as grossly insensitive and callous. Furthermore, if such research receives funding from governments, the money and resources could be channelled from other pressing needs.

Populations have mixed in the past and mix more today, and some cultural anthropologists suggest it is difficult to define linguistic and genetic populations (Lock, 1994). In attitudes to bioethical questions we also find broad diversity across many cultures. This is seen in the International Bioethics Survey performed in 1993 in a variety of countries, where there was a similar range of diversity of ideas in numerous open response questions on issues such as images of disease, nature, life and genetic technology in each country, and the range within each country corresponded to the same range found between all (Macer, 1994). In this way we could see cultural diversity in a similar way to genetic diversity, neither supports the notion of race. It could be said that health discrimination and cultural or religious discrimination tend to spread and substitute for "race" discrimination, although they all involve the labelling of groups of persons.

It has been amply demonstrated that, while there is a wide range of diversity between human individuals, the average differences among human groups are small. Accordingly, there is no scientific basis for believing that there are races which are more "gifted" or "smarter" or "better", and thus racism is not supported by contemporary scientific research. However, this argument needs to be carefully expressed or it may unwittingly appear to rely on the assumption that if you could in fact demonstrate that some races were more "gifted" than others, had "better" or "smarter" genes than others then those races would be superior, and the other races inferior.

All population genetics research should be carried out in a way that is sensitive to the ethical obligations found in international law. However, we should also be clear that those who seek to use the findings of population genetics to support movements and ideas which are hostile to fundamental human rights will no doubt do so. The correct response to this is not to say that the findings will prove the opposite, i.e. fight against racism, but to recognise that what science finds is what science finds, and these findings should be put in support of fundamental human rights which derive from the universal belief in the inherent dignity of the human individual. Such values cannot be "proved" by science, and neither can they be "disproved" by science. UNESCO should actively encourage greater public acceptance of variation and vulnerability, and promote the value of human diversity. While there are fundamental human values which should form the basis of all bioethical reflection we should nevertheless have regard to those other cultural values upon which all societies are not necessarily agreed, learning to respect the different ways different societies do their ethics.



### III.1.2 Eugenics

Eugenics, a word coined by Francis Galton in 1883, was defined by him to refer to the "science" of improving human stock by giving "*the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable*". While Galton associated eugenics with racism, the new eugenics proposed since the Second World War is not necessarily racist but refers to the elimination of inherited genetic defects either by genetic counselling backed up by abortion and even infanticide, or the improvement of an individual's genetic inheritance (cf. Kevles, pp. 251-268). So eugenics, and with it notions of "superiority" and "inferiority", does not have to be applied to race.

Indeed it is a mistake to identify eugenics only with racism. Eugenics stems from habits of mind, from the desire to protect "my group", and from a negative attitude to persons with physical or intellectual disabilities. Contemporary eugenics is generally not so much racist as it is connected with a desire to limit the number of people whose lives are held to be of such low quality that such lives, in terms of the burdens that they impose on societies as well as the affected individuals, are not worth living. It is naive to imagine that scientists as scientists cannot be racist, eugenicist, or paternalist.

The danger is that genetic findings may be inflexibly interpreted as the only story of human, biological, and cultural evolution. In the first decades of this century, the racial hygiene movement, relying on eugenics based on a mistaken science, proposed negative attitudes to whole groups of human individuals. By the middle of this century eugenics had fallen into disrepute. But today, increasingly more strength is being given to genetic explanations of human behaviour, as can be seen in the scientific and popular press over the past decade (Nelkin & Lindee, 1995).

Eugenics can and is practised within a population precisely on the basis of "genetic reductionism", that there are some lives which, it is popularly claimed, constitute a burden to the community, to the individual concerned, to that individual's family, and whose quality of life is so low that these lives are not worth living. Such eugenics has nothing to do with race, but is based upon disability.

The problem is that in the way that the argument is often expressed there is an underlying assumption that genetic differences between individuals constitute a rational basis for labels of "superior" and "inferior". The point is that eugenics is built upon an attitude that seeks its justification in science, just as racism is an attitude that may seek its justification in science. These are habits of mind and ways of thinking philosophically that are hostile to the key notion of the inherent dignity of the human individual and the inviolable and inalienable human rights that arise from the international consensus about the value of human beings. Human value does not change according to health, sex, race, theories of personhood, or any other factor.

With both eugenics and racism we are dealing with political and social constructs and not scientific categories. Eugenics may also be linked to distaste of persons with disabilities, to Nietzsche's idea of the threat that the disabled and chronically sick pose to the healthy (Nietzsche, 1910), and to the economic burden on the community which comes from the provision of long-term care for the disabled, the elderly, and the chronically sick. It is very important to realise that scientific information, in and of itself, is never likely to significantly undermine race as a political category or eugenics as a political and social movement.

We should not have the misconception that eugenics is a thing of the past, although, in present times, eugenics may express itself in not so obvious ways. For example, there are cases where insurance companies have cancelled policies of families who include a member found to have a genetic risk factor for a disease. This has been called genetic discrimination (Billings, 1992).

It should also be noted that present day eugenics has been expressed at the level of national government policies. For example, the population policies of the Singapore Government is guided by eugenics - women who graduate from universities are encouraged to bear more children in the belief that their children have higher "intelligence", while less-educated women are offered disincentives to have more than two children (Chee & Chan, 1984).

It may be pointed out that the inclusion of a many groups of people as possible, including groups of persons at risk of eugenic discrimination or at risk of racism, could work against racism as the total human race will be represented in genetic maps and libraries, if we compare it to the situation where the human genetic map was only derived from one population. The concerns that persons who suffer from particular diseases have of discrimination increasingly voiced in relation to contemporary developments in genetics research. The Report on genetic screening and testing of the IBC discusses some of these issues.

### III.1.3 Stigmatisation

Stigmatisation may occur when population groups in which there is a high incidence of genetic disease are selected for scientific investigation thereby drawing attention to their genetic differences. Care needs to be taken that targeted groups do not become stigmatised in some way simply because they are of scientific curiosity, or because they are more frequently studied and more is known about them they seem to have a greater predisposition to disease. Such stigmatisation can lead to unjust discrimination.

It is not surprising that some people are suspicious of genetic research which appears to have selected them for scientific investigation. Understandably they can see a danger that researchers in these projects will target the most "interesting specimens", because they are a fading population group. Nevertheless, the scientifically and ethically legitimate aspirations of population geneticists ought to be encouraged even where they are misunderstood. Where misunderstandings do occur, and they can occur on both sides, participating scientists, potential research subjects, and pressure groups need to be sufficiently open to each other to allow opportunity for those misunderstandings to be discussed and resolved.

### III.1.4 Genetic Reductionism and Holistic World Views

"Genetic reductionism" is used to refer to the evaluation of individuals with reference only to their genetic inheritance. Western science has frequently sought to explain the whole by a greater knowledge, by a part that is deemed to be most fundamental. Some researchers, pursuing Darwinian theory, propose an explanation of human beings in their origins as well as their evolution by reference only to DNA. Individuals have been categorised according to specific markers of inherited susceptibilities. Whatever the theoretical and scientific benefits of such categorisations, research scientists must always have regard to a more holistic appreciation of human beings, considered both as individuals with an inherent dignity, and as communities living in a given environment and culture.

It is precisely at this point that the objections of some population groups to population genetics have been most forcefully articulated. It is a mistake to imagine, for example, that opposition to certain research projects is based upon misunderstandings and confusions about scientific aspirations, and how the scientific information will be used. It is much more fundamental than that. It is a clash of philosophy and cultural insight concerning our understanding of the origins of humanity, the responsibility of individuals and the safety of the community in terms of past, present, and future generations. For many indigenous peoples, the dignity of their ancestors are "*in our blood, our hair, our mucus, our genes*", accordingly some research projects are seen as an unwelcome interference "*in a highly sacred domain of indigenous history, survival and commitment to future generations*".

The categories of populations that are chosen include those that can answer specific questions related to contemporary 'ethnic groups', language groups and cultures. Populations that are anthropologically distinct, that are linguistic isolates, and those in danger of losing their genetic identity will be chosen, as well as populations that are dominant in particular regions. The dominant population groups have nothing to fear, however some members of minority groups are already at risk of ethnic attacks and are therefore sensitive to any information that could be misused against them. For example, if the genetic knowledge can be used to classify them as distinct, e.g. French have a gene to make them good wine-makers and drinkers, it could become a point by which they are ostracised - though, the information could also be used for admiration. The usual cause for loss of genetic identity is not racial cleansing but the genetic admixture caused by intermarriage between different population groups. We could also expect concern from those groups who are also physically threatened by attempts to eradicate them, such as Kurds in Iraq, Tutsi in Rwanda.

If genetic reductionism derives from a misunderstanding of science and is suggestive of discrimination against a "genetic underclass", it also represents a threat to those mythologies or cosmogonies which are different from the dominant world cultures. The sensitivities and legitimate cultural and social norms of particular population groups have to be respected and honoured in any population genetics research. One of the ways to address the concerns of groups of persons at risk of eugenic discrimination, or at risk of racism, is to have good communication with disability support groups and ethnic communities. For example, Australian aborigines have suffered racism since European colonisation of Australia, and they have expressed concern that decisions about the research were made independently of them - largely in the United States of America or Europe. The planners of population studies in general could counter these concerns and the risk of actual abuse, by including the indigenous peoples in the planning stages as well as in the ethical discussions of these studies. "*The human rights of people in populations should be respected*", and these people should be seen as "*partners in the work rather than merely subjects of it*" (Cavalli-Sforza, 1994).

One of the fundamental points of opposition of indigenous groups towards genetic studies of human history is that the results may contradict indigenous people's views of oral and traditional history, and the meaning of genes and genealogy. For example, Maori people have two words to describe the human gene, one meaning "life spirit of mortals" (*Iratangata*) and the other genealogy (*Whakapapa*), which connects Maori with themselves and others (Mead, 1995). The gene and genome are not the property of individuals but rather are part of the heritage of families, communities, tribes and entire indigenous nations. In this regard, the UNESCO position on the human genome being part of the common heritage of humanity is more compatible with the views of indigenous persons, than the view discussed in the patent section of those seeking patents on genes.

One response to the opposition has been to place some distance between population genetics research and patents by asserting that patenting is not the primary purpose of such research, and that, in the event that genetic products of the research are commercialised, financial benefits would be shared with the people from whom the genetic material originated. Although some have found this acceptable, others have pointed out that this only serves to incorporate indigenous peoples into a system that views living organisms and community knowledge as commodities which can be patented, "owned", and traded.

The discussion on the ethical, legal, and social issues arising from human genome research reflects a particular world-view, which has arisen in the context of a world economy that is dominated by the multi-national corporation's drive for profits. The wrangle over patents, for example, reflects this world view. Yet, an alternative world view is evident when researchers gather germ material from peasant farms and tropical rain forests, and acquire knowledge and expertise from indigenous peoples and peasants, without being asked a single cent in remuneration.

Indigenous peoples' organisations have begun expressing their own value systems and discussing ways of conserving and protecting indigenous knowledge and culture. In the process, they have opposed the patent system as being fundamentally in conflict with their own value system. One analysis refers to the indigenous value system as the "*co-operative innovation system*", and that of modern science as the "*institutional innovation system*", and calls for the recognition of the contribution and value of the former toward the world's food supplies, farming systems, and medicinal needs (RAFI/UNDP).

### ***III.2 Bioethics and Genetics Education***

Public understanding of population genetics requires bioethics and genetics education. Such education has universal support. The questions are: what? by whom? to whom? and who pays? Bioethics and genetic education has been called for also in the Report on genetic screening and testing of the IBC, and is consistent with the founding goals of UNESCO. Population genetics research involves contact with and sampling of different populations. This presents opportunities to involve researchers and participants in a two way process of education.

As discussed above, the researchers should involve local participants in the research. This presents a chance for advanced genetics training, and training in taking consent and consultation from participating groups of people, not a concept currently found in the local scientific or legal environment! Researchers should also develop collaboration in the international context. Indeed, the process of anthropological research actually involves education of the researchers in the local customs and beliefs, which can then be shared with the rest of the world in efforts to help understanding among peoples. In this way all can learn through research.

The people participating in the research will be able to learn of the reasons why the sampling is sought and of the research goals. They may be interested to meet people from out of their community, though the contact should not create expectations which cannot be fulfilled. There is the need to share results. Some representatives of indigenous populations, however, have expressed concern that they do not want to know the results of scientific studies that challenge their local understanding of history. There is also the education of researchers during the process of their search negotiations and of the results of any investigations, of the attitudes of local groups and populations. The process of anthropological research actually involves education of the researchers of the local customs and beliefs, which can then be shared with the rest of the world in efforts to help understanding among peoples.

In this way all can learn through research that is entered into with a willing spirit to learn. There are further issues that need special attention for population genetics, especially those discussed in the ideology section above. Racism and eugenics are deep-seated attitudes, often related to a desire to protect the power of "my group", rather than rationally arrived at positions. It is generally believed that the misuse of genetics also depends to some extent on the level of education of genetics that people have. If education of genetics, as well as the bioethical issues it raises, is increased, many hope this would reduce the tendency for racism. Contrary to this, however, in the first part of this century most educated biologists supported eugenic thinking (Paul & Spencer, 1995). Some would maintain that social eugenic programs of that time were based on false genetic knowledge, however, either interpretation of history illustrates the power of education.

There is a need for public and student education. Advances in biology and medicine have generally led to pressure upon educators of how students can be prepared to face the ethical dilemmas that the technology often raises. In school and university education during the 1960s to 1990s, in many countries, science has been taught independent of social or ethical values. However, science educators have discovered during the last two decades that the most efficient way to educate science is to discuss the science together with examples of technology and put the facts into the social context. This method of teaching is generally called the Science, Technology, and Society (STS) approach (Ramsey, 1993). Bioethics is one part of the approach of STS. There are a diversity of views on how to effect efficient education of social issues and even the science itself (Waks & Barchi, 1992), however, the point is that students learn more science when it is combined with practical applications. The problem is that value education has also been abused in the past to promote discrimination, and the weight of the word "scientific" can make people believe that such a value is also scientific. There is a need to work on what can be taught, and to promote decision-making, and recognition of human diversity.

The funding of educational efforts obviously cannot be absorbed totally in the budgets of the population genetics research. Therefore, there should be some commitment of the funds to education found in the Human Genome Project research programs for ethical, legal, social impact and educational issues.

## **IV. Conclusions**

### ***IV.1 Summary***

Recently research involving human subjects has become more regulated. In addition to international bodies such as UNESCO or HUGO, and national funding agencies, there are already national laws in many countries to involve local research ethics committees, such as Institutional Review Boards (MacKay, 1993). Current population genetics research is under

the oversight of different layers of control which vary widely around the world. Some research is only under the discretion of individual researchers, most seek consent from the persons who provide the tissue samples, and the international regulations on research involving human subjects are clear that informed consent is needed. Some funding agencies demand ethical review, such as NIH-funded research in the United States of America. Some universities in the world also demand ethical review, and the trend is to have more review. The HGDP being an international project will demand international standards of consent and confidentiality, which when appropriately implemented in the local situation will be at least as good as ethical guidelines for existing research.

In addressing the ethical, legal and social issues of human population genetics research, several points of principles need to be considered. The body entrusted with the responsibility of overseeing such research should include substantial and legitimate representation of the target populations. Indeed, a wide representation of people's groups should be included in all stages of population genetics research projects. Considering that the protection of the intellectual and cultural property rights of the sampled populations is a legitimate concern, specific mechanisms on how to protect these rights ought to be formulated. Furthermore general statements of possible benefits flowing from research projects to local populations, such as the HGDP's claims that it will lead to the development of scientific laboratories in local areas, should be formulated concretely and specifically so that it becomes obvious how this will happen.

The International Bioethics Committee of UNESCO needs to consider whether they should outline some principles of ethical guidance, and give further explanation of practical measures and procedures. As has been pointed out by Majumder (1995), member of HGDP Executive Committee from India, in some countries the positive image of a United Nations body such as UNESCO would ease the concerns of local politicians and groups if they were to take a direct interest in the oversight of the HGDP. In fact as we observed during the consultation process during the drafting of this report, some researchers and some population groups have asked UNESCO to review the ethical issues, and to establish a committee to continue the ethical review of the research, and proposals. However, this would require the development of more detailed guidelines addressing the ethical and commercial issues raised by the HGDP. Such guidelines would also be useful for general population genetics research. In any case, detailed guidelines should involve local authorities (communitarian as well as national) at first, to ensure that communitarian and national concerns, interests and conditions are fulfilled and respected.

The broad involvement of UNESCO, WHO, CIOMS, HUGO, ICSU, and possibly other bodies within the regulatory committee is important. There is a need to include representatives of people's groups in all stages of population genetics research projects, and in the oversight committee. In North America the HGDP committee has included two representatives of indigenous peoples groups, and this should happen in a global sense, though we must ask who are suitable representatives. The answer to this may depend on the locality and situation, and should be flexible.

Regarding the HGDP, the scientific goals are generally valid, and the HUGO HGDP Committee has produced a good introductory report on the reasons for the HGDP (HGDP Summary Document, 1994). The North American HGDP regional ethical committee has produced detailed guidelines, which has progressed the ethical review of future population genetics studies conducted within their auspices (Greely, 1995). The ethical guidelines do take account of the critiques of most writers, however, we can say that the organisers would have received less critique if they had more actively involved leaders of indigenous people's groups in the planning of the project. Indigenous people's organisations have opposed the HGDP on several bases, a fundamental one being that, while many groups of indigenous peoples face physical and cultural extinction, the project has not expressed concern about their eventual disappearance, but has instead expressed urgency in collecting tissues from these groups before they disappear as separate entities. The ethical oversight committee of the HGDP should address this issue in concrete ways.

The goal of population genetics to understand human history is controversial because of feared misuse, but the possible medical goals seem to be universally accepted except for the fact that the medical techniques may be patented. The possible patenting of products from the material collected from sampled populations has given rise to concerns that financial benefits are derived from them but will not benefit them in anyway. These concerns are based upon their past experience in having had their plant seeds and their knowledge of medical plants appropriated by outside parties. Cell lines and DNA collected during population genetics projects can be a potential target of commercial research, as shown in several patent cases. Although some researchers and the HGDP have committed itself to protecting the intellectual property rights of the sampled populations, the mechanisms for doing so are not clear and need to be specified.

The claim that the HGDP will reduce racism is debatable since it will be impossible to provide any proof that it will or will not happen until after the event. However, the misappropriation of population genetics to support racism has always been strenuously resisted by L.L. Cavalli-Sforza, one of the principal architects of the HGDP (e.g. Bodmer & Cavalli-Sforza, 1970). Nevertheless fears about the possible uses to which information gathered in the HGDP could be put have been expressed which cannot be ignored. At an early stage in the project's planning, several groups speaking for indigenous peoples called for a halt to the Project. However, it would seem to be impossible to stop the general progress of this project, and it is not within the mandate of UNESCO to call for a moratorium on such a project or on population genetics research. The response of UNESCO has been to ask other groups to join in the regulation of population genetics, and the HGDP. Invitations to join the ethical oversight committee of the HGDP should be formally extended to indigenous communities who could select their own representatives. These principles apply to population genetics in general.

The use of research results should in no way harm persons and not result in possible discrimination of the individual and population concerned. Future increased ability to identify people genetically at risk for genetic and common diseases, needs to be accompanied with the measures to protect the individual from stigmatisation and misuse of information by a third party. (Note: we rely on the 1994 UNESCO IBC Report on Genetic Screening and Testing, and the 1995 UNESCO IBC Report on Genetic Counselling).

## ***IV.2 Sanctions***

While as described earlier, regulatory oversight usually foresees a certain degree of scientific and ethical review prior to acceptance of a research protocol, once accepted, ongoing monitoring and surveillance usually are not assured. Even less certain is the possibility of sanctions in whatever form. Disciplinary measures including for example, suspension, withdrawal of privilege and fines, constitute the usual avenue of professional measures. In addition, where research subjects have been harmed, civil and criminal sanctions are also possible. Funding bodies may withdraw funds and sometimes even retroactively. The latter is rare however. In any event, unless involving great numbers as in the HIV blood testing scandals and the recent breast cancer trials, cases of research fraud or of failure to respect basic ethical norms are usually not brought to public attention.

If researchers are to become more accountable and actual practices more transparent, other forms of sanctions, or at least of publicity, should be envisaged. Stricter, standardised reporting requirements, on a regular basis, and publication of such reports are one such avenue. We consider the latter to be a basic ethical obligation that should be universally applied.

If researchers are to be subject to greater scrutiny, the same holds true for the media whose duty of honest, scientific reporting and preservation of privacy needs to be underscored. Whole populations, communities and the researchers themselves have often been wrongly depicted and wrongly represented with the resulting unjust labelling and discrimination. Such practices only serve to undermine public confidence and participation in research.

### ***IV.3 Conclusions***

The scientific and philosophical traditions that have long permeated research are also present in population genetics. The prevailing attitude in science is that research is in and of itself a good. Therefore, if properly explained and understood, participation should be forthcoming. Communities and populations, however, have their own cultural traditions and histories that need to be understood and respected. Moreover, population genetics is not simply a multiplication of the individual ethical and legal issues already raised by genetic research. There are different concerns and traditions in each group under study, and even among individuals within any group. The degree of information, consultation and co-operation must reflect such differences in participants. Likewise, the role and responsibilities of the researchers and of the local and national authorities, as well as the societal implications, will differ.

Having examined then, the ethical issues particular to population genetics, their philosophical basis, their research methodologies and possible utilisation of research results and most importantly, the need for education because of fears of identification and stigmatisation through selection, of discrimination through participation, and, of possible eugenics through interpretation, we have recommended in this report the following issues as crucial to ethical review of population genetics research at institutional, and regional or global levels:

- 1) accessibility to populations;
- 2) consultation with populations;
- 3) individual and group consent mechanisms;
- 4) ongoing ethical review;
- 5) inclusion of representatives of populations in decision-making;
- 6) communication, education, benefits, and feedback strategies at the population level;
- 7) confidential data and sample banking;
- 8) continual scientific review and monitoring; and finally,
- 9) appropriate sanctions.

At its Second Session, the IBC was requested to consider establishing a committee on the ethical questions that might arise in the HGDP. This proposal has been supported by WHO, CIOMS, ICSU, and HUGO. We recommend that such a committee should be more broadly conceived so as to be available for ethical consultation for all human population genetic research projects, and not only the HGDP. Given the concern shown about population genetics and in particular for the HGDP by indigenous peoples' organisations, we strongly recommend their inclusion in such a committee. While there is a negative side to a centralised population genetics project, there is some merit to the idea that co-ordination and review may help ensure ethical practice of individual researchers.

We suggest that a paragraph could be added to the preamble of the future UNESCO declaration on the human genome and human rights, for example: "Bearing in mind that human cultural and genetic diversity is an intrinsic value of the human species, which should be recognised in all communities".

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