FACTS against MYTHS

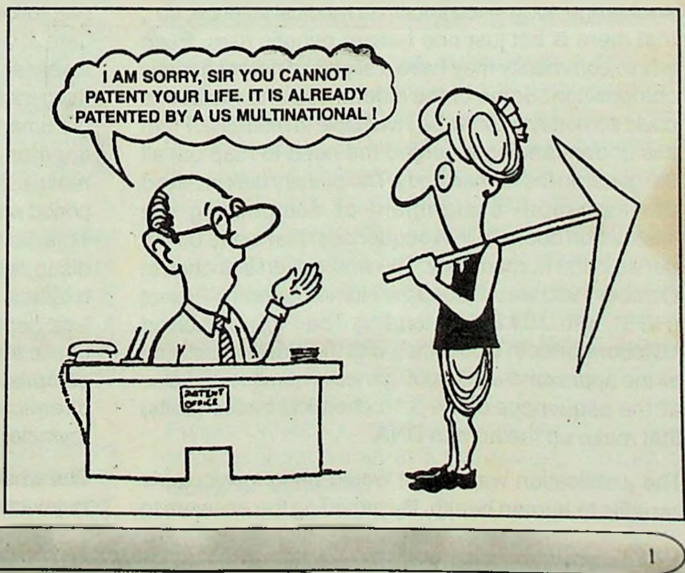
VIKAS ADHYAYAN KENDRA Vol VII # 3/2001 INFORMATION BULLETIN

Colonising the Web of Life:

The Myths of the Human Genome Project (HGP)

COMMENT

Prior to the 15th century, Europe imported manufactured goods and spices from Asia. Lacking in goods to export against these imports, the balance of trade was not a favourable one. To overcome it, Europe began to explore sea-routes around the world and thus began the so-called 'The Age of Great Adventure'. In reality, however, it was the Age of Colonial Plunder, the Age of Christopher Columbus — the first white man who "discovered" America – and Vasco da Gama. Along with weapons and food supplies each carried a Papal Bull allowing them to claim whatever lands they found in the name of Catholic Spain or Catholic Portugal. The world was carefully divided between the two. The Decree allowing them to claim such lands were known as "terra nullus". Irrespective of the indigenous peoples they found living there, these lands were officially declared "barren". Since then, the commercial enterprises (TNCs today) have repatriated and amassed enormous wealth and power, discarding responsibility for several hundred years and continuing to practice the colonialism on which they were based. Today, the doctrine has been resurrected in its new 'avatar' and directed, not at distant lands, but at life itself. They have found rich new worlds to plunder: the genetic wealth of diverse species, the work of farmers and indigenous people and the intellectual wealth that they have accumulated and handed down over millennia. Thus, more than 500 years after Christopher Columbus "discovered" a world new to him, people continue to have a problem with explorers. In addition, just as before, the explorers (TNCs) today are trying to stake a claim this time through gene technology and patenting. The former is based on two broad assumptions: that genes are the major determinant of the development of an organism; and those particular genes can be equated with particular characteristics. Patenting on the other hand enables TNCs deploying this technology to guarantee that it works solely for their benefit. Its proponents maintain that the patenting of genes, particularly from certain rare species of plants and animals is justified for the 'greater human good.'



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Colonial Plunder

The voyage of Columbus to the New World marked the beginning of the so-called 'Colombian Exchange' that brought in maize from South and Central America and later other crops to Europe, all under colonial control. Rubber was smuggled out of Brazil to Kew Gardens, London. From there it was taken to the botanical gardens of Singapore where it was distributed to launch the rubber industry of SE Asia where the rubber boom caused a rubber bust in Brazil and the deaths of hundreds of thousands of people. In 'exchange', sugarcane travelled from S. E. Asia to the New World, where systems of human slavery were instituted to tend the cane. The boom-bust-famine cycles of sugar production are well known. Coffee came from Africa and Arabia, bananas from S. E. Asia.

Colonial powers attempted to control biological materials through control of production. The Dutch limited production of cloves and nutmeg to three islands in the Moluccas (Indonesia). The French brandished the threat of the guillotine at anyone who dared to take indigo off Antigua in the West Indies.

Explorers were not simply looking for gold and silver. They had their eyes on plants. By the 18th c. 9,000 plants were introduced into England that formed the basis of the European dye, chemical and drug industries. These made possible the plantation economies in the South that brought tremendous wealth to Europe. For the most part the search for plants was a search for new and valuable species of plants. This great robbery in a way made possible the industrial revolutions, capitalism, 'development', and 'advancement' of Europe.

With the rise of plant breeding techniques the importance of botanical gardens, as a source of agricultural inputs declined. The US built a system of plant introduction station and finally a gene bank, the modern-day equivalent of the botanical garden. The Colombian exchange continued to work. Gene pools still flowed from South to North. Moreover, scientists from the North freely collected crop varieties from the South. Ninety percent of plant germplasm collected in the past 30 years have ended up in the gene banks of Europe and North America yielding billions to the farmers and agri-businesses of these northern countries. However, with the rise of anti-colonial struggles, new methods of extraction, appropriation and control were introduced. Old methods of coercion and of physical control of production sites were no longer viable. Slowly, the idea of plant patents was broached after the turn of the century. (Patents are means of allocating ownership, assigning control, regulating access and apportioning benefits).

(cf: FAM # 9, 1998)

The study and mapping of the human beings was the next logical step. The rationale was based on the knowledge, long since known to medical science, viz., that there is not just one human genetic map. Each ethnic community may have a slightly different genetic composition. Some of the differences and mutations could someday prove to be invaluable to medicine. From this understanding emerged the need to map out all the genes in the human body. The primary task involved the mammoth assignment of deciphering the 'instruction books' (DNA sequences) that make up the genes in the human body. The whole effort launched in October 1990 was dubbed the Human Genome Project (HGB), with US$ 250 m. funding. The Project involved 16 laboratories in 6 countries with the aim of identifying all the approximately 50,000 genes in humans and also all the sequences of the 3.1b.chemical bases (units) that make up the human DNA.

The justification was that it would bring incalculable benefits to human health. By providing the answers to the age-old questions of who we are, why we get sick and why we get old; the HGP would, in effect, revolutionise the science of diagnostics and medical care. It would provide new cures for hitherto incurable diseases make medicine truly preventive by removing the genetic causes of disease and prolong the life span of human beings to astonishing lengths. An important impetus to the whole Project emerged from the realisation that we are living in extraordinary times – a period when our bio-cultural diversity is rapidly shrinking. This is more than visible in vanishing cultures, disappearing languages, and endangered human habitats. Accordingly, an enormous amount of hype was generated with world-wide propaganda to make public the Web of Life written in the alphabet of DNA comprising of four letters — A, G, C and T (the base chemical units, adenine, guanine, cytosine and thymine, which constitute a DNA molecule).

The whiff of mega bucks immediately attracted TNCs to invest into the HGP in a big way. Simultaneously

Gene Boutiques!

Among these populations, singled out for genetic study, are: the Hadza (around 200 remain in Tanzania); the Kung (roughly 15,000 members reside in the Kalahari desert) and certain Somali communities; the Plains Apache (1,000 remain in Oklahoma), and the Delaware (numbering around 600); the Akuriyo (about 50 remain in the Amazon), the Yanomami (approximately 20,000 live along the border of Venezuela and Brazil), and the Dorasque of Panama (rouhgly 50 remain); the Yukaghir (fewer than 100 live in Siberia) and the Chukchi (10,000 in the Chukchi peninsula of North-eastern Siberia); and several Onge Greater Andamanese population (in the Indian Ocean of the Andaman Islands). In India, at least 73 castes, religious and Adivasi groups were considered for intensive study. These are divided into two communities. One community selected for study is for DNA collection. These include the Dogras of Jammu; Kulu Rajputs; Ramgarhias of Punjab; Jats of Haryana; Paliwal of Rajasthan; the pastoral Rabaris of Rajasthan; Lahan-Chake Kumbhar potters of Maharashtra, the tribal Gawdas of Goa, priestly Namboodris and the Nairs of Kerala, Vellalas and the traditional Kalans warrior caste of Tamil Nadu; the Kammas of Andhra; land-owing Reddis of Andhra; Chamar leather workers of UP; the traditional Rastogis scribes of UP; UP Brahmins; Kayasthas of West Bengal; Thakur landlords of Bihar, Sarguga Brahmans of MP; Agarwals of M.P; Kalitas cultivators of Assam and Rajbansis of the same state.

The other group is singled out for cell-line studies. These include the Kashmiri Pandits; Kiner Kanets; Sansis of Haryana and Rajasthan; Bhatias of Alwar district of Rajastha; Rajputs of Jaisalmer; Lohanas migrants from Pakistan; Audich of Gujarat; Chitpavan Barahmans of Maharastara; Mahars of Nagpur district; Coorgis of Karnataka (to "test the hypothesis of their Grecian origins"); Iyengars of Tamil Nadu; Cochin Jews; and the Muslim, Hindu and Christian Siddis of Gujarat, Karnatka and Andhra, among others.

Another category of communities includes what the HGP calls "religious isolates". These are: Parsis, Mopla Muslims of the Lakshadweep, Dawoodi Bohra Muslims, Ahmediya Muslims and the Neo Oswal Jains. Many Adivasis groups – from the Andamans to Himachal, and from Gujarat to Tripura – are also to be studied. While many of these groups were selected because of their linguistic and cultural uniqueness, some are also considered to be 'genetically distinctive', that is, scientists have speculated that they probably have genetic compositions that are slightly different from that of most other humans.

the academia and Universities, scientists, etc., in the North, also jumped on the HGP bandwagon. HGP became an informal consortium of international scientists and universities who aspire to collect information on human genome variation. Molecular biologists are into big time, acting as Directors, Consultants and shareholders in biotech firms that are seeking to exploit on every aspect of genetic research. Some of these mega firms include Biogen, Genetech, Genzyme, Raepligen, NeoRx, and ImClone who have produced everything from predictive tests to drugs, hormones, and modified genes.

In its early years of growth the HGP focused narrowly on Anglo-European populations betraying its ethnocentric bias. The founders felt the need for a broader sampling of ethnic populations that would not only better the Project's goal to combat common human disease, but also assist anthropological efforts to reconstruct the story of human evolution.

In its major undertaking the HGP had planned to obtain blood, tissue, and hair samples from genetically distinct populations, many of who are considered 'endangered' i.e. populations that may either shortly vanish from the human family or become genetically assimilated into other ethnic groups. In October 1992, HGP scientists identified 722 populations that constitute highly desirable candidates for genetic study. (see box above)

India, among the countries of the South, is among the leading countries that has also already invested in biotechnology under the aegis of the Department of Biotechnology (DBT) which has since also invested in the so-called bio-prospecting venture, the Humane Gnome Project. It established three major centers – the PGI (Chandigarh), Guru Nanak Dev University (Amritsar) and AIIMs (New Delhi) – to measure genetic discoveries. Work is also ongoing in agriculture, parasite research, etc. Other Indian institutions with lab and fieldwork facilities include the Indian Statistical Institute-Calcutta, Department of Human Genetics at Andhra Pradesh, and centres of human biology at Punjab University, anthropology at Sagar University, physical anthropology at S.V. University-Tirupati, and Guwahati University.

The HGP is no doubt a scientific wonder and the discovery has been proclaimed the most dramatic scientific advance since the invention of the wheel. It could change life more than the wheel did. Not surprisingly, however, this has raised a number of disturbing questions around what can and should be done and who has the means to do it. For TNCs it means mega business. There is therefore a demand to limit scientific experiments, for instance, on humans but the debate conveniently getting focussed on money, patents, and sharing among the rich North. There is, also the major concern that scientific breakthrough will benefit merely the rich North rather than the South because of their access to new drugs. Thus, apart from the need to view the whole Project beyond the hype generated over it there is need to demystify HGP and also take a closer look at a whole range of privacy and civil liberties issues linked to it.

MYTH: ***By enabling scientists to map the entire human genome, the HGP will revolutionise healthcare and also help them to diagnose and cure genetically-based diseases – from sickle-cell anaemia to manic depression and schizophrenia – by replacing bad genes with healthy ones.***

FACT: Scientists warn that despite its potential, only 5% of the entire genome is ever expressed i.e. a gene's message reaches the end of its one-day journey from cucleic acid to protein. Nothing is yet known about the role of the remaining 95% of the genome[2]. Such a warning means that the routine tests for detecting predisposition to diseases and other human characteristics has serious implications for human health, the legal system, for insurance, for employment practices, etc. For instance, despite genes being located for cystic fibroses, muscular dystrophy and the various cancers, no single therapy has yet been developed.

On Valentine's Day 2001 scientists were to announce with great fanfare the complete human map to the world. The effort however was a big failure. The 'Book of Life' ended up having as few as 30,000 genes! There was little in the results to justify extravagant claims publicly trumpeted about this costly project that has cost the public $3 b. in the US and hundreds of millions of pounds in the UK.

Beyond the hype, the reality is that if the gene coding, for instance, for the enzyme monoamine oxidase is faulty, the individual carrying it may be prone to violence. But this enzyme is also responsible for digesting substances found in red wine, cheese and chocolate. So, there are instances where the presence of the faulty gene has led, not to violence, but to high BP, insomnia, agitation on eating certain foods and so on. It is just that the probability of arson and assault in such cases is higher. The media often misses this fine print and reports it as 'Gene for arson found' or "Gay gene discovered". The same is true for alcoholism. Essentially, all such genetic studies are based on random sampling and one can talk only probabilistically about these findings without any degree of certitude.

Similarly the case for schizophrenia – another coin-tossing probability! Genes in some families may like breast cancer – influence it but not in others; the environment is also the key. There *are* cases which indicate schizophrenia may have a genetic basis. A small section of the world population has tiny pieces of chromosome 22 missing. This causes all kinds of problems —heart diseases, cleft palate, etc. In addition – it's a damp-squib probability again – one in 10 among such people also develops schizophrenia. Screaming tabloid headlines notwithstanding, the schizophrenia gene is yet to be discovered.

Another matter of concern is the other serious ethical dimension of the Project. For instance, the claim that genes are causes of ailments and can change behavior begs the question as to what would 'improving" genetic-stock — `micro-eugenics' – entail? The Madras-based daily, the Hindu (14-9-1997) had reported that a Swedish daily from Stockholm, `Dagens Nyheter' had revealed that 60,000 Swedes were forced to undergo sterilization between 1935 and the 1970s as they were declared unfit to procreate. 90% of them were women! Ostensibly, the aim was to "improve the human race by better breeding". This program was based on the pseudo-scientific theory of eugenics widely used by Hitler to create `a pure Aryan race". Apart from offering a panacea for most if not all-human diseases the myth also offers to unravel the mysteries of human behaviour. (Cf.FAM,#1,1997)

Today, with "gene technology" also hailed enthusiastically in India especially by a section of the ruling elite there is greater cause for concern. "Gene technology" is being discussed in the traditional marriage bazaar. Just as IT spawned a new business: computerized matchmaking (CMM), the advent of biotechnology with its new bag of tricks, and the mapping of the human genome, have opened up new vistas in matching-making. The more the `match-maker' knows about genes of the prospective bride or groom, the craftier the matchmaker can be in choosing the `right' partner, to produce near flawless children, the major criterion of arranged marriages. Thus, matching-making is in danger of veering into uncharted territory to say the least.

Above all, genes are important but it is merely half the story. They define potential. It is the environment that ensures that potential is fully met.

In conclusion, one of the shocking findings of the announcement (see above) is that there is no molecular support for racial distinction among human groups. Race characteristics are very superficial from the genetic perspective.

MYTH: ***Individual genes wholly determine our bodies, behavior and health.***

FACT: The announcement (Cf.above) on Valentine's Day 2001 saw the collapse of this myth!

Simple physiological facts are for sure the result of particular genes. However, most behavioral traits and certain special abilities, if at all they can be determined genetically, cannot be pinned down to any one gene. In most instances, complex human traits are the result of many genes working in tandem. Thus, as Dr. C. Venter (the US scientist whose private company was involved in a race with the publicly funded HGP to sequence the genome) stated, this discovery indicates that biological determinism cannot be right and that our enviroment and the way we respond to it is highly critical. That is, no genes work in isolation, rather they function in a complex network. External (e.g. social) and environmental factors have critical role to play in the human condition. Genes and genomes are also subject to environmental influence, and are given to changing and mutating in response to environmental and external factors.

MYTH: ***DNA, blood samples, etc., from rare or endangered species including humans helps to identify certain 'disease genes' for diabetes, etc., that eventually will lead to a cure which under existing conditions is impossible.***

FACT: Apart from the uncertainties of the whole HGP there is also the wider concern of a) who owns the genome project and b) that of patents.

Under the new patent regime HGP is an extremely sensitive issue today particularly when indigenous populations, for instance, are involved. It also involves the issue of privatization vis-à-vis privacy. The genome project required huge screening of selected populations.

While indigenous populations may represent important scientific resources for genome researchers, many also are communities who had been colonised or enslaved, displaced from their habitats by so-called Development Projects, forced into impoverishment, virtually wiped out by diseases introduced into their communities by the erstwhile colonial powers, exploited as cheap labour, exposed to nuclear weapons testing e.g Netrahat firing test range in Jharkhand (formerly in Bihar) on their homelands by governments, and generally marginalised not only within the global economy but also within national economies. Already among the genes and cell lines patented and sold by TNCs are those stolen from indigenous peoples under the pretext of providing medical care, and even coercion is used. DNA databases of entire populations such as those Iceland and Tonga have been sold to private companies. The Swedish government is in negotiation with another company for the 'ethical' takeover of its population database, and the UK government is planning to establish its own. Thus, given this historical marginalisation of indigenous populations and its role in the relationship to the commercialization of DNA by mega corporations, the HGP is a highly dubious project. In 1993, the Canada-based international non-governmental organisation, Rural Advancement Fund International (RAFI), publicly maintained the Project to be ethically flawed displaying fundamental failures in comprehending the socio-political environment in which the Project must perform. In 1997, it urged the organisers to disband their Project in light of its consistent failure to respond adequately to the concerns of indigenous peoples, and because the Project was impeding dialogue on the broader goal of protecting human diversity.

MYTH: ***Genetic-testing technique will protect the health of people especially the health of employees in firms, etc., against unnecessary risks e.g. exposure to radiation and contact with chemicals and toxic waste to things like noise, stress, etc. Thus, genetic testing is extremely beneficial for the workers.***

FACT: A hidden agenda lurks behind this myth. The threat is for the corporate sector and others is to avoid hiring or employing people with features or traits, etc., that (supposedly) disqualifies them for the work. Genetic tests would be one more in a series of tests and evaluation used for selecting employees. Moreover, gene-testing raises the problem related to the methods. Whether for purposes of security or selection, there is always a problem with projects of sampling and registering data of a personal character, Whether it is done by way of genetic testing or other means. The risk is always present that the information, even through collected for justifiable purpose, is not sufficiently safeguarded against wrongful use of various kinds. The more intimate and private this information, the greater the potential harm to people's survey. Assuming the details of the genome of a person were known, it is then quite easy to predict the person's future diseases or health. The person's privacy, a basic human right, will be at risk. A company or government department, for instance, may desire to know the genetic makeup of its employees to get details of their health situation. Health nursing companies would also wish to get details of the genetic makeup of the applicants. In short, individual privacy is lost. Further, MNCs dealing in life saving drugs will be least interested in producing cheap drugs for the poor. Instead, given their profit motive and according to specific gene-related diseases they will manufacture very expensive drugs that only the rich will be able to afford.

It is no doubt true that genetic testing would obviously be for the benefit of employees with such a genetic disposition. Therefore, it might appear to be a justifiable and a viable way for employers complying with their fundamental responsibility for the wellbeing of the employees. Logically, it can be assumed that the employer has already undertaken all possible efforts

to make the work place neat, clean and safe as possible for the protection of the workers, and that the notion of gene testing is to introduce protection of a secondary kind. As a means of minimizing the risk to employees of developing a serious illness, genetic testing would respond to their basic right to a life without unnecessary pain and suffering, which underlies the principles of beneficence.

A major problem in making this testing mandatory as with AIDS testing for all employees or workers is that the worker is thus forced to give away information about his or her genetic structure and dispositions. In all likelihood this could violate another fundamental interest and right of the employee. How this can be a violation of a workers' right can be spelled out along two lines.[3]

- The basic right of autonomy (especially formulated as the right to privacy) includes the right not be forced to reveal personal and intimate information about oneself. It is evident that this right could be overridden if the absence of such information implied danger or harm to someone else, but that is not the case here;
- This Right to Privacy would seem to imply a right not to be informed about one's genetic disorders against one's own wish, that is, a right to remain uninformed. A person may well believe that ignorance about a whether or not s/he carried a genetic disposition for some ailment like (say) AIDS makes it more likely that s/he can enjoy a good life. This right to make this deliberate choice for ignorance might be undermined by this measure, for example, if a worker suddenly finds himself or herself removed from his or her usual job.

Employers' Responsibility & Workers' Right

The counter argument that still in the long run the test will benefit the employee anyway. Thus, in the workers' long term interest it is necessary to override the persons autonomy so as to provide the benefit for him or her. However, assuming that the employees have been fully and sufficiently informed about the risks and dangers they may be exposed to at work, as well as well as about the specific risk to those who carry a special genetic disorder, there can be no reason to assume that the employee is incapable of making a reasonable and right judgement about what is for his or her own best in this situation. If the employee is completely aware of the facts and still thinks it for the best not to reveal or to be informed about his or her genetic status, there is no justification for forcing a test. To be sure, an employer is justified in many respects in obliging workers to comply a with various security measures without admitting any choice or reservation on the part of the employee – the wearing of helmets or protective gear or safety belts for example. Yet, the relevant point is that such measures do not interfere with the personal and private sphere in the same way that genetic test does. They do not breach the right of autonomy.

Incidentally, some 740 patented gene tests are already in the market, and hundreds more are in the pipeline. For cases where such tests can help to diagnose and treat patients, exorbitant license fees have prevented them being used. On the other hand, healthy people testing positive are denied employment and health insurance. Insurance companies in the UK now require individuals to reveal the results of genetics tests. At the same time, prenatal and pre-implantation diagnoses are eliminating human fetuses and embryo-carrying genes said to predispose them to cancer as a result.

MYTH: ***The massive investments costs on R&D over the HGP – to the advancement of science — makes the patenting of DNA data absolutely essential. After all, knowledge is the common heritage of humankind and justified for greater common good as this applied science provides a short cut to new cures.***

FACT: Yet, those who stand to benefit from these advances – if the historical status quo persists – are not the indigenous peoples of the South but largely the rich North. Thus, there is the potential danger of the peoples of the South especially indigenous populations becoming the object of study and collection and also a target of economic exploitation under the pretext of advancing science through the strategy of patents.

However, it is indeed true that prior to the advent of patents, common ownership of knowledge was the overriding norm with authentic research and propagation having stronger roots in sharing than in colonising. A significant number of researchers do indeed pursue a cure not for profit. The vast majority of farmers and agronomists involved in plant and livestock breeding do so in order to strengthen biodivesity rather than to weaken it. None presumes to demand lifetime royalties for the plants or weeds they produce. None so far has sought to hold the public to ransom for the cures they discover. No doubt, there is a competitive ness about medical and agricultural research, but most has been on professional rather than pecuniary grounds. In fact, the vast majority of medical breakthroughs have been based on remarkable patterns of international collaboration. First of all, patients and the public have offered themselves (freely) into research and monitoring programs. The public had contributed vast amounts of cash to support medical research – whether directly into medical charities or indirectly through taxes and tax concessions.[4] Finally, medical institutions themselves have shared ideas and information in pursuit of common cures. The words "patent" and "license fee" never entered the exchange. Now, unfortunately, they do. The advent of patents — through WTO intervention having the power to force countries to change their laws and their constitutions — the dynamics have changed for the worse. The reason being that these institutions favour the protection of IPRs made by corporately sponsored scientists. GATT

MARKETING THE HUMAN GENOME[5]

Study of GENE is one of the most advanced branches of science especially biotechnology + Commercial Interest

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Study of variations in GENES that determines genetic Individuality for Various Diseases and Individual Characteristics

TNCs institutions, involved in this activity

1. Decode Genetics Inc. (Iceland)
2. Hoffman La Roche (Switzerland)
3. Curagen (US)
4. Genset (France)
5. Orchid Biocomputer (US)

What do these Firms Do?

1. Create a Massive Database on Genealogical family data and medical records for studying the genetic causes for common diseases
2. Based on the research, develop drugs or Diagnostic tests
3. Patent every information on genes

The End Result

All these activities of these firms will convert a *restricted, specialised, sophisticated biotech research activity into a Major Mainstream Commercial Venture*

How?

Only certain companies will have the data monopoly on Genes and Pharmaceutical companies need these data to develop drugs and medicines. To gain access to these data, firms have to pay heavily.

What about 'Donors' who gave the valuable database?

1. Data is neither available, nor accessible, nor comprehensible
2. They do not know what is being experimented on their genes

Who Gains?

The rich who spends billions of dollars on "cures" (e.g. treatment for baldness, aging)

For This

Commercially interesting and related data are collected without obtaining consent from the gullible donors or from their community or from their government

Is this Ethically Correct?

for instance had produced a chapter on TRIPs which includes patents. Another instance is Germplasm, which regarded, as 'the common heritage of mankind' is therefore patentable. This distinction between IPRs and common heritage supports a system, which allows the rich North to extract genetic and organic raw materials from the poor South and convert them into highly profitable ventures for sale in the North. This then raises the other (legitimate) question of compensations.

With patents under WTO rules for global agreements hospitals especially government run institutions will simply be unable to foot the bill. Whether this applies to genetic discoveries relating to cancer, etc., or whatever, once patents comes into medical research, prices race in maximizing profits. The risk is that new treatments arising from such technologies are unlikely to improve health prospects. Instead they will simply open up another divide between those who can afford the treatment and those who cannot. For India and countries the South the health-wealth divide is even starker under the new WTO patent and plunders regime. The rules allow for bio-piracy on a scale unseen for centuries.

MYTH: Extracting DNA, etc., samples from animal and human species, etc is neither unethical nor is it carried out in secret. All such experiments are conducted under mandatory guidelines of informed prior-consent

FACT: However, a major lacuna in these guidelines is the total absence of any statements on how the DNA or a product derived from the endangered species may become a marketable commodity that could potentially benefit the private sector or a TNC. Individuals participating in genetic sampling projects is often told that they are making a major contribution in the advancement of science and to the cause of humanity. However, they are not necessarily informed of the commercial dimensions of the Project. As a result, many indigenous peoples of the South see themselves as the unwitting subjects of corporate patent claims. Above all, they maintain that the design and implementation of a survey of human genetic diversity must include their full participation. And, ' that means indigenous peoples' control over samples after collection and full protection from patents claims on our tissues there should be no military access to the samples under any circumstances...[6]

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