MEETING REPORT

# Debates about the social implications of human genome research*

The Human Genome Project (HGP) is one of biology's few 'big science' projects[1]. Apart from being the source of new terms, such as the oxymoron 'millionaire-scientist' that reflects the immense commercial potential that the sequenced genome holds, it is also probably one of the most widely debated and discussed scientific projects. The controversies that have dogged human genome research (HGR) 'from the start'[2] can be broadly classified into scientific, social and philosophical. Questions pertaining to all these classes were discussed in a conference comprising of sociologists, anthropologists, lawyers and scientists at the National Institute of Advanced Studies (NIAS), Bangalore.

HGP stems from the long and celebrated heritage of molecular biology, a heritage that M. G. Narasimhan (NIAS, Bangalore) traced in his talk at the conference. However, the project has been the subject of debate among scientists right from its inception in the 1980s (see Box 1). ' "Absurd", "dangerous", and "impossible", scoffed numerous critics, who noted that the technology did not exist to sequence a bacterium, much less a human. And even if the project's starry-eyed proponents could by some miracle pull it off, who would want the complete sequence data anyway?'[2] The relentless march of HGR over the years, and its promise especially in the medical arena (predictive screening, accelerated drug discovery, gene therapy and so on)[3–5], have put many of these early doubts to rest. However, Ratna Puri (Gangarams Hospital, New Delhi) showed that in India genetic diagnosis of diseases is a rather mixed blessing. With genetic counselling an almost non-existent art, the patients find it gruelling to understand and come to terms with the enormous amount of new and disturbing information that is thrust on them. She said that there are also associated problems – genetic tests are expensive, insurance does not cover treatment for genetic disorders and this adds to the economic burden, there is a societal stigma attached that patients have to face, they are denied employment opportunities … the list can go on. A decade after the publication of the 'rough draft' of the human genome, there are widespread debates about whether the megaproject has been as useful as it seemed[6]. One can only agree with Collins that HGP is 'a good example of the "First Law of Technology", wherein the promise of a new approach is usually overestimated in the short term, but underestimated in the long term'[5].

HGR also has social and ethical problems on which the scientific aspects overlap[7] – the issue of whether scientists will, in their eagerness to commercialize products that result from HGR, forget their responsibility towards society; is it necessary to limit the use of genetic information to avoid controversial applications such as genetic enhancement of humans[8]; how should the discussions about the safety of new technological advances be mediated; what are the repercussions on society, keeping in mind the social, political, biological and economic variety that exists in the world? N. R. Madhava Menon (Parliamentary Legal Chair, New Delhi) emphasized that the point of reference for any scientific development should be 'basic guaranteed human rights', and any scientific advance must be evaluated by balancing human rights and threats to these rights. To ensure ethical treatment of humans,

**Box 1.** The Human Genome Project story

Why do we need to sequence genomes at all? James Watson says, 'Traditionally biologists have focused on one small part and tried to understand it in detail ... (But) to understand the genetic processes underpinning life, we need more than a detailed knowledge of particular genes or pathways; we need to place that knowledge in the context of the entire system – the genome'[13].

Watson claims that HGP began with the Keck telescope in Hawaii – the money that was to go into the making of the telescope was ultimately diverted to fund the first of biology's 'high-profile' projects[13]. Despite popular scepticism, the optimism of Robert Sinsheimer, James Watson, Francis Collins, Craig Venter and many others, and the efforts of 'more than 2000 scientists from over 20 institutes in 6 countries'[14] ensured that the rough draft of HGP was completed in 2001.

There are an unusually large number of landmarks in genome research – the number of events listed in the HGP timeline makes this evident (http://www.ornl.gov/sci/techresources/Human_Genome/project/timeline.shtml) . Some of them are truly remarkable – after the rough draft was published in 2001 with about 150,000 gaps, the completed draft was published in 2003 with just 341 gaps. The Single Nucleotide Polymorphisms (SNP) consortium was set up in 1999, and in two years, they reported more than 1.4 million SNPs. The HapMap project, started in 2002, reported more than a million SNPs in 2005, and 3.1 million in 2007 (http://hapmap.ncbi.nlm.nih.gov/). Recent inclusions to the growing list of achievements are the 1000 genomes project, which aims to document human variation by sequencing a thousand different people (http://www.1000genomes.org/), and the Human Microbiome Project[15], that aims to sequence the microbes that contribute to human health and disease (http://nihroadmap.nih.gov/hmp/). Will all these projects really accelerate advancement in medicine, and enhance our understanding of ourselves? We will know the answer only with time.

*A report on the conference, 'Shifting perimeters: social and ethical implications of human genome research', jointly organized by the Indian Institute for Advanced Study (IIAS), Shimla, and National Institute for Advanced Studies (NIAS), Bangalore, held at NIAS during 15–16 November 2010.

guidelines have been published by both national and international organizations: Ethical Guidelines for Bio-Medical Research on Human Participants by the Indian Council of Medical Research (http://www.icmr.nic.in/ethical_guidelines.pdf), and the Helsinki Declaration by the World Medical Association (http://www.wma.net/en/30publications/10policies/b3/17c.pdf) are examples. Menon opined that it is not as much the lack of ethical guidelines, as the lack of modes of enforcement that is the cause for widespread concern. The American ideology that 'anything under the Sun that is made by man is patentable' heightens the anxiety, because many believe that 'overriding commercial interests will ensure that the entire area of genomics and its applications will soon get mired in a sea of patent problems'[9]. In fact, as an Editorial[10] in this journal points out, 'it is worth noting that the shares of some biotechnology companies, on occasion, zoom upwards when gene estimates are raised and plummet when the number is lowered. Clearly, there is money to be made in genes; the larger the number, the greater are the chances for commercial exploitation in the postgenome era'. This leads us to questions like 'Who owns genetic information?' and problems such as ensuring privacy of genetic information. A number of the ethical and social questions have been thought about by the Ethical, Legal, Social Issues branch of HGP (http://www.ornl.gov/sci/techresources/Human_Genome/elsi/elsi.shtml), though Sasheej Hegde (University of Hyderabad) pointed out that a much broader discussion on morality is required. Shiv Visvanathan (Dhirubhai Ambani Institute of Information and Communication Technology (DAIICT), Gujarat) examined whether science studies in the diverse society of India, which is simultaneously peasant and industrial, oral and digital, can contribute to HGR, especially in the ethical issues that are involved.

Now, how can a democratic government address problems that technological advance throws up? Or as H. Sharat Chandra (Institute of Bioinformatics and Applied Biotechnology, Bangalore) said, how do we balance individual concerns and societal concerns? Wiebe Bijker (University of Maastricht, The Netherlands) spoke about his experience in helping the Netherlands government make policy decisions. He says, 'The key point is to distinguish different kinds of controversy. In some cases there is no doubt about the scientific knowledge (e.g. the toxicity of asbestos); then the government and the people should only listen to scientific advice. In other cases (e.g. human enhancement), the scientific knowledge is uncertain; then stakeholders and citizens also need to be consulted. Of course, the real problem is to decide whether a controversy is of the first or the latter kind. If scientific advisory bodies have enough status and authority in society, and when an open ear is lent to possibly conflicting evaluations from civil society and stakeholders, this need not be a problem.' He also stressed that the scientific bodies, such as the science academies in India, need to put in a lot of work to maintain their status in society (pers. commun.).

K. Thangaraj (Centre for Cellular and Molecular Biology, Hyderabad) spoke about how his team had worked on genetic composition of the various ethnic groups of India, traced their origins and documented differences among them. Although this is an exciting scientific study that helps us trace our origins as a species, the threat of racial discrimination based on genetic differences lurks in the background. Norma Tsotsi (Steve Biko Centre for Bioethics, South Africa) presented a vivid picture of the political tensions that human genome research is associated with in South Africa. There, like in India, diverse ethical and cultural groups co-exist, but the fear that Apartheid inflicted on the minds of people is still not totally gone. Genetic profiling, studies about human ancestry and studies about differences between races are looked upon as social issues that can affect allocation of resources, insurance and employment. There are doubts in people's minds, such as, 'Does the Human Genome Diversity Project really bring people together as it claims?' Research on germ line gene therapy and stem cell research is not allowed.

Genetically diverse populations like in India and South Africa have additional cause for worry due to bio-piracy. Considering that companies competing to make sequencers in a way accelerated HGP, and that commercial aspirations of scientists are a matter of concern, Peter Glasner (Centre for Economic and Social Aspects of Genomics, UK) suggested that serious thought should be given to the newly emerging field of bioeconomics that may make use of new forms of currency, such bio-knowledge, bio-value and biomaterials. He also pointed out that the current medical practices in India leave much to be desired, and given the hype that anything 'genome' is capable of stirring up, bioeconomics should be especially an important concern in the country.

HGR may also lead to philosophical and legal questions, such as what constitutes a 'person' – is it the genome, the embryo, or the physical human being, or something else altogether? What is it to be alive?[11] What is 'property'? Is a genome a person, property or a quasi property, like dead bodies and embryos? Some of these questions, that potentially may have further repercussions on the patent debate, were discussed by Linda MacDonald Glenn (Albany Medical Center, New York). D. Venkat Rao (English and Foreign Languages University (EFLU), Hyderabad) spoke about the importance of examining the concept of 'life' in various cultures. Discussions about what constitutes a 'human' are no doubt interesting, but HGP may not be able to answer them directly. As David Baltimore says, 'The most exciting new vista to come from the human genome is not tackling the question "What makes us human?", but addressing a different one: "What differentiates one organism from another?". The first question, imprecise as it is, cannot be answered by staring at a genome. The second, however, can be answered this way because our differences from plants, worms and flies are mainly a consequence of our genetic endowments.'[12]

The conference clearly showed that many of the scientific, social and philosophical questions about HGP overlap at many regions. Some of the participants also stressed on the importance of locating debates on the social implications of HGR in a cultural and geographical setting, because important concepts like 'bioethics' may have different definitions in different contexts. We are only beginning to appreciate the importance of these issues, and further conversation involving people of many disciplines is the only way in which we can hope to address some of them. Maybe, that would lead to 'a new set of ethics, a new government, a new mentality, and have implications for our disciplines, policy regimes, for the society and our species', as Peter deSouza (Indian Institute of Advanced Study, Shimla) put it. He also

suggested the compilation of a book containing the proceedings of the conference; this might serve as a 'first step' towards reviewing the Indian position with regard to commercialization of HGR and so on. But is a useful conversation between the 'two cultures' really possible, when even a common understanding of terms as apparently simple as 'human' or 'life' is hard to come by? Peter Glasner (pers. commun.) says, 'Clearly a meeting of minds is difficult, but what is important is to establish that the categories being used are socially constructed and not just "given". Many senior scientists are happy to recognize this, and science after all progresses by knocking theories/concepts down in the face of advancing knowledge. Nothing is set in stone, either for natural or for social scientists – the danger is in reifying concepts so they take on a life of their own'.


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MEETING REPORT

# Geomicrobiology – an Indian perspective*

What molecular-scale interactions underpin geochemical cycles? What are the links between the abundance and structure of microbial communities and rock/sediment geochemistry? What are the effects of microbiota on landform evolution, climate and ecosystem performance? Many such and other fundamental questions regarding the role that microbes play in geological processes controlling the chemical composition of our planet are the realm of geomicrobiology. This interdisciplinary field of research has received attention recently due to the tremendous potential it offers to understand and control our environment, decipher the conditions during emergence of life on our planet and the diverse chemical transformations that can sustain life[1].

To evolve an effective national-level programme by identifying key issues and relevant questions to be addressed for geomicrobiological research in India, a brainstorming workshop was held recently under the aegis of the interdisciplinary 'Science of the Shallow Subsurface (SSS)' programme that was launched by the Department of Science and Technology (DST), New Delhi to bring together scientists specialized in different disciplines to obtain an accurate description of subsurface properties and processes using geological, geochemical, geophysical and geobiological, including microbiological approaches (http://www.dst.gov.in/scientific-programme/ser-ssss.htm). The unique SSS programme, both in terms of magnitude and interdisciplinary nature, supports research by geologists, geophysicists, zoologists, botanists, microbiologists, chemists, geographers, hydrologists and others, and includes scientists affiliated to premier research institutions, university departments and colleges from all over India.

The workshop included lead talks and project concept proposals by about 20 scientists from different institutions/universities of the country. It was also attended by several scientists participating in the SSS programme and a number of experts in microbiology, biochemistry, molecular biology and geology from the country.

V. Rajamani (Jawaharlal Nehru University, New Delhi); also the Chairman, Programme Advisory and Monitoring Committee for the DST–SSS programme, in his inaugural address highlighted the importance of integration of Earth and life sciences. He pointed out that it is the interaction of minerals and microbiota that controls air and water chemistry, climate and ecosystem, and an integrated study will help manage and guide changes in the surface environment for sustainable development. M. Mohanty (DST) emphasized the importance of geomicrobiological research in India and the prominent role that DST and the Ministry of Earth Sciences could play in promoting such research.

In the opening session, G. Archana (Maharaja Sayajirao University of Baroda (MSU), Vadodara; also the event coordinator) pointed out that while the origins of geomicrobiology could be traced to early studies by pioneering soil microbiologists of the first half of the last century, recognition of this field as an independent, new, interdisciplinary, scientific area happened in the last decade or so, from the emergence of specialized journals and review series dedicated to the subject. Advances in molecular biological tools to study bacterial communities

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