

## Human Genome Project

(This article is a draft of a paper published in the magazine '*Red Pepper*' in 2001: exact reference unknown)

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From the media reaction, you could be forgiven for thinking that the rough draft of the Human Genome is the equivalent of the alchemists' philosophers' stone. Hyperbole in the newspapers and broadcast news heralded the book of life, the code of codes, the blueprint to life, the cure for cancer, the end of ageing: not since 'electricity so cheap you wouldn't need a meter' has a scientific development had such a public impact.

Let's put this in perspective. Our scientific knowledge itself is still very limited: we don't know how many genes there are, for example. Nor do we know what most of these genes do. And most importantly, there are no effective gene therapies, and very few treatments arising out of genetic knowledge. So cancer and mortality will remain a problem for the next few centuries. At present, the major impact of genetics will be in diagnostics: we will be able to detect more genetic conditions prenatally, and we will be able to discover if we have a risk of contracting a range of diseases.

But sometimes ignorance is bliss: would you want to know if you were going to contract a degenerative and incurable condition like Huntington's Disease? Research shows that only 1 in 8 affected people wanted to find out. And disabled people are deeply concerned about the development of more antenatal tests,

and more selective abortion. While supporting women's right to choose, are we confident that reproductive choices are free and fully informed? Most people would understand the desire to avoid the birth of children with terrible genetic diseases, but what about those conditions which do not greatly undermine quality of life? Reducing suffering is a worthwhile goal, but eliminating diversity is not. We must listen to the stories of those who experience impairment, before deciding that disability is a tragedy to be avoided at all costs.

And, of course, biomedicine must be put in social context. First, we know that advances in health over the two centuries have owed more to improvements in basic hygiene, diet and living conditions than they have to medical innovation. Deprivation and unhealthy behaviour are the major causes of illness in most of the population. By focussing on genes, we ignore collective and structural interventions which could make a greater impact in improving the health of society. Second, genomics will not be good news for the developing world. Indigenous peoples are being raided for their genetic material. Expensive new medicines and therapies are unlikely to be available outside the West. The basic infectious diseases are not areas where major pharmaceutical investment is taking place, and nor is there a willingness to invest in social and economic reform on a global scale. Meanwhile, the US government spend \$3 billion on the Human Genome Project.

Third, the story of the Genome is a story about profit. The modern philosophers' stone can literally turn base pairs into gold. Leading molecular biologists hold equity in new biotechnology companies. Patenting of genes is legal in the United States,

where there are now over four million gene patents, where there has been a 'Wild West Gold Rush' to gain territory. By comparison, the Wellcome-funded British genome researchers have made their material publically available, for which they should be praised. Patenting threatens the development of new therapies, and causes difficulties for the National Health Service in providing diagnostics and treatment, because biotechs may block research, or may demand licence fees for applications. Genetic insider dealing will be a major problem in the decades ahead.

Finally, problems arise over genetic privacy, and the danger of insurance companies, governments and employers getting access to citizens' genomic information. Surveys in the USA have shown that nearly 50% of people with genetic disorders in their families have been discriminated against by insurers. In the UK one-third of the people surveyed had problems with insurance, and 13 percent of those were at no risk of developing gene-related health problems. Fears of discrimination may even deter people from undergoing necessary medical tests. It is vital to develop strong regulation of access to genetic information, and use of genetic information, in order to prevent the development of a 'genetic underclass'.

The Human Genome is too important to be left to scientists. Neither do we want a free market in genetic intervention. Balanced information and full public debate is necessary, not media hype and decisions behind closed doors. Limits should be placed on medical research: in particular, the bans on human reproductive cloning and on germline gene therapy should be strictly policed. Meanwhile, the problems of gene patenting and genetic discrimination need urgently to be addressed at a global

level. The Genome announcement is the beginning of the story, not the end of it.