

Ethical issues associated with the Human Genome Project

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The Human Genome Project is one activity where glimpses of the future are visible now. Some particular possible ethical consequences of the enterprise are clear already – they are devilishly difficult and concern many of our basic understandings of what it is to be human.

Aims of the Human Genome Project

The Human Genome Project is an international program of research that will change society worldwide and affect every person.¹ It is a 15-year commitment to a continuous research effort that began about 10 years ago and receives \$US200 million annually in the USA alone. Applications from its discoveries will probably continue throughout the twenty-first century.²

The underlying premise of the Human Genome Project is that increased knowledge about genotypes will be beneficial for humans, particularly where the basis for a particular disease is due partly to the possession of a particular gene or combination of genes.

The Project seeks to determine the make-up of every human gene, with the eventual aim of being able to improve health by altering the genotypes of individuals to eliminate or offset undesirable or dangerous genes. To the extent that the Project aims to know about all human genes, it is likely to have an effect on all human beings. The application of knowledge gained from the Human Genome Project may be consequent to knowledge about genes, but it is inevitable and is alluded to already.³

Consequences of the Project

Many disturbing questions have already arisen and more will arise concerning the knowledge that has been gained and will be gained from the Project. Examples of these are given in the box on page 94.^{4,5} These questions remain unanswered, and largely unaddressed. There have been, however, several encouraging developments.

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First, the Human Genome Project has been associated from the beginning with consideration of the ethical, legal and social issues (known widely as ELSI) that might arise from it, and 3 to 5% of its funds have been reserved for these matters since its start.⁶ Second, the consideration of difficult ethical issues has proceeded steadily and some of the implications are being examined by working parties – the Task Force on Genetic Information and Insurance, for example.⁶

It is, therefore, not correct to assert that ‘nothing has been done’, as much has been done and continues to be done. Further, it is quite possible that those in charge of ELSI are aware of many of the future implications but are concentrating initially on what they perceive as the first questions that have to be considered.

The Australian Federal Government is applying itself to consideration of the Project’s consequences. The Federal Attorney-General and the former Minister for Health and Aged Care have jointly commissioned an inquiry from the Australian Law Reform Commission and the Australian Health Ethics Committee to, among other things, ‘provide protection from inappropriate discriminatory use of genetic samples and information; and reflect

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the balance of ethical considerations...'. Public submissions were sought late in 2001 by means of an Issues Paper, and the final report of the joint inquiry is due later this year.⁷ Also, the Federal Parliament enacted the Gene Technology Act in 2000, and this came into force in June 2001.⁸ This Act has set up a licensing system for genetically modified organisms in Australia and created a statutory 'Office of Gene Technology Regulator'.

Issues to consider in the future

Many of the quite predictable problems remain unaddressed publicly so far, and the numbers and scopes of possible social and ethical issues are large and wide-ranging. One such issue is human diversity – including diversity based on less than 'good' genes. It is my belief that genetic diversity is more likely in an unregulated system and that society is better off when such diversity is present.

Another set of issues relates to the increasing or prolongation of life. With genetic manipulation and the modification or elimination of 'bad' or 'dangerous' genes, or combinations of genes, humans are likely to live longer. Are we anticipating

immortality, or the prolongation of life to, say, an average of 120 years? Do people want to live for this length of time, and should they be able to die earlier if they so wish?

Biomedical research and improvements in public health over the past century have produced great changes already in our societies. Australians had an average longevity of about 56.5 years in 1901; the latest figures show that Australian women born in 1997 have an average anticipated longevity of 81.3 years and males an average anticipated longevity of 75.6 years.^{9,10} When it becomes possible to use the new knowledge produced by the Human Genome Project, these numbers will increase again.

As people live longer, other issues arise about the nature of the larger populations that may follow. If we are to live longer than we do now, will environments degrade even faster? If populations increase, will there need to be an even greater fall in fertility than has occurred already if we are to end the world's 'population explosion'? Or do we anticipate that increases in food production will allow more people from wealthy countries to be fed – even if millions from less fortunate countries continue to starve? Where will everyone live and how will they exist decently? How will they find water, jobs and food?

Review of the literature

These questions are so important that one would have expected that they would be covered *in extenso* by those writing about the Human Genome Project. If medical scientists do not care to address such questions, then they need to work with colleagues with the necessary skills, interest and time to do so – an exemplary kind of team operation. Review of many published articles shows that authors do one of the following:

- ignore completely all ethical and social aspects of the Human Genome Project, often because they are dealing – legitimately – with quite technical matters
- discuss particular ethical issues – such as those associated with cloning, prenatal diagnosis, genetic screening, selective termination of pregnancy, eligibility for insurance or gene therapy^{2,3,11}
- discuss wider ethical 'principles' (of the Beauchamp and Childress type, i.e. autonomy, confidentiality, beneficence and fairness¹²) in the specific context of the genetic revolution.¹³

There are discussions of how to access information in a rapidly moving field and on the ethics of moves recently to 'commercialise' some of the developments, both issues with ethical elements embedded in them.³

Most papers contained no discussion at all directed towards the wider social consequences (such as those identified above) which will surely follow application of the new techniques, although some authors indicated that such a discussion should occur.

Ethicists, moral philosophers and biomedical scientists

It may well require ethicists and moral philosophers, as well as biomedical scientists, to address the issues together. The Human Genome Project will add more and more ethical and social issues, and these will be different from any we have considered before. Many of these will be discipline-specific (and will include consideration of 'classical' ethical issues particularly relevant to the practice of clinical genetics), but some will be more general and will invite consideration of the society that might emerge once genomic advances are applied.

Included among these is the question of the 're-emergence' of eugenics. The likelihood that pressures will emerge to 'require' the avoidance of certain genotypes is very high and needs to be addressed, and the issue determined well in

advance. Issues of immigration restriction, compulsory sterilisation, involuntary euthanasia and incarceration have been raised already in some quarters.

My personal view is that people should be free to possess any genotype free from coercion, but this may not be the universal official view in the decades ahead. There needs to be a commitment in every country and in international agreements not to allow any of the unacceptable outcomes that have happened in the past to occur again, and specifically to rule out the proscription of certain genotypes or the acceptance of compulsory sterilisation or the compulsory termination of pregnancies with unacceptable genotypes.

Once we have the knowledge

One thing is clear. Society will be different from what it has been hitherto when the human genome is understood. Let us hope that the new knowledge will not be an entry to new tyranny and to new forms of social control. Let us hope that the Project will not result in a diminution of human happiness or contentment, or in a lessened sense of human fulfilment.

We need to provide responses now to as many of those implications as we can.

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Issues arising from the Human Genome Project

- When we become able to do more genetic manipulations in humans (as we have already done successfully in plants), what will be the consequences for society, for humanity and for human life?^{4,5}
- Will we be allowed to be born only if we have an 'acceptable' genome, and who will decide this?
- Will selective abortion of fetuses without 'acceptable' genomes become the 'norm'?
- Will postnatal 'correction' of genetic defects or predispositions become the 'norm', and will each of these processes be voluntary or compulsory?
- Will human reproduction continue as it has for millennia or will that haphazard process be replaced with something else, such as laboratory matching of 'good' strands of DNA?
- If gene therapy is possible, what rules will be used to define those to whom it can be applied?
- Will gene therapy be expensive and available only to the wealthy, or will it be included in a system of national public funding for medical services?
- If gene therapy is included in publicly funded medical services, will it attract a co-payment for all or only some diseases?
- What will be the consequences for the length of human life, both for individuals and for communities?
- What will be the consequences for fertility and for human reproduction – for example, will China's 'one child' policy become standard practice for all advanced societies, or is even that restrictive policy too generous to consider in the future?
- Who 'owns' the information contained in any genome?
- What are the prospects for future discrimination on the basis of genetic differences?

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