ETHICAL DILEMMAS: WHO SHOULD DECIDE – SCIENTISTS, GOD OR LAWYERS?

Very soon we will know each and every one of the 100,000 genes in the human genome. With it, we will have the ability to determine every facet of ourselves, from our gender and health to looks and personality. By manipulating a single gene on chromosome 14 we could stay eternally young. Many of the world's diseases could become things of the past. There is even talk of bringing extinct species back from the dead. These are amazing frontiers; but where and how far should they be allowed to go? And who should decide? Scientists, God or lawyers?

Take God first. It is perhaps tempting to imagine that, by leaving God to decide, nature would be permitted to run its course. But, in reality, there is no 'natural' status quo ante to return to; from our Neolithic ancestors onwards, humans have always been tampering with the natural world. Now, however, instead of artificially selecting strains of wheat or breeds of sheep, we can do the same, at source, to ourselves. It is hard to see how science could replace God any more comprehensively. God has been relegated from overall architect to an ethical consultant, leaving scientists and lawyers and, crucially, politicians and electorates, to determine our future course.

As the creators of new technologies, it is scientists who are best placed to see both the risks and potential rewards of their findings. But scientists cannot be left to their own devices in Frankensteinian isolation. Science itself has become synonymous with Big Business. Increasingly, dividends are the driving force behind technologies while ethics, religion and public concern attempt to apply the brakes. Within this market-led climate, it falls to governments and lawyers to intervene with legislation to direct research and control how – if at all – new technologies are to be used. In doing so, governments need to be reliably informed by scientists. So too – fairly and without media sensation – must their electorates, such that decisions carry conviction with ordinary people. To this end, where possible, thorny issues should be put to referenda in which Big Science can be called to public account and the views of all – religious, medical,

environmental or ethical - voiced, (as the Swiss did, for example, before approving research into the genetic modification of crops).

However, these are not just domestic concerns. There is a pressing need to govern scientific development at an international level, too. Like concerns over nuclear proliferation, the technologies being developed and marketed are so supranational in their implications that domestic policies alone cannot be sufficient to regulate them. Any variation in regulatory standards would simply cause research to emigrate to those jurisdictions with the greatest laxity (witness, for example, current calls from UK scientists to relax the provisions of the 1990 Human Fertilization and Embryology Act in order to compete on equal terms with the US). Instead, an international body like the United Nations should set out a clear regulatory framework, akin to, say, the Antarctic Treaty - a largely successful co-operative treaty on the scientific uses and conservation of Antarctica - in order to direct and govern research worldwide.

To appreciate the need for this, take the Human Genome Project again. What began in 1990 as collaborative, internationally funded research, with it's findings posted daily on the world-wide web, has fast been overtaken by US biotechnology companies performing their own human gene sequencing and attempting to patent their findings. It is here that a Genetic Information Treaty could legislate to declare not only that the human genome is public property and not, of itself, patentable, (as opposed to later medical inventions derived from it), but, also, to limit its permissible uses to, say, the global prevention of certain classes of life threatening or life diminishing diseases. It might forbid the use of genetic information for conferring social advantage or for denying the natural processes of aging and death; or its use for cosmetic self-enhancement or achieving valetudinarian perfection. Similarly, genetic modification, embryo screening, sex selection, genetic privacy and limitations on the uses of human cloning are, also, major issues on which universal policy is urgently needed.

Whatever rules and regulations exist, lawyers will always be called upon to push the letter of the law to its limits. But, just as the Universal Declaration of Human Rights acts as an ideal standard against which human rights abuses can be condemned, having global legislation to direct scientific developments would

give a clear indication as to both the intended and unacceptable uses of new technologies. Contraventions could be heard in a specialist court - an ethical and scientifically based equivalent of the Human Rights Committee.

Such legislation might assist judges in reaching pragmatic solutions in cases like that of Diane Blood or the Masterton family, without fear of their rulings setting uncontrollable precedents. For instance, a central tenet of any Genetic Information Treaty might be the preservation of natural sex ratios, outlawing any suggestion that choice of gender should be a fundamental human right. However, there may be isolated caveats which claimants, such as the Mastertons, could invoke in order (as they sought) to replace the loss of their three-year-old daughter with another girl. In this way, the technology is not denied to absolutely everyone. However, it is available in only the most exceptional and deserving of cases without, at the same time, opening the floodgates to, not only sex-selection but, perhaps, in turn, hair colour, eye colour or sexual orientation.

The contingencies and issues involved here are as complex an ethical, moral and legal minefield as our species has ever faced. We will only ever have 20/20 vision with hindsight. At least, guided by internationally drafted, ethically sanctioned, science-based legislature, we can hopefully harness some of the benefits of what are remarkable technologies with a degree of accountability and reassurance. More work for lawyers - but vital for our futures.

(997 words)

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