

Biology, Bioethics and Society

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It is common knowledge that science and technology have advanced at a bewildering, some would say alarming rate over the past decades. The non-scientific lay-person is often left wondering where we are all going, and whether scientists are often engaged in a game which provides great fun for themselves while endangering the stability of the world as we know it.

In the biological field, there have been advances particularly relating to unravelling the mysteries to be found in the genetic code, and secondly to utilising the capacity of cells derived mainly from an embryo to grow in vitro and reproduce vital organs and even whole embryos. These two areas have produced brilliant results and have at the same time raised several issues of ethical importance.

One may summarise some of the reasons why this research has raised such fundamental problems within society, a process not previously encountered in the history of science.

Firstly, society today is much more involved and attuned to the results obtained by science than it has ever been. This is the result of the concurrent revolution in the ease of accessibility and transfer of information, mainly through such means as the internet, a phenomenon which has barely celebrated its tenth anniversary. However, it is also related to the higher education level achieved by the general public today, compared to a generation ago, thus enabling more people to participate in the debate.

Secondly, there is the fact that biology involves every one of us, and therefore advances in this area are likely to affect us intimately. Compared to the earth-shattering advances in nuclear physics in the first half of the 20th century, which were intellectually brilliant and which have led to the construction of the most destructive weaponry, but where debate was largely limited to a relatively small number of involved persons, the biological revolution of the second half of the century has found a much more eager and numerous population which was ready, able and

interested in understanding the implications of the findings described.

A third reason for the widespread interest is the individual benefit that could be achieved through modern bio-technology. It is a fact that the initial techniques of in vitro fertilisation were of considerable benefit to the significant minority of infertile couples who could not achieve their ambition of parenthood in other ways. Likewise, pre-natal diagnosis ensured that couples were enabled to ensure that their children did not suffer from disorders to which they themselves were genetically prone.

The unravelling of the genetic code might very well prove to be the highest achievement by human beings throughout the history of scientific endeavour. Genetic information is on a totally different level from other data relating to the normal structure and function of the human body. It is predictive of future health, it is shared between different members of the extended family, it is relevant throughout the life of the individual and not merely over the disease-episode like other frequently performed tests. For these reasons it may lead to discrimination at the workforce, insurance, or to group and ethnic discrimination. Hence the importance of measures directed at ensuring that genetic information is obtained only after thorough counselling of the members involved, and that strict precautions are undertaken to ensure that data is kept secure and confidential. This is important both at the individual level, as well as that relating to large collections of tissues to be found in laboratories and data-banks.

More recently the public has been assailed with news relating to the creation of new life which bypasses the normal union of sperm and ovum. The production of Dolly was a landmark not so much due to the biological novelty of the technique, or the likelihood of widespread application in the medical (as opposed to the veterinary) world, but more to the power of the imagination in conjuring 'Boys in Brazil' type scenarios which many reasonable people find objectionable.

Lastly, and perhaps most important of all, we are now entering the stage where stem cell technology offers to provide the ultimate in spare-part tissues, organs, and other biological material to replace those lost through disease, age, wear and tear, etc. Stem cells taken from embryos, bone marrow, or other tissues which still have pluri-potential capacity to multiply and differentiate have been utilised and made to multiply in vitro to

produce, for instance, muscle cells, brain cells, etc which are functional when injected into a diseased host. Such technology obviously offers considerable hope to those suffering from diseases which include Parkinson's disease, heart disease, as well as conditions relating to kidney, liver and other organ failure.

It is therefore obvious that unlike previous scientific revolutions, the biological revolution of the latter half of the 20th century is unlikely to leave many of us unaffected. We would all eventually be looking forward with anticipation and great expectation to the time when all our illnesses will be cured, all our failing organs replaced, and all diseased tissue cured by replacement, implantation, injection or other manipulation of stem cells and their products.

What are the ethical issues involved in such procedures, and why is the public wary of such issues? I propose to summarise some of the more urgent or worrying ethical issues relating to advances in biology in recent years.

1. *Prenatal diagnosis and abortion.* There is no doubt that the biggest ethical issue in Malta relates to abortion. Malta is the only country in Europe which does not allow abortion even for the prevention of serious genetic disorders. As a result those requiring abortion for any reason find their way to centres overseas. Recent statistics from UK show that over one per cent of pregnancies end in the UK as abortions. Statistics for other abortions carried out in other countries in Europe are not available. The issue here is whether testing for genetic disorders (e.g. thalassaemia, fragile X chromosome etc) is justifiable when no measures may be taken to prevent the condition in the fetus. Pre-implantation genetic diagnosis (PGD) involves the genetic analysis of cells from the embryo prior to implantation with the idea of discarding defective embryos and implanting into the uterus only 'healthy' embryos.
2. *Cloning.* This topic has become the focus of media attention out of all proportion to its practical importance. The Council of Europe Bioethics Convention (Oviedo Convention) prohibits cloning of human beings. Visions of multiple cloned infants (as depicted in the film 'Boys from Brazil') have been encouraged and condemned. The technique has, unquestionably, value in veterinary practice,

but in the human situation it has been largely limited to the relatively rare situations where normal reproduction with other reproductive technologies has been impossible (e.g. infertility, lesbian relationships etc). Its use to provide 'designer babies' has also been rightly condemned.

3. Use of *embryo stem cells*. The flourishing technology relating to stem cell research often involves the destruction of the embryo. In most countries, 'left-over' embryos from in vitro fertilisation programmes are used for the purpose. Anachronistically, in the UK, embryos to be used for research have to be created *ad hoc*, a process which is forbidden by the Bioethics Convention. Countries like Germany which forbid embryo research have allowed the importation of stem cell lines which were in existence prior to January 2002 in an attempt not to stifle research in this important and growing area. The greatest moral dilemma in my opinion will arise when products derived from this research become available on the market. Will countries like Malta avail themselves of essential products to treat the various disorders mentioned above knowing that they have been derived from such technology involving destruction of embryos? This will raise considerable ethical issues comparable to the questions raised about utilisation of findings from unethical research performed during the Nazi era.

4. *Patenting the Genome*. One major issue relating to utilisation of research is the availability of the research findings to other workers and to society at large. The major involvement by private and commercial organisation in the potentially very lucrative genomics research has resulted in severe restriction in the use of research findings. One typical recent example is the patent issued relating to the use of the so-called 'junk DNA' – DNA which is not involved directly in coding, and which for a long time was thought to be inactive, but which now has been shown to be very much involved in controlling the coding of active DNA. Patents relating to the use of such DNA threaten to stop research in this important area, and result in unacceptable increase in prices of the products derived from this research. The whole issue of whether the human genome should be subject to patenting has been raised several times, and remains a thorny problem which needs to be resolved. The recent

report that the World Trade Organisation has succeeded in convincing several Western pharmaceutical companies to provide urgent drugs to the poorest countries in the third world at a fraction of the normal price leads one to hope that progress in this area is possible, and that altruistic considerations are not entirely dead.

5. *Data protection.* Two major factors have combined to make this a very urgent issue. The first factor results from the enormous quantity of data that is available and that may be considered personal and sensitive. This includes all health-related data, and in particular genomic data which may predicate present and future health conditions. The second factor depends on the ease of storage and access of computerised data which necessitates special procedures to ensure its protection. Data protection legislation has been promulgated as an EC Directive and has been adopted as Data Protection Acts in most countries. In Malta the Data Protection Act ensures privacy and transparency. It ensures that the data subject is aware of information kept about him or her. Other sources of stored data include data banks and also tissue banks held in most hospital and research laboratories. The informed consent of the individuals concerned is not always a priority with such banks.

Ethical issues and the public

Involvement of the public in unravelling ethical issues has been encouraged for a long time. Lay person participation in ethical committees, and in particular research ethics committees have been a requirement for some time. The public is also encouraged to participate in formulating views relating to current ethical issues, through public discussions, conferences, and the media.

The level of participation depends not only on the interest generated by the various topics but also on the level of preparedness by society as a whole. This in turn relates to the level of sophistication and education of the general public. It is no use emphasising the need for public participation and issues relating to public rights, (including patients' rights) if in general, people are not interested enough or motivated sufficiently to be assertive and demand that such rights are respected.

In Malta we have special issues that need to be tackled. In the first

instance the level of science education is relatively low compared to the rest of Europe. This has been the result of past neglect and lack of emphasis of the importance of science subjects at tertiary level – they were considered to be less useful in obtaining a job, and even now are considered to be less well-paid than other spheres of life, including particularly business, administration and computer studies, not to mention the older professions of law and medicine. Unless and until science studies are given their due importance, the level of education and sophistication in scientific matters is bound to remain at a low level. In particular, there is an urgent need for well-qualified science teachers capable of imparting an interest in science at an early (including primary school) stage, and of encouraging such interests at secondary schools.

From the ethics point of view, it is difficult to maintain an interest in this topic apart from the odd subject that occasionally hits the public through exposure in the media. On such occasions, chances are that the importance of such topics is blown out of proportion. One such occasion was the story relating to the Maltese Siamese twins which provided heated discussion relating to the morality of performing complex surgical interventions when the outcome involved the necessary death of one of the twins. The very extensive literature relating to this topic in the specialised journals is still divided on the issue. I say that the public interest as shown in the media was disproportionate not because the topic in itself is not important ethically, but because of the rarity of the situation that hardly touches on the lifestyle of anyone except the affected individuals and their family. On the other hand it is very difficult to involve the public in a debate involving the mundane, day to day issues of bioethical concern. Such issues include the role of informed consent, data protection, stem cell research, etc.

An important role of the Bioethics Consultative Committee is to bring such issues to the notice of the public and to encourage discussion and debate. For the past five years, this Committee has organised yearly conferences relating to various issues of ethical significance. The Proceedings of such conferences has been published and are available for the public. Moreover, the material presented at these conferences has been the subject of discussion in the media, and has thus been instrumental in disseminating such information. Other ways of preaching the message has been through the website (www.synapse.net.mt/bioethics), and through the use of a regular Newsletter.

This year the topic chosen has been one relating to Science, Ethics and Society, which puts particular emphasis on the role of the public in this area. Various views have been expressed relating to this role. In summary one may say that there is a very definite role of the public including:

1. *Watchdog role.* The voice of the public should be heard particularly in relation to what is considered acceptable scientific activity and what is not. Issues include genomic modification, (including the introduction of genetically modified organisms), the limits of research, etc
2. *Active participation in ethics committees* as mentioned above.
3. *Ensuring adequate legislation.* One of the biggest hurdles in Malta relates to the absence of adequate legislation relating to several issues. Legislators are influenced by what they perceive as issues of interest to their electorate and respond accordingly. Where there is little interest among the voters there could very well be inertia among the legislators.

The role of the scientist.

It is very easy for the scientist involved in unravelling the mysteries of science to become carried away by his or her own momentum and involvement, and to forget the broad scenario and responsibilities. Scientists are, in general, neither philosophers nor do they tend to be intimately involved in social issues. As a matter of fact, within the scientific community, self-selection usually favours those who shun political and social involvement to a life devoted to individual and often solitary research.

It has become, however, abundantly evident that scientists cannot lock themselves in ivory towers and remain uninfluenced by public opinion. Recent regulations in the US, for instance, outlaw funding for research involving cloning and this would automatically reduce the interest of organisations and individual scientists to embark on such work. These regulations arise as a response to the general concern expressed by the public. Another area where the public has had a very significant input into the sort of research work that scientists do is that relating to genetically modified organisms (as mentioned earlier in the paper by Dr

Marion Zammit Mangion). A public boycott of the products of biotechnology will result in significant curtailment of funds for research (and jobs) in the particular area.

The role of the scientist as a public educator cannot be ignored. It is often the case that there is a mutual interaction between what the public is interested in and what it is exposed to. One cannot expect the public to show even a minimal interest in science if its scientists are not prepared to come out and meet it half way. It is therefore the role of individual scientists, as well as science organisations, to stimulate interest in research and in science in general.

Scientists are a class of human beings engaged in a specific type of work. As in any such groups there are bound to be the mavericks, those who indulge in doubtful and shady practices, those who prefer to undermine the standards of scientific research in the hope of being first and being acknowledged as such. Every profession has to deal with a small minority of such persons, and it is the role of every profession to have a mechanism to ensure that such persons are censored and eliminated.

Because of the very nature of scientific research, particularly commercial research where potential rewards may be very considerable and where, therefore, there is a considerable degree of secrecy, it is often difficult to know precisely what is going on until a very late stage of the work. Even research ethics committees themselves are often not in a position to monitor research work that has been approved. The need for peer-review, and if necessary 'whistle-blowing' has to be emphasised in this as in any other area of human endeavour.

Finally, in an age where research has become globalised, where participation with other groups has become almost mandatory,¹ it is important to ensure that ethical issues have been thrashed out and approval obtained by all the individual groups involved in the project. This is particularly important where research involves commercial organisations who prefer to do their basic research in countries where ethical standards are not as high as in their own country. Participation with such groups should be undertaken only if it can be clearly and transparently shown that no corners have been cut and not ethical principles have been sacrificed.

¹ Note, for instance, the current emphasis on the need to have multiple groups of scientists from different countries applying for EU grants.