

Irish Council for Bioethics

National Playwriting Competition 2006/2007



Adam Hart-Davis/Science Photo Library

This viewing theatre for anatomical dissection at the University of Padua in Italy was the first of its kind in the world

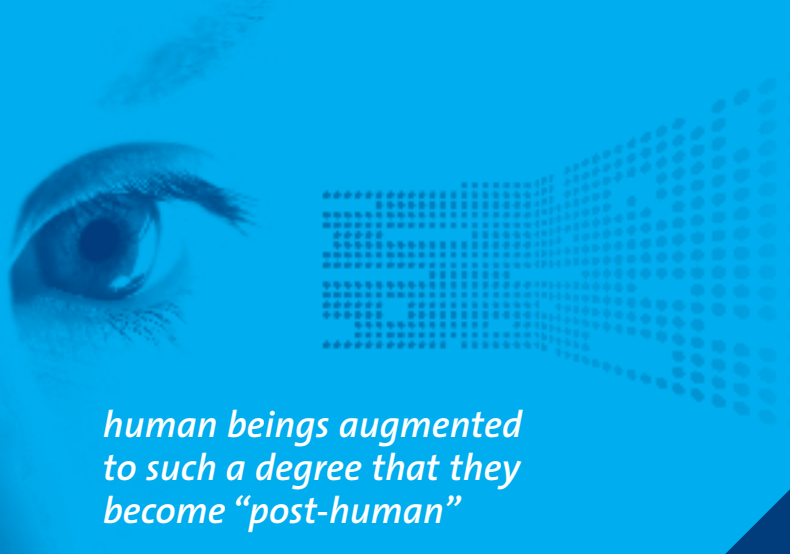
Introduction to Bioethical Issues

BIOETHICAL ISSUES

The following list of bioethical topics is for illustrative purposes only. Proposed plays do not necessarily have to be about any of these topics, however, the theme of the play must be based on bioethical issues.

1. Human Enhancement: Making Better People?

All of us share a desire for self-improvement. Whether through education, work or by adhering to religious or ethical codes, each of us seeks to become a "better human" in a variety of ways. But now a new set of possibilities is opening up. What was once the province of science fiction - human beings augmented to such a degree that they become "post-human" - is rapidly becoming fact. Advances in biotechnology, neuroscience and computing mean that within the next 30 years, it may become commonplace to alter the genetic make-up of our children, to insert artificial implants into our bodies, or to radically extend our life expectancy. Fundamentally, the enhancement issue is about what kind of human beings we want to be. Should future people be stronger, more intelligent? A common view is that we should not be tampering with human nature, while others see considerable scope for improvement of the human race.



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2. Using DNA to Solve Crime: Balancing Criminal Investigation with Human Rights

DNA fingerprinting has made an invaluable contribution to crime detection and crime prevention. The UK DNA Database provides many positive statistics; for instance, it is estimated that in a typical month the database links suspects to 15 murders, 31 rapes and 770 car crimes. However, numerous ethical questions arise with respect to who should have samples taken, for what crimes samples should be taken, how long samples should be retained on file and who shall have access to stored genetic information.

Under what circumstances should people have their DNA taken is unclear i.e. should a database include samples from people who are cautioned, arrested, charged but acquitted or only those who are convicted of a crime? Should samples be taken only in the case of serious crimes e.g. murder or assault or should samples also be taken for lesser crimes e.g. driving and public order offences? There are those who argue that only people guilty of criminal behaviour would fear having their profile stored on a database and that everybody should be willing to provide a sample. However 32% of black men in England and Wales are DNA profiled as opposed to only 8% of white men, which has led to concerns about discrimination.

Concerns are also raised about how long DNA should be stored on a forensic database. There is no doubt that scene of crime samples should be retained, in case an individual convicted of an offence alleges that a miscarriage of justice has occurred. In fact DNA evidence was used to vindicate a number of convicted individuals who were on death row in the US. But what of an individual's sample? For instance, should they be destroyed once a convicted person has completed their sentence or should they be retained indefinitely? Some say the retention of DNA samples will greatly benefit society while others fear that even though someone had repaid their debt to society they would be continually under suspicion and discriminated against.

DNA can provide sensitive information about individuals and their families such as their susceptibility to a genetic disorder like Huntington's disease. This increases the potential for genetic discrimination by government, insurance companies, employers, financial institutions and other organisations. For instance, were genetic information about a person to be given to an insurance company, that person might be prohibited from taking out life cover and in turn be prevented from acquiring a mortgage.



3. Organ Donation and Transplantation: Meeting the Demand Ethically

There is currently a severe global shortage in the number of donor organs available for transplantation. Despite Ireland having one of the highest rates of organ donation (per million population) in the world, the numbers of people on transplant waiting lists here are increasing. Presently Ireland operates an opt-in system where people are asked to sign an organ donor card. However, in order to reduce transplant waiting lists other options are being explored each with their own social, ethical and economic implications.

Traditionally human organs used in transplants were acquired from brain dead donors (i.e. where permanent stoppage of all brain activity occurs). Now the expansion of posthumous donation criteria to include cardiac death (i.e. where stoppage of heart and lung function occurs) is being contemplated as is the establishment of a live donor programme where organs e.g. kidneys are donated by a relative. Another system being considered is that of “presumed consent” whereby if someone does not expressly opt-out e.g. via their driving licence form, they are presumed to be willing donors. Some international commentators have gone so far as to call for automatic posthumous donation similar to other mandatory civil obligations like jury service or compulsory military service where individual consent is not required.

There are concerns that the global shortage has driven people to use more sinister methods of procuring organs for donation. In recent years a black market in organs has arisen where people from developed nations in desperate need of a transplant travel to developing countries and pay tens of thousands of euro to receive a life-saving transplant. There are grave concerns that the commercialisation of organ donation has led to the coercion and exploitation of the economically disadvantaged. People have also raised concerns regarding the practice in the Philippines of offering prisoners the chance to have their death sentences commuted to life imprisonment in return for an organ and in China where organs are procured from executed prisoners.

4. Biometrics: National Security or Personal Intrusion?

Biometrics refers to the technique of identifying people using unique physical characteristics e.g. fingerprints, iris of the eye, voice pattern or facial pattern. Biometric data can serve many purposes, including: civil and criminal identification, surveillance and screening, health care, e-Commerce and e-Government. Given post September 11th political and social anxieties, biometric data is being used for security purposes, as a means of identifying citizens. Indeed biometrics is increasingly being encountered in air travel as passengers are required to undergo fingerprint and iris scans before being allowed to travel to certain destinations. Under the US visa-waiver programme participating countries have to begin using biometric passports. In 2005 Irish citizens made approximately 500,000 visits to the US. Therefore, in October of this year the department of Foreign Affairs launched the new e-Passports, which have an inbuilt microchip containing biographical information as well as a digital photograph of the holder.

While the use of biometric data promises to augment security and reduce the occurrence of specific crimes, such as identity theft and the abuse of social funds, it evokes a range of social, legal, and ethical concerns. In particular it raises questions about the effect it will have on the concept of identity and whether its use will result in the discrimination of particular individuals or communities.

As with DNA there are fears that personal information contained in e-Passports might be accessed by organisations not involved in security, such as insurance companies and employers which might lead to the discrimination of individuals. There are also concerns about the reliability of biometrics and whether people will be at risk of having their personal information copied. At a recent hacker’s conference a German security consultant showed he could clone data contained in e-Passports similar to those introduced here. There are also concerns that biometrics will allow Governments to intrude into citizens’ privacy and that people might be monitored without their knowledge or consent. *(The film Minority Report explores issues related to this topic)*

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5. End of Life Issues: Your Body, Your Death, Your Choice?

In Ireland a number of severely premature babies are born every year. Due to the complications associated with premature birth some of these babies have little or no chance of survival. Recent medical advancements allow doctors to keep these babies alive for longer but increasingly the question is asked whether it is in the babies' best interest to do so. The debate on whether it is more humane for doctors to withdraw treatment given the suffering and the limited possibilities for a favourable outcome or whether they should do everything in their power to keep severely premature babies alive was highlighted during the case of Charlotte Wyatt. Charlotte was born with serious heart and lung problems when her mother was 26 weeks pregnant. Doctors, who argued that Charlotte would be in constant pain and have a very poor quality of life, won a legal battle against Charlotte's parents to allow her die if she were to stop breathing. Despite the ruling Charlotte survived and recently celebrated her 3rd birthday, however she is still extremely ill and resides in hospital much of the time.

Terry Schiavo was in a persistent vegetative state for 16 years. Her husband and family disagreed over the removal of her feeding tube, which would result in her death. As Terri had left no written record of her wishes it was unclear what medical care she would want. After several court appeals Terri's feeding tube was removed and she died in March 2005. An advance directive is a statement made by a competent adult relating to the type and extent of medical treatments they would or would not want should they be unable to express their wishes. While writing an advance directive can remove the burden of making difficult medical decisions from family members or friends, concerns are raised as to how a person could comprehend the wide spectrum of illnesses they may face in the future and express a preference in advance. For instance, a healthy person may state a preference for death over disability, but may change their minds when they are faced with the reality.

In recent years a number of Irish people with terminal or debilitating diseases, e.g. multiple sclerosis (MS) have travelled to Switzerland to be aided to commit suicide by the group Dignitas. While they are not legal in this and many other countries, euthanasia and assisted suicide have sparked much bioethical debate. The case (UK) of Diane Petty, a woman suffering with MS who was refused legal permission to allow her husband assist her in committing suicide is an example of how divisive the debate is. One group argues that it is an individual's right to choose when and how to die and that keeping people alive who are in unbearable and terminal pain is wrong. The other group raises concerns that a society, which allows euthanasia and/or assisted suicide, may adopt the attitude that the infirm or disabled are a burden to society and argues that human life should be valued and preserved in all circumstances. (*The films Million Dollar Baby and The Sea Inside explore issues relating to this topic.*)

6. Control of Infectious Diseases: Ethical Dilemmas in a Pandemic

Infectious disease is caused by a biological agent (e.g. virus, bacterium or parasite), which can be transmitted from person to person or from organism to organism. Infectious diseases cover a panoply ranging from MRSA to HIV to avian flu. The 2003 global outbreak of severe acute respiratory syndrome (SARS) and the regular outbreak of MRSA in Irish hospitals provide abrupt reminders that infectious diseases continue to pose a threat to human health.

Given the current threat of an avian flu pandemic, there has been increased discussion of the ethical issues pertaining to the control of infectious disease and a number of ethical questions have arisen. How far do healthcare workers' duties extend and what are they due in return for their efforts? Healthcare professionals have a duty to provide care not least during an outbreak. However, given the risks posed to healthcare professionals and their families, society must ensure that those who face a disproportionate burden in protecting the public are themselves protected and awarded accordingly.

To what extent should measures taken to protect public health override individual freedoms? Quarantine seriously disrupts lives, limits personal liberties and jeopardises workers' livelihoods. The dilemma facing public health officials is how to implement quarantine in a fair manner that does not discriminate against individuals or specific groups without justification. How will scarce resources be distributed among the public? Should vaccinations be given to healthcare workers, the elderly, children or should they be distributed on a first come first served basis i.e. those who show symptoms of the disease first. What obligations do developed countries have to assist poorer nations in the event of a global pandemic? For example, the case has been made that the chances of a pandemic such as avian flu breaking out in South-East Asia far exceed the chances of an outbreak in Europe. Therefore, it has been argued that precious vaccines and resources should be sent to South-East Asia in order to curtail further spread of the disease.



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7. Human Genetics

Despite having already succeeded in mapping and identifying the whole genetic sequence of humans, scientists do not know yet the exact function of most genes. A gene contains information on hereditary characteristics such as hair colour, eye colour, and height, as well as susceptibility to certain diseases.

The term embryo refers to about the first six weeks of development after a sperm fertilises an egg. This can happen naturally but as 1 in 6 Irish couples experience fertility problems some seek medical assistance in the form of in-vitro fertilisation (IVF) during which, fertilisation occurs outside of the mother's body with the embryos then being placed in her womb. While it is unknown to what extent genes can influence somebody's skills, psychology or overall health, it is possible to carry out tests on embryos created during IVF (before placement in the womb) in order to detect severe genetic defects. This technique is known as pre-implantation genetic diagnosis (PGD). Concerns have been raised that this technique will result in a modern form of eugenics where people with certain disabilities will be screened out of existence, while others argue that PGD is a way of reducing pain and suffering. (*The film Gattaca explores issues relating to this topic.*)

PGD is also used to help treat ill children. For example, in the USA parents of a girl, Molly Nash, born with a rare, incurable disease called Fanconi's anemia underwent a controversial procedure to conceive another child who could help cure Molly. Embryos created using IVF were tested for signs of the gene responsible for the disease. Embryos that did not carry the disease underwent further testing to find those that would be a tissue match for Molly. As a result a boy, Adam, was born who was free of the disease and who could donate cells from his umbilical cord to treat his sister. Many people argue that there are a number of ethical problems with this "saviour sibling" technology. They question, whether Adam would have been born at all had Molly been a healthy child or whether he was born only to save her life. Adam and Molly's parents refute this and say that they would have had another child anyway but that this technology ensured Adam would be healthy and that Molly's life would be saved. Critics also express concern over whether children, like Adam, will constantly be called upon to donate tissue or maybe even organs, e.g. kidneys to their sick siblings. Concerns too are raised about the possibility of "saviour siblings" viewing their birth merely as a means to an end and seeing themselves as an instrument to cure disease. Another argument against selecting "saviour siblings" is that a number of healthy embryos, which are not exact tissue matches, will be discarded.

8. Stem Cell Research

Stem cell research is a rapidly evolving technology and has the potential to offer a wide range of medical benefits to patients. However, stem cell research, in particular research involving embryos which results in the destruction of the embryos, raises many ethical issues. One of the key areas in the debate centres on the moral status of the embryo (see the section on Human Genetics for an explanation of the term embryo). The wide spectrum of opinions on the moral status of the embryo ranges from viewing it as a ball of cells, as a developing human being or as a person with the same rights as someone who has been born already. There are numerous examples of how divisive the debate on the status of the embryo is, including cases where couples have disputed what should happen to their frozen embryos and where widows have asked to have embryos, which were created while their husbands were alive, placed in their wombs.

Supernumerary embryos (embryos that are not placed in the mother's womb during IVF) are usually either frozen for future use or destroyed about 5 years after creation. Some people argue that harvesting stem cells from these embryos is permissible given that they will be destroyed regardless. Indeed they argue that there is a moral imperative to use these supernumerary embryos for research into fatal and debilitating diseases suffered by those already born. However, those who afford higher moral status to the embryo reject this argument and compare research on supernumerary embryos to performing research on terminally ill people. They also argue that allowing embryos to die is not equivalent to actively terminating them.

The creation of embryos specifically for research may be problematic even for people in favour of stem cell research involving supernumerary embryos. Those who confer significant moral status on the embryo argue that their creation specifically for research represents disrespect for human life because creating an embryo, which is never intended for transfer to the womb, treats the embryo merely as a means to an end. Others fear that allowing embryos to be created for research would set science on a "slippery slope" to reproductive cloning. Also the creation of embryos for research purposes would require the donation of a large number of eggs and there are fears that vulnerable women might be induced into donating their eggs for financial gain.



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