

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Emerging biotechnologies between April 2011 and June 2011. The views expressed are solely those of the respondent(s) and not those of the Council.

## **Nuffield Survey on Emerging Technologies**

**April 2011**

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### **1 How would you define an 'emerging technology' and an 'emerging biotechnology'? How have these terms been used by others?**

New innovative technologies in the fields of technology, biology and medicine.

### **2 Do you think that there are features that are essential or common to emerging biotechnologies? (If so, please indicate what you think these are.)**

In every generation there were innovations with tremendous implications on human life. Emerging technologies are not exceptional. There is promise and there are significant challenges.

People tend to fear new technologies and innovation. This was the case when medicine increased the role of man at the expense of the role of God, when the radio was invented, when television was introduced, when video games became part of life. Fear and suspicion are natural human inclinations, and the worse guide for innovation.

### **3 What currently emerging biotechnologies do you consider have the most important implications ethically, socially and legally?**

People used to think that our fate lies in the stars. Now some assert that our fate is in our genes.

Gene therapy to treat:

- Sickle cell disease
- Cystic fibrosis
- Tay Sachs disease
- Down syndrome
- Duchenne muscular dystrophy (common in children)
- BRCA1
- Haemophilia
- Hereditary colon cancer

Transplant of animals' (pigs) organs in human beings.

Ethically problematic: human enhancement technologies.

### **4 Are there examples where social, cultural and geographical factors have influenced the development of emerging biotechnologies (either in the past or currently)?**

Science is a **social construction**. "Things" depend on how people conceive them within a given context, within a given reality.

We need to explore:

**Motivation** - what prompted you to do something?

**Intention** - what did you want to achieve by doing something?

**The pedagogic problem** - how to keep the public informed; how to bring the public to some understanding of a given issue.

The media packages the information in an interesting way; tend to conceptualize issues in black-and-white, to sensationalize, to attract attention to the extremes at the expense of a detailed analysis; at the expense of a penetrating, well-informed, varied discussion. We must insist on nuances and complex reasoning.

In the genetics context, we need to weigh the interests of the **community as a whole v.**

**the interests of individuals.**

**Whose interests trump others?**

**5 Are there examples where social, cultural and geographical factors have influenced public acceptance or rejection of emerging biotechnologies?**

In Sweden, more than 60,000 people were sterilized between the 1930s and 1960s. There was a law that allowed sterilizing feeble minded people and anti-social individuals. Gypsies were considered to be anti-social (the common slogan: gypsies are thieves).

China passed a law in 1944, fetuses that are genetically defected should be aborted.

Different people of different religions and cultures will have different attitudes regarding pre-natal testing.

**Islamic law** objects to any interference with the life of the foetus.

**6 Are there examples where internationalisation or globalisation of research, markets and regulation have influenced the development of emerging biotechnologies?**

Seems to be less debate on animal rights.

**7 How have political traditions (such as liberal democracy) and political conditions (e.g. war) influenced the emergence of biotechnologies?**

There were 30,000 gypsies in Germany. Large numbers were sterilized from 1937 onwards. Some 20,000 were killed or died during WWII.

**Eugenics** in Nazi Germany.

The **Human Genome Diversity Project (HGDP)** - evoked outrage among aboriginal people. They argued: You took everything from us, and now you want to take our DNA. That's the ultimate insult. The aboriginal wanted

that the products of research will be used for the benefit of the aboriginals; that financial consequences will be utilized in their best interests. These are legitimate demands.

**8 Are there ethical or policy issues that are common to most or many emerging biotechnologies? Are there ethical or policy issues that are specific to emerging biotechnologies? Which of these, if any, are the most important?**

Possibly more than before, the question and the strength of the rationale that urges the right to ignorance. Is there a right not to know?

A woman who knows that she has the propensity for breast cancer might choose to get married soon, and to have children soon, even if this means marrying the wrong person, and bring children to this world when she is not ready.

Suppose parents object to having a test for the Down's syndrome, saying that they would want the child anyway.

This is even if there is a propensity in their family to this disease.

Should we compel them to do the test?

Should we say that they do not have the right to ignorance?

**Factors that influence research:**

Knowledge;

public opinion;

availability of resources;

competition between different research teams;

law - boundaries drawn by legislation;

ethics - some things should not be done; drawing boundaries.

**9 Do you think that some social and ethical themes are commonly overlooked in discussions about emerging biotechnologies? If so, what are they?**

Differentiating between gene therapy and gene enhancement.

**10 What evidence is there that ethical, social and policy issues have affected decisions in (i) setting research priorities, (ii) setting priorities for technological development, and (iii) deploying emerging biotechnologies, in either the public or private sector?**

Within forty years we evidenced a complete moral reversal regarding transplantation of organs from people on the verge of death to help other living. Some forty years ago this idea was regarded as repugnant. Nowadays many people are proud to carry with them donor cards.

The issue of brain death will be settled only when we will be able to probe the brain completely and understand all its complexity.

## **Ethics**

**11 What ethical principles should be taken into account when considering emerging biotechnologies? Are any of these specific to emerging biotechnologies? Which are the most important?**

First, do no harm;

Dignity of a person (The term 'dignity' might have different connotations, entailing different notions, in different communities);

Human dignity v. multiculturalism: We should take into account different cultural values and perspectives;

Autonomy (in liberal societies; less so in less liberal);

Informed consent;

Transparency is essential for the credibility of research.

### **Issues concerning privacy and consent:**

- rights and duties of family members
- consent to testing children
- counseling and the right to ignorance
- rights of employers and insurers

One nightmare is a world where parents will manipulate the production so as to bring to the world their 'dream child'. If man created God, why can't man create humans?

Confusion between **ends and means**: say parents want to create a beautiful, perfect child because they think beauty would contribute to her

life and enrich them. They say that because they conceive the child as **an end in itself** they want to enhance her life by devising beauty. But is it really the right characterization of the rationale? If the **child** is an end in itself then her beauty is secondary. If the **beautiful child** is an end in itself then the parents will be dissatisfied with an un-pretty child. Beauty is the end decided by the parents for their child.

Other parents may opt for the perfect, smart child. Same reasoning.

People are quite horrified by this scenario, almost or maybe as much as they are with regard to the selection of the child's gender, or devising and enhancing anti-social characteristics, say terror or violence.

Another nightmare is the further and increased exploitation of the so-called "**third world**" by the so-called "**first world**": people as commodities, or vegetables.

Some people favour of a global organ market, in which people from poor countries will sell organs to people of rich countries, on the ground that such deals work for both communities. Selling organs might be the only way for people of poor countries to advance their economic position.

This reasoning raises questions re free will and free choice. How free are these people to make decisions and to formulate choices? Knowing how crude people are, we can assume that people of rich societies would limit the rank of choices that people of poor countries have so as to push them into the organs market. **Asia might become the meat market of Europe.**

Yet another nightmare is **Sophie's choice** scenarios.

We need to distinguish between germ-line therapy designed to decrease the likelihood of disease, and germ-line therapy designed to promote certain intellectual or vocational capacities.

Genetic information has to be reserved only to individuals and their families. Employers should not demand their employees to take these tests.

**12 Who should bear responsibility for decision making at each stage of the development of an emerging biotechnology? Is there a clear chain of accountability if a risk of adverse effects is realised?**

Industrial responsibility for proactive identification of risks.

Responsibility lies with scientists; labs; research hospitals; funding bodies.

Because of the interactions between emerging biotechnologies and the environment, responsibility also lies with countries and the international community at large. We need to think of the implications of our conduct on the lives of future generations.

**Policy**

**13 What roles have 'risk' and 'precaution' played in policy decisions concerning emerging biotechnologies?**

It is clear to me that where the knowledge lies, and the technology available then we are bound to progress. The issue is how to avoid the risks.

Policy making is guided by the principles of vigilance, scrutinizing options, learning from experience, and caution.

Competition increases risk.

To doubt is a necessary component of any research and more so of biotechnological research. We need to review, affirm, assess, examine, re-examine, verify and question methods, procedures, results.

**We need to take into account:**

abilities;

economics - availability of resources;

politics, especially if more than one country is involved;

law - what should be embodied in law; which limitations the law sets;

public consensus is an end in itself - we want the backing of the public so we will be able to pursue research;

ethics (hopefully an important component).

**14 To what extent is it possible or desirable to regulate emerging biotechnologies via a single framework as opposed to individually or in small clusters?**

There is a greater need of regulation of gene testing and screening. Regulation is the first to take before legislation.

Regulation and maybe later on legislation to prevent black markets;

Regulation and legislation to regulate cooperation between states.

Legislation to prevent abuse;

Legislation that distinguishes between therapy designed to alleviate suffering, or to cure genetic diseases, and gene enhancement of capacities (say, we want a child with a talent to sport or music).

Legislation regulating who has the right to know (privacy);

Legislation to regulate the relationships between doctors and patients (truth telling, counseling before and after treatment);

Legislation to include gene therapy to the public at large, or only to those who can afford paying;

Legislation to prohibit germline gene therapy (if you can do somatic to alleviate suffering and pain, why not alleviate suffering from your offsprings? The distinction has to be between therapy designed to cure disease, and enhancement treatment designed to produce a better, or 'perfect' child);

Legislation to protect the rights of children, or women ("we want a son");

Legislation to protect the rights of animals subjected to tests;

Legislation of what information insurance companies are entitled to receive.

## **Public engagement**

### **15 What role should public opinion play in the development of policy around emerging biotechnologies?**

Crucial role. But science usually pushes forward, and scientists want to act free of public scrutiny and pressures. They fear that their progress might be hampered if the public will be asked. So they do what they wish and only then public discussion is evoked.

The public should become aware of the potential and risk. Following awareness, the public should gain insights and understand the issues. Then the public can become involved via citizens' committees and public polls.

Another idea is public consensus conferences, following Denmark where they have consensus conferences on scientific issues aimed to involve more people in the decision-making processes. The results of these conferences are brought to the attention of parliament. We should increase public awareness of these conferences via the popular media. **The media** have an important role to play in educating citizens, bringing issues to the fore, generate consensus, mobilize feed-backs between decision makers and the public.

Scientific citizens' conferences were usually covered by the scientific press but not in the mass media. We need to reach the vast public who reads the *Sun* and *News of the World*.

We should establish inter-disciplinary bodies to educate politicians and decision-makers about the implications of their decisions on various fields and people.

**16 What public engagement activities are, or are not, particularly valuable with respect to emerging biotechnologies? How should we evaluate public engagement activities?**

This survey is an excellent example.

High school education.

Ethical education in medical/nursing schools.

Public debates, starting with a video that shows an ethical dilemma. For instance, “**Gattaca**”: Hawk is interviewed for a job. He wants to become an astronaut. He is asked to give a blood sample. After three seconds the answer comes from the ‘interviewer’: you are hired.

“What about the interview?”, asked Hawk.

“This was it”.

**17 Is there something unique about emerging biotechnologies, relative to other complex areas of government policy making, that requires special kinds of public engagement outside the normal democratic channels?**

Consider, for instance, the question of whether we have property rights on our tissues.

Our instincts tell us that we ought to have some sort of control over our tissues: “Hey, that’s mine. I could have a say about what you intend to do with them”.

A surgery is performed. Some tissues will be thrown into the bin. Does it matter whether they will go to the bin or to the lab for some test?

Can we demand to know what the doctors intend to do with them?

Should doctors ask our consent to make use of our tissues?

Two issues: That doctors will make use of our tissues to make advances in medicine, to develop drugs, and to make money. “If they make money from my tissues, I want a share in it”.

The second concern is that my tissues will be used for unethical purposes.

Ethics committees should review the purposes of research: What use will be made from my tissues?

The integrity and decency of doctor-patient relationship require **informed consent**.

To eliminate the possibility of greediness on the part of patients demanding a share in profits made out from their tissues, we can say to them that if they insist they will not be entitled to any benefits resulting from the use of tissues removed from **other** patients.