

*If Cloning is the Answer,
What was the Question?*
Power and Decision-Making
in the Geneticisation of Health

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Dolly the cloned sheep was an unexpected scientific triumph. In replicating an adult mammal for the first time in 1996,¹ Dolly's creators at the Roslin Institute in Scotland overturned long-established assumptions about cell biology and cell differentiation (*see* Box, p.3).

But Dolly was a public relations disaster too. The public worldwide was shocked. The idea of evil megalomaniacs creating row upon row of identical copies of themselves seemed no longer the stuff of futuristic fiction but an imminent possibility. The public demanded to be reassured that the Dolly techniques would never be applied to humans.

Now many scientists and biotech companies became alarmed. Even if they themselves had no corporate interest in duplicating human beings, they feared that broad bans on the Dolly techniques could interfere with genetic and biological research more generally. Public concern about cloning, no matter how "misinformed", "emotional" or "uneducated", could undermine confidence in gene testing, gene therapies and a range of medicines and vaccines which use genetic technologies and knowledge — products on which many biotech and pharmaceutical companies were, and still are, pinning their financial futures. For the industry to mishandle a "serious ethical issue, such as human cloning", warned Carl Feldbaum, President of the US Biotechnology Industry Association, would threaten the survival of emerging biotech companies.²

It was time for some serious PR damage limitation. Scientists, medics and industry representatives went before the public to emphasise the potential benefits of human cloning techniques in particular and medical biotech research in general. Assiduous attempts were launched to "educate" the public into a view of health as something which demands the therapies which the biotech industry is seeking to provide.

In the process, many social, economic and environmental aspects of health and disease slipped further into obscurity, as did questions of how the potential benefits of biotech would be obtained and distributed, and how they could alter significantly our perceptions of ourselves. In the past few years, it has become harder to raise key questions relating to the increased geneticisation of our lives and societies. Yet only by paying attention to such questions will it be possible to lay the groundwork not only for a thorough and responsible discussion of the issues raised by human cloning and genetic engineering, but also for more democratic decision-making about the ways in which our societies are organised.

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Research into “therapeutic” applications of cloning paves the way for the replication and genetic engineering of human beings, irrespective of the good intentions of legislators, scientists and companies.

Cloning Bans Give Green Light For Cloning

A first step in allaying public fears has been to deny categorically that the techniques which yielded Dolly might be used to produce humans.³ Replicating human beings, insist governments, biotech companies, scientists and medical bodies, would be abhorrent.⁴

But they do not deny that the techniques might be applied to humans for other purposes. Far from it. Human cloning techniques, they explain, could be used for other “morally unobjectionable”⁵ or “beneficial” purposes: to produce organs or tissues to replace or rejuvenate failing and diseased parts of the body; to assist in cancer research; to develop products to slow or reverse ageing; to test new pharmaceuticals; to test embryos before implanting them in women’s wombs during in-vitro fertilisation (IVF) (*see* Box, p.4). According to a British government-sponsored consultation, this “therapeutic cloning”⁶ should never be confused with “reproductive cloning” — even if both involve research into how to replicate human embryos and how to engineer human beings genetically.⁷

This powerful and neat distinction between end uses has allowed legislators and scientific bodies to outlaw (in theory) the replication of human beings while at the same time countenancing the research that would make it possible. Once this research has accustomed the public to the idea of cloning for spare organs and the like — the *London Financial Times* estimates a period of five years may be adequate⁸ — moratoriums on human replication could be reviewed. By that time, it is assumed, the promise of, for example, curing “hundreds of thousands of sufferers of Parkinson’s disease” with an “injection of nerve cells grown in a laboratory dish”⁹ would make the unbreakable links between medical or therapeutic cloning and the replication of humans seem unworthy of concern.

The medical benefits being claimed for cloning technology cannot be achieved, in other words, without also laying the basis for replication of human beings and for human genetic engineering. Yet these benefits themselves deserve a careful critical look. In particular, the following questions need to be raised:

- What causes the ill-health and disease which the potential applications of cloning technology might treat?
- Would we all benefit or just some individuals?
- What sort of assumptions about health, science, gender, race and society does the current fashion for promoting these technologies rely upon? What does it conceal?
- What commitments would society and scientific research have to make in order to obtain the potential benefits?

Discussion of issues such as these should be an integral part of the broad public debate that scientists, medical professionals, government and the biotech industry are calling for before they contemplate proceeding with human cloning.

Confusing Mechanisms With Causes

One benefit being advertised for human cloning techniques (and indeed for genetic research more generally) is that they could help to cure,

Cloning, Replication and Genetic Engineering

The word “clone” is derived from the ancient Greek word, “klon”, meaning twig, because it was first used to refer to plants propagated vegetatively or asexually, such as potatoes or geraniums. Applied to humans in a strict scientific sense, it means human beings who have the same DNA in the nuclei of their cells.¹

Proponents of human cloning often claim that the technique is nothing new because cloning occurs naturally in the form of identical twins, who result from an embryo dividing in two of its own accord during its early stages. Twins, however, have two genetic parents, not one, and are not genetically identical to either, obtaining half their DNA from each.

The First Replica Mammal

Dolly, the first cloned adult mammal, was not produced at the Scottish Roslin Institute by dividing an embryo, but by a quite different process which does not occur in nature at all.

A cell taken from the udder of an adult sheep was deprived of nutrition in a way which caused it to revert to a state characteristic of embryonic cells before they have specialized into the different cells of the body. The nucleus from this cell was then extracted and put into the “shell” of an egg (taken from another sheep) from which the nucleus had been removed (an enucleated egg). A jolt of electric current was applied in order to jump-start development; shell and inserted nucleus fused and began to divide and divide again like an embryo. The resulting embryo was then implanted in the uterus of a third sheep, and Dolly was born on 5 July 1996.

Until Dolly’s birth, it had not

been thought possible that a cell from an adult mammal could be returned to an undifferentiated state in which it had the potential to become any kind of cell in the body.

Yet Dolly was in many respects a fluke. In the experiments which led to her birth, more than 400 mammary gland cells were deprived of nutrition to make them quiescent. Nuclei from 277 of these cells were then inserted into enucleated egg cells. Only 29 of these developed sufficiently to be inserted into the uteri of sheep — of which only one resulted in a live birth.

Indeed, cloning continues to be plagued by technical obstacles. The vast majority of cloned embryos do not develop, and miscarriages, stillbirths, and abnormalities are rife. The Roslin Institute itself has admitted that animal welfare may have been compromised during the Dolly experiments because of such failures.

The work which resulted in Dolly, moreover, was at the time rather a sideshow to the Roslin Institute’s main research into cloning embryonic and fetal (rather than adult) cells and genetically engineering them. This can be seen from the fact that, rather than take cells from a living animal, the researchers used those from the frozen udder of an anonymous pregnant sheep that had died three years previously.

Indeed, for a time, it was not even certain whether the cell from which Dolly was derived was an adult cell at all: the researchers themselves speculated at first that Dolly might have been derived instead from a fetal cell circulating in the mammary gland.

In any case, the Roslin Institute has said it does not intend to repeat the experiment.

Embryo Cloning and Genetic Engineering

The main goal of Roslin’s cloning research is exemplified neither by Dolly nor by Megan and Morag — two sheep born in 1996 produced by transferring nuclei from embryonic cells (rather than from adult cells, as in the case of Dolly) — but by the genetically-engineered clone, Polly, born in 1997.

Polly was produced from the cell of a 26-day-old sheep fetus into which had been engineered a human gene for Factor IX, a protein that can be used to treat people with one type of haemophilia, the inherited disorder which prevents blood from clotting properly. Researchers hope to produce from clones like Polly whole herds of living factories mass-producing valuable drugs in their milk.

Roslin had been injecting human genes into fertilized sheep eggs so as to transform animals into drug or organ factories. It found that this procedure was too “inefficient”: only two per cent of the injected eggs grew into adult animals and only a small percentage of the survivors had the human genes. In searching for a more efficient method which would produce the transgenic animals more quickly, it turned to cloning.

Scientists are now trying to work out how to replace genes in cell nuclei, rather than just add them, so as to raise transgenic pigs whose internal organs, roughly the same size as those of humans, could be transplanted into people with a reduced risk of rejection.

1. The term “cloning” is also used to describe the generation of multiple copies of genetic material in the laboratory and the cultivation of single-cell organisms such as bacteria.

Proposed Applications of Human Cloning

Grow-Your-Own Organs

One of the best-promoted advantages of cloning techniques is that they would supposedly make it possible for people to grow new body cells to replace or regenerate failing ones.

The first step would be to create a human embryo in the same way that Dolly was created. A cell would be taken from someone whose liver or kidney or bone marrow was failing; the cell would be returned to its undifferentiated, embryonic state, its nucleus then placed in a egg (donated or from the patient) whose own nucleus had been removed, and the combination encouraged to develop into an embryo.

Within a week, the embryo would be taken apart to extract the inner mass of embryonic stem or totipotent cells. These “mothers of all cells” have the potential to differentiate into any the various 216 other different types of cell in the body (skin, blood, liver, kidney, heart and so on). They could be directed through technical means into becoming liver, kidney, bone marrow or other kinds of cells and then transplanted into in the body of the disease sufferer or accident victim.

Such cloning techniques, it is argued, could produce spare heart cells, insulin-producing cells for the treatment of diabetes, or new neurons for the treatment of Parkinson’s and spinal cord injuries.

One advantage of such “personalized”, grown-to-order spares over conventional organ transplants would be that the patient’s immune system would be less likely to reject them since, genetically (at least as far as nuclear DNA is concerned), they would be the patient’s own tissue. There would be no need to wait for suitable organ donors to be found, nor to store organs for long periods of time.

Yet the implications are not only medical but social. To Stuart Newman, professor of cell biology at New York Medical College, this “fabrication of human beings for entirely instrumental purposes” is an “unprecedented step in human cultural history”.

Halting Cancer, Reversing Ageing

Cloning human embryos, it is argued, could help researchers find out how cells reproduce themselves. One result might be products which prevent or reverse the processes of ageing (when cells stop reproducing) including diminished appetite, thinning of the skin, and decreased lung and kidney function. Another could be treatments for cancer, a disease in which, by contrast, cells reproduce without stopping.

Pharmaceutical Testing

Cell lines and tissues derived from embryonic stem cells could also be used to test the safety and efficacy of potential new pharmaceutical drugs. If the experimental tissue is genetically identical, the reasoning goes, any differences between test and control groups can be attributed to the drug being tested rather than to genetic differences. It is also argued that such testing would reduce the need for testing on animals and on healthy and sick people.

Cloning and IVF

In future, every time a woman undergoes in-vitro fertilisation, a number of “spare” embryos could be produced through cloning.

One of these embryos could be tested for genetic abnormalities to determine whether one or more of its counterparts should be implanted in the patient’s uterus. Others could be frozen for future use in case the woman wanted another child but did not want

to go through the hazardous procedure of egg retrieval again. Still others could be preserved as backup organ factories in case the child ever needed to replace or rejuvenate any of its body organs.

Egg “Shell” Disease

It has also been suggested that the cloning technique could be used for the benefit of women who carry certain genetic diseases in the genes of their egg “shells”.

An embryo could be produced from a woman’s egg and her partner’s sperm via IVF. The nucleus of the embryo could then be removed and placed into an enucleated, disease-free egg obtained from another woman. If the new combination developed sufficiently, it could be placed in the uterus of the first woman to bring to term.

Human Genetic Engineering

Techniques refined through experience with cloning could also be used to alter the nuclear DNA of an embryo by inserting new genes or replacing “faulty” ones. This is called germ line therapy or human genetic engineering.

Human Replication

Cloning techniques could be used to give genetic children to adults who could not otherwise have them: sterile men or women without ovaries.

It should be noted that all the depersonalising language used here — “take a cell”, “remove the nucleus”, “introduce it into an unfertilised egg”, “implant and bring to term” — make it easier not to think of the people and processes involved (see Box, p.8).

treat or slow the progression of many diseases for which at present nothing much can be done — cancer, Parkinson’s and Alzheimer’s are often mentioned.

This claim rests on the assumption that these diseases are simply a matter of body cells not behaving as they should. Cancer, for instance, is seen predominantly as a condition in which cells multiply endlessly. Cloning human embryos, it is argued, could extend knowledge into how they do so with a view to finding treatments to stop them. Similarly, Parkinson’s disease, a progressive brain disorder caused by the death of a certain class of brain cells, might be blocked, it is thought, by transplanting certain embryo cells into the cranium. Transplanting them into the pancreas of a diabetic, by the same token, could encourage production of insulin (*see* Box, p.4).

What is invariably left out of these descriptions is what causes cells to behave abnormally or to cease functioning in the first place. As US biology professor Sandra Steingraber, who became a cancer patient at the age of 20, points out:

“Cancer arises through a series of incremental changes to chromosomal DNA. Some of these DNA alterations can be inherited, but the vast majority are acquired during the lifetime of an individual when genes perfectly healthy at the time of conception become damaged.”¹⁰

While molecular genetics has certainly provided much information about how cell behaviour and DNA alterations are implicated in cancer, “to say that ‘DNA alteration is at the heart of cancer induction’ . . . confuses mechanism with cause”, says molecular biologist Bonnie Spanier.¹¹ “It does not necessarily follow”, she concludes, “that genetic research is the best approach for understanding what causes cancer or how to prevent it”:¹²

“A large majority of human cancers are influenced or promoted by environmental carcinogens in our workplaces, in air, water, and food, in such cultural habits as sunbathing and tobacco use, and in our social conditions such as poverty and stress.”¹³

Many people with Parkinson’s, likewise, have a history of exposure to pesticides, herbicides or industrial solvents.¹⁴ Yet, as organic dairy farmer Mark Purdey points out in the case of Parkinson’s and other degenerative nervous disorders:¹⁵

“Researchers have tended to focus upon ‘natural causes’, such as viruses, genetic defects, stress, hysteria and naturally-occurring toxins as possible causes — investigation of which soaks up the bulk of research funds — while disregarding the large numbers of synthetic pollutants that have permeated food chains since the industrial revolution.”¹⁶

Moreover, cells derived from cloned embryos (or from aborted fetuses) may replace dying nerve cells in the brain, but they are unlikely to stop whatever is killing them in the first place.

Similarly, the underlying cause of the worldwide increase in the incidence of diabetes — the World Health Organisation (WHO) projects a more than twofold increase in incidence of the disease by 2025, with up to 300 million people being affected — cannot be that people are suddenly sprouting “diabetes genes”. If certain individuals are indeed genetically predisposed to the disease, something must be triggering its growing incidence.¹⁷

It is partly because they ignore the role of chemical pollutants in causing diseases such as cancer and Parkinson’s that the assumptions of human embryo cloning research come to seem reasonable.

Privileging the role of genetic anomalies downplays the importance of the “environments” of the gene in causing disease.

It may well be, as Harvard biologist Ruth Hubbard suggests, that it “is far easier and more convenient for scientists to pretend they will conquer cancer by studying the molecular transformations of genes and cells” than to press for a lowering of exposures to carcinogens and other pollutants.¹⁸ Nonetheless, it would surely be more rational and efficacious to improve individuals’ and societal health and to alleviate suffering by pursuing this latter course than to clone human embryos for cancer molecular research or to undertake speculative programmes of genetic alteration. It is largely through obscuring the wider causes of these diseases that human embryo cloning techniques come to seem beneficial, plausible and reasonable.¹⁹

Environments are Everywhere

Just as a heightened focus on the cellular causes of disease ignores the economic, political and social forces that contribute to cell misbehaviour, so too the privileging of the role of genetic anomalies in causing disease involves downplaying the importance of the “environment” of the genes. Such anomalies may be inherited from one or other or both parents, present at birth, or acquired later in life. Again, this may obscure wider causes of ill-health — in ways that favour cloning or genetic technologies and knowledge as “self-evident” solutions, but that in reality fail to address the underlying reasons for the condition. Indeed, as Spanier comments:

“Only if the gene is the sole determinant of life does it become possible to look to genetics alone for solutions to problems such as illness . . . and human imperfections . . . On the other hand, if the determinants of what constitutes and directs life are presented as a balance among metabolism, energy conversion and reproduction, in dynamic interaction over time with the environment in which life occurs and of which it is a part, then the search for solutions becomes similarly multifocal, stressing the environmental context as much as the internal environment.”²⁰

For example, the inference that genetic testing of cloned embryos in IVF procedures (*see* Box, p.4) — and indeed of prenatal testing in general or of embryonic/fetal genetic engineering in future — will lead to a healthy infant seems plausible only if the role of a number of environments is ignored, that of the gene, the egg and the mother, for instance, and if infant health is considered during pregnancy but not afterwards.

● *The genetic environment*

Genes are often presented as “objects” — a particular sequence of DNA bases which codes for a protein — which “determine” biological outcomes. Traditional genetic understanding holds that a gene is a distinct and independent unit which can be isolated from the rest of the DNA and moved elsewhere while still carrying out its function.

But rather than being physically-bordered control mechanisms, genes are more part of complex dynamic interdependent processes between all the small and large molecules and ions in a cell, which are in turn affected by interactions with adjacent cells.²¹ Moreover, a gene may behave differently depending on its location on the chromosome and the presence or absence of other genes. There are few genes that result in a specific genetic condition

irrespective of their environment.²²

Moreover, while in line with more general social practices and commitments to “centralized control, to hierarchical organisation, to difference as dominant-and-subordinate”,²³ this way of according special “ruling” privileges to nuclear DNA or genes is scientifically incorrect.

- *The environment of the egg*

In most depictions of embryo cloning, the contribution of the egg “shell” or cytoplasm into which a cell nucleus derived from another embryonic, fetal or adult organism is placed (*see* Box, p.3), is downplayed. The nucleus does not, in fact, provide all the DNA of the resulting organism (if the cloning technique is successful and if the constructed embryo develops to full term). And genes or DNA don’t grow embryos all by themselves.

The egg cytoplasm provides mitochondrial DNA — packages of DNA inside a cell that are entirely separate from the chromosomes in the nucleus.²⁴ This mitochondrial DNA is now believed to be implicated in some diseases and some body processes, such as ageing, one of the proposed targets of research into human embryo cloning.²⁵

Other components of the egg’s cytoplasm also become part of the resulting embryo and play a major role in directing its development. Indeed, the first 8-16 cell divisions in a human embryo are believed by some scientists to be “orchestrated” not by the nucleus, but by the egg cytoplasm.²⁶

Furthermore, the egg cytoplasm is believed to play a critical role in returning differentiated adult cells (skin, blood, bone cells, for instance) to the undifferentiated embryonic state (in which they have the potential to become any type of body cell), a process without which recent scientific breakthroughs in cloning would have been impossible.

- *The environment of the mother*

While a variety of prenatal gene tests are already offered to prospective mothers in some countries, less attention is typically paid to ensuring that they have adequate nutrition, housing and income and a domestic life free from stress, violence and abuse before, during and after pregnancy.²⁷ Nor is much attention usually paid to the variety of toxins which may exist in their workplaces, homes or neighbourhoods — aside from those in cigarette smoke or alcoholic drinks to which responsibility for exposure can be assigned to pregnant women.

Yet these environments can be at least as critical as an embryo’s nuclear DNA endowment to an infant’s immediate and lifetime health. For instance, some reports suggest that babies of women living near toxic waste dumps have a one-third higher risk of birth defects.²⁸

- *The infant’s environment*

An emphasis on genes and good maternal behaviour obscures the fact that infant health is only partly a matter of what happens before birth. No matter how many prenatal genetic tests are undertaken, a healthy baby is not guaranteed because the tests are not foolproof and because other events may happen.²⁹ Most disabled people become disabled because of what happens to them after birth, not because of genetic conditions. In Britain today, car accidents are the main cause of death in children.³¹

Conversely, finding a genetic predisposition in an embryo to a disease or condition does not mean the child will develop the disease in later life.

Explanations of ill-health that ignore a gene’s wider environments invariably lead to misleading accounts of disease causation.

What's In A Name?

"That which we call a rose by any other word would smell as sweet", argues Shakespeare's Juliet. If her beloved Romeo changed his surname, Montague, he would somehow cease to be an enemy of her family, the Capulets, because he would be perceived differently. "Tis but thy name that is my enemy," Juliet insists.

Calling something by a different word does make a difference. Wellcome Trust research into public perspectives on human cloning concluded that "the language chosen when describing scientific research has a major impact on participants' responses to the ideas." "Gene therapy", for instance, was viewed far more positively than "genetic engineering" or "genetic research". It "sounds quite friendly" said a participant.

The New "Pre-Embryos"

Embryo research provides another example of the importance of names.

During the 1980s in Britain, the public and Parliament debated whether or not to set limits on in-vitro fertilisation (IVF). One of the issues concerned scientific research on (non-cloned) human embryos left over from IVF procedures, or "genetically defective" ones which were not implanted in a woman's uterus. If research on these "leftover" embryos was to be legalised, for how many days or weeks would the embryo be allowed to develop before research was stopped and the embryo destroyed?

Laboratory embryo research was initially rejected by both special interest groups and many ordinary people alike. Embryo research proponents countered by beginning to refer to the embryo during its first two weeks of existence after fertilisation as a "pre-embryo". This new terminology, contends sociologist Michael Mulkey:

"was intended . . . to

convey to lay people that the potential subjects of laboratory experiment were not even proper human embryos . . . Many of those active within the world of science . . . regarded the introduction of this ostensibly technical term into the public debate as an attempt to hide what were really moral and political judgements behind an illusion of scientific objectivity".

The illusion triumphed.

"At the beginning of the debate, most parliamentary speakers insisted that such research was immoral because it involved experimental manipulation of defenceless human individuals. By the end of the debate, most speakers maintained that experimental activity in this field was legitimate because it was, and would continue to be, confined to a minute collection of cells called the 'pre-embryo' which preceded the emergence of the human individual."

Thus under the British 1990 Human Fertilisation and Embryology Act, research can be carried out on human embryos in the laboratory for up to 14 days, after which they must be destroyed. Britain is also one of the few countries in the world which allows embryos to be created expressly for the purpose of research. In other countries, research can be carried out on "leftover" or surplus embryos only.

An End in Sight

Some scientists try not to use the word "embryo" at all, calling the early organism a "collection of undeveloped cells". Michael West, president of US biotech company Advanced Cell Technology, says of the human/cow cloned embryos his company has produced:

"people don't realise that we're talking about cells that have not become anything yet. There are no hands and feet, and I think a lot of this debate is over mental images that words like 'embryo' portray".

Redefining an embryo as a cluster of cells could circumvent legislation which prohibits patents being taken

out on human embryos but not on cells.

What an organism is called also varies according to what its destiny is. Viewed down the microscope during an IVF procedure, the bundle of cells is a human being, a new life, "your unborn child". The same cells are "research tissue" when they are earmarked for laboratory investigation, no longer a "human". The same embryo becomes "a life-saving tissue generator" when its fate is to provide stem cells to be implanted in someone with a failing brain or liver. Meanwhile, the creation of human/cow cloned embryos to replace failing organs becomes "tissue engineering".

To "Clone" or To "Transfer"?

University of Alabama professor of philosophy Gregory Pence, who is unusual in stating publicly that he favours the replication of existing human beings, suggests the phrase "nuclear somatic transfer" or "human asexual reproduction" should be used instead of "cloning", which in his opinion drastically biases the discussion at the outset in the worst possible way.

Steen Willadsen, a leading researcher in animal and human cloning, is fairly sure that humans will be intentionally cloned one day, but "it probably will not be called cloning."

David King of *GenEthics News* turns the tables on this strategy of using euphemisms. He suggests that germ line therapy in humans be called what it really is: human genetic engineering.

Sources: M.M. Mulkey, M., *The embryo research debate: Science and the politics of reproduction*, Cambridge University Press, Cambridge, UK, 1997; Pence, G. E., *Who's Afraid of Human Cloning?* Rowman & Littlefield, Lanham, Maryland, 1998; Kolata, G., *Clone*, Penguin, London, 1997.

Explanations of ill-health that ignore these wider “environments” almost invariably lead to reductionist — and misleading — accounts of disease causation. Any farmer knows that the health of the soil is at the root of successful farming. A plant with genes to grow tall will be short if it receives inadequate sunlight, water or nutrients. By analogy, as the Harvard Working Group on New and Resurgent Diseases stress:

“disease cannot be understood (let alone countered) in isolation from the social, ecological, epidemiological and evolutionary context in which it emerges and spreads. Indeed, if one lesson has emerged from the spectacular failure of Western medicine to ‘eradicate’ certain diseases, it is that diseases cannot be reduced to a single cause nor explained within the prevailing linear scientific method: complexity is their hallmark. Indeed, such is the network of factors that lead to disease that the conventional classification of diseases into ‘infectious’, ‘environmental’, ‘psychosomatic’, ‘autoimmune’, ‘genetic’ and ‘degenerative’ is probably applicable only to a few diseases where one factor overwhelms all others.”³²

Individuals or Society?

Just as the wider environmental causes of ill health, disease and disability tend to be obscured by a genetic focus, so too are social influences. Yet these are often the most powerful determinants of health. Inferences that the applications of human cloning and genetic engineering are critical to improving our health ignore these findings.

Poorer people in developed countries, for instance, have annual death rates anywhere between twice and four times as high as richer people in the same society.³³ A health study in New York’s Harlem found that, at most ages, death rates were higher than in rural Bangladesh. In Brazil, infant mortality rates varied between different areas of the same city from 12 per 1,000 live births to 90 per 1,000 live births.³⁴

Such health inequalities, according to British sociologist Richard Wilkinson, cannot be attributed solely to differences in medical care or different genetic susceptibilities between social classes, and are only partly explained by individual health-related behaviour (smoking tobacco, drinking alcohol, taking narcotic drugs, lack of exercise, poor diet). They are due, rather, to the “effects of the different social and economic circumstances in which people live”³⁵ — including unemployment, poverty, bad housing and environmental pollution. “Much more important than the small differences medicine can make in survival from cancers and heart disease are differences in the incidence of these diseases.”³⁶

All the broad categories of causes of death in developed countries — heart disease, respiratory illness and cancer (some of the main targets of biotech research) — are related to income distribution, argues Wilkinson. He concludes:

“To feel depressed, cheated, bitter, desperate, vulnerable, frightened, angry, worried about debts or job and housing insecurity; to feel devalued, useless, helpless, uncared for, hopeless, isolated, anxious and a failure . . . It is the chronic stress arising from these feelings which does the damage.”³⁷

Wilkinson found that the healthiest societies were not the richest, but

The most powerful predictor of human disease is not genetic endowment but economic inequality.

Because the health impacts of unemployment, poverty, housing, stress and pollution are not widely reported, treating disease through cloning and genetic technologies seems credible.

Because health services do not have limitless funds, not everyone will benefit from cloning and other genetic technologies.

those that had the smallest income differences between rich and poor. Inequality and relative poverty have absolute effects: they increase death rates.³⁸

The extensive research indicating the negative impacts on human health of unemployment, poverty, poor housing, stress and environmental pollution tends not to be reported publicly. Claims that human cloning techniques can help find answers to cancer, the diseases of old age and so forth continue to be credible in part because of this silence.

Prioritising Limited Public Health Care

“Opponents of human cloning (as I am) cannot afford to ignore the benefits that such cloning might provide for all humankind.”

*David Tracy
Divinity School
University of Chicago³⁹*

Suppose, however, that human embryo cloning did yield some of its speculative benefits, such as replacement organs or new cancer drugs or medicines to slow the onset of old age or embryonic tests and treatments for some genetic diseases. Would they not benefit everyone, not only in the industrialised North but also in the developing countries of the South? Would they not make it worth putting aside any qualms about the use of embryos or worries that they would be paving the way for the replication of humans and for human genetic engineering?

It is unlikely that the benefits, if realised, would be available “for all humankind” because health services, whether public ones provided by the state or private ones financed by private insurance schemes, do not have limitless funds. Decisions about what is provided and to whom and on what basis have to be made against a backdrop of older people comprising a larger proportion of the population in the West, heightened expectations of medicine, and a growing number of new, expensive treatments.⁴⁰

The British government recently decided to restrict the availability on the National Health Service (NHS) of Viagra, a new drug which temporarily overcomes male impotence, to men with major illnesses or those made impotent by medical or surgical treatments — an estimated one in five of impotent men in Britain. Viagra’s manufacturer, the US pharmaceutical company Pfizer, estimates that the NHS bill would be £50 million if it was available to all impotent men who wanted it — three times more than the NHS spends on impotence at present.

Given that the NHS has only a certain amount of money with which to buy drugs, should it go on those for which there is “medical need” or those “lifestyle” treatments which could lead to a medical improvement in quality of life?⁴¹

Cost-benefit decisions entail making value judgements over who should get what treatment. Already, in the US and the UK, the elderly and the terminally ill — groups who are claimed to be in line for huge benefits from cloning research — are in fact often the first targets of rationing.⁴² The way the availability of Viagra has been restricted

Prospecting for Eggs

The Economics of Ovary Manipulation

If the essential contribution the human egg shell makes to the genetic composition and development of the cloned organism is rarely mentioned (see p.7), neither is the source of the large numbers of eggs required for research into the potential applications of human cloning.

Most human eggs used in the laboratory production of embryos for research or implantation in a woman's uterus come from two sources. One is women undergoing hysterectomies; the other is women trying to have a baby through in-vitro fertilisation.

Both groups are given a cocktail of hormones to stimulate their ovaries into ripening more eggs than the single one which is usually released per cycle; these are then retrieved surgically just before they leave the ovaries. British law limits the number of laboratory-produced embryos which can be placed in a woman's uterus to three.

The side effects of these hormonal drugs are profound. Women who become pregnant through IVF procedures have four times the normal incidence of ovarian cancer; those who do not, ten times.

Whose Demand?

What drives the demand for human eggs has historically been the needs of embryo researchers — the needs of childless women tend to come a distant second.

For decades, embryo research has been perceived to be limited by a "shortage" of laboratory eggs. While IVF procedures have led to more embryos being in scientific circulation — in 1990, an estimated 5,000 human embryos were being used for research purposes each year in the UK, compared to only about 500 children born each year by means of IVF — there are still not enough to meet research

requirements.

One obstacle is the reluctance of many women to undergo the risk and discomfort of the IVF procedure or, if they do go through with it, to donate any "by-product" eggs or embryos to research.

Various measures are being undertaken to secure a bigger resource flow. In December 1998, the British regulatory authority legalised the practice of giving a woman free IVF treatment if she agreed to donate half her collected eggs; in July 1999, a private London hospital was offering free sterilisations to women in return for their eggs. In the US, some young women studying at university have reportedly earned \$1,500 each for their tuition fees by selling their eggs.

The Cloning Connection

The advent of cloning technologies only adds to pressures on researchers and scientists to obtain or "mine" as many eggs and embryos as possible.

At present, women or couples in Britain have to give their permission for any of their "surplus" embryos to be donated to other patients or to be used for research. Under British law, these embryos can be frozen for up to five years, after which they have to be either used or destroyed. (It is difficult to thaw frozen eggs without destroying them.) In the US, there is no time limit on storage.

In 1997, the bulk of some 5,000 British five-year-old embryos had to be destroyed because the genetic parents could not be found or did not respond to enquiries about how they wanted the embryos to be used. Now it is suggested that stockpiled embryos should become "public property" after five years so that they could go to research or couples wanting children.

Research demand has also caused scientists to turn their attention to female fetuses, each of which has some seven million

eggs in its ovaries, as opposed to the one or two million to be found in newborn baby girls, the even smaller number present at puberty, or the mere 400 released by the average woman in her lifetime. Jon Tilly at the Massachusetts General Hospital in Boston is trying to change the genes responsible for this decline in numbers so that baby girls can be born with the full seven million eggs which are present in female fetuses.

Roger Gosden's application to the British Medical Association in 1993 to try to find a way to mature eggs in the laboratory from the ovaries of aborted female human fetuses was refused, not least because it raised difficult questions about producing people from a genetic parent who had never herself been born. Of less concern was the probability that an egg-maturing production line would lead to pressures on women to have later abortions by means of Caesareans or induced labour so as to obtain as many intact fetuses as possible — might free abortions be performed in return for the fetuses?

As scientific demand for eggs continues to grow, Gosden's ideas of "egg banking" aims are now being considered more favourably. Instead of mining aborted fetuses for their ovaries, however, some scientists suggest that it might be more "ethical" to take slices from the ovaries of living women, put them on ice, and then, when embryos are wanted, thaw them out, mature some ovarian follicles, and fertilise the resulting eggs through IVF. This procedure, it is suggested, would be ideal for career women in their early twenties who would like to preserve their "younger", healthier eggs for future attempts at having children. The technique is also being proposed for cancer patients whose treatments are likely to leave them sterile.

continued overleaf . . .

One advantage promoted for this procedure is that the women would not have to be given what are now acknowledged as potentially-harmful drugs to stimulate their ovaries. Besides, the technique would be cheaper than IVF. For all the PR gloss, however, the technique could also increase the supply of mature eggs for research.

Replacement Eggs

Because of the shortage, scientists are also looking at ways to reduce their need for industrial supplies of human eggs. Researchers at the US biotech company Advanced Cell Technology, for instance, are trying to create a kind of clone by combining nuclei from adult human skin cells with cow eggs, avoiding the need for human eggs entirely. The scientists argue that mining the resulting "chimeras" for embryonic stem cells (used to regenerate failing human organs) would obviate the need to destroy human embryos for this purpose.

Other researchers are trying to get around the need for human eggs altogether by figuring out biochemical ways of reprogramming ordinary body cells so that they start

developing the way fertilised eggs do — growing and differentiating into skin, blood, liver, and whatever other biological materials are in demand.

From Dolly Parton to Dolly the Sheep

As researchers isolate eggs from women and reconceptualise them as chemistry-set components, some also objectify women in time-honoured ways. Because Dolly was cloned from an adult sheep's udder, for example, Roslin researchers decided to name her after the US country-and-western singer Dolly Parton "who was also known . . . for her mammaries".

Such breast fetishes are nothing new in the biological sciences, and they have real practical social effects. When Carl Linnaeus was devising his taxonomy of species in the 18th century, he hit upon the presence of breasts as the distinguishing characteristic of a certain group of animals now known as the "mammals" — even though mammae are not in fact a universal characteristic of the class he intended to distinguish and they function in half the "mammals" for only a relatively short period of time, if at all.

It is not as if Linnaeus had no other choices. He could easily have highlighted a characteristic

which all the members of the class share: hair or three ear bones or a four-chambered heart. Or he could have called the class "the lactating ones" or "the suckling ones" instead of zeroing in on the sexually-charged part of the (human) female body. Given these other possibilities, Linnaeus' coinage can be regarded as a political act which served to reinforce the idea that (middle- and upper-class) women were, as female mammals, domestic, reproducing creatures-with-breasts, not potential enfranchised citizens or professionals in the 18th-century state.

At the time such women were also being encouraged to give up the practice of wet-nursing (giving their infants to other women to breastfeed). Wet-nursing, which resulted in high infant mortality, had alarmed officials who were concerned about a decline in European population at a time when increased labour was needed for military and economic expansion.

Sources: Schiebinger, L., *Nature's Body: Gender in the Making of Modern Science*, Beacon Press, Boston, 1993; Kolata, G., *Clone*, Allen Lane, Penguin, London, 1997.

suggests that any anti-ageing drugs coming out of genetic research would probably be rationed as well.⁴³

In the US in the early 1970s, a committee of lay people from Seattle was asked by the medical community to formulate rules governing access to scarce kidney dialysis machines. The committee concluded that priority should be given to:

"breadwinners, family men who were fine upstanding members of the community. People who did not have a job, those who seemed unstable or who lived on the margins of society, were denied the life-saving treatment. Men were favoured over women, married over single."⁴⁴

Given such trends in assigning priorities to products and people in a context of limited resources, there is no evidence to suggest that the fruits of cloning research would be distributed any differently. In fact, disputes over how to contain costs will only be exacerbated with the advent of cloning and genetic technologies.

By contrast, if a political decision has been made to limit public

health care and welfare resources, some technologies and products which could save costs by reducing demand on public services will *not* be rationed, but rather promoted vigorously. Prenatal testing is a case in point.

US researchers believe that the steep decline in the number of infants born with Down's syndrome over the past three decades as a result of amniocentesis and ultrasound — more than 90 per cent of Down's syndrome pregnancies detected by amniocentesis are terminated — “will have a significant impact on the medical services used by infants with Down's syndrome”.⁴⁵ The British National Health Service is now planning to extend prenatal testing for Down's syndrome, currently offered to women over the age of 35, to *all* pregnant women, in order to save “the costs of maintaining people with Down's”.⁴⁶

With the advent of genetic testing of embryos, these policies could well be extended, as “defective” embryos are not implanted and a growing range of “defective” fetuses are aborted in order to avoid producing children “we claim we can no longer afford to raise”.⁴⁷

At the other end of the human lifespan, efforts are being made to prevent “expensive and debilitating aging diseases” through, for instance, human embryo cloning and genetic technologies in order to capture “direct and substantial savings to the economy”.⁴⁸ Some commentators fret that, if successful, “the extraordinarily long-lived elderly [would] become an overwhelming social problem”.⁴⁹ Yet those elderly people not deemed worthy of the treatments or unable to pay for them may well feel pressured to die. It is not surprising that debates about physician-assisted suicide or euthanasia have become more topical in Britain and the US.

Thus in societies which limit their health care and welfare resources, the benefits of human embryo cloning and of genetic technologies are not likely to be available to all.

The products of cloning and genetic technologies will exacerbate disputes over how to contain health costs.

Genetics in Health Markets

“It makes as much sense to talk about the ‘potential benefit to humanity’ of a medical breakthrough without specifically considering access to that benefit as it does to discuss the quality of health care without addressing access to that care.”

*Lori Knowles
Associate for Law and Bioethics
The Hastings Center, New York⁵⁰*

The increasing privatisation and marketisation of health care around the world is likely to make treatments harder to get for many people, raising still further questions over exactly who among humanity will benefit from the new cloning and genetic technologies.⁵¹ If cloning research gets priority over efforts to improve distribution, this trend is likely to be entrenched still further.

Even in publicly-financed health care systems such as Britain's National Health Service, which has not been formally sold off, free market thinking has crept in through the back door — and with it the likelihood that access to certain kinds of medical treatment (including many of the new genetic technologies) will increasingly be determined

The increasing privatisation and marketisation of health care is likely to restrict access to new treatments further.

by “ability to pay”. The latest set of NHS reforms introduced in April 1999 established partnerships between hospitals and health authorities; in addition, for the first time, the NHS will have to operate within a fixed annual sum, regardless of sudden demands like ‘flu epidemics or the arrival of a costly new drug. Comments one *Financial Times* journalist:

“No one has mentioned privatisation in the context of this set of reforms. But if a government ever wanted to move to an insurance-based model for the NHS — whether social insurance or private insurance — [these reforms] would make it far easier to do so”.⁵²

Under the government’s Private Finance Initiative (PFI), meanwhile, private companies will finance, build and operate public infrastructure such as new hospitals. The NHS is to pay the companies some 8-10 per cent of the annual revenue a PFI hospital receives from selling its services. At the end of the 25-40 year contract, the companies, not the NHS, are to own the hospital.⁵³ As capital costs have risen, NHS trusts and health authorities have had to make savings on other budgets — such as clinical services to patients — to pay for them.⁵⁴ An increasingly competitive and profit-driven environment will have “an enormous effect on the way limited health care resources are allocated — who is cared for and what kind of care they receive.”⁵⁵

As health and health care are increasingly privatised, patients become consumers. The British Institute for Economic Affairs suggests that screening of healthy people for breast cancer, cervical cancer and high blood pressure, for instance, should be made available only to those willing to pay for them. Advertising directly to consumers, it is claimed, will ensure “equal access” to the tests.⁵⁶

New Products, New Markets

The products of cloning and related genetic research are also unlikely to “benefit all humankind” for the simple reason that they are directed mainly towards diseases and conditions whose treatments are expected to yield large enough profits, not necessarily those diseases and conditions which are the best candidates for the new approaches.

Thus the major targets for human genetic and cloning research are not so much rare genetic diseases as the diseases of industrialised countries and the diseases of old age — in particular, cancer, heart disease, obesity and nervous disorders (including depression and neurodegenerative diseases, such as Alzheimer’s and Parkinson’s).⁵⁷ As a representative of French pharmaceutical company Sanofi said at an industry conference on patent protection for the pharmaceutical and biotech industries, “here are the diseases which are big markets and for which there are no cures — and which we all want to go for.”⁵⁸ Other illnesses are likely to “remain unexplored and untreated”, no matter what the scientific promise of doing so, “because the market or the patients — the clients — are not economically interesting.”⁵⁹

Likely to be left out of biotech firms’ purported rush to “benefit all humanity” are diseases whose patients (or whose insurance schemes or public health services) cannot pay for treatment. Anyone setting the research agenda for a biotech company will find their eyes constantly drawn toward the North American market, which accounts for 40 per

cent of the estimated annual \$300 billion prescription drugs industry and 60 per cent of drug company profits.⁶⁰ North America, Japan and Europe combined account for over 80 per cent of pharmaceutical drug consumption, Africa for less than two per cent.

Good commercial sense can also steer companies disproportionately towards products for which a demand can easily be created.⁶¹ Genetically-engineered human growth hormone is one lucrative prospect: an average annual prescription costs \$20,000. It has been approved for use in the US for children who have “insufficient” naturally-occurring hormone. One of the world’s top biotech firms, the US company Genentech, agreed in April 1999 to pay a \$50 million fine for having promoted the drug illegally over nine years to children who did not have a hormone deficiency but simply were not as tall as their peers. A 1996 survey by the *Journal of the American Medical Association* estimated that 40 per cent of patients were receiving the drug for non-approved uses.⁶²

Some researchers have proposed that this hormone could also be used to slow the ageing process — despite the fact that long-term use might elicit diabetes, arthritis, high blood pressure and congestive heart failure. As Ruth Hubbard suggests, the creation of demand for such products and the fact that the hormone can be produced, via genetic engineering, in industrial quantities helps turn the “normal process of aging into a disease”.⁶³

The best candidates of all for mass marketing are tests for “genetic disease” that could be used on large numbers of healthy people, followed by drugs aimed at “preventing” or treating these conditions. As Hubbard remarks:

“Pharmaceutical companies and physicians stand to make a good deal of money from inventing new diseases as fast as new diagnostic tools are developed that can spot or predict their occurrence.”⁶⁴

Every deviation from an invented “genetically standard human” has the potential to be labelled a correctible abnormality, ensuring that biotech and pharmaceutical companies need never run out of customers:

“If an atmosphere can be generated in which none of us feels safe until we have assessed the likelihood that we or our children will develop sundry diseases and disabilities, we will be willing to support this new industry in the style to which it would like to become accustomed”.⁶⁵

One side effect will be “to transform every healthy individual into a potential patient”⁶⁶ or consumer for the saviour technologies of human embryo cloning and genetic engineering.

The claim that research into human embryo cloning might result in a flood of new cures also ignores the commercial imperatives that drive corporations toward providing long-term treatments rather than cures. A *Financial Times* guide to new medicines asked whether the pharmaceutical industry was directing its research efforts in the best way to benefit human health. Its conclusion was an unequivocal “no”:

“Obviously each company is trying to develop drugs that will produce the highest commercial returns. And under present pricing systems, the return is likely to be lower for a quick cure than for a long-term maintenance therapy that keeps symptoms under control without solving the underlying problem.”⁶⁷

The major targets for human genetic and cloning research are not so much rare genetic diseases as the diseases of industrialised countries and of old age.

Hard commercial realities do not sit comfortably with claims of “medical benefits for all”.

Access to medical resources and decent public health cannot be easily attained if medical research is so heavily committed to private property and profit-making.

For instance, a 1998 survey by the Pharmaceutical Research and Manufacturers of America (PhRMA) found that of the 350 new biotechnology medicines in development, 151 were for cancer or related conditions.⁶⁸ Researchers acknowledge that many of these treatments may slow the progression of a cancer, but will not halt it altogether or cure it. Concludes US health activist Judith Brady, “regardless of any individual oncologist’s dedication, in a health care-for-profit system, cancer is the goose that lays the golden egg”.⁶⁹

Altruistic-sounding claims that embryo cloning could treat currently untreatable, potentially fatal diseases, meanwhile, ignore the awkward economic fact that the profits of large pharmaceutical companies have come in recent years mainly from sales of a few “blockbuster” prescription drugs — those which earn more than \$1 billion a year. The patents on a record number of these drugs expire in the next few years — and firms have little in the pipeline to replace them. Once a 20-year patent runs out and any company can legally manufacture the drug, sales usually drop by 90 per cent. Merck is expected to lose \$3.5 billion of sales by the year 2002 as its top-selling products go off patent; Eli Lilly, meanwhile, will face generic competition to Prozac, its highly-lucrative anti-depressant.⁷⁰ Many of these companies are hoping products derived from genetic research will “treat” this problem, even if few marketable products have so far been found.⁷¹

These hard commercial realities do not sit comfortably with researchers’ belief that their work will have genuine medical benefits. As Lori Knowles concludes of the “concern for global justice” displayed by Geron, the US company which financed and patented the research into the isolation of human embryo stem cells:

“We know that Geron wants to reduce human suffering, but it also needs to respond to the pressures of the market and has an obligation to give its shareholders the best return on their investment. Let’s be candid. We should simply admit that access to medical resources, decent public health, and global justice cannot be easily attained if medical research is committed to private property and profit making.”⁷²

Is Public Finance the Answer?

It might be argued that public financing of genetic research could ensure that economically uninteresting illnesses were explored; that research results were made publicly available rather than being privately patented; and that any gene patents which followed belonged to the state to be used for public health rather than private gain.

Current trends in public financing, however, do not suggest that this is a route which would ensure that the benefits of the new genetic medicine are distributed more equitably. In practice, much public money subsidises private companies, while public research has itself become reliant on private funding, or has been handed over exclusively to private companies. Public or state regulation, meanwhile, has been heavily influenced by commercial interests.

Public subsidies for private biotech companies tend to be aimed at boosting national economies rather than benefiting public health. The British government’s rationale for wanting to keep the UK at the leading edge of medical genetic research, for instance, is to energise

AIDS, Health, Trade and Compulsory Licensing

Laboratory mice are useless for testing potential anti-HIV drugs or vaccines — they don't develop AIDS or anything like it.

Thus laboratories such as the Oregon Regional Primate Centre in the US are desperate to clone genetically identical sets of rhesus monkeys, which, unlike mice, can develop AIDS and could become genetically-identical control test animals. "We are working really hard to make it happen in any way we can", says researcher Tanja Dominko.

However, even this determined effort to exploit genetic technologies for the public good is unlikely to benefit more than five per cent of the world's HIV-positive people if current disputes are anything to go by. Commercial interests, backed by US government bullying, may well prevent these benefits from reaching the rest.

Writing off the South

Nearly two-thirds of the world's 33 million HIV-positive people live in sub-Saharan Africa. In nine southern African countries, between one-fifth and one-quarter of the population aged between 15 and 49 years old have HIV/AIDS. Some 11.5 million people in sub-Saharan Africa have died of AIDS, accounting for 90 per cent of all AIDS deaths. In Asia, there are about six million HIV-positive people.

Certain combinations of two or three pharmaceutical drugs hinder the ability of HIV to multiply inside the body and thus help to keep HIV-positive people from developing full-blown AIDS. Sales of these anti-retroviral drugs total US\$3 billion a year.

Several such drugs were developed by the US government, which has given exclusive licences to various US companies to make and sell them. For instance, the US

government's National Institute of Health financed, researched and patented didanosine (ddl), a drug used in double- and triple-therapies, but gave an exclusive licence to US pharmaceutical company Bristol-Myers Squibb to manufacture and market ddl in return for a royalty of five to six per cent of net sales.

Triple-therapy drugs cost about \$1,000 a month per patient, while drugs to treat the chronic infections that can kill people with AIDS (TB, meningitis and fungal diseases) can cost \$100 to \$150 a month — a price that is well beyond the reach of most people and health services in the countries of the South. Less than one per cent of AIDS drugs are sold in sub-Saharan African countries.

Given that the rate of HIV infection is slowing in the United States and Western Europe, pharmaceutical and biotech companies with anti-HIV products might be expected to turn to the South to expand their markets — after all, 70 per cent of new HIV infections occur in sub-Saharan Africa. Instead, firms merely encourage more people in the North to be tested for HIV and more HIV-positive people there to take double- or triple-drug therapies.

Compulsory Licensing

Jamie Love of the US Consumer Project on Technology estimates that the price of most AIDS-related drugs could be reduced 50-90 per cent if countries in which AIDS has effectively become a national health emergency could produce generic or non-brand name versions of patented drugs via a compulsory licence, a well-established practice in the patent field.

A compulsory licence is given to one or more companies by a national government to use a patent, copyright, or other form of intellectual property within the country, without the authorisation of the patent holder but in return for

some compensation to the patent holder, usually 1-10 per cent of sales.

Many compulsory licences are issued in the US for public interest reasons or to promote more competition in business. The US government has issued compulsory licences to the army on satellite technology and night-vision glasses; to various companies on technologies to reduce air pollution; on nuclear technology; and in the biotech industry to other biotech and pharmaceutical companies.

The Trade Related Intellectual Property (TRIPs) agreement of the World Trade Organisation (WTO), which introduced pharmaceutical patents into international trade agreements for the first time, still allows compulsory licensing (under Article 31) if it is necessary to protect a nation's health. The US government and the US pharmaceutical industry, however, are fighting hard to prevent the compulsory licensing of essential drugs, particularly AIDS drugs, in the South.

Thailand

After the Asian financial crisis, Thailand was in no position to afford AIDS drugs sold at US prices. Local health groups accordingly lobbied the Thai and US governments to license local companies to manufacture anti-HIV drugs and drugs to treat opportunistic AIDS infections. They pointed out that many lives would be saved and that the patent holder, instead of receiving virtually nothing from the Thai market, would benefit from a steady if unspectacular stream of compensatory payments. Commenting on ddl, NGOs pointed out that:

"if Bristol-Myers Squibb, which has not paid for the research and development of the drug, is permitted to maintain its monopoly on ddl and permitted

to charge high prices, we will be unable to purchase the drug and may die.”

In response, the US government persuaded the Thai government not only to drop its plans for compulsory licencing of ddl, but also to change its patent and trade laws to outlaw compulsory licencing altogether. It threatened to reduce Thailand's access to the US market for its jewellery exports, one of Thailand's major sources of foreign exchange, while at the same time offering to cut tariffs on Thai jewellery and wood products entering the US. This was in spite of the fact that the US government does not even have patent rights on ddl in Thailand.

South Africa

Pressured by the pharmaceutical lobby, the US government is employing a similar tactic in South Africa, a country where more than three million people — 16 per cent of the population — are HIV-positive, including one-quarter

of pregnant women in the poorest provinces.

Here the price of anti-HIV drug treatment as set by companies such as Bristol-Myers Squibb would amount to almost 40 per cent of an average worker's salary.

In 1997, South Africa amended its national legislation to allow compulsory licencing of patented AIDS drugs so that local companies could make and sell cheaper generic versions.

Yet implementation of the legislation has been suspended until a challenge lodged by some 40 drug companies with the South African courts is resolved. In the meantime, the US has put a wide range of trade sanctions on South Africa, including denying it tariff relief on certain exports.

The Law vs Politics

Given the difficulties faced by Thailand and South Africa with AIDS drugs, Jamie Love concludes that:

“the problem for developing countries is not whether compulsory licencing of

pharmaceuticals is legal, because it clearly is legal. It's the political problem of whether they will face sanctions from the United States government, for doing things that they have a legal right to do, but which the United States government does not like.”

The irony is that lowering prices in the South would not be a serious threat to either the profits or the research and development funding of the large Northern pharmaceutical companies, given that it could only increase sales income from the South and that the bulk of drug transnationals' income will continue to come from the North.

Source: Consumer Project on Technology website: <http://www.cptech.org/ip/health>

a flagging economy — although the jobs biotech provides are few in number compared to the number of people out of work and require a high level of educational achievement, while profits get shunted largely to institutional shareholders. British Prime Minister Tony Blair's main response to calls for a moratorium on genetically engineered crops and foods due to uncertainty about the effects on environmental, animal and human health (including cancer and birth defects) was that “we are not going to destroy an entire industry”.⁷³

Thus the Department of Trade and Industry has given nearly £3 million a year to cloning research (even as a government-sponsored consultation into human cloning was underway during 1998) so as “to keep Britain ahead in this controversial field”.⁷⁴ The Roslin Institute has received at least £7.4 million of public money for its cloning research⁷⁵ from the Department of Trade and Industry, the Ministry of Agriculture, Fisheries and Food, and the European Union. Among other corporate welfare measures, British biotech firms have been able to obtain 100 per cent write-offs against tax on research and development-related revenue and capital expenditure. So far, the financial benefits have accrued mainly to the few scientists-cum-entrepreneurs involved who have been able to patent their work and list their companies on stock exchanges.

Private pharmaceutical research is highly dependent on public money. As Thomas Caskey, president of the research institute of

Merck, a top pharmaceutical company, notes of drug research:

“About 95 per cent of the fundamental discoveries that point you in the right direction come out of basic science funded by government and not-for-profit sources.”⁷⁶

Commercial imperatives affect not only biotech and pharmaceutical companies’ own in-house research programmes, but also the agenda of the numerous public medical research institutions which have become dependent on industry funding.⁷⁷ As science journalist Steve Connor points out:

“Many eminently trustworthy scientists from university and government laboratories now have to look for industry funding to carry out their work, making it more difficult for them to be seen to be free of vested interests.”⁷⁸

The results of public research may well be handed over to private companies to profit from by manufacturing and selling products derived from the research. In the US, for instance, the governmental National Institutes of Health developed Taxol, a drug used to treat breast and ovarian cancer, and paid for all the clinical trials. It gave exclusive production and manufacturing rights, however, to Bristol-Myers Squibb (BMS) for zero royalties. BMS went on to charge cancer patients in the US \$10,000 for an annual course of the drug, in spite of the fact that it costs only \$500 to manufacture, putting the treatment out of reach of many sufferers. When challenged about this arrangement, which yields BMS US\$1 billion a year in subsidised sales, the US government has argued that what benefits BMS benefits the US economy.⁷⁹

Nor has the use of public research money helped poorer patients outside the US obtain the drug. The US put South Africa on its “watch list” for bilateral trade retaliation after South Africa decided in 1998 to authorise national companies to manufacture generic versions of Taxol.⁸⁰

State regulation may not necessarily act as a check on this public/private, commercial/scientific nexus.⁸¹ For instance, of the four members of the human cloning working group requested by the British government to investigate whether the country should change its legislation, none represented concerned citizens’ groups. The biotech and pharmaceutical industry, however, was represented through George Poste, the “chief science and technology officer” for SmithKline Beecham.

SmithKline Beecham is considered to have led the whole pharmaceutical industry into genomics (the study of how genes are implicated in disease), “probably has more genetic information than any other company in the world”⁸², and is active in building up resources in bioinformatics (the use of information technology to make sense of the vast volumes of genetic and biological data pouring out of research laboratories).⁸³ The company has given financial support to groups of patients with genetically-linked diseases. Perhaps unsurprisingly, George Poste is lobbying hard for Britain’s National Health Service to switch to a health care system based on genetic testing.⁸⁴

To claim in the face of such facts that public regulation and funding of genetic research would ensure equitable access to the products of cloning and genetic research is to fail to take account of the “formal

State regulation does not necessarily act as a check on the links between public and private or commercial and scientific genetic research and funding.

The human body has become a resource to be mined, harvested, patented and traded commercially for profit as well as for scientific and therapeutic advances.

and informal economic institutions wherein reside the real brokers of genetic research benefits”.⁸⁵

Clones For Sale

Given the economic imperatives driving cloning and genetic research and underpinning health care more generally, it is not surprising that the human body has become a “resource to be ‘mined’, ‘harvested’, patented and traded commercially for profit as well as scientific and therapeutic advances.”⁸⁶

Even in the early days of mammal cloning research in the 1970s and 1980s at the University of Wisconsin — much of it supported by W.R. Grace (now owned by US agrichemical company Monsanto) — it was the “economic promise of cloning” to multiply embryos from prized cattle costing \$500 to \$1,500 apiece which provided the impetus.⁸⁷

“Companies saw gold . . . Scientists would take precious cattle embryos, divide them into their constituent sixteen or so cells, and slide the nucleus from each of those cells into an enucleated egg. The result would be sixteen embryos.”⁸⁸

Similarly, the main aim of the Roslin Institute, which produced Dolly, and PPL Therapeutics, the company formed to raise funds and commercialise research at Roslin, is to produce pharmaceutical drugs in the milk of animals more cheaply than drugs that can be produced by existing methods. The vision is to create “flocks and herds of living medicine factories”⁸⁹ or “bioreactors”, as Roslin calls them. Ronald James, a director of PPL and a former venture capital portfolio manager, had the idea in the early 1990s that there were “riches to be made by any company that could figure out cheap, reliable ways to make valuable protein drugs . . . that cost hundreds of pounds per dose”,⁹⁰ not least because “genetically-engineered animals can be used to make products on a scale no chemical factory could achieve”.⁹¹

The Roslin group is also trying to engineer cows with human genes to produce what the group claims is human-like milk. Acknowledging that human milk is “superior for human infant nutrition”, Roslin’s patent application on this technology nevertheless argues that:

“Many mothers find breast feeding difficult or inconvenient. Moreover, in countries where infant food supplements are in great demand, it would be highly desirable to be able to supply a milk product with the nutritional benefits of human milk.”⁹²

Roslin seems unaware of the strict code adopted by the World Health Assembly in 1981 governing the marketing of breastmilk substitutes; the code aims to prevent companies from promoting bottle feeding and from suggesting that such feeding is equivalent to breastfeeding — artificial feeding results in over 1.5 million infant deaths every year.

While the milk from Roslin’s genetically engineered cows should contain the major whey protein found in human milk, it would be difficult, if not impossible, to engineer genetically many of the antiviral, anti-parasitic and anti-infective properties of human breastmilk (which protect an infant from many diseases until its own immune system is developed) or all of its nutritional components, not least

because these aspects are not yet fully understood. A mother's milk is tailor-made for her baby — in contrast to any genetically engineered version — and “delivered” in a uniquely safe way.

Yet as Patti Rundall, Policy Director of Baby Milk Action, an organisation which aims to end the avoidable suffering caused by inappropriate infant feeding, points out:

“The baby milk market is highly profitable — it is currently worth about \$7 billion a year. If the public can be convinced, either through genetic engineering or clever marketing, that artificial milks come closer to, or even match, the ‘gold standard’ of breastmilk, the potential for increased profit inevitably increases.”⁹³

Roslin's commercial arm, PPL, is also one of several companies racing to produce a pig engineered with human genes to provide spare parts for organ transplantation to humans — an estimated potential market of \$6 billion.⁹⁴ Comments Ron James, “kidneys are where the really big market is.”⁹⁵

The tie-up between the US Geron Corporation and Roslin Bio-Med⁹⁶ (under which Roslin Bio-Med becomes a wholly-owned UK subsidiary of Geron) will combine three patented technologies — nuclear transfer or cloning; replication of human embryo stem cells; and replication of the enzyme telomerase (which is critical for cell replication and the life-span of a cell) — to try to generate human cells and tissues that can be used to repair organs damaged by degenerative diseases, such as diabetes, Parkinson's, cancer and heart disease, without the threat of rejection from the patient's immune system (*see* Box, p.4).⁹⁷ Geron's R&D vice-president believes that the firm has cornered the market on organ repair — “we have it locked up”, he said. The company hopes to create other products as well which can generate an earlier financial return: laboratory cultures of heart, skin or blood cells (derived from embryonic stem cells) on which to test new pharmaceuticals; and genetically engineered cloned animals to provide human blood products and organs for transplantation.⁹⁸

Meanwhile, scientists at the University of Hawaii, by producing tens of cloned adult mice using a “relatively efficient” version of the Dolly technique,⁹⁹ have opened up “the possibility of creating made-to-measure mice on a commercial scale”¹⁰⁰ — ideal for testing pharmaceutical drugs. Comments *Financial Times* journalist David Pilling:

“It is a little like Henry Ford and the car; he did not invent the car; he worked out how to mass produce it — and this was what made all the difference.”¹⁰¹

An economics-driven impatience with nature reveals itself in dismissive descriptions of “natural” human reproduction, which is labelled “remarkably inefficient”¹⁰² because of the millions of eggs and sperms that “go to waste.” “Most embryos die before a woman is even aware she is pregnant”, goes another lament.¹⁰³ A female human fetus is described as having a “stockpile” of some seven million eggs in its ovaries, although the average woman releases only 400 eggs in her lifetime, most of which go “unused”.

It is only a short step from thinking in such language to being able to say that aborted fetuses will only “go to waste” if their brain cells are not transplanted into people with Parkinson's or their ovaries mined for immature eggs. A *Financial Times* editorial notes breezily that “no

Describing human reproduction as “inefficient” because most eggs, sperms and embryos “go to waste” is one way of justifying commodification of the human body.

Diseases, Drugs and Donors in the Third World

In the past two centuries, many successes have been scored against infectious disease. Yet two points are worthy of note.

First, European deaths from airborne diseases such as TB, whooping cough, influenza, diphtheria, measles and scarlet fever declined before modern medicine devised effective forms of treatment or immunisation.

Second, such diseases, together with malaria, cholera, dengue fever and AIDS, kill more people today than heart disease or cancer, on which much of today's medical research is focused — and their incidence is rising alarmingly.

These observations suggest that new cloning and genetic technologies, even if they do yield successful new products, will have a limited effect on world health if applied in the context of mainstream medicine.

Economic globalisation, meanwhile, has contributed to the resurgence of some infectious diseases and the emergence of new ones. After Thailand's economic collapse, for instance, dengue fever increased because pools of water collected as construction projects were left unfinished, providing a breeding ground for disease-carrying mosquitoes.

Malaria's comeback has been helped by the building of large dams and irrigation schemes which increase areas of stagnant waters, and by the movements of migrant workers who bring the pathogen into regions where it previously did not exist. Use of pesticides and synthetic drugs has led to the evolution of resistant strains of mosquitoes and pathogens: far more people die from malaria today than did three decades ago.

Essential Drugs & TRIPs

It is not that pharmaceuticals do not play an important role in health, simply that few effective drugs actually find their way to the poorer areas of the South.

The World Health Organisation (WHO) estimates that between 1,300 and 2,500 million people — more than one-third of the world's population — have little or no access to "essential drugs", defined by WHO as those "indispensable" drugs which "should be available at all times, in the proper dosage forms, to all segments of society".

What drugs are available are often unsafe, ineffective, or of low quality. Many of them have been dumped on the South because they remain unapproved in the West. Some drugs developed in the 1950s and 1960s to treat tropical diseases, on the other hand, have begun to disappear from the market altogether because they are seldom or never used in the developed world.

Nonetheless, pharmaceutical expenditure accounts for a substantial part of the health budgets of most Third World countries, even if it accounts for just one-fifth of the world's pharmaceutical consumption.

Many countries have tackled these problems by implementing national essential drug policies or by manufacturing the drugs themselves, advances which are now threatened by the World Trade Organisation's agreement on Trade Related Intellectual Property Rights (TRIPs) which requires member countries to introduce "product" patents instead of "process" patents. Many developing countries have been able until now to manufacture a patented drug legally by a process different from that originally used.

The implications for Third World countries with pharmaceutical industries are grave: higher consumer prices of pharmaceutical drugs; larger foreign exchange outflow as a result of more imports and fewer exports; and fewer people employed as a result of lower domestic production.

Lack of Research

Just four per cent of drug research money is devoted to developing new pharmaceuticals specifically

for diseases endemic in the South anyway.

To put it another way, less than 10 per cent of the \$56 billion spent each year globally on medical research is aimed at the health problems affecting 90 per cent of the world's population. While pneumonia, diarrhoea, TB and malaria account for more than 20 per cent of the disease burden of the world, they receive less than one per cent of the funds devoted to health research. Even with extended and enforced patent protection in the countries of the South, it is unlikely that Western companies will devote much effort to research which might benefit "financially non-solvent populations".

Predictably, the remedies proposed by the Global Forum for Health Research, a WHO-pharmaceutical-aid agency industry collaboration, are state subsidies, guaranteed markets and "streamlined regulatory requirements" for private sector corporations — which would only entrench their power further.

The role for people in the South in a globalised medical system involving genetic engineering is perhaps less as health beneficiaries than as donors of body parts and cell lines. Organs of both dead and live children are already widely sold in Brazil, with the justification that this market alleviates poverty. In Thailand, meanwhile, recent scandals involved the alleged trading in organs of patients who were deliberately allowed to die or were operated on without the consent of relatives.

Sources: Koivusalo, M. and Ollila, E., *Making a Healthy World*, Zed Books, London and New York, 1997; *The 10/90 Report on Health Research 1999*, Global Forum for Health Research, Geneva, 1999; Aphaluck Bhatiasavi, "Body parts trade: Doctors may face criminal charges", *Bangkok Post*, 21 July 1999.

real ethical dilemma exists” over the use of human embryonic stem cells as “they come from embryos that would otherwise be thrown away” or are simply a “by-product” of in-vitro fertilisation or come from “foetuses that are already aborted”.¹⁰⁴

Free Market “Choice”

The speculative applications of human embryo cloning are more easily made to seem “beneficial” when the environmental, social, economic and political causes of ill-health and disease are obscured, and when the “benefits” are presented in an abstract way which hides issues of access and commercialisation. Yet these purported benefits also receive support from more general contemporary attitudes towards health, death, life and children.

In the last few months, consumer advocates have observed with some consternation that it is now difficult, if not impossible, for people in Western countries to avoid eating genetically-engineered (GE) foods. GE ingredients are used in the majority of processed foods, while non-GE crops, including organic ones, are highly likely to be pollinated by GE plants from neighbouring fields. Whether to eat GE foods or not is hardly, at present, a permitted “consumer choice”.

It is sometimes argued that these concerns do not apply to genetic medicine. Patients/consumers, it is said, do have a choice about whether to avail themselves of germ-line therapy or organs grown in genetically-engineered pigs.¹⁰⁵ Yet closer examination of current medical realities reveals that it may be more difficult to avoid such “choices” and their consequences than might first appear.

Take, for example, prenatal screening, which is often presented in impeccable feminist language as something which “enhances women’s choice”. After all, no one forces pregnant women to screen their fetuses, nor, if the test indicates the presence of a certain gene or chromosome abnormality, to undergo an abortion.

Yet the “context in which testing and termination decisions are taken” is one full of social pressure and lacking in “balanced information for pregnant women”. As British sociologist Tom Shakespeare notes:

“30 per cent of obstetricians would not give a woman a test for Down’s if she did not agree to have a termination after a positive diagnosis. Only 32 per cent of obstetricians reported counselling pregnant women non-directively.”¹⁰⁶

A woman’s agreeing to the genetic testing of her unborn baby — or agreeing to abort it as a result — may thus be less an expression of choice than an instance of conformity, a response to coercion, or even a co-opting of her needs to fit established biomedical goals.¹⁰⁷

If a woman chooses to continue her pregnancy after her fetus has been diagnosed (in theory reliably and accurately) as having certain “unwanted” genes or anomalies, moreover, it becomes easier to maintain that it is her individual responsibility, and possibly that of her immediate family, to raise and look after the child without expecting any welfare support from the state or society. Several decades ago, some commentators were already arguing that carrying to term a fetus believed to be “genetically defective” could be considered fetal abuse. A 1995 study in three European countries showed that prenatal screening is the single most important factor influencing both laypeople’s

Agreeing to a prenatal test, and possible subsequent abortion, may be less an expression of choice than an instance of conformity or response to pressure.

“We know the real territory which genetics assumes as its own — the quality of our lives.”

Bill Albert
British Council of
Disabled People

Increased prenatal & preimplantation embryo testing is likely to result in “consumer eugenics”.

and health professionals’ attribution of blame for the birth of a child with Down’s syndrome.

As anthropologist Gail Landsman concludes, simply the availability of a prenatal test for Down’s syndrome (which is assumed to be accurate) enables blame to be placed on mothers for their children. The 1995 study itself, moreover, “contains an implicit assumption that the birth of a child with a disability requires assignment of blame”.¹⁰⁸ In July 1999, this assumption was made explicit when Bob Edwards, the British embryologist who helped pioneer in-vitro fertilisation, informed his colleagues that it would soon be a “sin” for parents to give birth to disabled children. “We are entering a world where we have to consider the quality of our children.”¹⁰⁹

In societies which already provide little practical assistance to parents in caring for and raising disabled infants, and in which mothers have become almost solely responsible for childcare and family health, the pressures on women not to regard giving birth to a genetically-“suspect” infant as a real choice may be even greater. In a public health system with limited resources, women may be pressured to have an abortion — as many professionals now admit, there is no such thing as non-directive counselling. Under an insurance-based health care system, meanwhile, insurance companies may well demand pre-embryo implantation and prenatal tests and refuse to give insurance for infants with certain genetic traits.¹¹⁰

As more and more genes are identified, women will have more and more types of “disabilities” to divide into acceptable and unacceptable, normal and abnormal.¹¹¹ They will come under increasing social pressure to bring their “choices” about whether to terminate their pregnancies or not into line with what their dominant society currently regards as normal or defective.

If prenatal diagnosis has led women increasingly to experience pregnancy as a “tentative” condition, to be committed to only when the genetic all-clear is sounded, so the genetic testing of “test-tube” embryos before they are implanted in a woman’s uterus, or the genetic engineering of “defective” pre-implantation embryos via cloning technologies, may well lead to embryos having to pass more and more quality control tests before being allowed out of the laboratory. Either way, the result is likely to be what has been called “consumer eugenics” or “a subtly creeping, democratically soft eugenics”¹¹² or the privatisation of eugenics.¹¹³

The more that any disability or even “abnormality” becomes categorisable as an avoidable misfortune, the more severe is likely to become the stigma and lack of social support and equal treatment which many disabled people already experience in society as their major disability.¹¹⁴ Small wonder that some disabled people see prenatal screening as “yet another form of social abuse” which “reinforces the general public’s stereotyped attitudes about people with disabilities” and is bound to result in increased “job discrimination, barriers to obtaining health insurance coverage, cut-backs on public support programs, and other similar negative actions”.¹¹⁵ “We know the real territory which genetics assumes as its own”, says Bill Albert of the British Council of Disabled People — “the quality of our lives”:¹¹⁶

“I would say to people who say that genetics is about removing illness and suffering from the world that I am somebody who they might think of as ill. The only way they could remove my

In The Blood? Genetics, Race and Discrimination

Overemphasizing genetic aspects of health can obscure the social and economic structures implicated in disease, in the process directing attention away from racism.

In the United States, the overall age-adjusted cancer death rate is 40 per cent higher among black men than white, and 20 per cent higher among black women than white. The mortality rate for black infants is more than double that for white infants. As US health activist April Taylor points out:

“If you are a poor woman or a Black woman, your chances of contracting and dying of either breast or cervical cancer are significantly higher than for other women. Many Black families live near toxic waste sites, have access to poor quality food and poor health care, and are living in immuno-suppressing conditions that can cause gene mutations.”

Avoiding the Issue

When activists in the US in the early 1970s highlighted the disparities in health and mortality between white and black Americans, the government response was not to look into why black people might have higher cancer or heart disease rates, nor to investigate the toxicity of food or of dump sites in black neighbourhoods, nor to explore the various economic and social conditions that might be contributing to racial health inequalities.

Instead, the government directed attention to diseases “of genetic origin” that blacks, but not whites, suffered from. Sickle-cell anaemia was one of the most prominently-discussed of these so-called “black diseases”. This ailment, so-called because of the sickle or crescent shape acquired by many of the blood cells of those afflicted, is

caused by a mutation affecting haemoglobin, the protein in red blood cells that carries oxygen to the tissues of the body. People with only one parent carrying this mutation will not get the disease and are believed to be protected against malaria. Offspring of parents both of whom have the gene, however, will acquire the potentially lethal disease.

The US government used genetic screening to detect (healthy, symptomless) carriers of the sickle cell gene, but little thought was put into how this might help the individual or community. No resources were directed into treating those with the disease, or to counselling those detected as carriers.

In fact, sickle-cell anaemia is not strictly a “disease of blacks” — individuals from a variety of backgrounds may have it. To confirm sickling’s status as a black disease, “biomedicine . . . had to construct the category of the ‘apparently white individual’,” an ethnological rather than medical category. In these ways, discourse about the affliction was used to shore up notions of racial difference between groups and to claim a “purity” and “superiority” for whites in the seemingly “objective” terms of genetics.

Even the failure of the 1970s’ prevention programme was used to reinforce racial stereotypes: it was implied that the failure resulted from the necessity of targeting an uneducated and poor community in general disarray.

As University of Texas anthropologist Melbourne Tapper points out, the 1970s’ programme also foreshadowed current attempts to use genetic talk to draw the line between health and disease in a discriminatory way. During the 1970s, many insurance companies, employers and some branches of the US armed forces rejected symptomless African-Americans who possessed the trait on the grounds that they had “medical problems”. As Tapper

notes:

“definitions of the normal and the pathological are . . . always more than a mere medico-technical matter”.

Racial Research

Many black people today do not participate in sickle cell anaemia research or in studies for new medicines, even if they might benefit, because of a profound distrust of medical research and experimentation among African-Americans.

This distrust is well-grounded in a long history of abuse. The most well-known example is the government’s “Tuskegee Study of Untreated Syphilis in the Negro Male” which started in 1932. Over 40 years, federal researchers monitored 600 black men in Georgia, 399 of whom had syphilis, 201 of whom did not. The men were given free meals, medical exams and burial insurance, and were told only that they had “bad blood”. They were not treated — even as they went blind and insane, and even after penicillin, which can cure syphilis, became widely available after 1945. The study ended only when it became public knowledge in 1972.

Reproduction Decisions

Advocates of the sickle cell testing programmes contended that, in order to “save” black children, trait carriers ought to be informed of their genetic status to promote “fully-informed reproductive decision making”.

Unmentioned was the “power of dominant groups, namely white males and health care authorities, to decide *which* diseases constitute unacceptable health risks”. As genetics researcher Carol Barash points out, also unspoken were several additional assumptions:

continued overleaf . . .

“that medical knowledge is accurate, accessible and acceptable; that childbearing occurs within marriage and is planned; that women have enough power in their lives and relationships to control the transmission of genetic disease; and that education can override strong cultural values.”

Also providing useful pointers toward answering the question as to who will benefit from genetic medicine is the long history of sterilization and contraceptive abuse directed at black women.

Legal scholar Dorothy Roberts argues that the first publicly-funded birth control clinics in the South of the US in the 1930s were based on the same premise that underlies today’s prosecution of crack-addicted mothers or mandatory sterilization or use of the contraceptive implant, Norplant, as a condition of probation for black women offenders: that certain groups do not deserve to procreate. The implications are several:

“If the public gets accustomed to black women being forcibly implanted with Norplant or jailed because they gave birth to a child while addicted to drugs, the public may become less quick to question a government program that uses these same techniques because it is believed that certain children are genetically predisposed to crime. Biological explanations for crime and reproductive penalties turn offenders into objects . . . which can be manipulated for the dominant society’s good”.

The Violence Initiative

The re-emergence of biological solutions to crime and the racial ideology of crime in the US is illustrated in the “violence initiative”, a research project premised on the theory that criminality has a genetic cause.

The aim of this research project is to find a genetic marker that would identify children at high risk of becoming criminals

and then to deter their criminal behaviour through drugs and other therapies. Children as young as five years old are said to be amenable to “preventive intervention”.

The programme however, is from the outset directed at black youth and “shares many characteristics with earlier attempts to use the biomedical and eugenic models for social control”, in particular, the “continued subordination of blacks.”

In Britain, meanwhile, the head of the prison service, Richard Tilt, speaking after an inquest into the death of a black prisoner in custody, said that black prisoners were more likely than white prisoners to die from “positional asphyxiation” when being restrained because of the prevalence in black people of the gene for sickle cell anaemia.

Potential For Abuse

So will genetic research benefit everyone? US health activist April Taylor thinks not:

“Given the history of medical abuse in [the US], there’s a strong possibility that biotech companies will target Black people, either to present them with costly cures or to extract their own genetic information to use against them.”

In a recent case at a lab at the University of California, Black and Latino women employees who thought they were being checked for their cholesterol levels were in fact being checked for syphilis, sickle cell traits and pregnancy.

Wider Discrimination

It has been argued that if pharmaceutical companies are successful in persuading medical establishments to switch over to a health care system which tests everyone for genetic predisposition to disease, genetic discrimination will be eliminated because everyone will be at risk for something. “We are all walking around with glitches in our DNA, which place us at risk for something,” says the director of the US National Center for Genome

Research, Dr Frances S Collins. Such a view is naive. As Ruth Hubbard comments:

“In an unequal society . . . different kinds of people experience disabilities and discrimination differently, depending on how they are labelled and how they are perceived.”

No one suggested that members of the royal families of Europe be sterilized because they were carriers of haemophilia.

Policies can certainly be drawn up to try to limit genetic discrimination in insurance and employment, or to curb social injustices which might result from the misuse of genetic information. But experience of the effects of existing anti-discrimination legislation does not bode well. More than 20 years after Britain last passed major legislation to combat racial discrimination, for instance, there is still substantial employment and earnings discrimination against black and Asian people.

Moreover, because the question of *who* defines misuse is unlikely to be asked, the use of genetic information is likely to perpetuate rather than curb social injustices.

Sources: Tapper, M., *In the Blood: Sickle Cell Anaemia and the Politics of Race*, University of Pennsylvania Press, Philadelphia, 1999; Roberts, D.E., “Crime, Race and Reproduction”, *Tulane Law Review*, Vol. 67, 1993, pp.1945-1977 ; Taylor, A.J., “High-Tech, Pop-a-Pill Culture: ‘New’ Forms of Social Control for Black Women” in Silliman, J. and King, Y., (eds.) *Dangerous Intersections: Feminist Perspectives on Population, Environment and Development*, South End Press, Cambridge, MA, (Zed Books, London) 1999; Rothman, B.K., *Genetic Maps and Human Imaginations: The Limits of Science in Understanding Who We Are*, W.W. Norton & Co, New York, 1998; Barash, C.I., “Sickle Cell Trait, Policy and Research Paradigms”, *Science As Culture*, Vol. 7, No. 3, Sept. 1998, pp.379-392; Roberts, D.E, *Killing the Black Body: Race, Reproduction and the Meaning of Liberty*, Pantheon Books, New York, 1997.

illness from the world is by removing me. And at the moment, that's the only way they can remove most things, most so-called disabling conditions. I don't want to be removed from the world, I don't want my fellow disabled people to be removed from the world, and that's the basic argument. Because there is no therapy except screening, and screening is about eliminating people.”¹¹⁷

Reinforcing the idea that disabled people are “defective human beings”¹¹⁸ for whose “defects” individuals are responsible can only make attempts to reduce welfare benefits to disabled people seem more reasonable. Nor can it be argued that this does not matter since science will have long since abolished disabilities: the vast majority of the disabled, after all, are not born with their impairment but acquire it through accident or illness.¹¹⁹

It may be argued that such worrisome social consequences need not follow on from other human cloning technologies, such as those which produce genetically-engineered embryos, replacement organs or new drugs. Yet these technologies also presuppose and reinforce far-reaching political and cultural changes.

Each implanted egg, for instance, presupposes a complicated and largely hidden social infrastructure for extracting industrial quantities of “surplus” ova from aborted female fetuses or from women undergoing fertility treatments (*see* Box, p.11). This system may not only put pressure on women to have later abortions so as to obtain an intact fetus, or to donate eggs in return for help in having their own baby through IVF; it is also intimately linked to a system of experimentation on lab-produced embryos propagated via cloning embryos which are genetic extensions of living individuals. Small wonder that participants in a Wellcome Trust research project into public perspectives on human cloning regarded the use of cloning technology in medical research as “good” only until they found out what was actually involved in practice: “as the participants’ awareness increased, so did their concern and apprehension”.¹²⁰

The language according to which cloning technologies are just another medical “choice” for patients/consumers thus not only pretends that isolated individuals of equal power make decisions in a theoretical vacuum, but also conceals how resources are diverted in order to make that “choice” possible.

Individual Responsibility for Health

Privileging the role of genes not only plays down the contribution of social factors to ill-health, disability and disease. It also adds weight to the idea that ill-health is an individual misfortune — to be tackled through making individuals aware of their genetic predispositions and then recommending to them individual programmes of risk-minimising behaviour.¹²¹

Yet while in many ways it seems reasonable to expect individuals to feel responsible for their health and that of their children — they are the ones, after all, to whom it matters most — it is also true that many of the “risk factors” for ill health are created or exacerbated by social institutions. To insist that health is an exclusively individual matter merely “protects those institutions that threaten individual health through discrimination, exploitation, pollution or iatrogenesis”.¹²²

Geneticisation, moreover, militates against making efforts for change

Privileging the role of genes adds weight to the idea that ill-health is predominantly an individual misfortune.

Insisting that health is only an individual matter protects institutions that threaten health through discrimination, exploitation, pollution and iatrogenesis.

Geneticisation militates against making changes which would benefit everyone's health, irrespective of their genetic predispositions.

which would be good for everyone's health, irrespective of their genetic predispositions. For instance, it creates an atmosphere in which a "safe workplace" is to be achieved not by cleaning up toxic production systems but by "weeding out the so-called susceptibles"¹²³ or putting the onus on them to prevent their "predispositions" from becoming reality. Comments a worker at a major US car manufacturer:

"For years, companies have been saying that workers' diseases are not caused by what we work with in the plants, but by smoking, diet, lack of exercise, and other problems with our life-style. Now they're saying it's the workers' genetic heritage".¹²⁴

Assigning genes to behaviours such as alcoholism and violence serves a similar social function. Concludes Ruth Hubbard:

"By erasing the social context, genetic predictions and labels individualise our problems, blame the victim ('If you get sick, it's because you have bad genes') and are authoritarian ('You should have had your genes tested and done what the doctor said')."¹²⁵

Under the genetic model, the "right" to be born healthy becomes not a reason to clean up the environment but an argument for not implanting or carrying to term embryos and fetuses which do not pass their gene tests.

The efficacy of the genetic approach to public health is also open to question in that "predictive tests contain rather little information to live by, since the answers they offer are almost always couched in terms of probabilities and contingent on other factors".¹²⁶

In addition, much "risky" individual behaviour is, on closer examination, not something susceptible in the aggregate to a moralising approach. Even if some individuals deemed to be at high risk of contracting a disease can be persuaded to change their lifestyles, this does little to influence the forces that encouraged the adoption of the lifestyles in the first place. Even as a few "at risk" individuals quit smoking, for instance, some children will be taking their first puffs.¹²⁷

Nor do those who are informed about their "genetic predispositions" necessarily change their behaviour. In one US study, men in the highest 10 per cent of risk for coronary heart disease could not be persuaded to make more than minimal changes in their eating and smoking habits despite six years of intensive attempts.¹²⁸ A 1998 survey concluded that many British young people aged between 16 and 24 years ignored public health campaigns to stop smoking, eat better foods and take more exercise.¹²⁹

One's Own Genetic Children

In many societies today, people attach value not simply to raising children, but above all to raising children which they have begotten or borne.¹³⁰ To use the words of British IVF guru Robert Winston, "For virtually all of us, the only thing that we will really achieve is the production of the next generation. Other contributions are so insignificant".¹³¹ In industrial societies, in which the role of the extended family, friends and neighbours in childrearing has been downgraded (although many of those responsible for children still in fact rely on them), having a chance to be involved in raising children virtually requires having one's own. Human embryo cloning

technology feeds on and reinforces these tendencies. As journalist Aminatta Forna notes:

“The reproductive industry holds a particular responsibility for the fetishising of genetics and, in particular, the fetishising of a shared genetic link with a child. In order to sell their ‘products’, large parts of the industry have successfully exploited the extraordinary grip ideas about genetics have rapidly gained in the public imagination . . . The genetic child, the fantasy child, becomes irreplaceable as the receptacle for the hopes and aspirations of the parents.”¹³²

By claiming that they are merely serving the real need many people feel to have their own genetic children, companies and researchers will try to sidestep responsibility for the wider consequences of human embryo cloning techniques. While it is unlikely they would be able to find hundreds of women willing to rent out their wombs for an experiment just to see if a human Dolly could be produced,¹³³ many women and their partners are only too willing to become guinea pigs if the promised reward is their own genetic children, as was shown by IVF in the 1970s.

IVF has accentuated a general feeling that knowing one’s genetic inheritance is crucial, and has also indirectly helped devalue adoption. In Britain today, it is harder to adopt children than to find the money to have a course of IVF treatment (at least £2,000) at a time when some 70,000 children of all ages are waiting to be adopted in the country and only about 500 IVF babies are born each year. Adoption has become a last resort for parenting.¹³⁴ Yet as biologist Barbara Ehrenreich points out:

“Millions of low-income babies die every year from preventable ills like dysentery, while heroic efforts go into maintaining yuppie zygotes in test tubes at the unicellular stage. This is the dread ‘nightmare’ of eugenics in familiar, marketplace form — which involves breeding the best-paid instead of the ‘best’.”¹³⁵

And again, while resources are poured into esoteric techniques for providing genetic children to women and men who might not otherwise be able to have the number of children they want, they are withheld from investigations into what might be causing infertility in the first place. This is happening at a time when chemicals which mimic the action of oestrogen are increasingly believed to contribute to the decrease in sperm count and quality, and when the incidence of the sexually-transmitted disease, chlamydia, which scars and blocks women’s Fallopian tubes, is on the rise in Britain, particularly among young women.

“Eliminating” Disease and Death

The increasing focus on genetics in medicine and on the potential benefits of human cloning techniques dovetails with and reinforces a fantasy common in the West that all disease can someday be treated, cured, and finally eradicated through technical means. Dr William Schwartz, author of *Life Without Disease: The Pursuit of Medical Utopia*, asserts that:

“our exploding knowledge of the genetic mechanisms of disease make plausible the once impossible dream of a largely disease-

*A genetic focus
in medicine and
health reinforces
a Western fantasy
that all disease
will be treatable,
curable and
finally eradicable
through technical
means.*

Written on the Body of the Embryo “Overpopulation”, IVF, Cloning and Genetics

Consider this paradox: if the numbers of people in the world are held by many to be increasing to such an extent that “overpopulation” is considered to be the major problem facing humanity, why are resources put into helping infertile women and men have children through various new reproductive technologies, including in-vitro fertilisation (IVF) and, possibly, cloning, and into extending people’s lives through organ transplants derived from embryos?

The paradox is imprinted upon laboratory human embryos in Britain. Research is permitted on these embryos for two seemingly contradictory purposes: “to promote advances in the treatment of infertility” and “to develop more effective techniques of contraception”.¹

But are these purposes really contradictory? Closer inspection of the history, practice, context and thinking behind contemporary contraception, population control, IVF, genetic medicine and cloning suggests not. All raise questions about who will be born, who will not; who will mother, who will not; and who will live and who will die.

Enhancing Women’s Choice?

Both contraception and new reproductive technologies, including prenatal and pre-implantation testing, are portrayed as expanding women’s choices, rights and control over their child-bearing. In practice, however, only some women are provided with only some of these choices. Other women are offered others or none at all.

For instance, although there is a belt of infertility across sub-Saharan Africa, women in the region are not offered IVF, nor provided with medical care to prevent infertility. If they are provided with anything, it is con-

traception.

To take another example, contraceptive techniques are becoming longer-acting and more difficult for users themselves to control or reverse. Whereas the Pill is effective for only 24 hours, injectables prevent conception for a few months, and difficult-to-remove implants for five years. Technology has thus made it easier to control the fertility of certain groups of women “from outside”.

This is not to deny that modern contraception has provided benefits for many women — and been welcomed by many. Indeed, although the contraceptive Pill was designed for poor black women so as to control their numbers, it was taken up readily and voluntarily by many middle-class white women largely for their own purposes.

Certain technologies, however, lend themselves to abuse more readily than others. In East Timor, women have been rounded up at gunpoint to have five-year contraceptive rods implanted forcibly in their arms. This type of violence would not have been so easy without the implant technology. As Maggie Helwig notes wryly, “you can’t force a man to use a condom at gunpoint”.

Who Gets Born?

Certain groups in Western society have been obsessed for more than a century with restricting the reproduction of *other* groups in society. Historical research illustrates how deeply eugenic thinking — which calls for fewer children from certain groups of people, usually poorer and darker-skinned ones — has informed population thinking and the development of contraceptives. Thus Margaret Sanger, often described as the founder of modern birth control, infamously said “More children from the fit; less from the unfit”. The heritage of eugenic thinking in genetic testing and genetic engineering is even more

apparent.

Indeed, on a theoretical level, the population, genetic medicine and eugenic discourses all reinforce each other. In 1971, Bentley Glass, president of the American Association for the Advancement of Science, the largest professional organization of scientists in the US, stated that the population explosion was the most pressing problem facing the planet and would force people to limit their family sizes. “When parents are able to have no more than two children,” he added, “they will want to be sure that those children are perfect”.

“The right that must become paramount is . . . the right of every child to be born with a sound physical and mental constitution, based on a sound genotype. No parents in that future time will have a right to burden society with a malformed or a mentally incompetent child.”

Glass went on to predict that parents would have fetuses screened for myriad genetic defects and would abort or not implant the “imperfect” ones, or would use genetic engineering to change their genes. He suggested that young people should store their eggs or sperm at an age when they would be healthiest for use when they were older.

Three decades on, his predictions may not have quite yet all been realised — but the idea that such practices are possible and desirable has gained ground. It has been suggested, for example, that young girls should have a part of their ovaries removed and frozen before being fitted with a contraceptive implant; when they are of a responsible age to have children, the implant could be removed and an egg thawed out for use. There are interesting parallels here to the logic behind “terminator” and “traitor” genetic engineering technologies in agriculture, which would make plant seeds ster-

ile unless they were bathed in chemical preparations.

The main commercial markets for prenatal and pre-implantation genetic tests are believed to be in the West. But countries with strict population policies limiting the number of children a woman can have will provide many willing consumers as well. If a couple is permitted just one child, as in China, they will obviously wish for it to be as “perfect”, healthy or socially acceptable as possible.

Natural or Social Causes?

There are other links as well between an approach which looks to population as the cause of poverty, hunger and environmental degradation and one which looks to genetics as the root of ill health. Both approaches function to obscure social, economic and political factors.

By attributing poverty to the poor’s natural reproductive habits, 18th century English clergyman Thomas Malthus absolved the rich of any material obligation to mitigate the human misery caused by unemployment and was thus able to “defend the interests of capital in the face of the enormous human misery which capitalism causes”. As anthropologist Eric Ross points out:

“While Malthus is remembered chiefly as the originator of a theoretical perspective which has left us with an unremitting anxiety about ‘over-population’, his greatest achievement, in fact, was to devise such an enduring argument for the prevention of social and economic change”.

Similarly, by attributing ill health to genes, many medical theorists today downplay the possibilities of mitigating misery through social and political change. Like Malthusianism, geneticism is consistently used to overwhelm reasoned debate about alternative explanations for society’s problems. Even those theorists who acknowledge that genes are but one factor in multifactorial, complex, interdependent interactions sometimes suggest that it will be easier to find cancer genes or to “fix” aberrant genes than to stop factories from emitting carcinogens, just as many populationists who acknowledge the importance of other factors still insist that it will be easier to “bring down the numbers of people” than to tackle social inequities.

Who Decides?

The questions of who will live, who will die, who will be born, who will not, who will mother, and who will not have always been issues for every society. In societies rife with discrimination and dominated by market thinking, however, the intersection of an increasingly

geneticised view of disease with population thinking, IVF and cloning is bound to put more power to decide such questions into the hands of remote authorities, and to conceal this power under the rubric of “health” and “consumer choice”.

1. Other permissible purposes are to increase knowledge about the causes of congenital disease or about the causes of miscarriage, and to develop methods for detecting the presence of gene or chromosome abnormalities in embryos before implantation. In the light of human cloning techniques, government advisers have suggested that legislation be extended to allow research for the purpose of development of methods of therapy for mitochondrial disease and of therapeutic treatments for diseased or damaged tissues or organs.

Sources: Glass, B., “Science: Endless Horizons or Golden Age?”, *Science*, Vol. 171, 1971, pp.23-29, cited in Hubbard, R. and Wald, E., *Exploding the Gene Myth*, Beacon Press, Boston, 1993; Ross, E.B., *The Malthus Factor: Poverty, Politics and Population in Capitalist Development*, Zed Books, London, 1998; Roberts, D. E., “Punishing Drug Addicts Who Have Babies: Women of Color, Equality, and the Right to Privacy”, *Harvard Law Review*, Vol. 104, No. 7, May 1991, pp.1419-1482; Richter, J., *Miracle or Menace? Vaccination Against Pregnancy*, Zed Books, London and New York, 1995.

free existence . . . The possibility of a broad-based victory over disease and a dramatic increase in the human lifespan in the not too remote future must now be taken seriously.”¹³⁶

It seems appropriate to remember that “utopia” is derived from the Ancient Greek word meaning “nowhere” — it does not exist.

A quarter of a century ago, too, there were euphoric proclamations that the Western world at least was on the verge of “eliminating death due to infectious disease”. Yet many agents of infectious diseases have developed resistance to drugs and chemicals and many new diseases have emerged as disease-causing pathogens have evolved and travelled, ecosystems altered, and climate changed. Most scientists now talk of “disease turnover” rather than the elimination of infectious disease.

The genetic model of medicine also provides materials for rebuilding the dream of conquering old age. As Richard Zaner of a Tennessee hospital comments:

Most agree that more public debate and discussion about human cloning are needed — but of which of its aspects? What information will be provided — and what not?

“Death itself is now often medically interpreted . . . as little more than a genetic error in the body’s somatic cells — a disease in that sense, susceptible of being forestalled or even prevented.”¹³⁷

One of the main advertisements for human embryo cloning is that it can produce an unlimited number of tissue-matched replacement body organs for transplant. Any questions about where the technology might be leading can be forestalled with the unanswerable retort: “The dying people who need transplants . . . do not wish to die.”¹³⁸ More fanciful souls, hoping to escape altogether what social critic Ivan Illich calls human beings’ “consciously lived fragility, individuality, and relatedness” in which the “experience of pain, of sickness, and of death” are a part of life, even look to cloning for immortality: “I may die, but if I am cloned, I won’t die”.¹³⁹

Public Debate — But Of What?

Everyone seems to agree that more public debate and discussion, education and information about human embryo cloning and genetic engineering are needed, and more democratic decision-making. But what will be debated and discussed — and what not? What information will be provided — and what not?

In the wake of the storm of controversy over genetically-engineered crops, it is obvious that proponents of human embryo cloning techniques and genetic engineering will need at least tacit public acceptance of their projects in order to proceed.¹⁴⁰ One British strategy for gaining this acceptance has been to test how squeamish the public is, stop the scientists there temporarily, and then ridicule or educate the “yuck factor” away so that the line can be gradually inched forward. As one University College London report concluded:

“The rate at which the general public can be reassured about the underlying technology is likely to be the single most important factor influencing the rate of uptake of genetic technology for health care.”¹⁴¹

Here it is critical to channel debate in certain directions and not others. For example, the Chair of Britain’s Human Fertilisation and Embryology Authority, Ruth Deech, has urged the importance of making the public “aware of the therapeutic benefits” of cloning — but not the importance of making them aware of how the therapeutic benefits are to be obtained, or of their “disbenefits”.¹⁴² As Wellcome Trust research into attitudes towards human cloning has discovered, the general public found it harder to comprehend *why* a sheep had been cloned than with dutifully learning *how*. Such “why” questions, the Trust concluded, led all too easily to the conclusion that the Dolly experiment had been “strictly for commercial gain”.¹⁴³

Similarly, the Royal Society, Britain’s oldest scientific institution, “favours a wider and well informed public debate of the scientific, technical, ethical and moral issues”¹⁴⁴ but does not mention economic and political issues. On the other side of the world, senior Australian judge Michael Kirby warns scientists and biotech companies that:

“unless there is a proper, thorough explanation to the community of the scientific arguments for cloning, the natural response of a community ignorant of the potential benefits is to simply say ‘this is unnatural . . . We should ban it’”.¹⁴⁵

Kirby does not say whether scientific or other arguments which might cast doubt on these potential benefits should also be explained.

If previous experience with “sensitive” new technologies (such as IVF was once) is any guide, the crucial benefits which are likely to be stressed are those which would potentially accrue to individuals who can elicit public sympathy and demonstrate the existence of “demand”: the distressed woman who cannot have children; the young, promising sufferer of a rare and fatal disease; the accident victim dying for want of an organ transplant; perhaps even the young girl whose social life is crippled by shyness. If enough real-life stories of individual tragedies which could supposedly be averted through scientific progress can be played out one after the other on news programmes or documentaries, it will seem churlish to ask questions about public health systems, inequity, distribution, exploitation, racism, eugenics and corporate control, all of which will recede safely into the background. Points out journalist Anne McElvoy, “scientists have been round this course many times before, and will respond by presenting the most persuasive examples of the benefits of their work.”¹⁴⁶

Nor will it be easy to bring up the awkward fact that many of the new treatments do not achieve their goal, or that they result in new problems. For example, genetically-engineered human insulin, which has been available since the early 1980s, is often touted as evidence that gene research yields benefits. The two companies which manufacture the product, Novo Nordisk and Eli Lilly, have denied that it might have negative effects. Yet many patients claim their lives have deteriorated after switching to the genetically-engineered version. Up to 20 per cent of diabetics taking it can no longer control their symptoms and can go into comas without warning. Doctors and specialists have, by and large, ignored patients’ distress and dangerous symptoms.¹⁴⁷ Only as a result of campaigning by insulin-dependent diabetics has animal-derived insulin once again been made available; and even then, only in some countries.

Similarly, even after two decades of use, it is not often reported that IVF still boasts at most a 20 per cent success rate, bringing “intense disappointment” for women who “walk away from the IVF clinic childless”;¹⁴⁸ nor that the number of British children born through intra-cytoplasmic sperm injection (whereby a single sperm is injected into an egg) with birth defects appears to be twice that of children conceived naturally; nor that five-year survival rates for heart and liver transplant recipients are still only 64 and 55 per cent, respectively.¹⁴⁹ Where “failures” are mentioned, it is likely to be only in those contexts in which they can be used to justify yet more research. Thus IVF practitioners are likely to refer to the low success rate of IVF only when they are arguing that more embryo research is needed in order to increase it.

One side effect of the PR-like focus on benefits to certain individuals is likely to be increased squabbling among different sectors of society over which diseases genetic research efforts should focus on — the “my-disease-is-more-important-than-your-disease” syndrome. Questions about how everyone’s health might benefit from basic and affordable public health, disease prevention and pollution control measures may well be obscured in the smoke raised by such disputes. As Ruth Hubbard stresses, although high-tech treatments can turn out to be a “real boon” to a limited number of individuals,

While high-tech treatments may benefit a few individuals, they drain resources away from public health and medical measures that could improve the health of more people.

Cloning in the Service of Animal Rights?

It is something of an irony that some supporters of research into cloning human embryos have taken up the arguments of campaigners against the use of animals in medical research and testing.

The cloning advocates argue that human embryo stem cells could be used to test potential drugs without the need for “less reliable and ethically controversial animal models”.

In theory, such cells could also reduce the need to engineer animals doomed to suffer. Britain’s labs now use some 350,000 genetically-engineered animals each year, many of them designed to display a “harmful genetic defect” which enables them to be used to study human diseases. Mice, for example, have been genetically engineered to develop cystic fibrosis, while sheep have been engineered to produce a protein which might treat the disease.

Many cloning advocates also claim that growing spare human organs from the stem cells of cloned embryos could reduce the need to manufacture transgenic animals as sources of transplant organs instead.

Such arguments may give the impression that human cloning research could be a force for animal liberation — after all, if people want to benefit from the end product, shouldn’t they or human tissues of some sort be used to test them rather than animals?

Arguments for using human rather than animal tissue for experimentation are also attractive to the pharmaceutical industry, whose research has long been restrained by the difficulty of predicting from animal tests alone what the effects of a particular drug will be on humans, and of obtaining enough healthy human volunteers on which to test potential new drugs.

But in fact the benefits of the

new cloning technologies are highly dubious for humans and animals alike. The biotech industry’s new “animal-rights” language is more plausibly read as a way of helping to further the commodification of all living creatures by dividing animal welfare advocates from potential allies.

More Animal Experiments, Not Fewer

From the beginning, research into cloning technologies, like medical inquiry generally, has involved animal research. The main difference has been that, while mice are the mainstay of much medical research, cloning investigations have concentrated on sheep and cows as experimental subjects because the research has been driven by the animal husbandry industry.

More human cloning, moreover, is unlikely to mean less genetic and cloning research on animals. Human embryo cloning and cell differentiation research, for one thing, presupposes “extensive basic research” largely employing animal subjects (although IVF in humans took place before parallel animal studies were conducted).

Nor will the advent of human embryo cloning stop animals being genetically engineered and cloned to mass-produce cheap pharmaceuticals in their milk for treatment of such diseases as cystic fibrosis and haemophilia, or nutraceuticals such as infant food.

Biotech companies in the US and Australia, meanwhile, are still aiming at mass-producing clones of elite livestock with desirable traits such as high milk production or tender meat. And genetically-engineered animals have many other alluring uses as well. As *The Economist* notes:

“Transgenic animals — those whose DNA has been fiddled to include foreign genes or to remove existing ones — are now commonplace in

academic laboratories and biotechnology firms. They are, essentially, living test tubes that allow scientists to model human diseases, try better treatments and generate larger quantities of useful proteins more cheaply than ever before. Compared with goats making human antibodies, pigs producing human clot-busting factors and designer mice, Dolly is a humdrum scion”.

The Human Connection

Experimentation on humans and experimentation on animals, far from being independent, are closely linked. As German activist Ingrid Schneider has pointed out, “It is not purely by chance that many pioneers of [new human] reproductive techniques were veterinarians”.

When cloning research intended to mass-produce desirable livestock varieties proved in the 1990s to be insufficiently profitable to sustain much investor interest, several of the leading scientists involved drifted into the burgeoning business of human in vitro fertilization where the future seemed secure and the money steady.

The crossover continues. Roslin-Biomed, which had previously concentrated on animal research, recently teamed up with the US firm Geron in a project to use human embryo cloning to produce spare organs.

Sources: Schneider, I., “From Cows to Women”, *Berliner Zeitung*, 2 November 1993; “Genetic engineering: Building to order”, *The Economist*, 1 March 1997, p.103; Arthur, C., “Huge increase in experiments on GM animals”, *The Independent*, 15 March 1999.

they unfortunately “drain resources away from the kinds of public health and medical measures that could improve the health of a much larger number of people”.¹⁵⁰

Ethical Gloss

As more and more dramas about the triumph of genetic science over human tragedy are played out in the public media, ethicists are likely to continue to ponder, for instance, the “philosophical implications for personhood” before invariably giving their stamp of approval to the new cloning developments — again without considering the social, economic and political context.

More often than not, ethics commissions and committees are put together and asked to investigate and pronounce on controversial technologies only *after* they have been developed.¹⁵¹ As social scientist Daniel Barben points out, instead of guiding or restraining genetic intervention or the further commodification of nature, ethics:

“are now increasingly being pressed into service as legitimation for precisely these projects. Ethics councils are being set up to signal responsibility, and institutes of ethics are being established to develop arguments legitimising what is currently still regarded as ethically reprehensible.”¹⁵²

As with calls for more public debate, analyses of economics and power politics usually get left out of these exercises.¹⁵³ For instance, the ethics advisory board of Geron averted its gaze from issues of the classification, control or commercialisation of cells derived from aborted fetuses or “leftover” IVF embryos. This omission:

“only highlights the tension between the altruism individuals are supposed to exhibit by donating their tissue for research and the current patent system, which encourages companies to stake lucrative property claims in that research.”¹⁵⁴

Similarly, a US government project assigned to predict the ethical, legal and social implications of the application of knowledge derived from the human genome project (the worldwide effort to map all the genes in a “standard human”) is not allowed to raise ethical, legal and social questions about whether the project ought to continue or not.¹⁵⁵

A Wider Conversation

Critically, public debates on where to “set limits” or how to “ensure access to benefits” divert attention from broader questions of what kind of wider health care system people want, and from questions about the nature of health and disease.

If cloning is the answer, what was the question? If the question was how to improve health and quality of life for all, cloning and human genetic engineering are probably not the answers. If the question is how to keep an existing health care system and industry going, then it scores nine out of ten. Just as in agriculture, genetically engineered crops may (supposedly) result in fewer applications of chemical pesticides for some farmers, which would be a benefit to people and the

Ethics committees often investigate controversial technologies only after they have been developed.

Public debates on how to ensure access to the benefits of cloning and genetic technologies divert attention from broader questions about health and health care.

Human cloning and related techniques can provide new resources of power and control to state and medical institutions.

Attempts to promote cloning and genetic technologies will affect us all, irrespective of their effectiveness and of who benefits.

environment; but what is problematic is the application of chemicals in the first place. Most debates and consultations fall into the trap of assuming that the status quo — whether embryo research or the sale of human body parts — is acceptable and that the only questions needing examination are the supposedly new ones.

In reality, many of the most important issues that the prevalent discourse on human embryo cloning and genetic engineering obscure are far from new. For decades, health professionals and activists have been struggling with, for instance, the way individuals' health has been divided off from, and given a privileged position over, public health; the importance of tackling environmental and social causes of ill health; the question of who is responsible for health. Human embryo cloning techniques and associated practices merely bring new dimensions to these familiar debates.

For centuries, societies have contended with issues about who gets born and raised and who does not; who gives birth and who does not; who raises children and who does not; who lives and who dies. Eugenicists have always argued that parents try to give their children the best start in life by providing them with education, food and so on: why not also try to give them the “best” genes possible? Human embryo cloning and related techniques add no new concepts to this argument but, if realised, could provide new resources of power and control — ones which would be made available not just to prospective parents, but to state and medical institutions as well. As a University College London report acknowledges, “modern genetics would . . . allow [eugenic or racial improvement] processes to be instituted in a precise and discriminatory way.”¹⁵⁶

This is not to suggest that debates about benefits are not an important and necessary part of the “ethical” discussion. But by themselves, they do not encourage the essential:

“larger conversation about the fabric of social relations that sale of biotechnologies feeds on or promotes; nor about the dimensions of the common good that biomedical research can or should serve; nor about the sort of communal relations that exchanges of certain goods, labour, expertise, and services might reflect or produce; nor about determining criteria for deciding which possible objects of ‘equitable access’ are deserving of communal resources.”¹⁵⁷

The potential of cloning technologies may not be realised — indeed it is not even close to being realised. Even if it were, however, and even if the technologies were legalised, it is unlikely that their use in producing babies and spare parts, or for other ends, would become widespread. That much is suggested by the fact that since 1978, just 500,000 IVF babies have been born worldwide.

Attempts to promote cloning technologies, however, will affect us all. No aspect of human existence will remain unaffected by discoveries in human genetics — irrespective of the new science's predictive accuracy or therapeutic efficacy. In their increasing claims on our attention and our resources, the new technologies will shape the way nearly everyone thinks. In that sense, it is not the spectre of cloned humans that should give pause as much as what the readiness to clone humans says about the way society is being organised.¹⁵⁸

1. Dolly was born on 5 July 1996, but was not publicly announced until 23 February 1997 in the British newspaper, *The Observer*, and the scientific journal, *Nature*, because the Roslin Institute wanted to obtain a patent on the nuclear cloning technique. The patent covers all mammals, which would include humans. See Kolata, G., *Clone: The Road to Dolly and the Path Ahead*, Allen Lane The Penguin Press, London, 1997; McKie, R., "Scientists clone adult sheep", *The Observer*, 23 February 1997, p.1; Wilmut, I., et al., "Viable Offspring Derived from Fetal and Adult Mammalian Cells", *Nature*, Vol. 385, 27 February 1997, pp.810-813, reprinted in Nussbaum, M.C. and Sunstein, C.R. *Clones and Clones: Facts and Fantasies About Human Cloning*, W.W. Norton & Co., New York and London, 1998, pp.21-28.
2. Quoted in "Time to act on cloning", editorial, *Financial Times*, 12 January 1998.
3. See Dawkins, R., "What's Wrong with Cloning?" in Nussbaum, M.C. and Sunstein, C.R. op. cit. 1, pp.54-55.
4. Those who suggest otherwise — US scientist Richard Seed announced in January 1998 that he could clone a human being in two years time — have been, in the main, quickly discredited as renegades. John Durrant of Britain's Science Museum and a professor of the public understanding of science said that "if you wanted to put the wind up people scientifically, you would be hard pushed to better Richard Seed". See McKie, R., "Fears of a clone", *The Observer*, 11 January 1998, p.23.
5. Schwartz, W.B., *Life Without Disease: The Pursuit of Medical Utopia*, University of California Press, Berkeley and Los Angeles, 1998, p.80.
6. "Cloning Issues in Reproduction, Science and Medicine: A Consultation Document", Human Genetics Advisory Commission and Human Fertilisation & Embryology Authority, London, January 1998 (report of consultation published in December 1998). Some of the potential applications of human cloning technologies which the 1998 consultation document suggests could be beneficial are basic research which is not of direct therapeutic value. Wellcome Trust research into public perspectives on human cloning decided to avoid the term "therapeutic cloning" because it "might obscure a deeper insight into participants' attitudes." See The Wellcome Trust, *Public Perspectives on Human Cloning*, The Wellcome Trust, (183 Euston Road, London NW1 2BE, UK) 1998, p.24. Also available at <http://www.wellcome.ac.uk>
7. Research into human cloning techniques facilitates the genetic engineering of humans — adding or replacing genes in a cell's nucleus before, via the cloning techniques, it becomes part of an embryo. The main aim of the Dolly research was not to replicate sheep but to engineer mammals with human genes. As *New Scientist* has said, "It's not cloning we should be worrying about, but its sister technology, genetic engineering". See "Into the Clone Zone", *New Scientist*, 9 May 1998, p.25; King, D., "Why human cloning research should not be funded", *GenEthics News*, Issue 21, Dec/Jan 1998, p.8, (PO Box 6313, London N16 0DY, UK. E-mail <genethicnews@compuserve.com> Website: <http://ourworld.compuserve.com/homepages/genethicsnews>)
A range of medical terminology describes the various stages of development from the point when an egg cell allows in a sperm cell through the egg shell or membrane, to fusion of the two cells, to division of the fertilised egg, to implantation of the organism in the placenta, to continuing development and growth: zygote, blastocyst, embryo, fetus. For ease of understanding throughout this briefing, I have used the word "embryo" to describe the organism from the stage when the egg and sperm cells fuse. I am aware, however, that to name the organism thus is also a political act (see Box, p.8).
8. "Time to act on cloning", op. cit. 2
9. "Brave new world . . . needs brave new ethics", *The Guardian*, editorial, 9 December 1998, p.23.
10. Steingraber, S., *Living Downstream: An Ecologist Looks at Cancer and the Environment*, Virago Press, London, 1998, (Addison-Wesley, New York, 1997), p.241.
11. Spanier, B.B., *Impartial Science: Gender Ideology in Molecular Biology*, Indiana University Press, Bloomington and Indianapolis, 1995, p.109.
12. Ibid, p.106.
13. Ibid, p.109. The damage takes place via direct carcinogens — substances which alter change or mutate DNA — such as radiation, industrial chemicals and some viruses, and via indirect carcinogens — substances which cause other changes in the body, for instance, a suppressed immune system or disrupted hormone function, so that an existing DNA mutation is more likely to develop into cancer.
Cell mutations that can lead to cancer occur regularly in the body, but a healthy immune system quickly detects and destroys them, often without the individual ever becoming aware of the tiny cancers. If the immune system is not functioning properly, the cancer cell may not be noticed and will keep dividing. Exposure to more and more industrial chemicals, a rapidly-changing environment, and changing patterns of food consumption are all thought to contribute to immune system disorders which are of epidemic proportions worldwide. A damaged immune system is implicated not only in many cancers, but also in susceptibility to infectious diseases and general ill-health.
The number of environmental agents that can cause cancer directly and indirectly is rising. There are now 70,000 industrial chemicals in the immediate environment of the average person in the West, compared to just 150 some 100 years ago. Some 2,000 new chemicals are introduced each year in industrial processes, many of which are not tested for their carcinogenic effects. Some may be weak cancer-causing agents on their own, yet have much greater effects when combined with other chemicals. Because of unexpected synergistic effects and the multi-causal nature of cancer, there is no safe level of exposure to a cancer-causing chemical. Because the "model" for assessing chemical effects is usually a white man, substances may have different effects on non-white people, women and children.
A 1998 report from the US Environmental Protection Agency (EPA) stated that eight chemicals known to cause cancer were present throughout the continental United States at levels exceeding the EPA's benchmark safety standards. See "Carcinogens Everywhere", *Rachel's Environment & Health Weekly*, #633, Annapolis, MD, 14 January 1999, Email <info@rachel.org> Website <http://www.rachel.org>; Gibbs, L.M and the Citizens Clearinghouse for Hazardous Waste, *Dying From Dioxin: A Citizen's Guide to Reclaiming Our Health and Rebuilding Democracy*, South End Press, Boston, 1995.
14. "Parkinson's", *Rachel's Environment & Health Weekly*, #635, 28 January 1999.
15. Exposure to synthetic chemicals is believed to play a critical role in Multiple Sclerosis, Motor Neurone Disease and Myalgic Encephalomyelitis (ME) as well as Parkinson's. The incidence of all these diseases is increasing in the West at a rate which cannot be attributed solely to the fact that older people comprise an increasing percentage of national populations, nor to increased genetic susceptibility.
16. Purdey, M., "Anecdote and Orthodoxy: Degenerative Nervous Diseases and Chemical Pollution", *The Ecologist*, Vol. 24, No. 3, May/June 1994, p.104. For instance, the cause of brain cells dying in Parkinson's patients was linked in the early 1990s to a gene found in a few Italian and Greek families. As *Rachel's Hazardous News* concludes, "Genetic causes of disease are very fashionable at the moment and it is easier to find research funds to study genes than it is to find research funds to study the effects of pesticides." See *Rachel's Environment & Health Weekly*, #635, op. cit 14.
17. The form of diabetes associated with the destruction of insulin-producing pancreas cells may be caused by an allergic response to toxic chemicals, a viral infection, or some other unidentified stimulus. Where the disease results from an insensitivity to insulin, it can be

- treated through exercise and a low-fat, carbohydrate diet.
18. Hubbard, R. and Wald, E., *Exploding the Gene Myth: How Genetic Information is Produced and Manipulated by Scientists, Physicians, Employers, Insurance Companies, Educators and Law Enforcers*, Beacon Press, Boston, 1993, p.92. For instance, the EU-wide “safer chemicals campaign”, which aimed to test and then remove chemicals suspected of causing the rising tide of cancer in Europe and sexual abnormalities in children, collapsed in February 1999 because of “lack of funding and political will”. Some 2,700 chemicals have been identified as being in regular use but have never been tested for potential damage to human health, including substances in household products, children’s plastic toys, cosmetics and hair sprays. See Brown, P., “Ducking the issue”, *The Guardian*, 10 February 1999, p.10.
 19. British government figures indicate that in 1996 more than 12,000 tons of cancer-causing chemicals were discharged by the country’s factories, a figure which dropped to only 10,000 tons for 1998. The third worst emitter of carcinogens in 1996 and in 1998 was Glaxo Wellcome’s pharmaceutical factory at Ulverston, Cumbria. See Friends of the Earth, Factory Watch, Friends of the Earth, London, 1999; Website: <http://www.foe.co.uk/factorywatch/>; *ToxCat* (newsletter of Communities Against Toxics-CATS), PO Box 29, Ellesmere Port, South Wirral L66 3TX, UK. Email <info@tcpub.demon.co.uk>

The consultation document produced by the British government’s 1998 consultation team on human cloning stated that embryo cloning research could “offer a greater insight into the origins of cancer”.

One of the members of the team was Dr Anne McLaren, principal research associate of the Wellcome Trust Cancer Research Campaign Institute. See “Cloning Issues in Reproduction, Science and Medicine: A Consultation Document”, op. cit. 6.

The Wellcome Trust is a major contributor to the human genome project, the international project to decode a complete set of human genes.
 20. Spanier, B., op. cit. 11, pp.93-94.
 21. Ibid., p.93, quoting Hubbard, R., “Genes as Causes”, in Hubbard, R., *The Politics of Women’s Biology*, Rutgers University Press, New Brunswick, New Jersey, 1990.
 22. A person with a single copy of the gene for Huntingdon’s or thalassemia, for instance, will invariably develop the disease, as will those with two copies of the gene for cystic fibrosis or sickle cell anemia. The majority of conditions associated with genes, however, seem to be multi-genetic and multifactorial. Many of the genes identified with particular types of cancers suggest that a person with the gene has a predisposition towards developing that cancer, but may not necessarily do so.
 23. Spanier, B., op. cit. 11, pp.92, 93.
 24. Thus clones produced by nuclear transfer, as Dolly was, are not clones in the sense of having DNA identical to that of another organism. As mitochondrial DNA can come only from the egg, it would be possible for a woman to replicate herself genetically through the process which produced Dolly only if she used the nucleus from a cell of her body tissue and her own egg. A human being cloned from a man’s adult tissue would not, in fact, be his genetically-identical clone because the mitochondrial DNA of the offspring would come from the donated egg.
 25. Spanier, B., op. cit. 11, p.62. Chromosomes in a normal cell have a cap at each end made up of structures called telomeres which protect the genes in the chromosome from injury. The telomere cap shortens each time a cell divides and replicates itself. When the cap is reduced to a certain threshold, usually after about 50 generations of cells, cell multiplication stops. Some researchers believe that preventing telomere loss is the key to halting the process of ageing. One option would be to stimulate the activity of the enzyme, telomerase, which has the capacity to rebuild the telomere cap. The telomere hypothesis, however, has also been criticised as being no more true than proposing that since everyone who grows old gets wrinkled, it is wrinkles that cause old age. Many cancerous cells, on the other hand, are believed to be able to divide and replicate themselves almost indefinitely because they contain telomerase.
 26. Cohen, P., “Why start with an egg to make a clone of an adult?” in “Into the Clone Zone”, *New Scientist*, No. 2133, 9 May 1998, p.28.
 27. The use of ultrasound techniques has contributed to a perception of women as simply “fetal environments”. The conceptual separation of the fetus from the woman has been facilitated further by various new reproductive technologies, including the physical separation of the egg and embryo from the woman and its isolation in the laboratory. The language and concepts of fetal rights, constructed in opposition to maternal rights, have added to this separation. See Martin, E., *The Woman in the Body: A Cultural Analysis of Reproduction*, Beacon Press, Boston, 1987; Duden, B., *Disembodying Women: Perspectives on Pregnancy and the Unborn*, Harvard University Press, Cambridge, MA, 1993.
 28. Abrams, F., “Toxic dumps: official inquiry ordered”, *The Independent*, 8 March 1999, p.9. For information on toxic waste issues, such as dump sites and incineration, see newsletter of Communities Against Toxics, *ToxCat*, op. cit. 19.

Neglecting the importance of the environment in which embryos develop is not necessarily wilful or deliberate, but it does go hand in hand with the belief that nuclear genetic inheritance is what is critical. For example, British IVF pioneer Robert Edwards failed for years to fertilise immature human eggs in the laboratory, succeeding only when he switched the petri-dish medium in which the eggs were kept to one a colleague had used to fertilise hamster eggs.

Yet he failed to learn from this experience. Edwards teamed up with gynaecologist Patrick Steptoe to devise hormonal and surgical procedures to extract mature eggs from a woman, fertilise them in the laboratory and put them into her uterus. For years, women were experimented on but no pregnancy resulted. Both doctors were on the point of abandoning their experiments when it finally occurred to Edwards that the hormones being given to the women to make them superovulate might be affecting the uterus in a way that prevented the embryo from implanting. When he tried obtaining an egg without the use of ovary-stimulating drugs, the result was the first IVF baby, Louise Brown. See “The Baby Makers”, part 1, broadcast on Channel 4, UK, 11 May 1999.
 29. US anthropologist Gail Landsman’s daughter is brain-damaged because the physician supposedly covering for her own obstetrician at the birth “never showed up to do a cesarean section until my uterus had already torn and the baby was asphyxiated”. Landsman interviewed mothers of infants and toddlers with disabilities to study how they viewed motherhood in an age of “perfect” babies and observed a sense of “the fundamental unfairness of bearing infants with disabilities despite the promises of genetic screening, prenatal testing, and high-tech nurseries and despite the mother’s compliance with the best scientific prescriptions for producing positive pregnancy outcomes”. See Landsman, G., “Reconstructing Motherhood in the Age of ‘Perfect’ Babies: Mothers of Infants and Toddlers with Disabilities”, *Signs*, Vol. 24, No. 1, Autumn 1998, p.83.
 31. Consumer Analysis Group survey, commissioned by Variety Club of Great Britain, based on official data, cited in Travis, A., “Children experience pros and cons of modern life”, *The Guardian*, 14 January 1999, p.9.

The world depicted in the 1997 Hollywood film, *GATTACA*, is peopled by “Valid’s”, who started out as genetically-tested and approved embryos in IVF procedures and who form the higher echelons of society, and “In-valid’s”, who were conceived conventionally, genetically-tested at birth for their myriad predispositions to disease, and who carry out most of the menial work in the society. One of the central characters in the film is a Valid — but ironically has no place in the “perfect” society because he was paralysed in an accident.
 32. The Harvard Working Group on New and Resurgent Diseases, “New and Resurgent Diseases: The Failure of Attempted Eradication”, *The Ecologist*, Vol. 25, No. 1, Jan/Feb 1995, p.26.
 33. Wilkinson, R., *Unhealthy Societies: The Afflictions of Inequality*, Routledge,

- London and New York, 1996, p.3.
34. *Ibid.*, p.53.
35. *Ibid.*, p.7.
36. *Ibid.*, p.67.
37. *Ibid.*, p.215. In biological terms, chronic stress affects endocrine (hormone) and immune processes, which have a powerful influence on rates of illness and death. Taking up or continuing with “unhealthy” behaviour such as smoking or eating certain foods or drinking can, in many cases, be a response to such social stress.
38. These conclusions have been borne out by many other studies. See *Independent Inquiry into Inequalities in Health Report*, chaired by Donald Acheson, HMSO, London, 1998. Website: <http://www.official-documents.co.uk/document/doh/ih/ih.htm>; “Major Causes of Ill Health”, *Rachel’s Environment & Health Weekly*, #584, 5 February 1998; “Cancer survival linked to wealth”, *The Guardian*, 23 April 1999, p.6; *Cancer Survival Trends in England and Wales, 1971-1995*, HMSO, London, April 1999; “Wealth and Health”, *Rachel’s Environment & Health Weekly* #654, 10 June 1999, Email <info@rachel.org> Website <http://www.rachel.org>; Marmot, M. and Wilkinson, R., *The Social Determinants of Health*, Oxford University Press, Oxford, August 1999.
- Closely related to the degree of income equality is the quality of the social life in a society, which Wilkinson argues is one of the most powerful determinants of health.
- This is not to deny that individual genetic susceptibilities and lifestyles do not play a part in the development of disease. But it is to suggest that many of the preconditions for living in such a way to minimise their impact are beyond the control of any but a privileged few. For instance, a 1999 report from the British National Heart Forum suggests that heart attacks in the top social echelons are in such steep decline that “the most affluent men and women in Britain may soon be able to forget their fears of dropping dead of a heart attack”, while for everyone else coronary heart disease remains a top killer and disabling. According to the Acheson inquiry into inequalities in health, since 1980, average income for the richest tenth of the UK population has grown by more than 60 per cent, while for the poorest it has fallen by 8 per cent. See Boseley, S., “Heart attack risk starting to vanish for the rich,” *The Guardian*, 28 April 1999, p.7.
39. Tracy, D., “Human Cloning and the Public Realm: A Defense of Intuitions of the Good” in Nussbaum, M.C. and Sunstein, C.R., op. cit. 1, p.193.
40. Schwartz, W., op. cit. 5, pp. 63,112.
41. More and more medical and pharmaceutical products are being produced not only to enhance the quality of our lives but also to tackle the causes of our distress — US pharmaceutical companies are lobbying for shyness to be classified as “social phobia” so that it can be registered as a disease covered by health insurance and treated by new pharmaceutical drugs. Comments *HealthMatters* of the Viagra dispute, “To believe that the NHS can solve every problem for every person who suffers it is to live in a fantasy land . . . If the NHS cannot afford Viagra and more hip replacements [and treatments for baldness, fatness, snoring or any other source of distress], nor any other expensive innovations alongside its existing portfolio of services, its financial basis must change.” But instead of increasing taxation, collecting the money and beating off demands from other public sectors, the government would be more likely to replace meagre taxation funding of the public health service with generous private insurance systems. See “Why Dobson must stand firm on Viagra”, editorial, *Health Matters* (PO Box 459, Sheffield S1 2UP, UK. Email <info@healthmatters.org.uk> Governments of the five largest European markets — Germany, France, Italy, UK and Spain — are trying to curb the amount they spend on drugs. Unsurprisingly, the pharmaceutical industry is lobbying hard for Europe’s health care systems to be deregulated, which could open the way to greater volume of sales of pharmaceutical drugs, higher prices and approval for new, more expensive treatments. See Pilling, D., “Losing the drugs war”, *Financial Times*, 13 April 1999, p.21.
- The British National Health Service spends some £100 million of its £5 billion annual drugs budget in England on drugs that do not work, have dangerous side effects or are not the best medicine on the market. See Boseley, S., “£100m bill for wrong NHS drugs”, *The Guardian*, 27 October 1998, p.1.
- A 1998 report in the US estimated that over 100,000 people die each year in the country because of adverse reactions to prescription drugs, an incidence three times higher than those killed in road accidents. This makes prescription drugs the fourth leading killer in the US after heart disease, cancer and stroke, despite the fact that prescription drugs are subject to more tests for their safety than any other “consumer product”. Unsurprisingly, the pharmaceutical industry is arguing that genetics can resolve this problem by tailoring drugs to an individual’s genetic make up. See “Another Kind of Drug Problem”, *Rachel’s Environment & Health Weekly*, #632, Annapolis, Maryland, 7 January 1999, Email <info@rachel.org> Website <http://www.rachel.org>
42. A study from University College London maintains that if public screening for cervical cancer in women stopped at the age of 50 instead of the current age of 64, there could be an extra 600 cases of the disease each year — but one-quarter of the £132 million annual budget for such screening could be saved. See Laurance, J. and Jury, L., “Useless medicine costs UK millions”, *The Independent*, 5 February 1999.
43. “Death’s cancelled”, editorial, *The Observer*, 24 January 1999, p.26.
44. Kolata, G., op. cit. 1, p.66. At least 40 million people in the US have no health insurance, a figure that is likely to increase as insurance premiums rise. See Rayner, G., “Winning the medical profits race”, *Health Matters*, Issue 35, Winter 1998, p.17.
45. *Reuters Health*, 10 December 1998, New York, citing report of Caruso, T. et al., in *Genetics in Medicine*, Vol. 1, Nov/Dec 1998, pp.22-28.
46. Shakespeare, T., “Down’s but not out”, *The Guardian online*, 5 November 1998, p.8.
47. Rothman, B.K., “On Order”, in Nussbaum, M.C. and Sunstein, C.R., op. cit. 1., p.287. Gail Landsman points out that while some children are considered too expensive to be born, others are considered worth saving, even if they have costly health problems. She points to the active treatment given to most infants born in North America with birth weights of 500 grammes or at 24 weeks gestation. “Such extremely low birthweight children who survive have been shown to be at high risk for pulmonary and central nervous system injury, including cerebral palsy, mental retardation and visual problems. Given expanded technological care, newborns with severe impairments now live, when not long ago they would have died”. Landsman raises the point not as an argument for letting some infants die, but rather as an argument for making decisions transparent as to which children live and which die, according to what criteria, and determined by whom. See Landsman, G., op. cit. 29.
48. “The question is not whether there will be savings, but how substantial those savings will be, whether we will find that we have only deferred expensive age-related diseases a few decades. For example, if we delay the onset of Alzheimer’s by 20 years, the immediate savings would be substantial, but not complete. We would have more time to save for later medical care and we would be able to amortize our costs over a longer-life span. We would also have 20 more years in which we might well die of other, far cheaper diseases, such as pneumonia or trauma”. See Fossel, M., “Reversing Human Aging: It’s Time to Consider the Consequences”, *The Futurist*, July-August 1997, p.27.
49. Schwartz, W., op. cit. 5, p.153.
50. Lori Knowles analyses the ethical deliberations, including a concern for “global justice” of Geron, the US firm which has financed and patented worldwide research into isolating human embryo stem cells and which bought Roslin-Bio-Med in 1999. Knowles, L.P., “Property, Progeny and Patents”, *Hastings Center Report*, Vol. 29, No. 2, March-April 1999, p.40.
51. Koivusalo, M. and Ollila, E., *Making a Healthy World: Agencies, Actors & Policies in International Health*, Zed Books, London and New York, 1997, Chapter 9, “Health Care Reforms”, pp.137-162.

52. Timmins, N., "Puzzled health service poised to swallow its reform pills", *Financial Times*, 31 March 1999, p.10.
53. Comments Francis Wheen in *The Guardian*, "It is like taking out a mortgage from a loan shark to buy a house which you already own and then discovering 25 years down the line that the property has been repossessed by the lender anyway". See Wheen, F., "In bed with the profiteers", *The Guardian*, 28 April 1999, p.5.
54. Gaffney, D. and Pollock, A.M., "Pump-Priming the PFI: Why are Privately Financed Hospital Schemes Being Subsidized?", *Public Money & Management*, January-March 1999, pp.55-62. Moreover, most PFI hospitals typically involve cutting the number of hospital beds by 30 per cent. Conclude researchers Allyson Pollock and Declan Gaffney, "These enormous cuts in capacity are not releasing savings to be reinvested elsewhere in the health service: they are being used to fund the profits of the private sector. The NHS is paying more for less". See Gaffney, D. and Pollock, A.M., *Putting a Price on the PFI: The illusionist economics of the Private Finance Initiative*, UNISON, London, April 1998, p.17; Gaffney, D., Pollock, A., Price, D. and Shaoul, J., "NHS capital expenditure and the PFI", *British Medical Journal*, 319, 3 July 1999.
55. Schwartz, W., op. cit. 5, p.60.
56. Thornton, J., *Should Health Screening Be Private?*, Institute of Economic Affairs (Health and Welfare Unit), London, January 1999.
57. Prescription drugs to treat these diseases already yield most of the pharmaceutical industry's revenue. The drugs that have made their manufacturers the most money over the past few years have primarily been those to treat heart disease, high cholesterol levels, ulcers, obesity and depression.
- One of the strongest growth areas is nervous system drugs, driven by the increase in consumption of anti-depressants which account for much of the annual 10 per cent increase in drug sales in the United States for the past decade. Drug companies have been trying to extend the prescribed uses of anti-depressant drugs "to cover illnesses such as social anxiety". The anti-depressant Prozac and the drug to treat schizophrenia, Zyprexa, have kept Eli Lilly's financial fortunes high. Rates of depression have increased over the past 30 years and are predicted to increase still further. Depression is now the second greatest cause of death in Europe and North America after heart disease, and one of the main causes of morbidity, according to WHO. Given that we are not all sprouting depression genes, the rising prevalence would seem to be more a result of societies which promote stress and depression, and the availability of drugs to treat them. It seems more plausible and profitable to tinker with brain chemistry than to tackle societal changes.
- Similarly, the World Health Organisa-
- sation believes that obesity is the world's biggest chronic health problem among adults. In Britain, nearly one in five people are obese, one in two overweight. Obesity can contribute to high blood pressure and cholesterol levels, and has been linked to heart disease, stroke and certain cancers. The direct health costs worldwide are estimated at £3.5 billion. Again, people cannot all be sprouting obesity genes, yet genetics is considered "the best hope of combating obesity" (even though a marketable product is several years away) instead of considering sedentary lifestyles and the fact that one of the cheapest ways of avoiding hunger is to eat low-quality, high-calorie, fatty foods.
- Cancer is a major target of genetic research because it kills so many people. In the United States, a man's chance of getting cancer during his lifetime are about 1 in 2, while a woman's chances are about 2 in 5. Over the last 45 years, the incidence of all cancers combined in the US has risen about one per cent each year, while the death rate for all cancers has increased at the rate of 0.2 per cent each year, an increase which cannot be explained by the increasing age of populations alone.
- See Pilling, D., "Strong US sales of anti-depressants stimulate the global drugs market", *Financial Times*, 22 January 1999, p.5; "The Cancer War Grinds On", *Rachel's Environment & Health Weekly*, #641, 11 March 1999, Email <info@rachel.org> Website http://www.rachel.org
58. Wright, G., "Is There A Future for Pharmaceutical Patents in the Twenty-First Century?", keynote address at EuroForum conference, "Patent Protection for the Pharmaceutical and Biotech Industries", London, 20 November 1997.
59. Barben, D., "The Political Economy of Genetic Engineering: The Neoliberal Formation of the Biotechnology Industry", *Organization & Environment*, Vol. 11, No. 4, December 1998, p.417.
60. Pilling, D., "Consolidation enters more frantic phase", *Financial Times Survey Life Sciences*, *Financial Times*, 15 March 1999, p.I.
61. Hubbard, R. and Wald, E., op. cit. 18, p.70.
62. A recent study indicated that the drug added a couple of inches to a child's final height. See Hintz, R.L. et al., "Effect of Growth Hormone Treatment on Adult Height of Children with Idiopathic Short Stature", *The New England Journal of Medicine*, Vol. 340, No. 7, 18 February 1999, pp.502-507.
63. Hubbard, R. and Wald, E., op. cit. 18, p.7. An internet advertisement for the drug, available without a prescription, claims that it is natural, organic and safe; decreases "body fat, wrinkling, cholesterol, insomnia"; increases "physical strength, muscle mass, energy level, sexual function, mental alertness"; stimulates youthful skin and hair appearance; improves neurological function; and rejuvenates cell and organ tissue.
64. Hubbard, R. and Wald, E., op. cit. 18, pp.69, 71.
65. *Ibid.*, p.118. Pharmaceutical companies in the US have been the leaders in developing "disease management" programmes for certain illnesses which are excluded from general health insurance schemes and for which insurance cover is provided separately. Those carved out are "chronic diseases that are expensive to treat: diabetes, asthma, cancer, Alzheimer's disease, stroke, severe spinal and head injuries, and major mental problems", diseases which are also the main target of genetic research. Comments Dr William Schwartz, "nearly all of the pharmaceutical firms engaged in disease management appear to be using the program for a marketing advantage in stimulating drug sales. They therefore design treatment programs that can be expected to make substantial use of their own proprietary products". See Schwartz, W., op. cit. 5, p.55.
66. Berlan, J.-P. and Lewontin, R.C., "It's business as usual", *The Guardian*, 22 February 1999, p.14, reprinted from *Le Monde diplomatique*, January 1999.
67. *FT Guide to New Medicines*, Financial Times, London, 1996.
68. The next highest areas were infectious diseases (36 medicines), AIDS/HIV/related disorders (29), heart disease (28) neurological disorders (26), other diseases (22), respiratory diseases (20), autoimmune disorders (19), skin disorders and transplantation (14), diabetes and related disorders (13), genetic disorders (10), digestive disorders (9), blood disorders (8), growth disorders and infertility (4 each) and eye conditions (3). See PhRMA, *350 Biotechnology Medicines in Development*, PhRMA, Washington, 1998, summarised in "Biotechnology Revolution Gains Momentum", *Health Horizons*, No. 35, Autumn 1998, p.22.
69. Brady, J., "The Goose and the Golden Egg" in Brady, J., (ed.) *1 in 3 women with cancer confront an epidemic*, Cleis Press, Pittsburgh and San Francisco, 1991, p.25. Even though there is no effective therapy for 60 per cent of the 1.2 million people diagnosed each year with cancer in the United States, cancer drugs still generate US\$6 billion a year in sales worldwide, an amount which is estimated to rise more than ten-fold by the year 2030 to US\$62.7 billion. See Friend, T., "Biotechnology vs. Cancer: 200 drugs move from the lab to human trials", *USA Today*, 8 March 1999. See also Cookson, C., "A crusade to top the wish list", *Life Sciences Survey*, *Financial Times*, 15 July 1999, p. VI.
70. Pilling, D., op. cit. 60, p.I.
71. The pharmaceutical industry as a whole commands high profits: about one quarter of gross sales compared to the 4-5 per cent that most of the top US 500 companies obtain. By market capitalisation, pharmaceutical companies account for eight of the world's top 25 companies. Although no single company has more than five per cent of the market, the top

20 companies are close to controlling 60 per cent of the world market by sales. See Pilling, D., op. cit. 60, p.1; *Scrip*, 23 September 1998, p.15.

The discovery of genes linked to specific diseases has proved unexpectedly difficult to transform into useful therapeutics. Moreover, the relationship between a single genetic mutation and “its” associated disease is proving to be much more complex than had originally been envisaged; the same is likely to be true, if not more so, for polygenic conditions. See Richmond, M.H., *The Implications of Genetics and Genomics for Healthcare and the Pharmaceutical Industry*, Final Draft, School of Public Policy, University College London, London, January 1999, pp.7, 22-23.

72. Knowles, L.P., op. cit. 50, p.40. Geron’s Ethical Advisory Board, convened after the research into human embryo stem cells had been carried out, believes that research on these cells can be conducted ethically under certain conditions, including that “all such research must be done in a context of concern for global justice”. The Board points out that “two features of Geron’s research render this commitment to just access particularly challenging. First, the research is undertaken in the private sector — in the context of market forces, patenting of products, interests of shareholders and investors, and a consideration of profit. These varied interests may compete with — but should not override — a concern for equitable access. Second, the research is highly technological and expensive, as well as under the proprietary rights of a US company. How to ensure adequate access for insured, underinsured, and non-insured patients in the United States, let alone on a global basis, will be an ethically and financially challenging task”. Such an admission makes it seem that Geron is engaged in ethical handwringing. But it has not challenged the market forces, patenting and profit interests which it cites as problematic. See Geron Ethics Advisory Board, “Research with Human Embryonic Stem Cells: Ethical Considerations”, *Hastings Center Report*, Vol. 29, No. 2, March-April 1999, pp.31-36.
73. In May 1999, however, British government advisers recommended that research be carried out into the potential health effects of eating genetically engineered food, particularly “foetal abnormalities, new cancers, and effects on the human immune system” — effects which the potential products of human embryo cloning would supposedly treat.
74. Atkinson, D., “Taxpayer foots £3m cloning research bill”, *The Guardian*, 21 July 1998, p.19.
75. The Department of Trade and Industry gave £2.3 million in 1996-1997 to the Roslin Institute; £2.5 million in 1997-1998; and £2.6 million in 1998-1999. See Atkinson, D., op. cit. 74.
76. quoted in Cimons, M. and Jacobs, P., “When Biotech Is Privatised, The Public

Losers”, *Los Angeles Times*, 7 March 1999. Guaranteed monopoly profits from products derived from public subsidies are in addition to what British Member of Parliament Alan Simpson calls the “voluntary contributions which come from the public in the form of their family history, medical records, blood and tissue samples, all given freely as part of the research effort.” See Simpson, A., “Can democracy cope with biotechnology?”, *Splice*, Vol. 5 Issue 2, Dec 98/Jan99, p.7.

77. Koivusalo, M. and Ollila, E., op. cit. 51, p.176.
78. Connor, S., “When science facts become science fiction”, *The Independent Weekend Review*, 22 May 1999, p.4.
79. US health activists are lobbying for legislation to prevent pharmaceutical companies overcharging for prescription drugs developed with public funds. Currently, patients with multiple sclerosis, breast cancer, colon cancer, heart disease and AIDS pay up to 100 times the actual cost for prescription drugs that have been developed with funding provided by the government.
80. In spite of such realities, the pharmaceutical industry maintains repeatedly that it needs patents on genes to recoup the costs of R&D and of meeting safety regulatory standards, neither providing evidence for this claim nor mentioning the public subsidies it enjoys. In private, pharmaceutical industry representatives admit that the purpose of a patent is to stop competitors selling identical or similar products. See, for example, Wright, G., op. cit. 58.
81. While the public may understand “regulation” of cloning and genetic research as ensuring that what is deemed unethical or unacceptable is not carried out, “regulation” is also understood as the state setting the rules for private company activities. The general trend in recent years has been for deregulation followed by reregulation which is more favourable to industry. Thus the pharmaceutical and biotech industry may welcome regulation which gives the impression that it is behaving in an ethical way so as to maintain public confidence in its activities, but will resist regulation which limits its activities. See, for example, Hildyard, N., “The Myth of the Minimalist State”, CornerHouse Briefing 5, March 1998; Richter, J., “Engineering of Consent: Uncovering Corporate PR”, CornerHouse Briefing 6, March 1998; Pfeffer, N., “Regulating reproduction” in Saetnan, A., Kirejczyk, M. and Oudshoorn, N.E.J., (eds.) *Localizing and Globalizing Reproductive Technologies*, Ohio State University Press, forthcoming 2000.
- Another issue is what the regulations actually cover. In Britain, for instance, legislation governing infertility treatment is concerned mostly with safeguarding human gametes and embryos, not with the women undergoing treatment. While those in favour of adult replication acknowledge that, at present, the technique would be dangerous, they seem

mostly to be thinking about potential fetal abnormalities rather than the physical and emotional dangers to the women involved at the various stages. For instance, writer Gina Kolata comments, “The Dolly experiment certainly gave grave hints of how ruinous cloning could be to most embryos, and no one could possibly expect to sacrifice hundreds of human eggs, embryos, even foetuses, to get one living clone. That alone . . . would make human cloning unethical”. See Kolata, G., op. cit. 1, p. 201.

Rules and regulations, moreover, can be drawn up, but implementing and policing them is another matter.

Who is regulating the welter of activity among biotech companies? asks a *Financial Times* article on biotechnology regulation. “Firstly, the financial markets” is the answer. Only later comes limited regulation governing safety, efficacy and ethical issues. See Pilling, D., “A can of (cloned) worms”, *Financial Times Survey on Biotechnology*, *Financial Times*, 6 October 1998, p.VIII.

In the United States, national legislation governing cloning, genetic, IVF and related research has concerned itself more with whether public funds can go towards such research than with setting limits on the research *per se*. Thus much of the human cloning and embryo research in the US has been carried out by private companies because public funds cannot be given to work that involves destroying embryos.

82. Green, D., “Drugs hit gene gridlock”, *Financial Times*, 7-8 February 1998.
83. Cookson, C., “Combination creates R&D powerhouse”, *Financial Times*, 2 February 1998, p.20.
84. See, for example, Poste, G., “Shaping the agenda for healthcare: rationing, risk, regulation and responsibility”, address to The Royal Society meeting on “Science, Technology and Social Responsibility”, 16 March 1999, London.
85. Cahill, L.S., “The New Biotech World Order”, *Hastings Center Report*, Vol. 29, No. 2, March-April 1999, p.48.
86. Nelkin, D. and Andrews, L., “*Homo Economicus*: Commercialization of Body Tissue in the Age of Biotechnology”, *Hastings Center Report*, Vol. 28, No. 5., Sept-Oct 1998, p.30.
87. Kolata, G., op. cit. 1., pp.133,136.
88. Kolata, G., op. cit. 1., p.158.
89. Green, D., “From cloned sheep to cash-cow”, *Financial Times*, 5-6 July 1997, p.9.
90. Kolata, G., op. cit. 1., p.182.
91. Radford, T., “Cloned goats join fight against illness”, *The Guardian*, 28 April 1999.
92. PPL Therapeutics international patent application, number PCT/GB95/01651, filed on 12 July 1995 on alpha-lactalbumin gene constructs, p.1.
93. Patti Rundall, personal communication, August 1999. For more information, see copies of *Baby Milk Action Update*, Baby Milk Action, 23 St Andrew’s St., Cambridge CB2 3AX, UK. Email <info@bab

- ymilkaction.org>
94. Arthur, C., "Pharmed animals go to market", *The Independent*, 5 March 1998, p.9. Human genes are engineered into the pig so that the animal's kidneys, lungs and hearts are coated with human proteins, rendering them less likely to be rejected by a human patient's immune system if they were to be transplanted.
 95. Pilling, D., "Send in the clones", *Financial Times*, 25-26 July 1998.
 96. Roslin Bio-Med was set up in 1998 to commercialise the cloning research of the Roslin Institute, except for the production of therapeutic proteins and nutraceuticals in the milk of transgenic animals, the rights for which have been transferred to PPL Therapeutics.
 97. A joint press release from the two companies stressed that "human pluripotent stem cells provide an unlimited source for virtually all cells and tissues. Nuclear transfer ensures that the cells and tissues will not be rejected when transplanted. Telomerase expression can provide the transplanted cells and tissues which an extended lifespan for durable therapeutic benefit." The target cells to replace are insulin-producing ones as well as nerve, heart muscle, liver, blood, bone, eye and skin cells.
 98. Radford, T., "Cloning boom with US tie", *The Guardian*, 5 May 1999.
 99. In this cloned mice technique, the nucleus of the adult cell was injected directly into the egg, whereas with Dolly, the nucleus of the adult cell was kept in a laboratory culture and "starved" back to its undifferentiated state. The Hawaiian mice technique reinforces the importance of recognising the role of the egg cytoplasm in encouraging embryonic development. See Wakayama, T., et al., "Full-Term development of mice from enucleated oocytes injected with cumulus cell nuclei", *Nature*, Vol 394, July 1998, p. 369.
 100. Pilling, D., "Dolly finds new play-mates", *Financial Times*, 23 July 1998, p.20.
 101. Pilling, D., op. cit. 95.
 102. Cohen, P., "Dolly helps the infertile: Cloning technology yields an important spin-off for IVF", *New Scientist*, 9 May 1998, p.6.
 103. Ibid.
 104. "Cell celebration", *Financial Times*, editorial, 9 November 1998.
 105. Use of the term "choice" strengthens the perception of food, health and medical products and technologies (including children) as consumer goods. Sometimes, however, not even the appearance of choice is present. Many of those who have to take life-saving medicines every day do not have a choice over the type of medicine they take. In several countries, for example, insulin is supplied by just one or two companies which no longer supply animal-derived insulin, but only the genetically-engineered variety. An estimated 20 per cent of diabetics who take genetically-engineered insulin have experienced life-threatening episodes as a result. See Brown, P., "Diabetics not told of insulin risk", *The Guardian*, 9 March 1999, p.6; website of Insulin Forum Switzerland: homepages.iprolink.ch.tenscher/engl/vers/english.htm
 106. Shakespeare, T., op. cit. 46.
 107. "Choice in Prenatal Testing: prenatal testing may actually limit choice on both the individual and the collective levels even more than it enlarges it", *GeneWatch*, Vol. 12, No. 2, April 1999, p.1.
 108. Landsman, G., op. cit. 29, p.94.
 109. Lois Rogers, "Test-tube revolution", *Sunday Times* (London) 4 July 1999.
 110. Adding to pressures on pregnant women are tests to indicate the presence of genes implicated in diseases which occur late in life — for instance, Huntington's disease, which usually develops around the age of 50 — or genes which suggest a "predisposition" to a disease, for instance, two of the breast cancer genes.
 111. Landsman, G., op. cit. 29, p.71.
 112. Schneider, I., "From Cows to Women", *Berliner Zeitung*, 2 November 1993.
 113. McEwen, J.E., "Public and Private Eugenics", *GeneWatch*, Vol. 12, No. 3, June 1999, pp.1,3. Some commentators suggest that ultrasound, amniocentesis and prenatal genetic testing have become so advanced that they have become a high-tech means of "genetic cleansing".
 114. Albert, B., "If you tolerate this, your children will be next", *Health Matters*, Issue 36, Spring 1999, p.12; Kaplan, D. and Saxton, M., "Disability, Community and Identity: Perception of Prenatal Screening: Most people will experience some form of disability, either permanent or temporary, over the course of their lives", *GeneWatch*, Vol. 12, No. 2, April 1999, p.4.
 115. Kaplan, D. and Saxton, M., op. cit. 114, p.6. These authors stress that equating disability with suffering and gene testing with avoidance of harm enables prenatal testing to be directed towards eliminating disabled people before they are born rather than addressing fundamental social causes of disability discrimination and the resulting lowered socio-economic status of people with disabilities.
 116. Albert, B., op. cit. 114, p.12.
 117. Bill Albert, British Council of Disabled People, quoted in Shakespeare, T., "Eugenics? Slipping down the slope", *Splice*, Vol. 5, No. 2, Dec 1998/Jan 1999, pp.4-5. For a copy of British Council of Disabled People's disability movement statement on genetics, see <http://www.bcodp.org.uk/genetics.html> Just as the sense of control which contraception can give is partly illusory — one in three babies born in the UK today are "unplanned" — so too the "mastery" derived from gene testing will remain largely in the mind, no matter how advanced the technology. People will still become disabled, get sick, have accidents, go hungry, be bullied, be unhappy, and so forth.
 118. Shakespeare, T., op. cit. 117.
 119. Albert, B., op. cit. 114, p.12.
 120. The Wellcome Trust, op. cit. 6, p.25. Fewer of these dilemmas might apply to people who choose to avail themselves of other promised benefits of human cloning technologies, if they are realised and approved for use. While such patients should be given information as to any potential side-effects and their likely success or failure rates, they may well not be given information as to how they were researched or produced or the conditions under which they were obtained.
 121. Lock, M., "Breast cancer: Reading the omens", *Anthropology Today*, Vol. 14, No. 4, August 1998, p.11.
 122. Ibid.
 123. Draper, E., *Risky Business: Genetic Testing and Exclusionary Practices in the Hazardous Workplace*, Cambridge University Press, Cambridge, 1991, quoted in Lock, M., op. cit. 121, p.11. See also Barben, D., op. cit. 59, pp.417-418.
 124. Draper, E., op. cit. 123.
 125. Hubbard, R. and Wald, E., op. cit. 18, p.74.
 126. Ibid., p.74.
 127. Syme, S.L., "To prevent disease: the need for a new approach" in Blane, D., Brunner, E. and Wilkinson, R.G., (eds.) *Health and Social Organization*, Routledge, London, 1996, p.22, quoted in Wilkinson, R., op. cit. 33, p.21.
 128. Wilkinson, R., op. cit. 33, p.20.
 129. Department of Health, *The Health of Young People*, HMSO, London, 1998.
 130. Posner, E.A. and Posner, R.A., "The Demand for Human Cloning", in Nussbaum, M.C. and Sunstein, C.R., op. cit. 1, p.237. This value seems to be connected to inheritance and the importance of passing on your property to your legitimate genetic children.
 131. Goddard, A., "Fertile with ideas for the infertile", *The Times Higher Education Supplement*, No. 1,384, 14 May 1999, p.19. Winston and his colleagues are researching the genetic engineering of human sperm, in particular, inserting genes into sperm, and the maturation of eggs from ovarian tissue (see Box, p.11).
 132. Forna, A., "Wanted: the perfect baby", *Independent on Sunday-Real Life*, 19 July 1998, p.5. See also Forna, A. *Mother of All Myths*, Harper Collins, London, 1998.
 133. McKie, R., "A clone again, naturally", *The Observer*, 10 March 1998.
 134. Posner, E.A. and Posner, R.A., op. cit. 130, p.237.
 135. Ehrenreich, B., "The Economics of Cloning", in Ehrenreich, B., *The Snarling Citizen: Essays*, Farrar Straus Giroux, New York, 1995, p.39.
 136. Schwartz, W., op. cit. 5, p.1.
 137. Zaner, R., "Surprise! You're Just Like Me! Reflections on Cloning, Eugenics and Other Utopias" in Humber, J.M. and Almeder, R.F., (eds.) *Human Cloning*, Humana Press, Totowa, New Jersey, 1998, p.120.
 138. Harris, J., *Clones, Genes and Im-*

- mortality: The Ethics and the Genetic Revolution*, Oxford University Press, Oxford, 1998 (first published in 1992 as *Wonderwoman and Superman*), p.168. The shortage of transplant organs has led British bioethicist John Harris to argue that all organs from dead bodies should be mandatorily available at death. He questions whether anyone is entitled "to conscientiously object to practices that will save innocent lives", and maintains that "we must get away from the idea that people can allow their bodies and those of their relatives to be simply buried or burned when they die. This is a terrible and cruel waste of organs and tissue". Harris' arguments epitomise the abstract idea that any medical approach can be pursued morally, irrespective of its wide-ranging effects on others and on societies, as long as some individuals "benefit" from the approach. See Harris, J., "We should recycle the dead to help the living", *The Independent*, 19 February 1999. In July 1999, the British Medical Association decided to lobby for a system of "presumed consent" to organ donation unless someone had notified a central database to the contrary. See Boseley, S., "Doctors want organs donated unless patients opt out", *The Guardian*, 9 July 1999, p.9.
139. Growing replacement organs from human embryonic stem cells looks benign compared to an earlier proposition — cloning a whole human being engineered not to have a brain or central nervous system so that s/he could serve as a mindless organ bank of spare parts. Michael Tooley of the University of Colorado, however, believes that to object to transplants from "mindless organ banks" because they seem "ghoulish" is "morally irresponsible in the extreme". See Tooley, M., "The Moral Status of the Cloning of Humans" in Humber, J.M. and Almeder, R.F., (eds.) op. cit. 137, pp.65-102.
140. The British government, among others, is concerned that opposition to genetically engineered crops and food will extend to the biotechnology industry as a whole, which in Britain is dominated by pharmaceutical and diagnostics companies. The public affairs director of the BioIndustry Association, Aisling Burnand, has commented that all the Associations's members "are afraid of a knock-on effect on other areas." The chief executive of biopharmaceutical company Chiroscience stated that "There is a crisis of confidence in the regulatory process [concerning genetically engineered crops and food] which we do not want to spread into the medical field." See Cookson, C. and Pilling, D., "Drug companies find food fears hard to swallow", *Financial Times*, 18 February 1999, p.8.
141. Richmond, M.H., op. cit. 71., p.78.
142. Quoted in Radford, T., "Cloning to be used to fight disease", *The Guardian*, 9 December 1998, p.11.
143. The Wellcome Trust, op. cit. 6, p.19.
144. The Royal Society, "Whither Cloning?", The Royal Society, London, January 1998, p.8.
145. Reuters, "Expert Advises Biotech Firms To Reach Out", Adelaide, 1 December 1998.
146. McElvoy, A., "Worcester woman and Woking man favour cloning. So that's OK then", *The Independent*, 3 February 1999.
- Comments John Durrant of the British Science Museum, "you can kill off a technology quite easily if you steamroller on". One way to avoid this, suggests Nigel Poole of Zeneca, is to foster more informed discussion: "That was done in the UK with in vitro fertilisation (IVF) in the early 1980s". See Blackledge, C., "European attitudes: Benefits that go against the grain", *Financial Times Survey Life Sciences*, *Financial Times*, 15 March 1999, p.IV. Scientists themselves can be susceptible to a "benefits" approach. In 1996, for instance, commenting on two sheep cloned from embryonic cells (not adult cells as Dolly was), Dolly's co-producer Ian Wilmut was reported as saying "This has no application for human beings" (McKie, R., "A clone again, naturally", op. cit. 133). In 1997, Wilmut was reportedly of the opinion that "most of the suggested applications for cloning of humans are non-sensical" and that all of his Roslin/PPL team members would find any such research "distressing and offensive" (Roger Highfield, writing in *The Daily Telegraph*, 7 March 1997, p.1, quoted in Franklin, S., "Dolly: A New Form of Transgenic Breedwealth", *Environmental Values*, Vol. 6, 1997, pp.427-37). Yet in 1998, Wilmut defended the idea of using human embryo cloning to improve the outlook for human diseases ("The First Human Clone", Panorama, broadcast on BBC1 television, 8 February 1999, 10-10.45pm), and in 1999 was announced as the team leader of the joint Roslin/Geron venture to clone human embryos for replacement organs.
147. Brown, P., Insulin Forum Switzerland, op. cit. 105.
148. Speaking on "No Issue", BBC Radio 4, 5 January 1999, 9.00-9.30pm.
149. Figures from UK Transplant Support Service, cited in Dobson, R., "Body swap", *The Guardian*, 14 July 1998, p.16. Similarly, it has taken 30 years for the stories of farmers who have been dispossessed by Green Revolution agriculture to be heard, their plight obscured by the higher yields such agriculture did achieve often at the expense of soil and food quality.
150. Hubbard, R. and Wald, E., op. cit. 18, p.112.
151. For instance, Geron Corporation, the private research funder of research into the laboratory isolation and culture of human stem cells carried out at the University of Wisconsin and Johns Hopkins University, and patent holder of the processes and resulting cells, set up an Ethics Advisory Board (EAB) — yet "most if not all of the scientific work had been completed before the EAB issued its ethical guidelines, even in their preliminary form". See Tauer, C.A., "Private Ethics Boards and Public Debate", *The Hastings Center Report*, Vol. 29, No. 2, March-April 1999, pp.43-45.
152. Barben, D., op. cit. 59, p.414.
153. Cahill, L.S., op. cit. 85, p.47.
154. Knowles, L.P., op. cit. 50, p.38. Knowles argues further that it is simply inconsistent to argue that couples should act altruistically and donate spare embryos or aborted fetuses because commercialising embryos is wrong, while permitting corporations and scientists to profit financially from cells derived by destroying those embryos.
155. Barash, C.I., "Sickle Cell Trait, Policy and Research Paradigms", *Science As Culture*, Vol. 7, No. 3, Sept. 1998, p.380.
156. Richmond, M.H., op. cit. 71, p.40.
157. Cahill, L.S., op. cit. 85, p.47.
158. Tiefel, H.O., "Human Cloning in Ethical Perspectives" in Humber, J.M. and Almeder, R.F., (eds.) op. cit. 137, p.196.

SUMMARY

If Cloning is the Answer, What was the Question? Power and Decision in the Geneticisation of Health

Since the birth of Dolly the cloned sheep in February 1997, assiduous attempts have been made to emphasise the potential benefits of human cloning techniques which do not result in a cloned baby: replacement body organs; cancer and ageing research; testing new pharmaceuticals, to name a few. Such research would pave the way for the replication of humans and for human genetic engineering.

By promoting such benefits, many social, economic and environmental aspects of health and disease have been further obscured — what causes the ill-health and disease which these potential applications of cloning technology might treat? — as have key issues relating to how these potential benefits would be obtained and distributed — in a free market economy of privatised health care services, would everyone benefit, or just some individuals?

It has also become harder to raise key questions about the increased geneticisation of our lives and societies.

This briefing explores some of these aspects and questions as a contribution towards laying the groundwork for a thorough and responsible discussion of the issues raised by human cloning and genetic engineering.

It was prepared by Sarah Sexton, who would like to thank all who contributed and supported it.

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