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Hansard Society
Online Consultation on

Human Reproductive Technologies and the Law

Commissioned by the
Science and Technology Select Committee

Summary Report
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www.hansardsociety.org.uk

Online Consultation on Human Reproductive Technologies and the Law

The Hansard Society e-Democracy Programme is piloting innovative consultation methods aimed at increasing public involvement and engagement with parliamentary decision making through the use of new media. We are interested in ways of informing representation and facilitating the broadest democratic communication.

This online forum commissioned by the Science and Technology Select Committee on Human Reproductive Technologies and the Law ran from 22 January 2004 for eight weeks at www.tellparliament.net. The aim of the forum was to get the views of a much wider group on the issues involved and to help the Committee shape the terms of reference for the official inquiry to be announced in April 2004. The site was designed with a view to encouraging people from all walks of life to take part in the online forum. This was emphasized on the site by the Committee's invitation - "*You do not need to be an expert to have a view on the creation of life*".

The Committee Secretariat holds the content copyright of the site. It provided a glossary and background information about the inquiry with a list of useful resources as well as the main headings with the scenarios in the online forum. Tellparliament.net was publicised through direct mailings, local media coverage, viral emails, web links and word of mouth.

333 people registered to take part in the online forum at tellparliament.net. 111 individual users logged on to the site and posted a total of 554 messages.

Out of those who registered 181 were members of various organisations, including academic institutions and 152 were private individuals. Out of those who actually posted messages on the site 54 were members of organisations, while 52 were members of the public. All the organisations that took part in the online forum are listed in Appendix 1.

There was an even split between male and female participants.

The deadline for the online forum participants to post their messages, should they wish to help the Committee shape the terms of reference for the official inquiry, was midnight on 15 March 2004. All the messages posted by then have been taken into consideration in this report. However, the Committee has requested an extension to the forum for two more weeks for additional comments and follow-up.

This report aims to summarise the responses to the online consultation, it does not aim to interpret or evaluate the views given or to suggest recommendations. All of the contributions to the online forum are available as a reference document and the web based discussion will be archived and accessible to view in full at www.tellparliament.net/scitech.

This report is not given as a representative view of the population but as a method of representing the experience and expertise of a balanced number of members of the public for whom legislation in this area is of direct relevance. The extracts in *italics* have been taken directly from the messages posted in the consultation.

The online discussion was structured around four main headings:

- **Screening and Therapy**
- **Surrogacy and Donation**
- **Consent and Confidentiality**
- **New Fertility Treatments**

To initiate the debate, the Committee Secretariat provided several scenarios under each of the headings. For the list of scenarios please see Appendix 2.

A section devoted to **Human Cloning** was added in the third week of the forum following the news story of research in human cloning in Korea. There was also a section for **General Comments** for participants to raise any additional points and to comment about the site itself.

The extracts included in this report reflect the depth and range of contributions to this consultation; they are, however, just a glimpse at the topics discussed. For a full account, readers are recommended to see the entire proceedings at www.tellparliament.net/scitech. The messages contain both technical and experiential detail that will greatly add to the understanding of the issues under consideration.

About the online forum

My point is that forums such as this allow all kinds of people to have their views heard and taken into account and it is a concern of mine that often people express views when they have no understanding of the issues involved. Perhaps I need to put my faith in the people who set these forums up to separate the informed from the uninformed? Perhaps, my choice of language may have been too vague. I am simply concerned that laws are usually made by people who have no comprehension of the complex issues involved and are driven by their own personal ignorance.

Contribution from Participant

Professionals in all walks of life have to apply discretion in daily practice - this doesn't represent inconsistency, rather the combination of individual circumstances and informed, impartial, professional opinion. It is our responsibility, and I hope the aim of this online exercise, to ensure that the 'professional opinion' empowered to make such judgements in the future is representative, informed and fair.

Contribution from Participant

General Comments

The General Comments forum, like the sub forum on Human Cloning, did not utilize scenarios to guide the discussion. As such, it followed the established model of internet forum posting which allows for online discussions to evolve organically along and according to the lines of interest of the participants. Though varied, the discussions remained focussed on the issues surrounding new and emerging Human Reproductive Technologies (HRTs). Summaries of the main points raised are laid out below and grouped thematically.

Value of Public Opinion and Public Input

'I welcome the Science & Technology Committee's democratic approach to the role of the public in this debate...' Josephine Q.

The participant was very much in favour of the Science and Technology Committee's decision to open up debate on human reproductive technology to the public, specifically highlighting pleasure at the fact that the debate was being widened beyond the scientific and academic communities. This posting arguably set the tone for the rest of the posts around this theme, with debate revolving around questions of 'What qualifies as 'expertise'?', 'What type of knowledge is necessary for issues where there are ethical questions?' and 'What are the rights/responsibilities of the public in debate around this issue?'

'The wider public must have a stake in deciding what impacts on them and perhaps, in arrogance, we too often underestimate the importance and value of public opinion. All credit to the science and technology committee for giving us ALL (scientists and the rest of us!) the opportunity to have our say in this consultation.' Phillipa Taylor

A recurring juxtaposition during the discussion was made between science and ethics, with many users placing the two at odds. Users noted concerns over the differences between scientific reasoning and ethical reasoning, and debated whether it was even possible for scientists to make reasoned decisions on ethical issues. There were two general sentiments. On one hand, the opinion was expressed that scientists role was to inform the debate but not to judge, as they were not trained ethicists. On the other, the argument was made that scientists cannot be left out of a judgement role, as they to have other societal roles, and in some instances, do have groundings in ethics. Users at this point returned to the call for greater public input on the ethical implications of making certain scientific decisions, allowing for input both by the scientific community and the public.

'I agree that scientists have their part to play and may well bring contribution on ethical issues as well as the science. But the rest of us also have a right, and responsibility as someone else says, to play our part.' Mikej

The user claimed to be a human geneticist and wanted to express some of his personal views on the matters being discussed. He laid out criteria for scientific evidence being accepted, delved into issues of the viability of research into adult and embryonic stem cell research, and in a moment of personal expression noted

'Finally I would like to say that the people who attack scientists in general as uncaring, selfish and insistent on pushing forward work with harmful potential, really should be required to substantiate their statements with verified examples. All the scientists I know care enormously about developing techniques which are useful safe and ethical, and do no harm to anyone. Obviously all invasive and some

non-invasive treatments carry some risk, but if that risk is known, it is explored and assessed and highlighted very thoroughly. Vervan

Public Knowledge and Understanding

The participant took issue with comments that the public has problems understanding the issues arguing that:

'If scientists and politicians are really concerned about not confusing the public, and communicating clearly, can I suggest that firstly they don't use euphemisms like CNR (for cloning) since after all people aren't born knowing what acronyms mean' Fiona

Users noted dissatisfaction with the incomplete or lack of media coverage of the oppositional viewpoints expressed on the use of HRTs. Users note that many of the statistics by those opposed to the use of HRTs, which they claim are important for the public to make a reasoned decision about the use of such technologies, are not mentioned in news coverage. Users also note that media coverage is often dismissive of the claims of those who are opposed to the use of HRTs. The inherent secrecy required by the institutions surrounding certain reproductive technologies was also identified as a concern, with users highlighting that as a result of such secrecy it was difficult for the public to understand the risks posed by the use of HRTs because many of the resultant children, participants, etc. were uninformed that they had been born using these methods, making it, some users argued, impossible to track the ill-effects of the use of such technologies.

'Of course, it's all too easy for someone to claim that the public have misunderstood one's viewpoint simply because we happen to disagree. Public figures who make this claim should bear in mind the possibility that once we have been properly informed, we may see through their arguments only too clearly ...' Dr Neville Cobbe

Human Fertilisation and Embryology Authority

The user initiating this post expressed concerns over the selection process of those who sit on the HFEA, and also concerns over its definition of the public. The user expressed special concern that the definition of the public used by the HFEA would exclude certain segments of the public from having an active say in the implications of reproductive technologies. There was both concurrence and dissent with the point of view expressed. Users expressed that it was insufficient for the HFEA to argue that the public was a difficult group to reach. Others argued that the composition of the HFEA was at issue, as there were no individuals reflecting a pro-life view involved in the decision making process. There was further discussion on the possibility of restricting the powers of the HFEA. One user noted that the HFEA's powers to restrict research or block access is, from his perspective, too far reaching.

'The current power of the HFEA to restrict people's access to reproductive treatments and services has never been properly justified or even articulated. The question should be asked as to what powers the HFE Act should give the HFEA beyond ensuring that clinics provide people with good quality treatment. The Select Committee inquiry should give careful and serious consideration as to whether the powers and responsibilities of the HFEA should be restricted - both with regard to its regulation of reproductive technology and its regulation of human embryo research.' Tony Gilliland

Debate around this point led into questions of the purposes behind regulation. One poster argued

'Tony Gilland's view is that there should be no regulation of assisted reproduction at all. If the select committee take this view, then politicians might as well shut up shop, as they will no longer be necessary. The view that regulation isn't necessary is analogous to saying when it comes to road safety that drivers can drive as fast as they like, on whichever side of the road they like, however they like, and that there should be no laws surrounding seat belts for children and babies' Fiona

The debate around this aspect of the work and role of the HFEA seemed to conclude with a consensus that it is Parliament's role (and inferentially by extension the role of governmental agencies) to regulate in areas such as human reproductive technologies.

Law and Reproductive Medicine

There were two propositions about the purpose of medicine made along this theme: that medicine is to be used to relieve human suffering and that medicine must uphold and promote human dignity. Users noted that therapeutic cloning of the use of saviour siblings undermines, from their view, the human dignity of the clone and the saviour.

'The point about these kinds of arguments is that they work if you adopt a certain kind of mindset; that is one than perceives there to be a need to be alert of potential dangers, and to draw people's attentions to ones that they have not even thought of so far. They make sense if you believe that regulation should primarily be based on a sentiment of risk-aversion, and that people should be encouraged to understand the role of regulation that way.' Ellie Lee

This sentiment was echoed along with calls to investigate whether HFEA had the technical skill to regulate in areas such as cloning and the newer reproductive technologies, as well as calls for ways in which to make it more accountable to Parliament.

'There must be a place for the precautionary principle in our discussion of these issues. We know that there are problems with cloning (e.g. tumour formation and premature ageing) such that it would be madness to ignore these and allow individuals and scientists to do what they want out of misguided respect for privacy... I agree that evidence based medicine must be promoted. It is therefore disappointing that the immense strides being made with adult stem cells are so often overlooked in favour of research projects involving embryos and cloning which, though eye-catching, turn out to have innumerable problems.' Martin Foley

Dr Ian Gibson's Comments

The user was concerned about the language used by Dr Ian Gibson, MP for Norwich and Chair of the Science and Technology Committee, in a radio interview. The user was concerned by what she perceived as Dr Gibson's desire not to debate the technologies but rather to foster their acceptance by the public

'Whilst I agree with the first and third sentences, I was somewhat startled by the second. On the surface, it would appear that Dr Gibson is saying that he wants a social climate to be developed whereby these new (crazy science fiction) technologies would be accepted by the public. In which case, it would appear that this debate is something of a waste of time, as the decision has already fundamentally been made.' Dr Elizabeth Allan

Dr Gibson clarified his comment in a posting to the site, stating that the use of the word accept may have been misleading, and that he simply meant that the legislation drafted to deal with the fears of the public in regards to the new technologies needed to be robust enough to allay those fears. With thanks for clarification directed to Dr Gibson, a follow on posting was made as to what exactly legislation, no matter how robust, can prepare for. The discussion on this theme ended with the comment 'may common sense prevail.'

Religion and the State

The poster was concerned that religious beliefs do not provide the basis for the discussion in the debate and that religious beliefs be not accepted as 'facts' as there is no way in which they can be proven to be such. There was discussion in response criticizing what one user described as the fashionable wave of dismissing religious beliefs and making decisions as a country that should be judged on the individual basis. The discussion concluded with an acknowledgement of the validity of the initial claim, but with an appeal that beliefs be brought into the discussion when discussing the best application and aims for the newly emerging technologies.

'But if we engage in a quest to legislate based on facts alone, we run into the problem that non-religious moral reasoning is based on the idea that reason can give us the right answer - itself a belief rather than a fact. The only facts available are about what is scientifically possible, not the values represented by allowing or withholding such possibilities.' Dr Gareth Leyshon

The skewing of the forum

The poster opening this line of discussion expressed concern that the views being posted on the site were not truly reflective of the multiplicity of views in society, and called on future readers to take note of the skewing of the forum.

'It appears this consultation has been 'hijacked' by christian groups, and I want to know where are the fertility nurse's, people who have been helped by IVF or other fertility treatments and jos public in general?' Jules

This initial comment led into a debate about the types of views being represented on the site and the validity and purchase of those views. There was objection by one poster that the debate had been 'hijacked' by Christian groups. Others however concurred, noting that it seemed that there had been some organization in the postings by certain constituencies to the forum. One user however had this to point out

'I do object though that my view is considered to be a minority view and extreme because I am a Christian. Political correctness seems to allow the non-Christian view to be put forward forcefully, even arrogantly, in a way that I would not dream of attacking other groups, and nor should I. We need a wide ranging and open debate on this issue, let us not get stuck on a debate about why we think the way we do but have an honest open and compassionate debate.' Keith

One user however seemingly effectively stopped debate around this theme with the following comment

'Similarly, it is disingenuous to suggest that conclusions reached by this forum might not be representative of the general public because the only views expressed here are of people who can be bothered to write something. Saying that 'the problem with a public consultation is that it tends to bring out the people

with very strong views' is like saying that democracy is flawed because the people who vote tend to be those with a strong interest in the result!

And ended with a message to the Committee:

Of course, your conclusions aren't going to be based on public opinion alone: democracy must take precedence over mob rule. But the very best submissions here rival much of what I read daily in scientific journals, and easily surpass much of what I have heard discussed in Parliament. You've succeeded overwhelmingly in your aim of eliciting high-quality discussion from the public on these critical issues. None of us will ever know the true extent to which our words will influence the Committee's final recommendations: please return our trust by ensuring our work is used honestly.' Edmund

Screening and Therapy

Scenarios:

- Going abroad to escape UK law
- A saviour sibling
- Sex selection to acquire an heir
- Gene therapy on embryos and sperm
- Choosing a child with dwarfism
- Sperm sorting - to avoid disease?

These scenarios focussed the discussion on the issues of sex selection, a phenomenon of 'medical tourism' that might be associated with new fertility treatments and a need for international legislation.

Sex selection

'Children today have fewer guarantees about the gender of their parents, under new adoption and IVF treatment practices. Why then, should parents be entitled to select the gender of their children? ... I do not think it is appropriate for the HFEA to endorse sexism by granting any licence for the express purpose of selecting against a particular sex.' Dr Neville Cobbe

'Even if sex selection was carried out on a case-by-case basis, there's little doubt that its acceptability would increase. Moreover there are important consequences for the child. For instance, what happens if a boy is produced instead of a girl? Considering the high-failure rate this is possible.' Slifenet

'I can appreciate a person's desire to have a child of one particular sex. I think it is especially difficult for those who are only ever going to have one child. I also feel sad for the children who are born into families whose parents continue to have children until one of the desired sex is born. If the HFEA was to legislate such an option to become available - I think careful monitoring should be made to ensure that the numbers of males and females born should mirror that in nature.' Jules

'My area of expertise is the human secondary sex ratio, or sex ratio at birth. My research suggests that the sex of the infant (and indeed the sex of the offspring in other mammals) is not a matter of chance but rather is the result of a finely balanced adaptation, based on whichever sex of infant the mother is at that time and in that place, most suited to raise. Unlikely as this may seem at the present time, my research suggests that it will not be too long before this hypothesis will be demonstrated at the proximate level; it is already being discussed in evolutionary theory. Clearly, if the sex of the infant is not, after all, a matter of chance, we should, I think, hold back on sex selection of infants until we understand more about normal processes.' Valerie J. Grant

'Sexual discrimination is now illegal in practically all areas of life, thank goodness. So how can we forget about the principle of equal rights in a case such as this, involving the most fundamental right of all - the right to life?' Spacedust

Sex selection for medical reasons or 'overriding medical indication'

*'assumption 1: people should be allowed to select reproductive technology for important reasons only - either personal or for the good of the (future) child
assumption 2: we should only interpose technology in the procreative process if the gains are great enough, otherwise the state has the right to intervene'*

assumption 3: all other things being equal, selecting sperm is a bit better than selecting fertilised embryos which is a lot better than aborting fetuses.'
Jeremytafler

'I think it's important to recognise that you can't reasonably deny access to 'something' because there is a chance that the couple may subsequently request an abortion (which may be acceptable within the current guidelines in any event). Who can presume the future with sufficient certainty to deny them assistance in their quest for a healthy child? ... Essentially you could end up denying this couple assistance with sex selection based on a personal presumption about the future which you find unconscionable. This is unfair and it definitely isn't empathic.' Dr Dan West

'The use of sex selection for 'medical purposes' will be almost impossible to regulate and it will be increasingly difficult in the long term to ensure that it is only used for 'serious' medical reasons. Whenever this term 'serious' medical condition is used, there are usually no specifics mentioned as it involves arbitrary decisions and definitions which are movable and will inevitably widen over time from the genuinely 'serious' medical reasons.' Philippa Taylor

'We must not discriminate against existing disabled people, but this is not to say that, if disability can be avoided in future children, we should not do so. We could only admire people with disabilities who, against all odds, manage to live as fully if not fuller than a non-disabled person. This, however, does not mean that a disability is something good to have. Fiona herself agrees that to inflict disability deliberately is an indisputable harm. Logically, it follows that if we have a possibility to avoid disability, not to do so would amount to inflicting it deliberately.' Nadia Whittaker

'I have a serious genetic condition which means I am a full time wheelchair user. I suggest that my right to exist is no less than that of people who have no such condition. PGD eliminates those like me, solely because they are like me. This is eugenics, and unacceptable in a civilised society. Eliminating disability is laudable. Eliminating disabled people is the ultimate in offensive eugenics.'
Adavis

Reproductive Tourism

'The more difficult case we need to deal with, however, is that of couples going to Spain or the US to start PGD from scratch. We need to find a general way to stop or at least inhibit 'reproductive tourism'. David King

'The HFEA should, where possible, not allow the bypassing of the law in this country through this kind of medical tourism. This scenario, and sex selection in general, encourage a completely consumerist attitude towards children. The message here is 'order what you want' rather than 'accept what you are given', i.e. the children are being treated just like possessions than people. Parental love should (ideally) be unconditional, not influenced by physical capacity (gender). Children should not be treated as products to just order and design. There are other considerations too - not just affecting the child born but any siblings, the wider family and potentially their peer group too. What emotional and psychological pressures will be felt by the child born after sex selection who is the 'right' sex? What if the selection is not 'successful?' What welcome will be given to the child who is the 'wrong' sex? How will siblings feel if they feel they are the 'wrong' sex?' Philippa Taylor

'It is a back door to eugenics. ...The HFEA has already banned sex selection, for good reasons, and should not permit people to deliberately bypass our own regulations through this kind of 'tourism'. No amount of regulations can prevent abuses. This is especially since it is so difficult to define and anticipate for the future all the eventualities which the regulators want to prevent.' Careorg

Baby Farming

The scenario with a saviour sibling prompted a philosophical debate on 'the reason to have a child' and tendency of 'the objectifying of a child' and 'baby farming'

'People rarely ask themselves a question what it is precisely that led them to a decision to have a child. Because the question is rarely asked, it is assumed that, unless there is a sibling to save, the main reason is nearly always to bring into the world a new human being, who would be not 'a means to some end' but an end in herself. This does not correspond to reality. Children are often conceived for a variety of ulterior purposes: be it to keep a relationship, to fulfil one's desire to become a parent, to create a 'proper' family, to take revenge on one's parents or to have a heirs. No one seems to mind that so many children are conceived as 'means to an end'. This is because the experience of bringing a new person into the world is so powerfully overwhelming that the initial motive gets completely absorbed by the birth of a new person. Surely, as long as this new person's life is not devastated by an extremely painful and incurable disease or an extremely hostile environment, she or he will be glad to have been born. If we think that in principle PGD is justifiable in some cases, choosing an embryo whose cord blood will save a life of another child is surely one of these cases. However, there is the issue of a theoretical long-term risk from having been involved in PGD. Can we justify subjecting the future child to this remote risk solely for the sake of the brother? ... Taking the risk can be outweighed by possible benefits from having saved one's sibling. These benefits may be of psychological, social and emotional nature.' Nadia Whittaker

'The selection of children as tissue donors is an example of the objectifying trend in techno-reproduction, albeit not a typical one. Here, the child is not selected for characteristics that will 'improve' it, but to benefit another child. This is in one sense more acceptable, since the aim of the procedure is undoubtedly good, and is not motivated by consumerist desires for 'enhancement'. But in another sense it is a more extreme example of objectification, because the primary reason for the child's being is not even to be a child as such, but as a source of spare parts for another. Furthermore, there are thousands of people who could benefit medically from matched tissue donation. Once this precedent is set, how will we prevent this eventually becoming a routine procedure, with thousands of babies being born as tissue donors for family members? As we contemplate such a scenario, expressions like 'baby farming' come to mind.' David King

However, a participant offered a pragmatic view on the creation of saviour sibling with a practical solution for the future cases

'I don't believe that there are insurmountable psychological sequelae which preclude the procedure and the undoubtedly regrettable waste of embryos is probably outweighed by the entirely defensible benefit being sought. Clearly we need a richer cell bank (sharpish) so that we can avoid this problem in the future.'
Dr Dan West

This post gave an opportunity for the supporters of use of unrelated cord blood to voice their opinion

'It is simply not necessary to go down the route of saviour siblings, a very unsuccessful and impractical response to a medical problem even without the ethical complications. Unrelated cord blood can cure the various medical conditions which have been highlighted in recent high profile cases (including thalassaemia). The more cord blood we harvest the more varied will be our pool of tissue matches and the more cures we will be able to provide. The USA has just passed a bill allocating \$10 million for research and cord blood banking. The UK should follow suit.' Josephine Q.

'It would be more useful and productive to start thinking through how we might build up an umbilical cord blood bank in the UK so that there is more opportunity to do ethical tissue matching here. Why is it that this kind of proposal never seems to get the same coverage, funding and support from Government and the HFEA as the more controversial and less successful 'saviour sibling' scenario?' Philippa Taylor

Rights of patients to conceive their own children

In reaction to one of the several 'Calls for adoption' by some of the participants in the forum as a 'a simple solution for all infertile couples and those with hereditary disorders.', an interesting post was made pointing out the need of parents to conceive their own children

'On a side issue though, the adoption suggestion is rather flippantly phrased and quite out of kilter with current opinion I feel. The needs of patients to conceive their own children have been increasingly recognised over recent years. This has culminated in NICE guidelines this month which unambiguously establish that fertility treatment should be offered to all in whom it has a chance of success, within certain sensible constraints (age, medical history...). This widely informed judgement is highly significant and 'adoption is a simple and cheap alternative' cannot be used to fob people off any longer.' Dr Dan West

Surrogacy and Donation

Scenarios:

- Animal-human hybrids for research
- A surrogate for a lesbian couple
- When is consent not consent?
- Making sperm and eggs from stem cells
- Paying a donor to cure AIDS

The majority of postings to all five threads were opposed to the proposed scenarios. This is particularly true of the first and the fourth. Concerns were over both safety and ethical issues, though these are not entirely separable. Supporters of the scenarios saw most restrictions on the use of technical possibilities as infringements on rights.

Animal-human hybrids for research

Only the initial post was favourable to this '*valid research tool*', though only for pure research. '*There are enormous scientific hurdles (followed by public debate etc) to overcome before addressing such specific health issues as that exemplified.*' Richard Fleming

Another post, however, highlights the above '*use of the word 'valid' ... conflating what is possible with what is desirable. It seems likely that he is using valid purely in the sense of being 'technically efficacious', that other meaning of valid as 'good in law' is unintelligible as presently such work is illegal. This is a dangerous conflation when considering bioethics in the age of genetics.*' Hilary Rose

The radicalism of the project is emphasized by others: '*There is a fundamental difference between animals created with some human genes, and the reprogramming of the human genome by animal reprogramming factors which have evolved to create rabbits, cows etc. The implications of this difference are both biological and ethical.*' Dr Elizabeth Allan

Biological difficulties include, among many, '*potential incompatibility between human chromosomes and a non-human cytoplasm, with unforeseen developmental consequences.*' [Dr Neville Cobbe], while ethical concerns range from the rare simplicity and undisguised extremity of: '*I believe the only justifiable reason for creating any embryo is to bring it to full term, and cherish it.*' [johnmryder] to greater elaboration: '*I am concerned that we seem to be increasingly living in a culture that views life as dispensable, unless of course it's your own life. If therapeutic cloning is taken as creating a life merely to create spare parts for another life, then it has more in common with sustaining oneself by cannibalistic murder than it does with any notion of therapy in the Hippocratic sense.*' Dr Neville Cobbe

Finally, it was maintained that other routes are available: '*there are currently greater possibilities for treating the degenerative eye disease using adult stem cell therapy, which does not involve creating hybrid embryos and has had more successes than embryonic stem cell research in treatment of diseases.*' Philippa Taylor

'Better alternative solutions exist already and there is no necessity to have this. There are alternatives offered by way of exploring the use of adult stem cell

therapy, and the use of umbilical cord blood stem cells (reference - Paediatric Bone Marrow and Stem Cell Transplant project at Duke University in USA), these should be pursued. We should use what is already there and available instead of creating an entity with unknown implications and consequences flowing from there.' careorg

Concluding the debate and summarising the ethical positions generally, this last post ends: *'It is unethical and irresponsible to make this legal. It is creating hybrids with unknown consequence and implications not only now, but for affected later generations. These generations would inherit the hybrid's legacy of animal-human manipulated genes.'*

A surrogate for a lesbian couple

Although there were more favourable posts here, opinions were stronger and more sharply divided. In heated debate, the scenario led to wider issues.

Again, there was initial support for the scenario: *'the prejudice of some should not inhibit the expression of reproductive freedom unless clear evidence can be produced to demonstrate harm.'* Richard Fleming

(These prejudices are exemplified for instance in the declaration that: *'Homosexual and lesbian relationships are themselves evil. It is absolutely wrong to allow them to look after children.'* Ian Elliott Benson)

The dangers of illegality are emphasized: *'Great care should then be taken to construct legislation, as driving issues underground and people into dishonest positions (as with the forthcoming DI changes) can only be damaging in the long run.'* Richard Fleming

The difficulties of legality beyond the UK are taken up: *'We should seek to prevent treatments which are illegal under UK law from being carried out overseas; to grant a licence to carry out a procedure which is illegal in the UK is illogical.'* Chris Johnson - *'And immoral'*, johnmryder

One contributor pinpoints a polarising tendency: *'The scenario is inadequate in that it does not say why the couple want a surrogate. It seems unlikely both women are incapable of carrying a child, so the question then becomes what are the implicit values of the scenario? I would suggest that it is posed as a consumer issue and thus has elicited very predictably either libertarian marketeering responses (yes, demand even for a child should be met by supply if technically possible) or ethical outrage (a child is not a commodity).'* Hilary Rose

The post goes on to choose between them: *'Although the way the scenario is set up pushes the responses towards the market and choice, I'm with those who say a child is not a commodity. Stay with the present law and accept that some medical tourism will continue.'*

This 'commodification', and the thinking behind current UK law is expanded in another post:

'The law should remain as it is and a licence should not be given to bypass the law. Payment for surrogacy is actually not permitted in this country (only certain 'expenses' are allowed). This is because paying for surrogacy arrangements potentially reduces children to objects of barter by putting a price on them. But people are not fundamentally things that can be purchased and sold for a price.'

'Another reason why payments to surrogates and surrogacy agencies are not allowed in the UK is because it is potentially exploitive, by the offering of financial inducements to often vulnerable women to undertake a risky and emotional procedure. Offering payment is clearly an inducement to take a risk, for no personal benefit, and some women will be more vulnerable to these risks because of their social, economic or personal situation. It is of concern already that currently many surrogates receive 'expenses' in excess of the recommended £10,000 limit, with some surrogates reportedly 'earning' up to £20,000.' [Philippa Taylor]

Commodification of children and their potential rights, as opposed to those of adults to parent them, are considered: *'Parental 'rights' should never take precedence over the long term physical and emotional well-being of another, deliberately engineered, human being. 'Wanting' a baby and procuring one as a commodity to assuage a vain reproductive obsession, does not show respect for that person and 'Love' is simply not enough.'* Christine

Or as another post had it: *'Children have a greater right to unambiguous lineage and certainty in their identity that adults have to have children.'* luisamares

Rights are closely considered from this quarter, distinguishing a legitimate right to parent from an unacceptable right to conceive:

'What do we mean by a right to parenthood? I would distinguish rights over conceiving a child, from rights over the care and education of a child once conceived (these are both dimensions of parenthood). ... Speaking of 'rights' over conceiving a child is more problematic, and could be developed in all sorts of directions - who has the right to have sexual intercourse with whom else; who has the right to have NHS funds spent on assisting their fertility; who has the right to try out innovative medical techniques without state regulation. But 'conceiving a child' is not in itself a human action to which a right might be claimed; it is a biological achievement which might be the result of human actions undertaken with or without technological help. Understood in this narrow sense, I state that no-one has the right to conceive a child - the concept of right does not apply.' DrGarethLeyshon

Questions over the ability, beyond rights, of same sex couples to provide adequate or more than adequate upbringing, and the effects, for good or ill, upon children are discussed, and references given to papers supporting this ability. This is, however, clearly doubted in many posts.

When is consent not consent?

There were questions over payment and definition of pressure in obtaining consent: *'Given the vulnerable situation she is in ... it is difficult to conclude that she has consented without pressure. In such situations and others, when it comes to decisions to be made by such women, particularly where risks are attendant, I am concerned that the women are fully informed and are under no pressure in making independent decisions. Lives and marriages are at risk.'* careorg

Whether paid or not, some felt *'very uneasy about the way women are exploited - including those who donate altruistically and those who are paid. If they are unpaid then they undergo painful and dangerous hormone doses and surgery that is not in their best interest, which exploits their good will. Equally payment acts as coercion and is equally exploitative. Having been a student in debt myself I can*

understand the inducement of seeing an advertisement to donate eggs, which seems tempting.' Fiona

Internal pressure is clearly a big factor: *'Often, people undergoing treatment in fertility clinics are incredibly desperate to have children and would (understandably) jump at any chance to do so, regardless of the drawbacks. It is especially unfair on the women involved, given the invasiveness of the procedure and the risk of developing ovarian hyperstimulation syndrome. As in this scenario, they may be pressurised too much to do so, without taking the stress of going through such treatment into account. It is unfair to exploit this desperation - sort of like telling someone that they can have their heart bypass operation only if they donate one of their kidneys.'* Spacedust

On the other hand, to withhold the possibility could have an elitist impact: *'If this option was not available we are restricting IVF only to those who are rich enough to afford it, or forcing those less well off to incur huge financial debts in order to pay for treatment. This goes against the whole principle of the NHS and I believe it would be morally wrong to make access to treatment a privilege of the wealthy only.'* Leslie Bean

The need for informed consent is critical in the posts, though among opponents of the scenario there is a suspicion that it is lacking: *'I remember that the programme [TV documentary on case studies' agonies, pain and unsatisfactory progress] showed the lack of information women are given and that both excruciating pain and the risk of ovarian hyperstimulation was treated as trivial by the fertility industry, when in fact its consequences are far from trivial for women.'* Fiona

Supporters are more sanguine about this: *'I doubt that there are any clinics that would pressure a woman into taking part in an IVF egg sharing scheme - HFEA regs demand that the women go through counselling to ensure they make a balanced and informed decision ... I think that women who choose to donate eggs in return for access to cheaper IVF treatment do so with the knowledge of exactly what they are agreeing to and probably with the hope that they may be able to help someone realise their dreams.'* Jules

Making sperm and eggs from stem cells

Largely opposed in the thread, this scenario gave rise to more genetic than moral concern.

In the first place, technical doubts over the possibilities are strongly expressed, including in the case of *'homosexual couples who wish to have a child that is the genetic offspring of both partners. I believe this may carry a high risk of serious complications arising from a lack of differential genomic imprinting. This could occur as all homologous chromosomes would come from parents of the same sex.'* Dr Neville Cobbe

Detail and citations are given, along with others for further problems. Concluding: *'If the desire of homosexual couples to have children related to them should override the welfare and health of any such children, this would surely be narcissistic selfishness in the extreme.'*, this post extrapolates a moral conclusion from a medical position. Another post outlines concern *'about abnormal DNA methylation and gene imprinting disorders.'* Dr Elizabeth Allan

Then, if successful development is actually possible, there were concerns over *'accidental marriages/ partnerships between siblings'* and, *'if the number of children produced did run into thousands, the loss of diversity could result in unforeseen consequences.'* Sleepy

Another post cites *'A sperm donor (suitably checked) in Italy some years ago donated to some 1,500 women. It was discovered later thanks to new diagnostic tools that he carried a rare form of hepatitis.'* Josephine Q.

'This technique, if it were possible, would appear to be a type of germline genetic engineering. Such engineering is not permitted in this country and most others for very good reason - it is risky, has unpredictable results and any errors or unforeseen results would be passed down future generations. As for the specific scenario proposed, it would presumably matter to the thousands of children born from one donor that none will know their parent, nor half their genetic heritage, nor who their thousands of half-siblings were, nor whom they could 'safely' marry/partner...' Again, a conclusion in favour of the child's rights: *'this proposal does not take into any account the welfare of children born as a result of such experimentation.'* Philippa Taylor

There was barely consideration of limited use, but: *'If, however, a limit is to be placed on the number of times stem cells could be used, it should be the same limit as applied to the use of donor gametes. I understand that at present a maximum of 10 children may be legally conceived from one donor, so at the very least the same constraints should apply to stem cell derived gonocytes. Similarly, the same level of background information should be available to any individuals created using such cells as would be available to any individual conceived using donated gametes.'* Dr Neville Cobbe

This left only the following qualified support: *'I think the use of stem cells to create egg or sperm cells could be useful to people with fertility problems and lesbian couples, but the health of the potential child must be a priority. I also do not believe that this technique should be used to produce thousands of children. It should be limited to the use of stem cells from the person who is going to parent the resulting child.'* Jules

Paying a donor to cure AIDS

Posts against the scenario ranged from rationalist caution to comprehensive doubt:

'I believe that the result of a risk-benefit analysis could indicate that it would not be in the woman's best interests.' srjones

'It would be unethical and impractical to try to pay more to encourage donation from people reluctant to do so.' Richard Fleming

'Financial enticement is a form of persuasion, which is a 'lighter touch' form of coercion.' srjones

'Payments for egg donation should not be permitted. Donating eggs involves an invasive and a risky procedure. There is the potential for the exploitation of women through the offering of financial inducements to undertake this risky and emotional procedure. Offering payment is clearly an inducement to take a risk, for no personal benefit and some women will be more vulnerable to these risks because of their social, economic or personal situation. If any sort of payments

were allowed, through either legislation or guidelines, the following difficult questions would need answering: How would a level of payment be set? Who would decide on the level? How would it be enforced? How often would it have to be reviewed? Furthermore, embryos do hold a special status and should not be specifically created to then be destroyed.' Philippa Taylor

Doubts over the possibility or necessity of the procedure are raised. For instance: *'the approach described in this scenario is a most inefficient way to create a cell line but I am not convinced that cloning by nuclear transfer would be terribly efficient either. Would not a transformed cell line derived from a population of resistant lymphocytes be more amenable to long term study?'* Dr Neville Cobbe

Support for the scenario is generally as cautious as opposition to it: *'Going through a donor cycle puts the woman under a lot of stress and considering that she has a higher susceptibility to illness because of her HIV there is not a high incentive to go through a cycle. Considering this could be a very important resource to HIV research, and that the production of human ES cells is allowed in the UK, the payment of donors should be a possibility, although other options such as using the somatic cells of the donor should first be explored.'* sjohnso

'Without the embryos it may be impossible to cure a disease and this may be a case where the payment is justified. Only a small number of people appear to show this resistance and if it is not possible to carry out this research in another way then it would be justified. HFEA regulations would prevent this situation from getting out of hand, and a free for all happening. I am sure that many researchers see themselves as special cases and so this would need careful handling.' billritchie

The most positive support came in a detailed response: *'An increase in the number of HIV-Resistant donors is important. Not only will it increase the number of HIV-resistant donated eggs, it will increase DNA variation in HIV-resistant genes. Too small a number, compared to the Paternal HIV-Resistant genes could create problems. This research is significant, not just to find a cure for AIDS. Research into HIV-resistant genes could help science understand how the body defends itself against virulent pathogens. ... Historically, scientific progress has been held back by a reluctance to make unpopular decisions. My nightmare Scenario is that, we have always 'shot ourselves in the foot' and are about to do so again by not agreeing to further AIDS-resistant genetic research. Since we take years to nurture and generations for our genes to 'adapt' to an increasingly hostile environment, I am more inclined towards it.'* G Thomas

Countered by: *'The notion that we need embryonic stem cells in order to avert an apocalypse has to be the most extravagant claim for this research that I have heard yet!' and the conclusion from Dr Neville Cobbe: 'I see no foundation for the notion that embryonic stem cells are essential in either the fight against AIDS or in helping us escape a pandemic of the Plague.'*, that main supporter of the proposed scenario provides these reflections on the debate:

'I am grateful for your reply to my posting. There is no apocalyptic scenario in my posting, nor any intention of creating one. ... What I find 'scary' is being an ordinary housewife voicing an opinion in the public domain without fear. I do not have the advantage of a medical training or the jargon to express it. Strangely, those with scientific training are equally reticent to post their opinions. So, I am grateful for your posting. The silence from the scientific community as well as the

public one was deafening. ... I hope online debates such as this one are not 'used' just to win an argument. The real battleground is not here. The References for my posting are being sent by letter post; in order to walk the dog, get some fresh air and maintain a healthier lifestyle. My thanks to the Science & Technology Committee, the e-democracy Project Manager and the whole team at Hansard for all their hard work.' G Thomas

Consent and confidentiality

Scenarios:

- Donor dads and anonymity
- Who owns the embryo
- Extracting sperm from a comatose man

The issue under discussion in the first scenario asked: 'Should the offspring resulting from donated sperm have the right to know their genetic father? And What about future donations where the donor knows that he may be contacted in the future by any offspring resulting from the use of his sperm?' Though a majority of posters supported removal of donor anonymity, some of the contributors also explored possible consequences of such a legislation and offered different accounts on the subject from a child and donor/parent point of view.

'Whilst I can see no logical difference between the wish of an adopted child to know the identity of its genetic parents and the wish of the child of IVF to know the identity of the donor, I imagine that changing the anonymity rules would greatly reduce the number of people prepared to donate sperm.

One donor could potentially father many children and I imagine that the idea of one or more of these getting in touch many years down the line would be quite terrifying! Particularly as the personal circumstances of the donor might have altered hugely. Certainly any changes should not be made retroactively, as this would be grossly unfair on donors who signed up under the original terms.' Sleepy

'Would the retroactive removal of donor anonymity be unfair on donors? It certainly seems unfair to expect donor conceived people like myself to accept that they are the only group of people who must remain deliberately deprived of their full identity, ethnicity, medical history and kinship networks.

Now that society is moving to a point where it is accepted that the withholding of full identity information from donor conceived people is a violation of Human Rights, there is an implication that former donors would be failing in their duty as citizens to continue to withhold information about themselves from the people they deliberately helped to create.' Christine

'The result of the recent decision will follow that of other places, whereby couples seeking this form of treatment go to places where anonymity is the rule (those who can afford it). Thus the children will not even know whether they are products of this treatment or not. The law should have been changed so that non-anonymous donations are encouraged - but not prohibiting the current practice altogether.' Richard Fleming

'The fact that a minority of people are conceived through natural lust outside of a legal relationship and are duped about their true full identity, does not excuse the deliberate creation of donor offspring. ...Wrongfully attributed paternity is no comparison to a situation whereby the medical profession, the donor, the state, the biological parent and the social parent all conspire to deliberately create and deceive the artificially conceived person (along with other members of it's family and the rest of society) about the true nature of it's origins.' Christine

'Potential sperm and egg donors must appreciate that they are getting involved in something momentous, the creation of human life. The decision to donate must be approached with seriousness and with full knowledge of the implications - that you may be the genetic father/mother of a child.' Martin Foley

'Also, children and parents will increasingly request (and need) information on their genetic heritage in order take appropriate precautions for their future health (e.g. regular eye check-ups and/or dietary or lifestyle changes). At the moment children born of donor insemination cannot even contribute properly to family history questionnaires. What if donor conceived children develop a major health problem - should they continue to be deliberately denied information that could help them in their understanding of their health? Making this law retrospective would clearly give rise to major concerns for past donors, yet we cannot ignore the needs and rights of DI children themselves. Whose 'rights' and needs are of most importance here?' Philippa Taylor

Some of the posters were more keen to offer practical solutions to donors' anonymity

'The obvious solution is to make the clinics responsible for the completion of the birth certificates and to have them put "by donation" (or equivalent) in the box for the father.' Rupert Rushbrooke

'A solution INSTEAD of the proposed ban on anonymity: However, I feel that the HFEA could allow for two lists - one for donors who would be happy to meet their offspring and another for those who would not. Then the parents could make the choice which best suits them and their circumstances. ... I wonder why the system of optional anonymity for donor's continues to be common practice in the USA despite the country having a stronger culture of litigation than the UK. ...I suggest that the HFEA 'deregulate' the collection, storage and use of frozen sperm, to allow private companies to develop. The UK could move towards a system similar to that in the US whereby private cryobanks could collect, store and sell donated sperm. The HFEA could still restrict NHS clinics to using 'known' donor sperm - but would free up private clinics to use either, allowing the parents to make the choice. This system would also mean that frozen sperm could be purchased by individuals who wish to inseminate at home, rather than attending a fertility clinic when it might not be necessary.' Jules

As so often in this online forum, the flow of the discussion strayed into a debate on nature of parenthood. In this case it was an account from a lesbian parent-to-be who also happened to be a potential egg donor.

'My personal belief is that the parent is the person who brings the child up in love and can be counted on to be there when it counts. Not a stranger with some matching DNA. I make these points as a hopeful mother to be, in the process of accessing donor sperm, and as a woman considering donating my eggs for infertile women. Should the law change to deny anonymity to donors then I shall definitely not be donating my eggs. The point is to give another woman the chance of motherhood and I truly believe that any child who is born to someone who has gone through so much to be a parent will totally feel loved and safe and secure and therefore their need to connect with the stranger who donated will not be as important as the relationship they have with their real parent(s).' Leslie Bean

'As a potential DI mother, it is a concern of mine that my child will not have a lot of information about the man who donated his sperm to make them and it is a decision I have agonised over for a long time. I personally would have preferred a known donor for my child, however I had to make a choice between no father or a father who I could not count on to be there for his child when he was needed. I

feel a loving parent (2 loving parents in my case!) CAN BE enough for a child and I am in touch with individuals who know this to be true. It is a whole lot better than having a dad who doesn't care or only wants a child when it is convenient for him. That can be much more damaging for a child. ... I can offer my child all they need to be healthy and happy, including father figures. Biology isn't all that.'
Leslie Bean

Who owns an embryo

This was one of the rare occasions in this online forum that participant found themselves in common agreement on the subject - the posters supported current HFEA requirements for consent from both parents to termination.

'Neither partner should be able to implant an embryo without the consent of the other. Therefore, either irrevocable consent should be given at the time of the IVF, or there should be shift towards storing gametes rather than embryos.' Sleepy

'I agree that once fertilisation has taken place and an embryo created, both partners should have to consent to its destruction - although better that this scenario should not arise in the first place. And in response to another comment about the anomaly that only the mother has to consent to a termination, perhaps this should also require consent of both partners (except perhaps in exceptional circumstances)?' MikeJ

'Furthermore if no consent is necessary the day will arrive when these stored embryos or gametes can be used for other purposes without the prior consent of the 'owner'.' Careorg

Posthumous use of sperm

The scenario sought comments on moral and legal aspects of extracting sperm from a comatose man. Though a participant drew an analogy with the Human Tissues Bill to emphasise the 'importance of consent when organs and tissues are taken from participants', the scenario triggered a predictable set of reactions:

'The law also states that the welfare of the child, including its need for a father, is to be considered. Should children be conceived after the death of a parent? Is this what we mean by fatherhood?' Josephine Q.

'... if it can be claimed that proof of consent is not required to take sperm samples from a comatose man, would this not also permit the removal of eggs from a comatose woman without her consent? I think it is worth questioning what other motives might lie behind any moves to relax the consent requirements...' Dr Neville Cobbe

'If no specific written consent is required, how can consent be proven to have been given? then who will decide about treatment? Where will a line be drawn as to who can receive treatment and who cannot? Will every woman whose husband goes into a coma have the right to collect his sperm, just in case? Enough sperm for one baby or several? What about when men request the eggs from the ovaries of dead wives or partners, to be implanted in the womb of a surrogate? There would be far more of an outcry if a man were trying to remove his dead wife's eggs without her consent.' Philippa Taylor

'I think that the sperm could be used by the partner of the diseased if he had given written permission. Without permission then I am afraid that the use of the

sperm for any purpose should be unlawful. In the case where both parties had frozen embryo's or frozen sperm intended for use then I think the permission would be implied - but then the HFEA regulations ensure that they sign something to say what would happen if a partner dies - I think they should sign to say whether or not they agree for them to be used at that stage - they should have the choice.' Jules

Human Cloning

Reproductive Cloning

The comments under this discussion thread were prompted by a message from the Committee Secretariat that posed a question: "If human reproductive cloning can be proved safe and with a high chance of success, what are the ethical reasons for preventing it?"

As throughout the online forum the participants were keen to explore different angles of the issues at stake rather than to directly oppose the proposed agenda:

'The only way to check whether human reproductive cloning was safe would be to do the experiment. Given the current rates of success in animal cloning, this would result in the vast majority of cloned children being grossly abnormal physically, mentally deficient or dying early - probably suddenly and unexpectedly.... In a Nazi society that carried out Dr Mengele-style experiments on a section of the population, these experiments might be acceptable. They are not acceptable in a humane, democratic society.' Dr Elizabeth Allan

Posters also voiced concerns about what kind of life the cloned human being would have and whether that should be taken into the ethical considerations, with responses falling on both sides of the debate. One user noted that the ethical and moral decisions would be based on individual comfort levels with currently practiced techniques. He noted

'Assuming that one can accept the deliberate destruction of vulnerable new human lives in abortion and IVF, then this kind of research should not pose any further moral discomfort. However, I find it deeply disturbing that so many people in our society can sit easily with such a holocaust. I also find the dogged assertion that embryonic stem cells must be used (instead of stem cells from placenta, umbilical cord or adult tissues) to be increasingly untenable.'

Dr Nevill Cobbe

The discussion on reproductive cloning however fed into commentary on embryonic stem cells, and commentary on new EU law in the form of a Commission directive on the topic. In particular, the discussion fed into a question on the use of embryonic stem cells in therapeutic cloning. One user, expressed opposition to cloning on the grounds that in cases where embryonic stem cells were utilized it still could not be proven viable and/or safe. There was a question raised however as to whether the same issues were being rehashed again. One user observed

'Some observers may be wondering where all the supporters of ES cell research and CNR are in this debate but in truth we are heartily sick of the same tired old arguments and I for one am wondering why we are raking over these issues again. It is barely two years since the House of Lords Select Committee on stem cell research and cloning published its report in favour of the New HFE (Research Purposes) Regulations 2001.' Maureen McHugh

The legislative framework, state-intervention and the public/private split also played roles in the discussion. The question raised was that if the HFEA could not account for children born using IVF, how could they account for it using human cloning. To this point, another user asked for a sense of proportion in discussions of reproductive cloning. He noted

'Let us assume that a human clone does indeed suffer some sort of psychological harm, but are there not other human actions that are perfectly legal and just as harmful? We allow pregnant mothers to smoke. Young children can be packed off to school and separated from their family. We do not prevent people from having large numbers of children without any visible means of supporting them. I'm sure I could think of an awful lot more. I am also struck by that the claims for psychological harm sound very similar to those being used by opponents of IVF 2 decades ago. I wonder whether this is just the yuk factor dressed up as ethical debate.' Robert Toppy

Human Cloning

The user voiced concerns about proceeding in the use of technologies when there was a lack of consensus on the fundamental nature of embryos

'Stem cell research is already very successful, why push forward a technology which will lead to death of embryo. Have we world wide decided on when life begins?' Sandra Williamson

There was an expression of concern over the safety of women who donate eggs for cloning research – human or therapeutic. There was also attention given to the 'special-status' of the embryo. One user noted

'Such research is producing results and helping patients. Research using adult stem cells or umbilical cord also avoids the ethical controversy surrounding the use of embryonic stem cells. Surely, if the so-called 'special status' of the human embryo means anything we are duty-bound to pursue all possible alternatives that do not involve the destruction of nascent human life. Those in the scientific community, the HFEA and Parliament who claim to regard the embryo as having 'special status' must do much more to convince the public that their words are not mere platitudes.' Martin Foley

A recurring theme in the discussion was 'life'. There were questions raised by users about when life begins, and based on this division as to what type of rights or consideration should be given to the foetus.

'In other words, ethical considerations override medical ones. With cloning we are talking about dealing with human life (and not just a "potential" human being as Julie Robbins and Gudeskind says). It cannot be emphasised enough that you cannot use human beings as a means to an end. In this debate, as with abortions, some people seem to think that because we cannot see the embryo in the womb or because it is so small in a laboratory, that it is OK to play with it or destroy - kill - it. Emphatically, it is not!!!' Mike Davidson

The issues of religion and God also became more of an issue as questions of life became more important to the discussion of therapeutic cloning. One user wrote

'If human reproductive cloning can be proved safe and with a high chance of success, what are the ethical reasons for preventing it? God, in His wisdom, has ordained that human life be created in the context of the marriage relationship. It is not a commodity but a treasure of inestimable value which God gives to us.' Ian Elliot Benson

In reply, another user wrote

'If God has an opinion on the topic, perhaps he should log on and tell us. It would be a lot better than having us try to interpret ancient writings from before people knew anything of cellular biology.' Brian Jordan

Issues of human dignity inherent to cloning also arose. One user argued that the process of cloning was an affront to human dignity and human individuality. One user, speaking of his personal experience as a 'genetic clone', made a comment

'I cannot agree that being a clone is "insulting to the inherent dignity of each individual". I speak on this matter with some experience, being a monozygotic twin - that is, a genetic clone. My twin and I are exactly genetically identical. Yet although we are very similar in physical appearance, and although we agree on many issues, we are totally distinct individuals, with different views and feelings on many issues. Thus, I do not think that we should take the step of assuming that being a clone, per se, would insult someone's dignity. I think the key issue is why that clone was created - in their own interests, or in someone else's.' Patrick Mahon

Therapeutic Cloning (TC)

The user noted that therapeutic cloning offered the best chance to cure many common chronic diseases. On the issue of the ethics of utilizing blastocysts in research into therapeutic cloning, the user made an interesting contribution couching questions of life in the idea of self-awareness

'I do not believe that TC is unethical as it has the potential relieve millions of their suffering and yet does no harm, since the blastocyst is unaware of its own existence and it has no emotional links to anyone. I suppose that some religions see a blastocyst as a human being and therefore regard failing to place it in the womb as murder. However they would accept the killing a sperm and an egg separately, a nanosecond before fertilisation would have taken place. They also accept the killing of animals and, no matter how hard we try, we cannot avoid killing insects as we move around; and animals and insects have feelings and relationships. Furthermore, if there is a God who created the universe, then he must have been aware that, in so doing, he had set in motion an evolutionary universe, where survival of the fittest would apply.' Stephen J Dobson

There was immediate debate on this post. Users reacted vehemently (in opposition) to the views expressed above. Users noted

'Therapeutic cloning raises massive ethical issues that are completely separate from abortion, namely the creation of cloned entities, human experimentation, exploitation of women, and the violations involved in cloning a baby in a highly experimental procedure and the psychological repercussions associated with being a sibling-clone-delayed-twin-parent-no-mother-or-father identity issues, merely on the basis of scientific hubris.' Fiona

'If we are committed to maintaining respect for the human embryo and if we wish to proceed by consensus, surely we should be investing greater resources into adult stem cell research which, as Stephen points out, avoids all the ethical problems associated with the use of embryos.' Martin Foley

A personal posting by a user who could benefit from treatments developed by the potential use of therapeutic techniques during the discussion was as follows

'It worries me too that unethical creation and destruction of embryos is being justified on the basis that it might find a cure for my "dreadful disease." I wouldn't want it on my conscience to think I'd been "helped" at the expense of destroying a human life.' Alison Davis

For those who supported the use of TC for the curing of human diseases, users argued that since adult stem cell research was more advanced, in their view, it was a waste of public funding to put money into therapeutic cloning. A point about the moral opposition to TC was raised by one user who asked

'Perhaps the potential future cures that are developed through embryonic stem cell research can come with a government warning - so that those who are morally opposed to them can decide not to benefit from them?' Jules

Questions were also raised about the 'slippery slope' - if TC is allowed, what will that be used as a precedent for in future? One user notes

'On a basic point of ethics, therapeutic cloning is clearly downhill from abortion. Its essential element is the scientific utilization of human beings purely as a means to an end. Thus it systematically violates a central ethical principle which abortion, whatever one's views about it for other reasons, does not touch on so calculatedly. I hope this explanation does enough to reveal the true direction and exposure of the slippery slope. As before, I have yet to see from the proponents of TC one single ethical argument in favour of therapeutic cloning that could conceivably outweigh the principle that human beings must be treated as ends in themselves, and never as means to an end.' Andrew

One user highlighted, that despite the ethical and scientific concerns, the individuals feelings on the use of therapeutic cloning may inherently be a personal one. He noted

'I am concerned that any creation of an embryo creates a potential human being. The thought of creating embryos simply for therapeutic purposes is abhorrent to me. I am scientist by training, so I realise that the quest for knowledge and understanding cannot be held back, but that we need ethical boundaries. The thought of creating embryos so we can harvest something from them and then dispose of them ranks alongside torture and murder to me. It may seem emotive what I am saying but I do not think deeply held beliefs can be ignored in any situation.' Gudeskind

New Fertility Treatments

This discussion forum evolved from the following scenarios:

- Male Pregnancy
- A new cell for an old egg
- Fresh sperm for sale
- An embryo from an egg
- Identical twins on demand
- A child with two mothers
- Sex selection on the web
- A mother or grandmother
- Regulating GIFT
- Eggs from ovaries

Exploration of the scenarios by the participants resulted in a set of recurring themes throughout the online consultation. However, some of them were most eloquently articulated under this heading. Therefore, rather than following the flow of the conversation developed under each scenario, we will present the main themes which were developed around clusters of arguments concerning new fertility treatments.

Infertility - a choice or condition

The question was raised about the difference between heterosexual and homosexual infertility and should the latter be treated as a medical condition.

'We started in 1978 with creating children artificially for heterosexual couples experiencing genuine infertility. It was always accepted that this was not the ideal way to solve infertility (costly, stressful, low success rates, etc.) and over the subsequent decades we have also concluded that IVF has a considerable number of side-effects and risks for the mother. We also note that it destroys a huge number of human embryos (worthy of respect according to the HFE Act), and can result in children born with worrying genetic problems, as well as all the complications associated with multiple births (another sequela of IVF).

Adults such as lesbian and homosexual partners, single women and single men (male pregnancy?), and couples wishing to choose designer qualities such as sex-determination, are none of them infertile per se, they are simply not choosing to avail themselves of the natural process for having children.

Should a medical procedure with so many patient risks and so destructive of early human life be made available to adults who are not infertile by any real definition of the word? And as an ultimate lunacy - paid for by the NHS if current NICE recommendations go ahead? *Josephine Q.*

A couple of counter-arguments followed

'Do you have any alternatives for solving infertility, if this is indeed not the ideal way? If it is not the ideal way should we then surely abandon it?

In comparison - breast cancer cures could be deemed not ideal - I mean they don't cure everyone and there are possible serious side effects of the drugs - should we then just abandon those as well?' Jules

'I would suggest that to be physically incapable of producing sperm is a fertility issue in much the same way as, say, a man who is physically incapable of producing sperm/ viable sperm. It is no less heartbreaking and no less simple a problem to overcome.' Leslie Bean

Alternative treatments for infertility

'Ethical cures for infertility. Major causes of infertility are age, body weight, smoking, environmental factors (particularly for men's sperm count. Sexually transmitted diseases (particularly Chlamydia) cause permanent damage to the reproductive tract. Tubal occlusion is a major cause of infertility. There are many possible solutions to these factors. And there are infertility treatments in practice using natural hormonal analysis, holistic health approaches, etc. which are having the same or better success rates than IVF. And even IVF can be practised within an ethical framework where no surplus embryos are created and eggs rather than embryos are frozen.' Josephine Q,

'Yes, alternative medicine has it's place - acupuncture may help increase chances of success with conception with IVF - but no-one would recommend that you stop taking the medicine your doctor has prescribed and replace that with homeopathic remedies or whatever. However, there is room for more research to enable less invasive 'cures' for infertility - I do think that the fertility industry has a vested interest in IVF and other techniques and that needs to be looked at - but that is not to say they are not the best options that may be available to some people.' Jules

'As an alternative to IVF and the various artificial reproductive technologies currently being provided, promoted and funded by the NHS, NaProTechnology is a less invasive, far more successful, ethical approach which would cost the NHS a fraction of what IVF treatment is currently costing the NHS and the tax payer. With NaProTechnology, there are none of the ethical dilemmas regarding the discarding of embryos, selective retention or hyper-stimulation and other health concerns. The underlying CAUSE is systematically and meticulously evaluated and treated with the use of the Creighton Model tracking system. This in turn assists with all future pregnancies (unlike IVF which is of no assistance at all). Finally and most appealing to couples is that conception occurs as an act of love, not in a laboratory.' Nicole Syed

'You may ask why everyone isn't using natural fertility programs if these are so much better than IVF. I don't think there's a single answer to this but possible reasons might include:

- pervasive fixation on IVF and suspicion of anything which appears to be 'alternative' within the medical establishment*
- many infertile couples may lack any knowledge of alternatives*
- the tendency to lump such treatments together with scientifically dubious herbal treatments or homeopathic techniques*
- the belief that modern natural family planning (NFP) is the same as the old-fashioned rhythm method (it isn't)*
- the fact that NFP was/is typically taught by groups to which the media and some elements of the medical establishment are ideologically opposed (e.g. the Catholic Church). Note that here NFP is actually being used to achieve pregnancy. Obviously, these techniques can only aid the 'historical' process of procreation and would not be applicable to many of the new scenarios proposed in this forum. Nor can these techniques overcome complete infertility.'* Edmund

Accepting the limitations of age

'Aging and going through the menopause is part of life - not an illness to be medically overcome - and people need to just get on with their lives.'

Why are people so desperate to have their 'own' child, as if it's the be all and end all? Why are we developing such an obsessive attitude to childlessness and baby-making in this country? Why isn't adoption made more accessible? Why don't people accept that not all their desires will be fulfilled, and that medicine cannot provide for all their 'ailments'? ... How can a civilised country justify the money, time, discussion, effort, glossy publications, costly committees and paper pushing put into the development and provision of reproductive technologies in the face of so many more immediate needs in the world??' Jax

'Medical science invests a great deal in being to extend life spans, treating age related illness (cancer etc) so why should it not help extend the opportunity for women to have a child after the age of 40 or 45? Why should women accept the limitation of age if medical science can help?' Jules

Welfare of the child

Comments posted under all the scenarios brought the issue of 'the welfare of the child' as the major though, according to some of the posters, most overlooked aspect of new fertility treatments. As with some of the previous discussions in the forum, the argument was developed through two starkly opposing positions. Here are some of the contributions on the subject:

'One important issue would be whether the resulting child would be psychologically harmed by spending the second half of term in an artificial womb. The connection between mother and child during pregnancy seems to be significant in the child's psychological development. Would such an artificial womb provide similar stimuli? If this question can be answered in the affirmative, then I would think that this scenario is ethically acceptable.' Kjt

'What would be the impact on the child of knowing that it was not conceived by human parents in the normal sense but was merely generated in an entirely artificial and unhuman way.' Luisamares

'For what is always at stake in human reproduction, and the last consideration of most regulators, is the offspring. Do we have no duty at all to the psychological and physical welfare of the children these new technologies produce? Some children will have a very hard time when they discover their father was selected and paid for over the internet, and his anonymous sperm couriered in a freezer container to the front door, with insemination performed with a turkey baster.' Josephine Q.

'The issues here go well beyond what happens in the bedroom, and beyond the debate about whether we can or should regulate the act of conception itself. The Government needs to also consider the needs, rights and long-term wellbeing of children born as a result of this, not solely the desires/needs of prospective parents.' Philipa Taylor

'The victims of these [new reproductive] technologies will inevitably be the children. Research shows overwhelmingly that children need a mother and a father and the stability provided by the marriage-based family. To deliberately deprive them of this is tantamount to child abuse.' Tony Shields

'Many contributors to these discussions have stated that research has shown that children need a father. I have no in-depth knowledge of sociological research but I would be surprised if the most important thing for a child is not a secure, stable

and loving environment. I would argue that if we have no cause for concern if these criteria are met. I would argue that the composition of that environment is of secondary importance. I can concede that a father is an advantage but I suspect that male role model or 'father-figure' would do. I am also concerned that the the State should somehow form value judgements about what constitutes an ideal family.' Robert Toppy

'I'm a sociologist, and I know of no body of research that 'overwhelmingly shows' that children need to be brought up in a home with a mother and a father. None of the concerns about same-sex parenting damaging children have been supported by research so far. I think the most important factor here is a stable and loving environment. And although I agree that role models of both sexes are important for a child's development, I don't think these necessarily have to be the biological parents. I think the most important thing in terms of providing a stable environment for a child is the amount of love and commitment parents are able to show - not the sex of the parents. And I think intolerance and bigotry are the biggest threat to the emotional well-being of all of us - children and adults alike.'
Alison

'Finally, speaking as someone who had two parents, I don't believe it makes any difference whether the parents are male, female, or both; what matters is that the child feels secure and loved. I had a mother and a father and I didn't feel either of those things, particularly as my father was rarely around. He was too busy going to church to pray' Leslie Bean

Buying sperm over the internet

Debate was initiated by the Committee's Secretariat scenario that stated 'A website 'Mannotincluded.com' offers an 'introduction' service, where clients can get fresh sperm from anonymous donors for insemination' and posed a question 'Should this be subject to regulation and licensing?'

'I do not think, in the first instance at least, that it would be practicable to control private agreements between individuals, even where money is involved. This does not mean that I condone such actions; merely that I cannot see how they could be policed effectively. But a company that sets out to facilitate such an action is in a different category altogether, and could (should) most certainly be regulated. This would serve many purposes, not least ensuring the welfare of the children and avoiding unwitting incest (by checking with the HFEA Register, for example). That such companies are merely putting people in touch (anonymously!) does not affect this, as far as I can see; this may be all that a pimp is doing, but he stands no less guilty under the law for it.' Tim

'It is not a 'bedroom act', it is a transaction which there would be no need for if our Government would catch up with the times and allow homosexual couples to access treatment on the nhs rather than leaving it up to the individual hospitals to discriminate arbitrarily. My concern is also around the safety of the sperm as it is fresh and there are no gaurantees that the donor has not become infected withan STI between the time of testing and donation. I believe these services should be subject to strict controls to ensure the SAFETY of the women (and therefore the unborn child). However, it is true that if everyone could have access to fair and unbiased treatment on the NHS this website may never have needed to be set up'
Leslie Bean

'I think the problem is the genetic safety of the sperm (hereditary diseases, etc) and the morality of to whom it is given, but otherwise I see no problem.' Johnmryder

'I believe that companies like 'man not included' are taking advantage a situation which is a result of the discrimination that exists within fertility clinic's which mean that many lesbians and single women are refused 'Donor Insemination' treatment. They also take advantage of the fact that the lesbians and single women who have been accepted for DI treatment, are treated as if they have a 'fertility' problem - which can result in unecessary surgical and medical procededures, time wasted spent on NHS waiting lists etc. When really the only problem is the lack of access to sperm. No wonder there is a market for 'man not included'.I think the important issue is that lesbians and single women should be able to access sperm that they know is safe for both their own health and any any child that may be produced. However, I would not want to see a service that does not discriminate against lesbians and single women be forced into one that does because of state intervention.' Jules

'Ideally, such a website should not be able to operate in this country, as it bypasses all the UK laws and regulations on this issue, appears to take no account of the welfare of any children born (in the short and long term) and there is no health screening or any sort of oversight involved.However if this website is going to continue to operate, then at the very least it should operate under the current regulations of the HFEAct.' Philipa Taylor

'No regulation can control the web easily, once regulation comes in, the providers will go offshore to unregulated regimes. It should be banned here to set an example, and with international treaties signed so as to discourage such practices, unless strictly regulated.' Careorg

Donors anonymity

'How is the child supposed to seek out their father when the father is just sperm? While it may be possible, and in some cases tragic, that children do grow up without their father, what gives us the right to deprive a child of this important and irreplaceable bond?' Fiona

*'As one of those adults unfortunate enough to have been born from the clinical act of donor insemination, who has been denied any knowledge about their father's experiences, personality, interests, beliefs, and who has been called ungrateful for complaining that such a morally indefensible way of creating human beings is wrong, I would like to suggest that donor gamete technology represents a new form of human slavery'*Christine

*'The HFE Act 1990 recognises that we should not attempt to bring fatherless children into the world. The current review of the Act should uphold this principle.'*Martin Foley

'One of the problems with regard to the new change in legislation (in April 2004) to ammend the rights of the donor anonymity, is that it is likely to mean that there will be a further shortage of donated gametes in the UK. This is likely to result in the importation of gametes from countries such as the USA, which is likely to increase the cost of treatment for the NHS.' Jules

'However, I must add that if the law changes so donors can be identified I will not be donating. The point is, that other people are given the chance to be parents when they otherwise would not be able to. A parent is someone who brings a child up in love, not a collection of genetics.' Leslie Bean

Egg donation

'I recently had the opportunity to speak to a woman who had altruistically opted to donate eggs and was I horrified to learn that although the minor possibility of a bad reaction to anaesthetic during the egg retrieval process had been outlined during discussions, she had not been told of the very real prospect that the drugs given to stimulate her ovaries could cause life threatening ovarian hyperstimulation syndrome or that there were some studies which suggested a link between fertility drugs and ovarian cancer. As this woman had already completed her own family she was not concerned that her own future fertility could be impaired through the donation procedure but I doubt that this issue will be made clear to potential egg donors involved with commercial companies.' Christina

'Money would be better spent in a stringent inquiry into the protocols and drugs used in egg harvesting.' Josephine Q.

'I have considered donating my eggs so another woman can have the chance to experience pregnancy and motherhood. I am very early on in the process. I have been made aware of all the health risks which are minimal (donors are monitored extremely closely for ovarian hyperstimulation syndrome which is uncommon and rarely causes death). I have been to a meeting, I have spoken to health care professionals, I have a pack full of information, before I can go ahead I will be expected to undergo counselling, a number of tests, and a consultation with a doctor. Only then, if they decide I am an appropriate donor, will I even be allowed to go ahead. I will then be closely monitored throughout the course of donation. Anything else I want to know I can find out for myself or contact the hospital. It is up to individuals to make that decision for themselves and to take responsibility for making sure they are fully informed.' Leslie Bean

Supermarket shopping

Many times in the forum the point was raised about the consumerist attitudes towards children and parenthood which, in the view of some of the participants, were encouraged by new fertility treatments available. Again, this sentiment was argued from *'the standpoint of the child'*

'It feels like supermarket shopping if you can pay for it you can get what you want. We really need to start thinking about what the children would want as well as the whole family needs not on a wish of a mother. It feels like the mother/fathers needs are paramount and no thoughts of the children's on how would the children react how it would effect them growing up.' S Williamson

'The scenarios that the committee is proposing seem to be loaded towards pushing for consumer 'choice' ie a marketised solution to profound cultural and ethical issues. Where is the standpoint of the child in this scenario? Are we not to consider his /her wellbeing? There are potentially huge and unexplored problems for a child that is 'made' not 'born'. Suggest the committee looks at the German National Ethics Committee, Habermas and McGribben for philosophical and every day reasons why this possible is deeply unethical.' Hilary Rose

Lesbian and Gay parenting

One of the most heated discussions in the online forum was focussed on the issue of lesbian and gay parenting. The position was strongly attacked and denounced by some of the proponents of the pro-life lobby in the forum but was, however, also defended by personal accounts from several gay parents-to-be.

'Accepting homosexuals does not mean we have to accept gay parenting.'
Josephine Q.

'Lesbians should be discouraged from continuing in their relationships, not given the ability to produce and look after children.' Ian Elliott Benson

'Whether you accept homosexuality and gay parenting or not - the fact is we are having families and will continue to do so in greater numbers in the future. Whether you and others agree with it or not we are here to stay and society will not disintegrate as a result!' Jules

'For lesbian couples to have their own children or for men to be pregnant destroys family life.These proposed technologies have a profound impact on our society's concept of marriage and the family and would do enormous damage to the basic building block of a civilised society. ... Children would be the first ones to suffer. Research shows overwhelmingly that children need a father and mother and the stability provided by the marriage-based family. ...These new technologies should be illegal, most definitely. The disintegration of communities, the rising rate of violent crime, and the widespread abuse of drugs are largely rooted in dysfunctional families.' David Catlow

'My partner and I are fortunate enough to be expecting a baby. After a great deal of thought and planning, sperm was donated by a close friend whom we went to University with (we're all well educated professionals, paying our taxes and living extremely normal lives). His long-term female partner has never wanted to bear children (shock, horror). Personally we were not keen to have an anonymous donor. The technology to enable a child to know both its genetic parents (in this case, two women) will be great and I look forward to the day that this can happen. Lesbians are women, first and foremost. Being defined as a lesbian is one part of that. It does not change the feelings, instincts or desires to have children that can occur in women (not all). It also does not stop us being 'good' people, for me that means believing much of the same that many religious people, bar that God sits above us all. Our children will be loved and brought up with high morals about what is good and bad, which will include accepting people for who they are, without discrimination.' JCM

'Just as a matter of interest, why is this scenario limited to lesbian couples? It could equally apply to heterosexual couples in which the male was infertile. Confining it to lesbian couples seems to have inflamed the discussion, perhaps unnecessarily. Isn't it true that no one has a right to have children? And equally, no one has a right to stop people having children, at least by tried and tested means.' Tim Roberts

'I would welcome the chance to be able to conceive a child that would be genetically related to myself and my (lesbian) partner. I would have to be assured of the health and safety for the potential child, but apart from that I have no other concerns. Our child (which we are currently trying to conceive through DI) will be dearly wanted, loved and cared for - the fact that he or she may never know

their biological father does concern us, but we hope that by being open and honest about his or her origins from the beginning, any curiosity will met early on and that they will be happy to accept us as their parents, without the desire to meet someone who genetically related. We hope our child will feel that the important people in his or her life are those that have cared and loved them'
Jules

'A child has a right to be created in a way that gives it an unambiguous lineage and parentage. To create a child with multiple genetic mothers is to give this child a very odd identity and abnormal status. I sympathise with those who desire to have a child but a child's interests must be respected and upheld. The child in this scenario will be disrespected in a fundamental and potentially damaging way. It is selfishness and irresponsibility of the highest order.' luisamares

Sex Selection

The Committee Secretariat sought opinion on a safe pill for sex selection. The Government has tried to ban it but it is easy to purchase over the internet. After debating challenges of regulating sperm banks online, the question of a sex selection pill available online provoked different responses from the participants

'A potential difficulty in criminalizing such a pill might be that the user group is one which we prefer not to criminalize - young families.' Kjt

'And what would happen if there was a general societal preference for one gender?' Johnmryder

'I think in theory this would be a much more humane way to choose the sex of your child than the situation in certain countries where babies of certain sex are often abandoned or murdered because the parents wanted a boy rather than a girl (for example). It will also lower the number of abortions (particularly backstreet abortions) carried out in such situations (for example, in China)where a particular sex is preferred and it is illegal to have more than one child.' Leslie Bean

'The whole issue of the child as a commodity, selected based on its sex, arises. If it is available abroad, it will be difficult to regulate. ... The government should enter into treaties internationally to discourage such a practice - by ensuring that regulations on such practices be banned, and not just be regulated, such that there is eventually nowhere for the pill to be sold.' Careorg

The Hansard Society will be publishing a summary report based on all the forum messages posted and post-consultation participants survey.

23 March 2004,

Milica Howell
E-Democracy Programme Coordinator
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Appendix 1

Organisations who posted messages

All-Party Parliamentary Pro-life Group
Archdiocese of Cardiff (RC)
Barrow Baptist Church
Bloodlines
Care
Catholic Church
Centre for Bioethics and Public Policy
Chartered Institute of Patent Agents
Christian
Christian Church
Comment on Reproductive Ethics (CORE)
High Wycombe
Human Genetics Alerts
Imperial College London
Imperial College London
Institute of Biotechnology, University of Cambridge
Institute of Cell and Molecular Biology, University of Edinburgh

Institute of Ideas
International Family Health
kcl
King's College London
Lancaster University
London FertilityCare Centre
London Metropolitan University
Manchester Metropolitan University

MRC Human Genetics Unit
N.S.S.
NHS

NIMR, MRC
Oxford
Oxford University
Parish of Godshill
Private individual
ProLife Alliance
QCA
Roslin Institute
Scottish Council on Human Bioethics
Scottish Stem Cell Network
Slaughter and May
Southampton University
SPRING
Student LifeNet
Student Union
The Missionary Training Service
University
University College London
University College London
University of Auckland
University of Central England
University of Kent / Pro Choice Forum
University of Oxford

Appendix 2

Scenarios for online consultation

Forum discussion thread: Surrogacy and donation

Animal-human hybrids for research

The Chinese population has a rare mutation causing a degenerative eye disease called autosomal dominant retinitis pigmentosa. Scientists hope that stem cell therapy could eventually provide a cure for the condition but they need stem cell lines with certain characteristics. They will need to develop a large number of similar stem cell lines. The possibility of related women donating a large number of eggs is remote. A more feasible alternative is to fuse an adult human cell with the enucleated egg of an animal such as a rabbit to create an embryo, in which the vast majority of the DNA is human, which will develop far enough for stem cells to be harvested. Should this be legal?

Legal status: Creating an animal-human hybrid embryo is illegal under the HFE Act.

Scientific status: Technique may be possible in the future.

Links:

<http://www.nlm.nih.gov/medlineplus/ency/article/002052.htm>

http://www.brps.org.uk/Graphics/G_Genetics.html

A surrogate for a lesbian couple

A lesbian couple wish to use a surrogate to carry a child. They are happy to pay, which while this is not illegal in the UK, they have been unable to find a volunteer surrogate. This is not illegal in the UK provided it does not involve payment to a third party through finding services. They would like to use a licensed UK clinic, and they have found a UK clinic that is prepared to undertake IVF for them and export frozen embryos to another EU country where payment to a surrogacy agency is possible. They need a licence from the HFEA to export the embryos. Should this be granted?

Legal status: The export of embryos is lawful but regulated by the HFEA. A licence is unlikely to be awarded to circumvent UK law.

Scientific status: Technology currently available

When is consent not consent?

A couple wish to have a child but the woman has failed to conceive. They try IVF but the first two cycles are unsuccessful and they have insufficient funds for a third. The clinic suggests egg sharing, whereby they give half the eggs from the next cycle to another couple in exchange for free treatment. While there is some evidence that being an 'egg-sharer' does not reduce the chance of the woman conceiving in that cycle, the woman is concerned that it would reduce their chances of successful treatment. Her partner is adamant that this is the only way they will have a child and, with the encouragement of the clinic, reluctantly she agrees.

Has the woman given a valid consent or has she been pressurised too much to give her consent?

Legal status: Regulated and permitted by the HFEA

Scientific status: Technology currently available

Links:

<http://www.hfea.gov.uk/PressOffice/Archive/1060181880>

<http://www.hfea.gov.uk/PressOffice/Archive/34673456>

Making sperm and eggs from stem cells

A technique has been developed for turning stem cells into cells that function as either sperm or eggs. Since stem cells can multiply and live almost indefinitely, this could mean that donors are never needed again. It could also mean that one person could be the genetic parent (father or mother) to thousands of children. Does this matter?

Legal status: Because of the HFE Act's imprecise definition of a 'gamete' this is presently lawful and unregulated

Scientific status: Not currently available. It may be possible in the future.

Paying a donor to cure AIDS

Scientists researching AIDS have found that there are small number of people who, despite repeated exposure to HIV, never develop AIDS. Studying these people could provide vital clues in developing a cure. Researchers seek to use donated eggs from resistant women to create stem cell lines. Unfortunately, it has not been possible to find such a person willing and researchers wish to pay a donor more than the permitted limited amount to attract a donor. Should this be permitted?

Scientific status: Technology currently available.

Legal status: Legal but requires HFEA licence. Very few embryos are created each year for research each year.

Forum discussion thread: Consent and confidentiality

Donor dads and anonymity

H is 18 and the product of IVF involving sperm donation. The donor is a married man with three children. He donated the sperm as his brother had fertility problems and he wanted to help those in the similar position. He had no wish to have any relationship with any resulting children and indeed did not tell his wife that he had donated sperm. H enjoyed a close relationship with his parents but they died when he was younger. He now wishes to meet his genetic father. At present all he had been told is basic information about the man's background. Should the offspring resulting from donated sperm have the right to know their genetic father? What about future donations where the donor knows that he may be contacted in the future by any offspring resulting from the use of his sperm?

Legal status: Anonymity is at present provided for under the HFE Act. The Department of Health has announced that it will ask Parliament to change in the law. It is intended that the change in the law will not be made retrospective.

Scientific status: Technology currently available

Who owns an embryo?

The law states that for the IVF process (including storage and the use of embryos) to continue, the consent of both partners is required. Recent cases have highlighted disagreements when the potential father withdraws consent after embryos have been created and frozen. Should there be a shift to storing gametes rather than embryos? Should the consent laws be changed to allow the woman to implant the embryo? Should the law be changed to allow the father to use the embryo without the woman's consent (for example with a different partner)?

Legal status: HFE Act states that effective consent - continuing consent in writing - is required from both partners until implantation.

Scientific status: Technology currently available

Extracting sperm from a comatose man

A man is badly injured and goes into a coma. He and his wife had previously let it be widely known that they wished to have a child. Doctors believe he has a good chance of recovery but the woman wishes to take sperm samples from him as there is a danger that his medical care will cause his infertility. Although there is no written consent to the taking or storage of the sperm, the woman says she will only use the sperm for IVF if he consents following recovery. Unfortunately, he does not recover but the woman now wishes to use the sperm for IVF. Should she be allowed to?

Legal status: In common law, gametes may be recovered from someone who is unconscious and hence incapable of giving consent if it is judged to be in their best interests for this to happen. However, storage of sperm without written consent is unlawful under HFE Act. A review of this provision in 1997 proposed that the HFEA should be given power to authorise storage of gametes until an incompetent patient, who is undergoing treatment that may render them infertile, recovers and is able to make a decision personally. It is now possible for men whose sperm is used posthumously to be registered as the legal father of a resultant child (Human Fertilisation & Embryology (Deceased Fathers) Act 2003). However, the requirement for written consent is maintained, except in respect of several cases which occurred between the coming into effect of the HFE Act in 1991 and the Act of 2003, where the question of written consent is specifically dispensed with.

Scientific status: Technology currently available

Links:

<http://www.newsrelease-archive.net/coi/depts/GDH/coi8851e.ok>

Forum discussion thread: New fertility treatments

Male pregnancy

A couple have embarked on IVF treatment but before they can be implanted, the woman is forced to have an emergency hysterectomy. The husband volunteers to carry the baby. By sacrificing a kidney, he can keep the baby developing normally until 20 weeks, at which point, the baby can be born via a caesarean and placed in an artificial womb. Should this be illegal?

Legal status: The use of an embryo in treatment services must be in accordance with the conditions of a licence issued by the HFEA. 'Treatment services' are defined by the HFE Act 1990 as being a range of services provided for a woman. At the time that the Act was drafted the scenario here contemplated would not have been possible. Should it [soon] become an available procedure, a court might rule that a purposive interpretation of the Act demanded that it should also be held to apply to men; or that as it involves using an embryo within s 3(1)(b), this can only be done under HFEA licence. Any person in a clinic who objected to such a proposed use would be able to rely on the conscientious objection section (S38) of the HFE Act to ensure that they did not have to participate in this experiment, even if it was to be decided that this could be lawfully undertaken given the two preceding objections.

Scientific status: Conjecture

Fresh sperm for sale

Currently, the HFE Act only regulates gametes that have been stored and used in treatment. A website "Mannotincluded.com" offers an "introduction" service, where clients can get fresh sperm from anonymous donors for insemination. Should this be subject to regulation and licensing?

Legal status: Lawful and unregulated

Scientific status: Technology currently available

Links:

<http://www.hfea.gov.uk/PressOffice/Archive/35645735>

An embryo from an egg

A couple wish to have a child but the husband does not produce viable sperm. A technique pioneered in the US has found that a combination of chemicals can make the egg produce an extra set of chromosomes and then start to develop as an embryo. It would be female but it would not be a clone of the mother. Should it be permitted?

Legal status: Lawful but the implantation of the embryo would require a licence from the HFEA.

Scientific status: Research on animals underway

Identical twins on demand

A childless woman is approaching the menopause but is keen to start a family with her new husband. The couple have failed to have a child naturally and begin IVF treatment. The couple wish to have two children and in view of the woman's age, they decide they would like identical twins using a process called embryo splitting. Should they be allowed?

Legal status: Lawful but regulated by HFEA but clinics are expected not to "produce embryos in vitro by embryo splitting for treatment purposes" (HFEA 6th Code of Practice).

Scientific status: Animal research well advanced and this may be available in the future.

A child with two mothers

A lesbian couple wish to have a child. A new technique involves the transplantation of an adult cell nucleus into a donated egg followed by the division of the chromosomes to create an artificial sperm for one of the partners to be fertilised using IVF. Any resulting child would be the genetic offspring of both partners. Should this be permitted?

Legal status: Implantation of an embryo, regardless of how it is formed, requires a licence from the HFEA.

Scientific status: Research underway and this may be possible in the future.

Links:

http://www.ferti.net/fertimagazine/hottopic/2002_05_01.asp

<http://www.timesonline.co.uk/newspaper/0,,173-926744,00.html>

<http://www.education.guardian.co.uk/higher/sciences/story/0,12243,1104683,00.html>

Sex selection on the web

A technique has become available to enable parents to choose the sex of their child without undergoing IVF. It involves a safe pill, which, when taken by the woman, ensures that only male or female sperm survive in the womb as desired. The Government has tried to ban it but it is easy to purchase over the internet.

Legal status: Unregulated beyond medicines regulation

Scientific status: Conjecture

Links:

<http://www.bionews.org.uk/commentary.lasso?storyid=1889>

A mother or a grandmother?

After four unsuccessful IVF cycles, a 45-year-old woman finally becomes pregnant. Unfortunately at 20 weeks, it becomes evident that the child has microcephaly (a small head) and would be severely brain-damaged and the doctors recommend

termination as the female child would not survive for more than a few hours after birth. The woman could only become pregnant again using donated eggs. She decides that she would like to extract immature eggs from the aborted fetus. It is possible to mature these in the laboratory and use them in IVF. Should she be allowed?

Legal status: Unlawful by virtue of HFE Act s 3A, inserted by the Criminal Justice and Public Order Act 1994 s 164

Scientific status: Research ongoing. The technique may be possible in humans in the future.

Links:

<http://news.bbc.co.uk/1/hi/health/3034266.stm>

<http://www.hfea.gov.uk/PressOffice/Archive/1060181530>

Regulating GIFT

Gamete intrafallopian transfer (GIFT) differs from IVF in that fertilisation takes place inside the woman. However, it still involves the woman taking hormonal treatment to stimulate egg production. The treatment is not regulated unless it involves donated sperm. As a result it can be undertaken in unregulated clinics. Should it be brought under the HFE Act?

Legal status: This is presently unregulated, although a recent European Union Directive on Human Tissues and Cells will require all such handlings to be supervised by a 'competent authority' of each member state of the European Union by 2006.

Scientific status: Well established technology currently available

Scientific status: Well established

Eggs from ovaries

A woman wishes to be allowed to freeze ovarian tissue for use in later life as she is about to undergo chemotherapy that will render her sterile. Immature eggs could then be matured in vitro. The technique would be useful for women who, for example, could not cope with the high doses of hormones generally used in IVF treatment. Should this be allowed .

Legal status: 'In vitro maturation' (IVM) is illegal in the UK under the 1990 HFE Act

Scientific status: Research underway. It may be possible in humans in the future.

Links:

<http://www.cnn.com/2000/HEALTH/women/10/24/women.ovaries.reut/>

<http://www.bionews.org.uk/commentary.lasso?storyid=1852>

Forum discussion thread: Screening and therapy

Going abroad to escape UK law

A couple wish to choose the sex of their child using PGD for family balancing reasons. It is not possible in the UK but a British clinic has agreed to extract cells for PGD for this purpose from embryos resulting from IVF then send them to a clinic in Spain. The Spanish clinic will then sex the embryos and indicate to the UK clinic which embryos should be implanted. Should this be allowed?

Legal status: The technique is lawful, but subject to regulation and IVF unlikely to be licensed on current policy which opposes sex-selection for non-medical purposes. Although the Spanish laboratory would be licensed, the UK clinic would require an HFEA licence to extract the cells.

Scientific status: Technology currently available

A saviour sibling

A couple have had a son naturally but he developed leukaemia and has relapsed following initially successful chemotherapy. The only effective treatment is a donation of matched stem cells, either from bone marrow or from umbilical cord blood. It has not proved possible to find a match from family or the donor 'bank'. The couple wish to have another child and there is a possibility that this baby's cord blood could provide the necessary cells if it was a perfect tissue match. It is possible, using PGD following IVF, to select a matched embryo.

Legal status: Regulated by HFEA but would probably not be licensed since the new child was not at risk of having the condition and PGD carries a theoretical risk to the embryo

Scientific status: Technology currently available

Links:

<http://news.bbc.co.uk/1/hi/health/2165710.stm>

<http://www.hfea.gov.uk/PressOffice/Archive/43573563>

Sex selection to acquire an heir

The husband of a titled couple is an only child and the only heir to a large estate. The couple have a 10-year-old daughter but soon after giving birth the mother was diagnosed with cancer. An elder son drowned during a sailing trip two years later. Before the mother underwent chemotherapy eggs were harvested, fertilised by IVF and the resultant embryos were frozen. The couple have now expressed a wish to screen those embryos to identify a male to implant. They state that they wish to have a boy to rebalance the family but the father has spoken publicly of his concern about the lack of a male heir and the loss of the family name. Should they be allowed to go ahead?

Legal status: Lawful but sex-selection by IVF and embryo screening is Regulated by the HFEA, whose current policy is not to permit sex selection for non-medical reasons.

Scientific status: Technology currently available

Links:

<http://www.bionews.org.uk/commentary.lasso?storyid=1843>

<http://www.bionews.org.uk/new.lasso?storyid=1822>

Gene therapy on embryos and sperm

The male partner has cystic fibrosis and the woman is a carrier for the condition. The couple wish to select an unaffected embryo resulting from an IVF cycle. After the first IVF cycle, it is found that all embryos are affected. Gene therapy has recently become available which can introduce a normal genes into the embryo. The treatment offers the prospect of replacing the affected genes so that neither the offspring or future generations would be affected. This is germline gene therapy. Should this be made lawful?

Legal status: Illegal under HFE Act

Scientific status: Research is being undertaken in animals and could be feasible in humans in the future.

Links:

<http://www.nlm.nih.gov/medlineplus/ency/article/000107.htm>

<http://observer.guardian.co.uk/print/0,3858,4779356-111712,00.html>

<http://www.telegraph.co.uk/core/Content/displayPrintable.jhtml?xml=/news/2001/10/23/wsperm23.xml&site=5>

Choosing a child with dwarfism

A married, fertile achondroplastic dwarf couple have one son, who also has the condition (achondroplasia is an inherited condition that results in abnormally short stature). The family wish to have a further achondroplastic child. They believe that if they had a new child with normal height the cohesion of the family would suffer and it would cause practical problems in their home. The chances of achieving this in a natural pregnancy are 50%. Should the family be able to make it certain using preimplantation genetic diagnosis?

Legal status: Currently lawful, subject to regulation by the HFEA but unlikely to be licensed by the HFEA on current policy

Scientific status: Technology currently available

Links:

<http://www.guardian.co.uk/genes/article/0,2763,681152,00.html>

<http://www.cmf.org.uk/index.htm?nucleus/nucjan03/news.htm#6>

Sperm sorting - to avoid disease?

A couple wish to have a child. The woman is a carrier of the gene for Duchenne's muscular dystrophy. They wish to select a female embryo using sperm sorting, which, if successful, would ensure that the child did not develop the condition (although there is a 50% chance that she would be a carrier). The couple state that they have ethical concerns to preimplantation diagnosis and IVF as it involves the destruction of embryos and wish to have a female child using sperm sorting. There is a concern that the couple are using the risk of an affected child as a means of selecting a girl. Should the regulators allow them to go ahead?

Legal status: Sperm sorting is currently lawful. Fresh gametes are not subject to HFEA regulation but has recommended to the Government that sperm sorting for the purposes of sex selection should be subject to regulation. Current policy is to license for sex selection only to patients with clear and overriding medical indications.

Scientific status: Technology currently available

Links:

<http://www.nlm.nih.gov/medlineplus/ency/article/000705.htm>

<http://www.hfea.gov.uk/PressOffice/Archive/1068631271>

<http://www.hfea.gov.uk/PressOffice/Archive/43573563>