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# Sex Selection: choice and responsibility in human reproduction



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# Chair's Foreword

People have tried to influence whether their child will be a boy or a girl for hundreds of years. But science has only recently provided ways for people to practice 'sex selection' with any likelihood of success.

Today, it is possible to detect accurately the sex of an embryo created during IVF. This allows people to choose whether, if their treatment is successful, it will result in a girl or a boy. In some countries, such as the USA, some clinics offer techniques that 'sort sperm', which means a woman can choose to be inseminated with sperm that will maximise her chances of conceiving a girl or, if she prefers, a boy.

The development of these techniques presents challenges and poses new questions. Is it right that people should be able to choose the sex of their child? If so, for what reasons? And if it is acceptable, should these new techniques be regulated?

Earlier this year the Secretary of State asked the HFEA to consult people about this and we were pleased to explore what people in the UK think. We feel that it is extremely important that people make their voices heard on this important area of public policy. This consultation paper explains the different ways that people can try to select the sex of their baby, and the reasons why they may wish to do so. We hope that you will read the document and take this opportunity to tell us your views. In Spring 2003, when we have considered responses, we will present policy recommendations to Government.

Please use the questionnaire at the end of this document to tell us your views by January 22, 2003.

Suzi Leather HFEA Chair

# **Executive Summary**

The HFEA's last public consultation on sex selection was held in 1993. Following this consultation, the policy of only permitting sex selection using licensed treatments for the avoidance of serious sex-linked genetic conditions was confirmed. Since then, however, the range and effectiveness of techniques for sex selection have increased.

People may wish to select the sex of their offspring for many reasons, for example because they carry a genetic disease that they do not wish to pass on to their children, because they already have children exclusively of one sex and want to have children of the other, or for a variety of social, cultural and economic reasons.

Sex selection can be performed at three stages: before conception, where sperm are sorted to produce male and female embryos; before the embryo is transferred to a woman, where embryos created by IVF are tested to select those of a particular sex for transfer; and after a pregnancy is established, where termination of pregnancy is used to halt the development of a fetus that is of the unintended sex. Of these, preconception sperm sorting, although not currently as reliable as preimplantation testing, promises to combine the advantages of a comparatively un-invasive technique with the avoidance of unnecessary embryo creation, although health risks associated with it are difficult to assess fully on the current evidence.

Whilst preimplantation testing of embryos is closely regulated in the United Kingdom, sperm sorting, where it does not involve using the sperm of a donor or creating embryos outside the body, is not. Consequently whilst strict controls exist to ensure the quality of preimplantation testing and to restrict its use to those circumstances that are currently regarded as acceptable, preconception techniques are not subject to any control. If they were to be regulated, this would therefore require an extension of present legislation.

There are strong arguments in favour of extending the availability of sex selection based on the assumed moral rights of individuals to exercise freedom of choice in areas which most closely affect them so long as no one, including the resulting child, is harmed. However the claim that no harm will be done is disputed by many who point to violations of divine law, natural justice, and the inherent dignity of human beings as reasons to oppose greater permissiveness. Objections arising from both principled and utilitarian considerations may be advanced, including claims that permitting sex selection for non-medical reasons involves or leads to unacceptable discrimination on grounds of sex and disability, potential psychological damage to the resulting children, and an inability to prevent a slide down the slippery slope towards permitting 'designer' babies. The arguments put forward against the permissive view may be tested against what is supposedly the least objectionable non-medical reason for sex selection, 'family balancing', to assess whether any form of sex selection, by any means, that is not carried out for serious medical reasons is morally acceptable.

The information contained in this document is intended to help respondents to answer the following questions:

- Should sperm sorting be regulated in the United Kingdom by the HFEA?
- Should the use of sperm sorting be permitted only when its reliability and absence of risk to health have been satisfactorily established?
- Should the use of sperm sorting be permitted in sex selection for medical reasons if the people seeking treatment request it?
- Should the use of sperm sorting be permitted in sex selection for non-medical reasons if the people seeking treatment request it?
- Should the use of preimplantation genetic diagnosis (PGD) be permitted for selecting the sex of offspring for non-medical reasons?
- Would it be preferable to combine sperm sorting with preimplantation genetic diagnosis (PGD) when selecting the sex of offspring for medical reasons (rather than using either technique singly)?
- Should sex selection (by either sperm sorting or PGD) be permitted for non-medical reasons when a family has at least two children of one sex and none of the other sex?
- Should sex selection (by either sperm sorting or PGD) be permitted for non-medical reasons other than family balancing?

# Part One: Introduction

### What is the HFEA?

1. The Human Fertilisation and Embryology Authority (HFEA) was created by an Act of Parliament in 1990 to regulate the clinical practice of assisted conception and the use of human embryos. We produce a Code of Practice for centres licensed to provide assisted conception and also provide guidance for couples and women considering any form of fertility treatment. We are committed to contributing to professional and public debate on issues relating to assisted conception and human embryo research in the UK.

### What is 'sex selection'?

- 2. One of these issues is sex selection, which for the purpose of this consultation means any practice, technique or intervention intended to increase the likelihood of the conception, gestation and birth of a child of one sex rather than the other.
- 3. People may wish to select the sex of their children for many reasons: for example, because they are at risk of passing on a serious genetic condition to children of one sex (e.g. haemophilia, which affects only males) and wish to select children who will be unaffected; because they already have children predominantly of one sex and would like a child of the other sex to complement their existing family ('family balancing'); or because of cultural or financial reasons for preferring one sex above the other (e.g. payment of dowries, inheritance of land, name or title).
- 4. Sex selection may be achieved in many ways, some of which are regulated by the HFEA in accordance with the provisions of the Human Fertilisation and Embryology Act 1990. The practices and techniques that are currently or potentially available to those who wish to select the sex of their offspring vary greatly in the likelihood of success and the invasiveness of the technique, as well as in their impact on the prospective parents and their moral acceptability.

# What is the purpose of this consultation?

5. Throughout 2002 we are conducting a comprehensive review of sex selection. In January we commissioned two independent reports, one on the range, safety and reliability of the techniques currently available for sex selection, and the other on the social and ethical considerations that relate to them. In June qualitative market research involving a number of discussion groups was conducted into public attitudes towards sex selection in the UK and to support this, we have commissioned further quantitative research on this subject.

- 6. The purpose of the review is:
  - to assess comprehensively the current state and likely future development of techniques for sex selection from social, ethical, scientific, technical, legal and regulatory perspectives, and to review arrangements for their regulation.
- 7. Following the review we will suggest options for regulation which will be presented to UK Health Ministers in 2003. A full report on the review, to include the results of this public consultation, will be published during 2003.
- 8. Our last public consultation on sex selection was in 1993, following which it was decided that licensable sex selection techniques should not be permitted for non-medical reasons in the UK. Since then the range and effectiveness of techniques for sex selection have increased significantly. As the use of assisted reproduction techniques has become more widespread and a greater amount of information is now available, public attitudes may also have changed during this period.
- 9. The purpose of this consultation document is:
  - to seek the views of the public concerning under what circumstances sex selection should be available to those seeking treatment and whether any new legal provisions should be put in place to regulate it.
- 10. At the end of this document you will find a questionnaire. We would like you to use this questionnaire to have your say in the debate over sex selection. We would especially welcome more substantial contributions from anyone who has a strong interest in this subject. The HFEA intends to listen carefully to all the arguments put forward.

<sup>&</sup>lt;sup>1</sup> This will be available on the HFEA website: www.hfea.gov.uk

# 7

# Part Two: Reasons For Sex Selection

11. Broadly, the reasons people have for wanting to select the sex of offspring fall into two categories: medical and non-medical.

# Sex selection for medical reasons

- 12. There are approximately two hundred known sex-linked diseases, most of which only affect males. These diseases vary in severity from colour blindness to haemophilia and Duchenne's muscular dystrophy. In the absence of cures for these diseases, medical selection of embryos provides couples and women with the option to avoid having children who may suffer serious and possibly terminal illness in early and later life.
- 13. Sex selection for medical reasons is already permitted by law in the UK, either by elective termination of pregnancies at risk or by testing embryos conceived through *in vitro* fertilisation (IVF) before they are transferred to the woman. Where this is allowed, those carrying out the procedures are required to be licensed and to follow strict guidelines.

### Sex selection for non-medical reasons

### Personal reasons

14. Sometimes prospective parents have a strong preference for having a child of one sex rather than the other. Often this is where they already have one or more children of one sex and have a strong wish to have a further child of the other sex (this is sometimes called 'family balancing').

# Social/cultural/economic reasons

- 15. Sometimes prospective parents want a son in order to carry on a family name, often where this is linked to the possibility of inheritance. In other cases parents just need sons to work the land or bring in wages, or wish to avoid daughters in order to avoid the payment of dowries.
- 16. Current legislation in the UK prohibits licensed centres (although not unlicensed clinics) from offering sex selection except for medical reasons. Some clinics in the USA and some other countries do offer sex selection for non-medical reasons using a variety of techniques.

Summary	Not prohibited	Not permitted
Approach of some countries to sex selection	UK (unregulated techniques)	UK (regulated techniques)
for non-medical reasons		Much of Europe
	USA	(signatories to Oviedo convention) <sup>2</sup>
	India	
	Jordan	

Article 14 of the Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Oviedo Convention), to which the UK is not a signatory, states: "The use of techniques of medically assisted procreation shall not be allowed for the purpose of choosing a future child's sex, except where serious hereditary sex-related disease is to be avoided."

# Part Three: Methods Of Sex Selection

- 17. The sex of offspring is determined by the chromosomes (carrying genes or DNA) that are present in the nucleus of every cell in the body. Human cells contain 46 chromosomes: 22 pairs (one of each pair coming from each parent) plus two 'sex chromosomes', denoted X and Y.
- 18. An egg produced by a woman during her monthly cycle always contains an X chromosome. Sperm produced by a man contains either an X or a Y chromosome. When a sperm fertilises an egg to produce an embryo, the resulting embryo will be either XX (female) or XY (male).<sup>3</sup>
- 19. Usually fertilisation occurs naturally in the woman's body after sexual intercourse. However, particularly when people are having trouble conceiving (infertility), embryos may also be created in a laboratory and then transferred to the woman when they are a few days old. At this stage the embryo is made up of only a small number of cells and is still invisible to the naked eye. This is *in vitro* fertilisation (IVF).
- 20. Broadly sex selection may be performed at three different stages:
  - before fertilisation takes place and an embryo is conceived (pre-conception)
  - after fertilisation outside the body but before the embryo is transferred to the woman and a pregnancy is established (preimplantation)

or

- after a pregnancy is established (post-implantation)
- 21. It will be important later on, when it comes to evaluating the uses of sex selection, to be clear about the exact nature of the choice that is being made with each method. When one thinks of sex selection one has to be careful not to commit the fallacy of thinking that by using these techniques one is choosing the sex of 'an embryo' or 'a child'. The techniques do not affect the sex of embryos or children who already exist: the choice is either about which embryos will be created in the first place (sperm sorting) or about which embryos, from among those that already exist will be transferred (PGD).

There are certain rare chromosomal abnormalities, which vary in severity, when people have more or fewer than two sex chromosomes. These can be detected through preimplantation genetic diagnosis.

# **Preconception sex selection**

- 22. Aside from alternative methods of dubious efficacy<sup>4</sup> which do not involve the intervention of a third party and which are therefore properly part of a couple's private life, clinical techniques have recently been developed that involve separating sperm that carry the X chromosome from those that carry the Y chromosome. The enriched sperm samples are then used for artificial insemination or IVF to increase the likelihood of producing embryos of the desired sex. Whilst there are variations, these methods fall broadly into two types:
  - gradient methods, where live sperm are put with a dense liquid and typically spun in a centrifuge to separate X and Y sperm (this may be combined with 'swim-up', where the sperm swim through a differentiating medium)
  - flow cytometry, where fluorescent dye which binds to DNA in the chromosomes is introduced to the semen sample, allowing the sperm to be separated subsequently using a laser
- 23. Both these techniques were originally developed in veterinary medicine in order to increase the chance of breeding livestock of a particular sex; however during the 1990s they made the transition to use in humans. At the time of the HFEA's previous consultation on sex selection (1993), it was concluded that "the data on sperm sorting techniques do not support the use of these methods for medical reasons at this time." However sperm sorting techniques have developed considerably over the last ten years and further data are now available.
- 24. Preconception techniques have the obvious advantage that the enriched sperm sample can in principle be used in artificial insemination, which is much less invasive than IVF. As participants in our group discussions recognised, this comparative un-invasiveness is likely to make these techniques attractive to a wider group of people.
  - "I suppose it depends on the degree of intervention and what you expect. If it's just eating lettuce and hoping it'll be a girl then that's one thing. If it starts involving tablets or chemicals, or if it's intrusive, [it's another]." (Mother, 41-60, Edinburgh)

<sup>&</sup>lt;sup>4</sup> There is a substantial amount of folklore concerning how to obtain a child of the desired sex, with many countries or regions having their own local variations. Although there is little or no scientific basis for the majority of these methods, the existence of so many 'old wives' tales' serves to illustrate that the desire to select the sex of offspring is not confined to a particular population or to a recent stage of history. Additionally, some studies have shown that occupational and lifestyle factors may affect sex ratios (for example, deep-sea divers, fighter pilots and heavy smokers may be significantly more likely to conceive daughters than the average population). Today, despite an absence of reliable evidence of success, some people try to influence the sex of their offspring through special diets and dietary supplements, or by the timing of sexual intercourse in relation to when the woman's egg is released (ovulation).

25. For some people, it is an important consideration that a technique reduces the likelihood of embryos of the unintended sex being produced, which would not then be used in treatment and might end up being destroyed. Many of the participants in our group discussions, even those who did not have strong religious views, drew attention to this, and this concern has also been recognised by the American Society of Reproductive Medicine:

"A safe and effective means of separating X and Y-bearing sperm before *in vivo* artificial insemination or IVF is more likely to be sought by persons contemplating reproduction, for it causes no destruction of prenatal life and is less invasive and costly than other methods." 5

26. Despite these apparent advantages, however, there are other considerations that must be taken into account. Firstly, and most importantly, any health risks associated with the technique must be considered. Following that, since none of these techniques is guaranteed to sort sperm with complete accuracy, the level of efficacy or error rate must be taken into account (although the error rate is likely to decrease as the technology is further refined).

### Gradient Methods

### (a) Risk to health

- 27. Whilst there is very little information on the health risks of using gradients in sperm sorting (and these will depend significantly on the nature of the gradient used) there is currently no reason to suppose that the risks to women or offspring would be significantly increased by the use of this technique as the procedure is similar to that routinely used to prepare sperm samples prior to IVF treatments.
- 28. Where, as some studies have suggested is likely, there are insufficient sperm available to give a reasonable chance of success using intra-uterine insemination (IUI) following the sorting procedure, IVF using the sorted sperm might be recommended. If this is the case, the risks associated with IVF (see below) should also be taken into account.

# (b) Reliability of outcome

29. In order to compare the success rates of the various treatments it is necessary to be consistent about the measure used. This is particularly important with sperm sorting, as success in separating sperm does not necessarily lead to similar success in producing a child of the intended sex.

<sup>&</sup>lt;sup>5</sup> Ethics Committee of the American Society of Reproductive Medicine, 2001

- 30. The basis for selection with gradient methods is the different constitution of X and Y chromosome bearing sperm (X sperm have on average larger heads, necks and tails, higher dry mass, and 2%–3% more DNA than Y sperm). However, because human sperm exhibit a large degree of variation from average this difference is a less reliable guide in humans than in animals.
- 31. Different gradient solutions have been tried and these yield different results. For example, albumin gradients typically appear to have 15-30% error rate in separating sperm but it should be noted that most of the reports of success have come from clinics that offer these methods on a commercial basis and their results have not been independently corroborated. Some laboratory studies suggest that if sperm sorting through albumin gradients does contribute to sex selection it may not be due to enrichment of X or Y sperm but rather to some other effect resulting from the exposure of sperm to the albumin solution. Other gradients that have been tried have not been shown to give clinically significant results in controlled studies.
- 32. Where gradient separation is combined with sperm migration in a medium ("swim up") some reports suggest clinically meaningful results in terms of birth outcome, although only in a small number of live births. However when genetic techniques have been used to assess the success of these methods in separating X and Y sperm other studies have not found meaningful changes in the ratio between the two.

Summary	Pros	Cons
Sperm sorting by gradients: pros and cons	✓ No apparent increased health risk	X Not completely reliable
•		X Reasons for apparent
	✓ Cheaper than more	effectiveness unclear
	technologically	
	intensive alternatives	X Currently unregulated, therefore no quality
	✓ Less likely that embryos will be destroyed	control

# Flow cytometry

### (a) Risk to health

33. Although reports of the success rates using flow cytometry are encouraging, some concerns persist regarding the possible side-effects of the technique. Flow cytometry uses a proprietary DNA-binding fluorescent dye to stain the X and Y chromosomes of sperm. The sperm is then sorted based on this fluorescence. Large-scale studies would be necessary to put beyond doubt the question of whether there is any likelihood of damage to the sperm through the use of this technique.

- 34. When the technique has been applied to domestic animals, however, studies indicate that offspring are normal. Data in cattle, pigs and rabbits from follow up studies on at least three successive generations (nine in rabbits) report no increased levels to malformation and reproductive dysfunction after flow cytometry has been used to sort sperm. However these studies have only involved a few hundred animals and there is some indication that using the technique decreases sperm motility and embryo survival rate.
- 35. Currently, the American Food and Drug Administration (FDA) is conducting a large-scale evaluation of this technique which should be complete within the next two years. If it is to be used in humans on a licensed basis in the UK, the HFEA proposes to monitor outcomes very closely.

# (b) Reliability of outcome

- 36. Some reports suggest that when genetic testing has been used to confirm the success of this technique, purities of X- and Y-bearing sperm of 70%–90% have been detected a 1995 report, for example, showed success rates of between 80% and 86% for sperm separation. Following this a report on 332 patients in which 96 pregnancies were achieved following 663 treatment cycles, the desired sex was obtained in 94% of cases (37/39) for parents desiring females and in 73% (11/15) for males.
- 37. However other studies have suggested that the error rate in separating sperm does not necessarily correspond to the rate of failure to produce a child of the intended sex, indicating again that other factors besides the chromosomal (such as the timing of fertilisation or the conditions within the woman's uterus) may play a part in determining which sperm will fertilise the egg and which children will be born.
- 38. However, pregnancy rates are good thus allowing the use of sorted sperm in intrauterine insemination (IUI) rather than the more invasive and expensive IVF. Whilst the success rate of artificial insemination per cycle remains relatively low (around ten per cent on average), there are likely to be sufficient sperm sorted at one time to allow a number of cycles to be carried out. This widens the availability of the technology and reduces costs although despite its apparently high success rate in separating sperm, even the small error rate (for selecting females) may be unacceptable to patients seeking to avoid a severe sex-linked disease.
- 39. Furthermore, this technique is currently only available under commercial licence from a company based in the United States, and the equipment required to provide this technique remains expensive.

Summary	Pros	Cons
Sperm sorting by flow cytometry: pros and cons	<ul> <li>✓ Relatively high success rate</li> <li>✓ Sperm can be used for insemination rather than more invasive IVF</li> <li>✓ Less likely that embryos will be destroyed</li> </ul>	<ul> <li>X Not completely reliable</li> <li>X Currently unregulated, therefore no independent quality control</li> <li>X No conclusive studies confirming safety for use in humans, although no contraindications from use in domestic cattle</li> </ul>

# **Preimplantation sex selection**

- 40. A more reliable way of determining the sex of offspring than those discussed above is to use a technique called preimplantation genetic diagnosis (PGD). The technique typically involves several stages: the creation of embryos in the laboratory by IVF, the removal of one or more cells from each embryo a procedure which should not impair the development of the embryos the genetic testing of those cells for the presence of X or Y chromosomes, and the transfer of embryos of the required sex to the woman.
- 41. Although this technique is highly reliable, because the embryos all have to be created before they can be tested it is likely that those that are not of the required sex will be discarded. On the other hand, there is also the possibility that if there are relatively few embryos created, or if those created do not develop sufficiently well to survive, there will be no embryos of the required sex available for transfer in any one cycle of IVE.

### (a) Risk to health

- 42. Because this procedure tests the sex of cells taken from the actual embryos that will be transferred and uses well-established methods of genetic testing, it has a high degree of reliability when performed by a skilled scientist.
- 43. As far as the resulting child is concerned, PGD is safer in theory than sperm sorting techniques because the testing is conducted on cells that have been removed from (and are not replaced in) the embryo that will be transferred to the woman. This means that there is no danger of the genetic tests used damaging the embryo itself.

- 44. However, because cells must be removed (biopsy) there is a small risk of damage to the embryo as a result of this procedure. Embryo damage during biopsy usually means that the embryos do not develop and are not therefore transferred, so there is no reason to believe that there is any increased health risk to a liveborn child following from this technique: embryos not damaged during biopsy should continue to develop normally.
- 45. Nevertheless, because PGD is conducted on embryos created by IVF, the risks that are associated with IVF in general must also be taken into account. These include ovarian hyperstimulation syndrome (OHSS), a potentially life-threatening condition that can be caused by the drugs used to stimulate the woman's ovaries to produce large numbers of eggs (although women at risk are identified prior to treatment), and risks associated with multiple births if more than one embryo is transferred.

# (b) Reliability of outcome

- 46. When performed by skilled clinicians and scientists sexing embryos by PGD has a relatively low misdiagnosis rate (less than one per cent on average). There is also a small risk that the probes used will not bind to the DNA and there will be a failure to diagnose; patients and clinicians will then be faced with a choice of whether to discard the embryo or risk transferring it when its status is unknown. (It is not usually possible to re-test embryos where a diagnosis is inconclusive.)
- 47. Whilst many now regard IVF as comparable with natural conception in its likelihood of success (around 20 per cent per cycle started) the success rate (again, per cycle started) following PGD is slightly lower than 'straightforward' IVF, at around 12 per cent.
- 48. Additionally, as eggs are used fresh and only a proportion of those fertilised will develop normally, clinicians typically fertilise more than they need to give a good chance of obtaining enough suitable embryos. Whilst in routine IVF treatments embryos, unlike eggs, can generally be frozen for future treatment so if the woman is unsuccessful at the first attempt, the frozen embryos can be thawed and transferred in a future cycle the survival rate of embryos from which cells have been removed for testing is currently very low, so this option is not generally available. Women may therefore have to go through repeated 'fresh' cycles (involving hormone stimulation with its associated risks and invasive egg collection) until they are successful.

<sup>&</sup>lt;sup>6</sup> In the UK, embryo biopsy practitioners are required to demonstrate that they can perform the procedure reliably without damaging embryos.

Summary	Pros	Cons
Preimplantation sex selection: pros and cons	<ul><li>✓ Established technique</li><li>✓ Reliable diagnosis</li></ul>	<ul><li>Invasive and disruptive</li><li>requires IVF</li><li>treatment</li></ul>
	✓ Closely regulated and monitored in the UK	X May result in embryos of the unintended sex being produced which might then have to be discarded
		X More expensive than sperm sorting techniques

### Combined methods

- 49. A third option is to combine the two approaches discussed above (sperm sorting and PGD) and to conduct PGD on embryos that have been created with sperm that has already been sorted into 'X' and 'Y' samples.
- 50. Whilst this approach still requires IVF and is likely to be more costly than either of the other methods used singly, it offers the accuracy of PGD with a higher chance of suitable embryos being available for transfer by minimising the chances that embryos of the unintended sex will be created in the first place. On the other hand as only two embryos may be transferred in one IVF cycle if more than two eggs are fertilised it may still result in more embryos being created than can be used.

# Post-implantation sex selection

- 51. The oldest methods of sex selection are those which involve selecting which children will be born by terminating pregnancies where fetuses are shown, through prenatal testing, to be of the undesired sex, or, indeed simply killing new-born infants of the undesired sex (infanticide).
- 52. Termination of pregnancy on grounds of fetal sex alone is illegal in the UK under the Abortion Act 1967, although in cases in which there is a serious sex-linked disease there might be grounds for terminating a pregnancy if the fetus is at risk or if continuing the pregnancy will risk damaging the mental or physical health of the woman or other children in the family.
- 53. Infanticide is illegal in the UK.

Summary	Pros	Cons
Post-implantation sex selection: pros and cons	✓ Very reliable diagnosis	<ul> <li>X Illegal in the UK         (except for the         avoidance of serious         disease)</li> <li>X Highly invasive         (involves termination         of pregnancy)</li> </ul>

# Part Four: Legal And Regulatory Issues

- 54. Aside from those things which are explicitly prohibited by law (with which this consultation will not be concerned), the Human Fertilisation and Embryology Act 1990 gives the HFEA the power to control, through the licences it issues, the kinds of practice that may take place in licensed centres. Licences under the Act are required by any centre that carries out *in vitro* fertilisation (IVF), uses donated gametes (including donor insemination), stores gametes and embryos, or carries out research using human embryos.
- 55. Following a consultation on preimplantation genetic diagnosis in 1999 the HFEA confirmed that sex selection using PGD (and PGD in general) should only be available where there is a significant risk of a serious genetic condition being present in the embryo. This is consistent with current guidance on termination of pregnancy following (post-implantation) prenatal diagnosis if a fetus is shown to be at risk. The terms 'significant risk' and 'serious genetic condition' are inevitably contested and require to be interpreted in relation to given clinical situations. The HFEA has developed guidelines on what constitutes reasonable grounds for the use of PGD.
  - "Haemophilia, that's different, that's a serious problem. Colour blindness isn't a serious problem." (*Mother, 41-60, Edinburgh*)
- 56. However where the treatment does not involve the creation of embryos outside the human body or the use of donor gametes (i.e. where the fresh sperm of a woman's partner is used for insemination) the HFEA does not have the power to licence and regulate the treatment.<sup>7</sup> Therefore whilst PGD is closely regulated in the UK, sperm sorting can be offered at unlicensed clinics, thereby escaping regulation. (Centres that are licensed by the HFEA for other treatments should not use sperm sorting techniques as this is currently contrary to the HFEA's Code of Practice.)
- 57. The Human Fertilisation and Embryology Act 1990 and the HFEA Code of Practice impose strict requirements on centres offering licensed treatments. These include:
  - that centres may only use those licensable techniques for which they have a licence from the HFEA

<sup>&</sup>lt;sup>7</sup> Similarly, methods of assisted conception that do not involve fertilisation outside the body, for example gamete intra-fallopian transfer (GIFT) – in which a woman's eggs are collected and returned to her fallopian tubes with her partner's sperm so that fertilisation occurs within her body – do not require a licence from the HFEA.

- that clinics complete an assessment of the welfare of the prospective child before any treatment may be provided
- that fully informed consent is obtained from people receiving treatment
- that people seeking treatment are offered independent counselling concerning the implications of their treatment
- that information relating to treatments is recorded and reported in order to safeguard this information and to permit monitoring of treatments and the centres providing them
- that an annual inspection is carried out of the premises, staff and records of all centres providing treatment
- 58. The HFEA cannot license any technique unless it believes the technique to be necessary or desirable for the purpose of providing treatment services. Therefore in determining whether a new technique is to be licensed the Authority as a whole must first decide whether a technique should be permitted in general (whether it is ethically acceptable, whether any health risks associated with it are acceptable, and whether its use is in the interests of public health) and then an HFEA licence committee must decide whether a particular centre should be allowed to use it.
- 59. When centres apply to the HFEA to use techniques they must satisfy the licence committee that their premises, equipment and personnel meet standards that ensure that they are capable of delivering an acceptable quality of service to the public. (Whilst unlicensed centres may operate to high standards, there is no independent assurance that those standards will be met.)
- 60. Arguing for the regulation of sperm sorting is therefore not the same as arguing for it to be allowed to take place. Depending on the view taken as to its moral acceptability, its desirability, and the risks associated with it among other things, regulating sperm sorting may mean that it will not be permitted in the UK. Alternatively, it may mean that it will be permitted, but only in strictly controlled circumstances (e.g. for certain purposes), or only when the technology is proven to be sufficiently risk-free and reliable.
  - "It should be monitored by... a specialist organisation. I don't want to be too hard on the medical profession, but doctors... may be quite lackadaisical about regulating." (*Female, 18-30, Belfast*)
- 61. If sperm sorting is to be regulated by the HFEA, this does not mean that it will be available on the NHS except for medical reasons. In fact, it is likely that (other than where it is used for medical reasons) the additional cost of regulating the technique will fall on those using the treatment.

Summary	Regulation	Permitted uses
Sperm sorting	Unregulated where fresh partner's sperm is used for insemination. Where donor sperm is used or when it involves IVF it is regulated by the HFEA under the Human Fertilisation and Embryology Act 1990	Not currently permitted for regulated uses. Can be offered by unlicensed centres for any purpose where use is unregulated
Preimplantation Genetic Diagnosis	Illegal without licence. Licences are issued by HFEA under the Human Fertilisation and Embryology Act 1990	Permitted only for medical reasons (avoidance of serious sex-linked conditions)
Termination of Pregnancy	Regulated under the Abortion Act 1967 (as amended)	Permitted only for medical reasons

# Part Five: Ethical/Social Issues

# What people have said

- 62. We have seen that some uses of sex selection are currently viewed as ethically acceptable. The question therefore is where to draw the line between acceptable and unacceptable uses of sex selection. This is a very difficult task and this section considers some of the arguments that help people to draw this line. Many of them will be relevant to the questionnaire that follows.
- 63. In our discussion groups we found that overall, having discussed the issues, people tended to fall into one of three broad categories, although sex selection was found to be a subject on which absolute agreement between two people on every point was very rare.
  - One group felt that any interference with natural conception including IVF –
    was wrong, and that resources should be put into supporting those with
    disabilities rather than preventing them from being born.
  - A second group felt that the current approach, of only allowing sex selection for the avoidance of serious disease using methods of proven accuracy, was correct although they thought that people should be able to use sperm sorting in combination with PGD.
  - A third group felt that if the technology exists people should be given access to it, since it has the capacity to fulfil people's wishes, provided that it does not cause harm to either the people concerned or to their offspring. Nevertheless, this group would like to see the use of the techniques closely monitored and regulated.

# **Medical reasons**

- 64. The most straightforward area in which sex selection might be seen as acceptable is where it is used to enable prospective parents to avoid having a child with a serious sex-linked disorder.
- 65. Despite a relative lack of knowledge about the medical reasons for sex selection, public opinion does appear to favour this type of intervention. The view taken by the HFEA at present is that where there is a clearly identified risk of a couple having a child with a serious genetic disorder, the choices must be left to the couple or woman, and that no pressure should be exerted upon the woman to have or indeed not to have a child that may have inherited a serious sex-linked diseasei.
- 66. There is a strong feeling from the general public and also from service providers that this area should be properly regulated. The HFEA's research also shows a desire

for more considered debate in this area to provide well-understood guidelines for sex selection on medical grounds.

"If that is what they are allowing at the minute, then fine, I agree with that, but they just have to be careful about bending the rules." (*Father, 41-60, London*)

- 67. However, the practice of sex selection in order to avoid children with serious disabilities gives rise to concerns about unacceptable consequences if choices made in individual cases were to be generalised to the whole population. Some are concerned that certain genetic conditions should not be allowed to be eradicated from the gene pool in this way since they may have intrinsic value. Others raise more general objections that permitting individual choice in this matter (which, for reasons of justice could not then be denied to any who were in a similar position) amounts to condoning albeit unintentionally an unacceptable 'eugenic' practice. A further objection often raised is that there is a considerable danger that others will draw from the choices of individual parents to avoid having a disabled child the illegitimate inference that disabled people are in some way inferior beings who should not have been brought into existence.
- 68. Similarly there are concerns about the morality of eradicating a certain condition from a family blood line, especially if the risk is not an immediate one. This serves to demonstrate that doing something for a medical reason is not the same thing as having a good medical reason to do it. Alternatively, whilst there may be good medical reasons to do something, there may be better countervailing reasons, medical or otherwise, not to do it.
- 69. Furthermore, people have serious reservations about how existing legislation and practice might be used to extend choices to couples and women who are looking for a child with certain desirable characteristics which have no bearing on that child's health or physical well-being. At what point might the desire to have a healthy child translate into wanting a more 'perfect' child?

### Non-medical reasons

70. The issue which attracts most controversy is the possibility of sex selection for non-medical reasons, the kinds of personal and socio-economic reason identified earlier (see Part Two). The HFEA's research indicates that when the public are invited to consider the acceptability of sex selection for these reasons, those interviewed quickly break down the argument into issues concerning one's situation

The eradication of a disorder from the germ line (as opposed to the living population) is unlikely to occur when sex selection for X-linked disorders is used since female 'carrier' embryos will still be selected. (This might be a reason for some to prefer sex selection to direct testing of embryos for the condition.) However Spanish doctors have recently turned the technique around to select (unaffected) male embryos from men affected by haemophilia in order to eradicate this condition from future generations of their family.

as citizen and consumer, to moral and religious beliefs, and to issues relating to parenthood and family. Concerns raised by participants in our research typically included:

As a citizen, do we have the right to restrict other people's choices?

If the method is available, then everyone should have access to it.

If both parents and the child are going to benefit, what can the problems be?

It will happen anyway, and we as citizens have little power to stop it.

If it is going to happen in the UK, it must be regulated.

Allowing sex selection for non-medical reasons will send out worrying signals about gender preferences.

Anyone who wants to have a child cannot approach parenthood with such specific expectations – on the other hand, nobody wants a child unconditionally.

Having a child is an adventure which cannot and should not be so rigorously planned.

- 71. Once one begins to think through the matter, there is a wide range of complex considerations to be addressed. But however complex the issues involved may be, they do need to be addressed. Sperm sorting is already being used in the USA, and other countries are readily offering sex selection by PGD for non-medical reasons to those who are willing to travel there for treatment. At the same time high-profile individual cases in the UK are regularly testing public and professional opinion and attitudes towards those who permit, provide and choose to make use of assisted reproductive services.
- 72. This consultation may not provide absolute answers to complex questions of medical ethics, religious opinion, individual freedoms and the rights of unborn children. What the consultation should do is provide the HFEA and the UK Government with views on how and whether legislation and related medical practice is truly benefiting patients, and how any regulation should be conducted to safeguard the interests of patients and the public, and protect the welfare of children born as a result.
- 73. In what follows, this document seeks to lay out the main considerations for and against sex selection for non-medical reasons in the light of recent advances in technology and research.

The permissive argument for sex selection

- 74. A fundamental argument in favour of permitting sex selection for non-medical reasons is that where no one, including any future child, is harmed by this technique, it is not the state's proper business to intervene in order to prevent it.<sup>9</sup>
  - "It should be up to the individual. A lot of people will choose to get pregnant and take what they get, others will want to choose, even if they haven't got any children so far." (*Father*, 25-40, *Edinburgh*)
- 75. This argument is entirely consistent with the further thought that it would be proper for the state to intervene in order to regulate this activity (as applies already in the case of IVF). Indeed there is a strong argument that this is an area in which regulation should be required partly to ensure that standards of public health and safety are maintained, but also to ensure that the activity is carried out in a way which complies with the reasons for which it is permitted.
- 76. If the HFEA were to regulate all forms of sex selection, however, an extension of its present remit would be required to cover the use of sperm sorting where this is not combined with IVF or some other technique which is currently regulated. On the other hand some have suggested that the degree of regulation might be relative to the method used and that if the method is comparatively un-invasive and does not involve the creation of embryos outside the body it should be left to individuals. Others did not accept this:
  - "Sperm sorting doesn't change the ethics, it just changes the plumbing." (*Father*, 25-40, *Edinburgh*)
- 77. There is more to be said about this permissive argument, but it is useful first to introduce the main arguments against sex selection for non-medical reasons.

Arguments against sex selection

### (a) 'Playing God'

- 78. Many people feel that those who practice sex selection for non-medical reasons are seeking to exercise control over a matter which should be left uncontrolled. For some people, this attitude is related to their religious faith it is for God, and not for man, to determine the sex of a future child.
  - "It's wrong for any reason. It's saying you know better than what Allah wanted for you." (*Muslim father*, 25-40, *London*)

<sup>&</sup>lt;sup>9</sup> The coming into force of the Human Rights Act 1998 has given a renewed force to arguments asserting the rights of the individual against interference from the state.

- 79. Aside from arguments that sex selection is contrary to divine law, many religious objections are concerned with arguments about not artificially inhibiting human flourishing or infringing the inherent dignity of human beings. Others seek to draw conclusions about what is acceptable from the notion of a common humanity that must be respected. However objections of this sort need not be religious; instead they can simply be informed by a recognition that in having a child parents are bringing into existence a human being whom they should seek to nurture, but not to design or control.
  - "In the end you have to say that some things just aren't right. This is more than choice because you are interfering with things. You're not saying: 'Oh, I'll have that one on the shelf there:" (*Male, 18-30, Cardiff*)
- 80. Whilst some faith groups disagree with all medically assisted conception, believing that it represents interference with the will of God, others who accept basic IVF still have principled reservations about embryo selection, particularly where this will result in embryos being destroyed.

# (b) Sex discrimination

- 81. When one looks to the non-medical reasons prospective parents might have for sex selection, they are bound to involve parental preferences for having a child of one sex rather than another and thus, one might say, for discriminating between the sexes. Hence, the argument goes, to permit sex selection for non-medical reasons is implicitly to condone sex discrimination for example, the kind of discrimination whereby male children are favoured heirs when questions of inheritance are considered.
  - "Having a boy is like magic gold but it feeds discrimination." (*Muslim father*, 25-40, *London*)
- 82. For many people this is an important consideration, especially for those proponents of the permissive argument whose liberal position includes a commitment to opposing discrimination on grounds of sex. They might respond that there are some non-medical reasons for sex selection which are not based on objectionable forms of sex discrimination. The standard case here is that in which prospective parents who have one or more children of one sex seek to ensure that a future child is of the other sex. This is sometimes known as 'family balancing' and is considered further below.
- 83. Issues of sex discrimination are likely to be tied up with other factors, such as social, cultural, political, religious and economic pressures, which underpin or nourish them. In the UK in general the force of these is diminished in comparison with other countries, although they are still prevalent in some communities and sociodemographic groups.

- "Times are such now that we shouldn't discriminate by sex... What can boys do that girls can't now? We all have different relationships with mothers and sons nowadays." (*Mother, 41-60, Edinburgh*)
- 84. One perceived problem with sex selection is that it sustains the belief that sex that physiological differences between men and women determines temperament, social behaviour and other characteristic qualities of gender. Most participants in our discussion groups felt it was wrong to try to enforce gender roles although many thought this was impossible in any case:

"If you choose a girl to take her to the ballet, then she could be the biggest tomboy in the world and you'd be disappointed. You can't choose." (*Mother*, 41-60, *Edinburgh*)

# (c) The balance of the sexes

- 85. In some countries, economic and social conditions have resulted in the use of sex selection being biased towards male children. Economic and social pressures may encourage couples to have male children who can inherit family land, provide for extended families, and get better paid jobs than women. Although the improved status of women in most societies continues to reduce the use of sex selection in this way, in China, for example, there are currently 117 boys born for every 100 girls. The greatest demand for sex selection for non-medical reasons worldwide continues to come from countries such as India where social, economic and cultural pressures still favour males. One study has calculated that worldwide there are 100 million 'missing women', women who were never born or who perished as infants as a result of sex selection practices, deliberate neglect or infanticide. It can be argued that not only does this perpetuate damaging social attitudes towards women, it also has a knock-on effect for future generations, with fewer prospective brides and mothers for the increasing male population.
  - "I think Nature gets it right on the whole, and I don't think we would look at China and places like that." (*Mother, 41-60, Edinburgh*)
- 86. In European societies however, including the UK, studies have shown the there is a preference for girls (although a preference for boys persists within some communities). Data also suggest that it is couples with two or three children of the same sex and nearing the end of their reproductive life that are interested in sex selection for social reasons. More generally, however, it can be argued that if sex selection were restricted to family balancing it would not significantly alter the overall sex ratio.

<sup>&</sup>lt;sup>10</sup> British Medical Journal, Vol. 324, 25 May 2002.

<sup>&</sup>lt;sup>11</sup> British Medical Journal, Vol. 304, 7 March 1992, pp.587-8.

### (d) Welfare of the child

87. Whilst sex selection for medical reasons appears generally to be about the health and well-being of the prospective child, non-medical reasons tend to be about the preferences of the prospective parents. As indicated above (Part Three) current data show that the most reliable current method of sperm sorting leads to error in about 25 per cent of cases in which a male child is sought and 5 per cent of cases in which a female child is sought. Hence there are grounds for concern that a couple who seek a sex-selected child for non-medical reasons but who do not get the male or female child they want may have difficulties in accepting their new child since it is of the 'wrong' sex, and that this may have profound implications for that child's welfare.<sup>12</sup>

"If someone wants a nose job and it goes wrong, then they just have to live with it. If someone's been allowed to do this so that they can have a boy and it goes wrong the consequences for that child are horrendous." (*Mother, 41-60, Edinburgh*)

- 88. Plainly these issues are contingent upon the limited reliability of current sperm-sorting techniques and one can envisage the improvement and development of much more reliable techniques in future. PGD is, as noted above, more reliable but it is also much more invasive, expensive and ethically problematic, since it involves the creation and disposal of unwanted embryos.
- 89. Even where a child of the intended sex is born, there are important anxieties about the child's welfare. How would a child react upon being informed that it had been selected for its sex? Furthermore there are similar concerns about the welfare of other children that may be affected by the birth:

"If you have to have three before you have the sex you want, what's your relationship with those three going to be like?" (*Mother, 41-60, Edinburgh*)

# (e) Equality

90. Sex selection for non-medical reasons is unlikely to be made available through the NHS. As a result, depending on its cost, it may only be available to the relatively well-off, and some feel that this is unfair.

"When the discussion's general, then you can think about these things in a moral way, but when it comes to individuals, you get greedy." (*Mother*, 25-40, *London*)

<sup>&</sup>quot;A woman shall not be provided with treatment services unless account has been taken of the welfare of any child that may be born as a result of the treatment (including the need of that child for a father), and of any other child who may be affected by the birth." (Human Fertilisation and Embryology Act 1990, section 13(5)) Whilst this does not exclude any category of woman from being considered for treatment, before providing treatment, licensed centres are required to take steps to discover whether there are any reasons why people should not be provided with treatment.

91. Clinics have been quick to see the potential market for services offering sex selection for social reasons, and the emotive nature of procreation is used as a means of encouraging women to go for particular treatments at particular clinics. It should be observed, however, that it is unlikely to cost as much as IVF (at least if it involves only sperm-sorting and IUI), which is not at present readily available on the NHS. So even if sex selection is not freely available to all, it can be argued that it is not easy to see that this is by itself a reason for prohibiting it, any more than the fact that IVF is not currently freely available to all is a reason for prohibiting IVF treatment.

# (f) The 'slippery slope'

- 92. It is sometimes argued that to permit sex selection for non-medical reasons is to take a step down a 'slippery slope' which will lead ineluctably to permitting parents to select embryos for frivolous reasons, and thus to the creation of 'designer babies'. Most people in our discussion groups connected the higher expectations and more specific demands of modern parents with consumerism entering into reproduction from other areas of life.
  - "Everything has to be designer for the young ones; when they have babies, they have to come with a Gucci label." (*Mother, 41-60, Edinburgh*)
- 93. On this view, there is no principled barrier between permitting sex selection and permitting selection of other traits such as hair or eye colour. However, the argument continues, this is an outcome which is plainly unacceptable and this just reveals, in a magnified form, the unacceptability of starting down this route with sex selection for non-medical reasons in the first place.
- 94. This concern is related to the fact that as new techniques become available people will always find plausible reasons for wanting to use them. Thus there will always be marginal cases which will erode the line that has been drawn between acceptable and unacceptable uses of technology.
  - "People always want more, and if they know they can, they will. And they'll argue 'who wouldn't want to have a more intelligent child?' Of course that child would have a better life, and if we allow people to choose the sex of their child, we wouldn't have a leg to stand on when they start on that road." (*Father*, 41-60, *London*)
- 95. Those who argue for the permissive approach may respond that the genetic techniques involved in the selection of traits, particularly behavioural and character traits such as IQ and sexuality, are at present entirely speculative and are likely to remain so for a long time. Many would argue that this response is not by itself persuasive, however, since the objection is that sex selection for non-medical reasons embodies a commitment to approving of potentially objectionable possibilities (such as the selection of the sexuality of a child) even if they remain only

hypothetical possibilities. Hence as long as those arguing for permissiveness endorse the judgement that these possibilities are objectionable, something further needs to be added about the acceptability of the reasons prospective parents might have for sex selection which does not carry over to the selection of other physical or character traits.

# Family balancing

- 96. As indicated earlier, it is an implication of these arguments against sex selection that the best case for sex selection for non-medical reasons is where it rests on the wishes of prospective parents who already have one or two children of one sex, to have a child of the other sex. For where this is the rationale behind it, objectionable forms of sex discrimination are not involved.
- 97. But it can still be argued that even family balancing remains objectionable for some of the other reasons outlined above:
  - it involves the attempt by parents to exercise control over a fundamental aspect of their future child, thus potentially interfering with the unconditional love that parents owe to their children and giving rise to anxiety about the attitude of the parents if a child of the 'wrong' sex is born
  - it is liable to involve the imposition of stereotypical gender roles on a child of the 'right' sex who has been born by this technique
  - unless more is said about the special nature of the rationale for family balancing, it is unclear what distinguishes it from objectionable forms of selection, such as the hypothetical selection of character traits
- 98. The reply to these points will be that for some prospective parents there is distinctive value in having a family in which there are children of both sexes both because the children will grow up with a member of the other sex and because some parents relate more directly to a child of the same sex than to one of the other sex. These are contentious claims, and many will say that there is nothing wrong or 'unbalanced' about a family in which the children are all of one sex. Those who take the permissive view might respond that their argument does not involve the claim that there is anything wrong about such families; all it does claim is that, for some people, there is something potentially better about families where children are of both sexes a claim which is much less contentious. The argument then turns on why, if this greater good can be realised by sex selection in a way which does no harm to others, should the state seek to prevent it?
- 99. Many will find this unpersuasive and will point back to the objections identified above as reasons against allowing this form of sex selection. As was remarked earlier, it is not the purpose of this document to argue for a position one way or another. Instead, the aim is to facilitate rational debate on this sensitive issue so that any decisions taken by Government are informed by public opinion. Therefore we very much hope that you will complete and return the enclosed questionnaire.

# Part Six: Appendices

# **Appendix 1: Glossary**

# **Assisted Reproductive Technologies**

(ARTs) — The collective name for all techniques used artificially to assist women to carry children, including IVF, ICSI, PGD, and IUI.

- Chromosome Chromosomes carry the information necessary for the development and functioning of the body. Humans normally have 46 chromosomes in the nucleus of their body's cells (22 pairs plus two sex chromosomes, denoted X and Y).
- Donor Donors are people who consent to allow their gametes or embryos to be used in the treatment of others. Although donors are the genetic parents of children created using their gametes, if the treatment is provided in a licensed centre in the UK they are not the legal parents of these children. (The legal parents are the woman giving birth and usually her husband or male partner if she has one.)
- Egg The gamete produced by the female during her monthly cycle. The nucleus of an egg always contains an X chromosome, having 23 chromosomes in all. In technical language the egg is sometimes called an oocyte.
- Embryo An embryo is produced by the joining of egg and sperm (fertilisation). The embryo develops into a fetus and then a baby.
- Fertilisation Fertilisation is the joining of a sperm and an egg to produce an embryo. Naturally fertilisation occurs

- in the woman's body (*in vivo*) but it can also occur in the laboratory (*in vitro*).
- Fetus After about 4 weeks of development in the woman's womb, during which its tissues have begun to differentiate, the embryo becomes a fetus.
- Flow cytometry (sperm sorting) —
  A method of sperm sorting that involves staining the X and Y chromosome-bearing sperm with different fluorescent dyes, and then sorting them according to the colour.
- Gamete The common name for eggs and sperm. A gamete has half the number of chromosomes of any other
- **Gradient** A dense liquid used to sort sperm.
- Gradient methods (sperm sorting) —

A method of sorting sperm based on the different constitution of X and Y sperm. The sperm are typically put with a gradient and subjected to centrifugation to separate them. (This may be combined with swim-up.)

Insemination — The introduction of sperm into a woman's body to create a pregnancy. Artificial insemination can be done using either freshly ejaculated sperm or sperm that has been frozen. Where the sperm of a donor is used (donor insemination or DI) this will have been frozen to allow time for the donor to be screened for transmissible diseases before insemination takes place.

In vitro fertilisation (IVF) — A common technique for overcoming infertility, whereby eggs are collected from the woman and fertilised with sperm in the laboratory. Up to two resulting embryos are then transferred to the woman's uterus to begin a pregnancy.

# Preimplantation Genetic Diagnosis (PGD)

— A technique that allows clinicians to test embryos created *in vitro* for the presence or absence of certain genetic traits that would lead to severe disability. The HFEA (jointly with the Advisory Committee on Genetic Testing, now the Human Genetics Commission) held a consultation on the circumstances in which PGD should be used in 1999.

Sperm — The gamete produced by the male, usually through ejaculation.

Millions of sperm are present in each ejaculate and roughly half of these will carry X chromosomes, the other half carrying Y chromosomes. In technical language a single sperm is sometimes called a spermatozoon.

Sperm sorting — The separation of sperm carrying X chromosomes from those carrying Y chromosomes prior to fertilisation in order to determine the sex of offspring.

Swim up — A technique for separating sperm, based on their ability to swim through a liquid.

Uterus — The woman's womb, in which the embryo develops into a baby.

# **Appendix 2: Consultation Criteria**

The Cabinet Office produces guidance for Government departments and agencies for UK national public consultations.

The consultation criteria

Reproduced from the Cabinet Office Code of Practice on Written Consultation (www.cabinet-office.gov.uk/servicefirst/2000/consult/Index.htm)

"The criteria in this code apply to all UK national public consultations on the basis of a document in electronic or printed form. They will often be relevant to other sorts of consultation

Though they have no legal force, and cannot prevail over statutory or other mandatory external requirements (e.g. under European Community law), they should otherwise generally be regarded as binding on UK departments and their agencies, unless Ministers conclude that exceptional circumstances require a departure

The criteria should be reproduced in consultation documents, with an explanation of any departure, and confirmation that they have otherwise been followed

- 1. Timing of consultation should be built into the planning process for a policy (including legislation) or service from the start, so that it has the best prospect of improving the proposals concerned, and so that sufficient time is left for it at each stage
- 2. It should be clear who is being consulted, about what questions, in what timescale and for what purpose
- 3. A consultation document should be as simple and concise as possible. It should include a summary, in two pages at most, of the main questions it seeks views on. It should make it as easy as possible for readers to respond, make contact or complain
- 4. Documents should be made widely available, with the fullest use of electronic means (though not to the exclusion of others), and effectively drawn to the attention of all interested groups and individuals
- Sufficient time should be allowed for considered responses from all groups with an interest. Twelve weeks should be the standard minimum period for a consultation
- 6. Responses should be carefully and open-mindedly analysed, and the results made widely available, with an account of the views expressed, and reasons for decisions finally taken
- 7. Departments should monitor and evaluate consultations, designating a consultation coordinator who will ensure the lessons are disseminated"

# Compliance with the Consultation Criteria

- 1. See paragraph 5
- 2. See paragraph 100
- 3. See pages 3 and 4 and Appendix 3
- 4. See Appendix 3
- 5. See page 34
- 6. See paragraph 7
- 7. See Appendix 3

# **Appendix 3: Further Information/useful links**

Additional copies of this consultation document are available free of charge and can be obtained by contacting:

Vishnee Seenundun Consultation Co-ordinator HFEA Paxton House 30 Artillery Lane London E1 7LS.

telephone: 020 7377 5077 email: admin@hfea.gov.uk

The consultation document can also be downloaded from the HFEA website at: www.hfea.gov.uk

If you have any questions regarding the content of this consultation, please contact Peter Mills, HFEA Policy Manager (contact details as above).

If you have any general questions regarding this or any other HFEA consultation, please contact Vishnee Seenundun, HFEA Consultation Co-ordinator (contact details as above).

If you have any complaints regarding the consultation please contact Kerri Treston, HFEA Consultation Complaints Officer (contact details as above).

# Part Seven: Questionnaire

The consultation is open to any organisation or member of the public in the United Kingdom. The consultation period will run for three months from October 22, 2002 to January 22, 2003. All responses received before the closing date of January 22, 2003 will be taken into consideration. Responses should be sent to:

Vishnee Seenundun
Consultation Co-ordinator
HFEA
Paxton House
30 Artillery Lane
London E1 7LS
email: admin@hfea.gov.uk

We welcome as much information as possible, and if there is insufficient space on the enclosed form for your comments please continue on a separate sheet of paper, indicating to which question the information you are providing relates. The HFEA would be pleased to receive submissions in any form, but it would be helpful, should you choose to submit information in an independent form, if you would also tick the relevant boxes on the questionnaire.

To allow a more detailed analysis of the information we receive it would be helpful if you could also indicate whether you have a professional or organisational interest in the issues discussed and are replying on behalf of an organisation.

Finally, please do not forget to include your full name and the name of your organisation where applicable, and to indicate whether the information you have provided may be made public. In line with the Cabinet Office Code of Practice on Written Consultation responses to this consultation may be made public unless confidentiality is specifically requested.

# PAGE 1

# HFEA SEX SELECTION CONSULTATION: QUESTIONNAIRE

Name:	
Organisation (if applicable):	
Address:	
Position of person responding	in organisation (if applicable):
	Do you agree to the HFEA making your response publicly available?
	☐ Agree ☐ Disagree
Those responding on behalf o	f an organisation:
	Which of the following categories most closely describes the nature of your organisation?
	<ul> <li>□ Clinical/scientific</li> <li>□ Consumer</li> <li>□ Disability</li> <li>□ Religious and faith</li> <li>□ Other (please specify)</li> </ul>
Those responding as private in	ndividuals (optional):
	Which of the following categories most closely describes the reason for your interest in the issues raised in this consultation?
	☐ Clinical/scientific ☐ Patient/consumer ☐ Other (please specify)



Please respond by placing a tick in one box for each question below.

# Regulation of Sperm Sorting (questions 1 and 2)

_	
1.	Sperm sorting should be regulated in the United Kingdom by the HFEA.  Agree Disagree  Reasons:
2.	The use of sperm sorting should be permitted <b>only</b> when its reliability and absence of risk to health have been satisfactorily established.    Agree Disagree  Reasons:
Uses	of sperm sorting and PGD (questions 3 to 6)
3.	The use of sperm sorting should be permitted in sex selection for <b>medical</b> reasons if the people seeking treatment request it.  Agree Disagree  Reasons:
4.	The use of sperm sorting should be permitted in sex selection for <b>non-medical</b> reasons.  Agree Disagree  Reasons:



	5.	The use of preimplantation genetic diagnosis (PGD) should be permitted for selecting the sex of offspring for <b>non-medical</b> reasons. (It is already available for medical reasons).  Agree Disagree  Reasons:
	6.	It would be preferable to combine sperm sorting with preimplantation genetic diagnosis (PGD) when selecting the sex of offspring for <b>medical</b> reasons (rather than using either technique singly).  Agree Disagree  Reasons:
(	Crite	ria for non-medical uses of sex selection (questions 7 and 8)
	7.	Sex selection (by either sperm sorting or PGD) should be permitted for <b>non-medical</b> reasons when a family has at least two children of one sex and none of the other sex.  Agree Disagree  Reasons:

Please send all three pages of your responses by January 22, 2003, to:

Vishnee Seenundun, Consultation Co-ordinator HFEA, Paxton House, 30 Artillery Lane, London E1 7LS

