



# Choices & boundaries report

**2006**

A summary of responses  
to the HFEA public  
discussion

HUMAN  
FERTILISATION  
&  
EMBRYOLOGY  
AUTHORITY

### 1.1 Aims of the public discussion

The aim of *Choices & boundaries* was to gather the views of the public, patients, the medical profession and interested parties on the use of preimplantation genetic diagnosis (PGD) for a group of inherited cancer conditions. The discussion focussed on conditions caused by a genetic fault that increases the likelihood of developing a specific type of cancer. They include inherited breast cancer, inherited ovarian cancer and a type of inherited bowel cancer, Hereditary Non-Polyposis Colon Cancer (HNPCC).

These inherited cancer conditions are potentially treatable, they do not develop until adulthood and the genetic fault causes a susceptibility to cancer rather than a certainty of developing it. This makes them different from conditions previously licensed by the Human Fertilisation and Embryology Authority (HFEA) for PGD. Because licensing of these conditions for PGD would be a departure from current practice, the HFEA wanted to engage the public on this issue and capture the views of interested members of society to inform the Authority decision.

There were two strands to the public discussion; a written document, to which stakeholders were invited to send responses, and an open meeting. Both the written document and the meeting discussed PGD for inherited cancer susceptibility in the context of guidance issued by the HFEA on PGD. The views expressed at the meeting and in the written responses are summarised in this document.

## 2.1 Licensing of PGD by the HFEA

### The Act

PGD is a technique that is regulated by the HFEA because it involves the creation of embryos outside of the body (*in vitro*). Although there is no specific mention of PGD in the *Human Fertilisation and Embryology (HFE) Act (1990)*, PGD is licensed under the HFE Act as a 'practice designed to secure that embryos are in a suitable condition to be placed in a woman or to determine whether embryos are suitable for that purpose<sup>1</sup>.' The use of PGD must also be 'necessary or desirable for the purpose of providing treatment services<sup>2</sup>'.

### The Code of Practice

In addition to the legal provisions in the HFE Act (1990), the HFEA produces guidance for clinics in the *Code of Practice*. This guidance includes a section on PGD. The PGD guidance in the 6th Edition of *the Code* was developed after extensive public consultation in 1999 and has allowed centres and the HFEA to make decisions about PGD applications. The full guidance is available on our website [www.hfea.gov.uk/HFEApublications/codeofpractice](http://www.hfea.gov.uk/HFEApublications/codeofpractice)

### Licensing decisions and the current guidance

If the HFEA receives an application to licence PGD for a lower penetrance cancer susceptibility condition, the final decision will be made by a Licence Committee. In reaching its decision, the Licence Committee will look at whether the proposed treatment is lawful under the Act. Then it will satisfy itself that the decision to provide the treatment has been properly made having regard to the current guidance in the *Code of Practice* and the Authority policy. The *Choices & boundaries* document invited the general public, patients and other interested parties to look at the same guidance and reach their own conclusions.

The guidance in the *Code of Practice* is that:

*Indications for the use of PGD should be consistent with current practice in the use of (post implantation) prenatal diagnosis (PND).*

*It is expected that PGD will only be available where there is a significant risk of a serious genetic condition. The perception of the level of risk by those seeking treatment is an important factor in the decision making process. The seriousness of the condition is expected to be a matter for discussion between the people seeking treatment and the clinical team.*

*In any particular situation ... [the view of the people seeking treatment] ... are expected to be considered when deciding the appropriateness of PGD. In any particular situation the following factors are expected to be considered when deciding the appropriateness of PGD:*

- (i) The view of the people seeking treatment of the condition to be avoided*
- (ii) Their previous reproductive experience*
- (iii) The likely degree of suffering associated with the condition*
- (iv) The availability of effective therapy, now and in the future*
- (v) The speed of degeneration in progressive disorders*
- (vi) The extent of any intellectual impairment*
- (vii) The extent of social support available and*
- (viii) The family circumstances of the people seeking treatment<sup>3</sup>*

<sup>1</sup> HFE Act 1990 Schedule 2 1(1)(d)

<sup>2</sup> HFE Act 1990 Schedule 2 1(3)

<sup>3</sup> HFEA Code of Practice 6th edition chapter 14

### 2.2 Why consider these conditions?

The HFEA has licensed over 50 single gene conditions for PGD, examples of which can be found on the website at

[www.hfea.gov.uk/about/hfea/policy/preimplantationgeneticdiagnosis](http://www.hfea.gov.uk/about/hfea/policy/preimplantationgeneticdiagnosis)

The conditions that have been licensed for PGD previously are serious conditions that are usually present in the child when it is born. There have been exceptions to this. For example, PGD has been licensed for late onset conditions such as Huntington's disease, which does not ordinarily manifest until late adulthood. The HFEA has also previously licensed a type of bowel cancer, Familial Adenomatous Polyposis (FAP). It is therefore not the fact that the conditions under review cause cancer or have a later time of onset that makes them a new issue for the HFEA licensing process. Instead, it is a combination of factors that make these conditions different from those that have been licensed before.

#### What is different about these conditions?

The inherited cancer susceptibility conditions discussed in *Choices & boundaries* are different from other conditions that have been licensed by the HFEA because of a **combination of three factors**:

1. they are late onset and
2. they are lower penetrance and
3. they are potentially treatable

#### Breast cancer and ovarian cancer

Inherited forms of breast and ovarian cancer can both be caused by faults in the (**BR**east **CA**ncer) BRCA 1 and BRCA 2 genes. Around 5-10 per cent of all breast and ovarian cancer are caused by an inherited fault in one of these predisposition genes. The age at diagnosis for breast cancer in women with such an inherited fault is about 10 to 20 years earlier than for sporadic breast cancer.

Women who carry a fault in the BRCA 1 gene have a lifetime risk of breast cancer of about 80 per cent, and 40 per cent of ovarian cancer — women carrying a fault in the BRCA 2 gene have a similar risk of breast cancer but a smaller risk of ovarian cancer. Men carrying these mutations have some increase of prostate cancer risk, and men who carry an alteration in the BRCA2 gene have a 5-7 per cent risk of developing breast cancer in their lifetime. Screening measures are not sufficiently sensitive and specific at present and so prophylactic options to reduce the risks of breast and ovarian cancer (mastectomy and oophorectomy) are often considered, although management of these risks is likely to improve with time.

#### Bowel cancer (Hereditary non-polyposis colorectal cancer (HNPCC))

Individuals with HNPCC have up to an 80 per cent lifetime risk of colorectal cancer and increased risks of uterine cancer (up to 60 per cent) and other mostly gastrointestinal cancers. Screening is available by colonoscopies annually from 25 years, and ultrasound scans may be offered to women with HNPCC. The age at diagnosis of colorectal cancer in the condition is usually in the forties but can be earlier.

## 02 Introduction (Continued)

### Onset

Most of the conditions we have licensed for PGD affect the child when it is born or from a very early age. The age of onset for inherited cancer susceptibility conditions is usually the late thirties or forties.

### Penetrance

Penetrance refers to the likelihood of developing a condition when the faulty gene that causes it is present. Most conditions that have been licensed are fully penetrant or highly penetrant, so if the gene is present the condition will almost always develop. The conditions that are being considered here have a lower penetrance than conditions that have been licensed before and for this reason for this discussion they have been called 'lower penetrance cancer conditions'. Although termed lower penetrance conditions, breast cancer caused by a mutation in either the BRCA1 or BRCA2 gene still has a penetrance up to 80 per cent. If the mutation is in the BRCA1 gene there is also a 40 per cent chance of developing ovarian cancer and the risk of ovarian cancer with the BRCA2 gene is slightly lower. For HNPCC, the lifetime risk of developing bowel cancer is up to 80 per cent and this condition also causes an increased risk of developing uterine cancer.

### Treatability

Although some of the conditions currently licensed for PGD are manageable, few are treatable. However, there are treatment options available for cancer such as chemotherapy or surgery and many people are treated effectively. For those who know they are at high risk of developing breast cancer or bowel cancer, preventative surgery to remove the tissue that would be affected is a risk-reducing option. It is also likely that the treatment options for cancer conditions will improve in the future.

### Why consider them now?

Several PGD centres have expressed an interest in applying to us to carry out PGD for breast cancer. No application has been received to date to do PGD for any of these conditions, and therefore there has been sufficient time to consider the issues, within the Authority and more publicly, without delaying a specific application.

## 03 Who participated in the *Choices & boundaries* discussion?

There were two stages to Choices & boundaries; an open meeting and a written discussion. The breakdown of people that participated in the meeting and the written discussion are below.

### The meeting

The open meeting was held in London on December 12th 2005. The meeting was introduced by Professor John Burn (a clinical geneticist with a specialist interest in colorectal cancer) and chaired by Professor Neva Haites (clinical geneticist and member of the Human Fertilisation and Embryology Authority). The public meeting was attended by 118 people. The biggest proportion of those that attended the meeting were academics and people who work in or with IVF centres.

### The written discussion

The written document, *Choices & boundaries*, was launched in November 2005 and was open to responses until January 2006. There were 283 respondents to the written document. A significant majority of those who responded to the written document were school pupils and interested, non-affiliated members of the public.

As the tables show, the distribution of stakeholders involved in the meeting differed from those that responded to the written document. The meeting and the written responses represented quite different groups of stakeholders. The issues discussed in *Choices & boundaries* were considered by a large number of pupils who responded to the document. The HFEA was really pleased that there was such a strong interest in this by younger members of the public and that *Choices & boundaries* had such a broad reach.

	Number	Percentage
Patient or Patient group	9	8%
IVF Clinician or scientist	14	12%
Academics	28	24%
Government departments / bodies and MPs	7	6%
Fertility counsellor	1	1%
Clinical/ scientific (Cancer)	11	9%
Journalist	3	3%
Genetics counsellor/Clinical geneticists	10	8%
Royal college	2	2%
Interest/ pressure groups	7	6%
Gene parks/ knowledge parks	4	3%
Medical others	4	3%
Religious groups	1	1%
Pupils	12	10%
Others	5	4%
	<b>118</b>	<b>100%</b>

	Number	Percentage
Patient or Patient group	4	1%
IVF Clinician or scientist	11	4%
Academics	10	4%
Interest/ pressure groups	5	2%
Government departments/ bodies and MPs	3	1%
Fertility counsellor	2	1%
Cancer clinician or scientist	2	1%
Genetics councillor/Clinical geneticists	3	1%
Unaffiliated	60	21%
Royal colleges	7	2%
Gene parks/ knowledge parks	2	1%
Medical others	5	2%
Religious groups	7	2%
Others	4	1%
Pupils	158	56%
	<b>283</b>	<b>100%</b>

## 04 The Questions

The intention of this discussion was to gather a broad range of views and to allow respondents to answer as freely as possible. To achieve this, the questions were open, allowing people to respond without having to choose from specific, predetermined options. Because the questions were open, it was appropriate to present themes and general findings rather than attempt a numerical analysis of the responses received.

Most of the questions were based on a general acceptance of PGD and were focussed on the extended use of the technique to include PGD for lower penetrance inherited cancer susceptibility conditions. This meant that some of the respondents who did not agree with PGD found it difficult to specifically address some of the questions.

All statements and views have been supported with a quote taken from the responses received where respondents were happy that their views be made public.

### Question 1: Do you agree with the use of PGD in general?

*Choices & boundaries* considered the extended use of PGD for a specific group of conditions. It did not reconsider the existing principles and guidance that are applied to the use of PGD by the HFEA. However, it was necessary to address this because it helps to put into context the responses to the other questions. It was important to know whether people agreed with PGD in general but not for these uses or, whether they disagreed with all PGD, which would naturally mean that they disagreed with any extended purposes. This question was not considered at the meeting where the focus was on the other questions in the discussion document. Therefore, the views summarised below only represent those from the written responses.

The views in response to this question were varied. There were people who agreed with the current uses of PGD, people who did not agree with any PGD and some who specifically stated that PGD should only be carried out for serious conditions. Of those that agreed with PGD the reasons for doing so were because it prevented further suffering within families where the condition is present whilst allowing people to have genetically related children. Some people also commented that PGD is preferable to having prenatal diagnosis followed by termination of an affected pregnancy.

The people that agreed with PGD, but only for serious genetic conditions, often did not qualify the statement with a reason but by specifying that the condition has to be serious it is clear that these people would not consider PGD to be appropriate for 'trivial' reasons. What is considered to be trivial was not identified and is likely to differ from person to person. This is something that is considered in the final question where the 'boundaries' are discussed. It is interesting that this view was expressed because the Guidance issued by the HFEA for PGD states that PGD should only be allowed where there is a significant risk of a serious genetic condition. What constitutes serious is another question that was considered as part of *Choices & boundaries* and this is discussed below.

The people that disagreed with the current uses of PGD did so because PGD results in embryos being discarded or killed, as they saw it. The people who felt this way are also likely to disagree with IVF treatment in general because embryos surplus to the needs of the couple are often also discarded. Other people who disagreed did so for a reason more specific to PGD. They felt that because ‘faulty’ embryos are discarded, it devalues the lives of people with those conditions and disabled people within society. By saying that it is acceptable to not replace an embryo with an inherited genetic condition, they felt it sent a message that the lives of people who suffer from the condition are not worth living.

Another reason given for disagreeing with PGD was the belief that it was drawing resources away from finding a cure for these conditions. People who gave this reason felt that instead of focussing on having children free from a given condition, the money should instead be spent on learning how to cure or treat it to make the lives of existing affected people easier.

“I do agree with PGD in general. PGD has already helped many couples to have healthy, genetically related children and prevented suffering.”

*IVF clinician*

“For fully penetrant conditions associated with high morbidity or significant mortality. PGD is much preferable to other forms of prenatal diagnosis that might result in the termination of a much more mature fetus.”

*Member of the public*

“No one has the right to decide if another life is worth living or not”

*Member of the public*

... with the improvement of IVF pregnancy rates and a possible increase use of PGD and PND, there is the risk that those born with a genetic disorder will become very few in number. [...].

As a result, extensive research to find new treatments for these disorders will be considered as unprofitable with any relevant investments in research remaining minimal.

*Scottish Charity*

### Question 2: Given the lower penetrance, later age of onset and potential treatability of inherited cancer conditions, do you consider them to be serious genetic conditions?

The HFEA guidance on the use of PGD states that PGD should only be available where there is a ‘significant risk of a serious genetic condition’. This question was asked to find out whether respondents felt that the factors that make these inherited cancer susceptibility conditions different from others licensed by us (later onset, lower penetrance and potentially treatable) would also preclude them from being considered as serious genetic conditions.

Some people felt that inherited susceptibility to bowel and breast cancer was a serious condition while others did not. There was also a group of people that specifically said that inherited cancer susceptibility conditions were not serious enough to warrant PGD.

#### **Inherited cancer susceptibility conditions are not serious**

Those that thought that inherited cancer susceptibility was not serious or not serious enough felt this way because the conditions are later onset and potentially treatable. The fact that the conditions would not even develop in everyone who has a faulty copy of the gene also contributed to some people’s view that these conditions are not serious.

Some people also reasoned that because the conditions are late onset, any person born now who carried the faulty gene would not develop the condition for thirty or forty years. This means that anyone affected by an inherited susceptibility to breast, ovarian or bowel cancer could live thirty or forty perfectly healthy years before developing the cancer, by which time the treatability of these types of cancers is likely to have significantly improved.

People that said the conditions were not serious enough to warrant PGD did so because it resulted in embryos being destroyed. To them the severity of the condition did not justify the discarding of human embryos.

### **Inherited cancer susceptibility conditions are serious**

The people that said an inherited cancer susceptibility was serious felt so because the conditions can be fatal, although treatable, people commented that the treatment itself is not trivial and is also not always effective. A number of people also commented on the significant impact that developing the condition can have on the person's family life, especially at a time when those affected may have young dependents. So although the impact is later, these people felt that the timing of development of the condition was significant and potentially very disruptive to the affected person's family.

Also relating to the age of onset of inherited cancer conditions, some people commented that although the conditions do not manifest until later in life, there is a significant burden associated with knowing that at some point the cancer may develop. One person likened this to the sword of Damocles hanging on a thread over their head. People affected by an inherited susceptibility to cancer are anxiously waiting for the cancer to develop (the sword to fall) all their lives.

"Carrying the gene does not cause a certainty of developing the condition. However, knowing that doesn't take the worry away."

*Breast cancer patient support group*

"they are not so serious that the preferred option is to end the life at an embryonic stage, annulling all the potential joy of that life for the individual and that family "

*Member of the public*

"Breast and ovarian cancer or colon cancers may be treatable, but there is a serious risk of death plus trauma of removing organs."

*Academic bioethicist*

"I think that all inherited cancer conditions are serious conditions"

*Embryologist*

"We know that progress is being made now in terms of treatment, therapies and understanding of cancer. We can expect that in 50 years time it will be an utterly different picture and that treatment will have been developed and be able to cure this disease."

*Bioethicist – Interest group*

No, potentially treatable cancer conditions are not serious genetic conditions until they manifest themselves. The individual can and should lead a normal life until then.

*Member of the public*

It is not always inevitable that the genetic condition will develop, nor does diagnosis indicate the severity. It only gives an indication of risk.

*Bioethicist – Interest group*

**Question 3: Does the penetrance of a condition affect whether you consider it to confer significant risk? What is the lowest penetrance that would confer significant risk?**

This question was asked to understand how people felt that penetrance relates to 'significant risk'. The chance of developing an inherited cancer such as those being discussed here depends on the penetrance of the condition; the higher it is, the greater the risk of developing the cancer. The HFEA guidance states that the perception of the significance of the risk by those seeking treatment is something that needs to be taken into account in the decision making process. So to some extent significance is subjective and is something that only the affected individuals seeking treatment can address. However, for the purpose of this discussion, the relative importance of penetrance could be determined by considering it in light of this guidance.

Some respondents did not answer this question, either because they felt that it was inappropriate to name a specific penetrance below which PGD would no longer be suitable, or because they disagree with all PGD. This question assumes a general acceptance of PGD: if people do not agree with the current uses of PGD it is difficult to comment on any extension of its uses.

Of those that did name a specific minimum penetrance that would confer significant risk the answers ranged from 1 per cent right up to 100 per cent. An example of a reason given for answers in the 1-10 per cent range was that any risk is enough. These people felt that any risk above that of the general population was enough to warrant PGD. The reason given by those people that thought 100 per cent was the lowest penetrance acceptable was that PGD involves the destruction of embryos and therefore only fully penetrant conditions should be tested for with PGD. A proportion of people mentioned 50 per cent as the lowest penetrance acceptable and the reason for this was that at this penetrance there was a higher chance that you would develop cancer than you would not.

There was a view that penetrance is not the only factor that should be taken into account. Interestingly, people thought this regardless of whether they felt that a high or low penetrance value was required to determine significant risk. People felt that penetrance cannot be considered without taking into account other features of

the condition. For some respondents this may mean that for very severe conditions, a lower penetrance may be acceptable whereas for a mild condition, only a very high penetrance would be acceptable.

Some people commented that significance is something that only the person at risk can determine. This fits with the point mentioned earlier suggesting that significance is subjective and the HFEA guidance that says that the significance of the risk by the person seeking treatment is something that needs to be taken into account when making clinical decisions about PGD.

*"Since affected embryos are destroyed, I think only a very high penetrance justifies PGD"*

*Member of the public*

*"I don't think penetrance can altogether be separated from seriousness of the condition. You ask us to pick a number without us being able to press the question of how serious the breast cancer associated with the mutation is.*

*I understand that the form of breast cancer associated with the BRCA mutation is very very serious and that obviously is a reason for thinking that the penetrance of that does not need to be very high."*

*Philosopher (bioethics)*

*"I think if the risk for that patient seemed high and frightening and there is a possibility to avoid that risk, I cannot see myself [...], arguing against it."*

*IVF expert*

*"The Society considers that a 30-80% risk of developing the condition is significant enough to justify PGD for serious genetic conditions"*

*Professional society*

*I reject the presupposition that any individuals with genetic conditions should be identified and selectively destroyed. This is regardless of risk.*

*Medical practitioner*

**Question 4: How much emphasis should be placed on the views of those people seeking treatment?**

The HFEA guidance on PGD states that the views of the people seeking treatment are a factor that should be taken into account. The views of people seeking treatment are also important for determining the significance of the condition. This question was asked to understand how important the views of the people seeking treatment are relative to other factors taken into account in the decision making process.

Some people thought that the views of the people seeking treatment are important and should be taken into account when considering the availability of PGD. Some people went further and said that it should only be the views of the people seeking treatment that are considered. The reason given for the above answers often reflected the experience that patients have with the conditions and that actually they are the ones that are likely to have seen family members suffering from the cancer that runs in their family and know what it is like to live with the knowledge that they may also develop the cancer.

Some people disagreed with this and thought the views of the people seeking treatment should be balanced with other views. This was because they felt that people seeking treatment are not objective whereas society and professionals are. They thought less emphasis should be placed on the views of the people seeking treatment than of professionals and society in general.

*“In my opinion almost total emphasis should be placed on the views of the people seeking treatment. It is the people from the families themselves that are best placed to assess the impact of the inherited condition.”*

*Geneticist*

*“What we think does not matter. It should actually be what the families think and at the end of the day they are the only people that can actually tell us how that affects them.”*

*Nurse*

*“Clearly people seeking treatment cannot be objective so little emphasis should be placed on their views when considering the ethics of this treatment.”*

*Member of the public*

*“Patients have a biased view point naturally and most clinicians empathise and are grossly biased also. If the public are properly informed about these issues then you can get the view point from society but if the public are not well informed then we cannot expect to get rational or sensible opinions from society”*

*IVF clinician*

**Question 5: Do you agree that the availability of PGD should be determined by current practice in prenatal diagnosis?**

This question was asked to understand whether people felt there are some conditions where PGD would be appropriate where perhaps prenatal diagnosis followed by termination of pregnancy would not be.

A proportion of people that disagreed with PGD did not answer this question.

**PGD availability shouldn't be determined by current practice in prenatal diagnosis**

Respondents to both the written discussion and participants at the public meeting seemed to think that the availability of PGD should not be determined by current practice in prenatal diagnosis. The reasons for thinking so, however, were not consistent. The difference in reasoning was largely dependant on how the embryo in vitro is viewed compared to a fetus in utero. Some people do not agree with either PGD or prenatal diagnosis followed by termination and therefore did not think that the availability of PGD should be guided by prenatal diagnosis. For some respondents PGD was more appropriate than prenatal diagnosis because PGD does not involve the termination of an already established pregnancy and therefore the availability of PGD should not necessarily be limited by current practice in prenatal diagnosis. There were also comments that legally PGD and terminations are regulated in a very different way so it is actually quite difficult to compare the two techniques.

**PGD availability should be determined by current practice in prenatal diagnosis**

Some people thought that the availability of PGD should be determined by prenatal diagnosis to ensure that there is consistency across services.

*"We do not really agree that the use of PGD should be consistent with current practice in prenatal diagnosis. [...] Perhaps PGD should be offered more widely because testing of the embryos occurs at an earlier stage"*

*Genetic counsellors*

*"If PGD were not available then [the patient] would probably decide not to have children. [Patients] don't want to go through the abortion route as they have enough stress in their life"*

*Patient representative*

*"We have done some work with cancer patients and whether they would have PND for [inherited cancer conditions] and 90% would say yes for breast cancer but only 2% would have a termination [if the fetus carried the faulty gene].*

*A lot more would want PGD if it was available."*

*Clinical geneticist*

*"The rules in the Abortion Act are that there has to be a substantial risk of handicap but that's not subject to any regulation from a third party like in PGD, it is entirely a clinical decision.[...] The two are very different."*

*Legal expert*

*"One issue for consideration is the status of the embryo. The view that we take - and I suspect it is one that is held fairly widely in society - is that the embryo in vitro does not have the same moral status as the fetus in vivo and there may be a different justification for terminating a pregnancy than to test and discard embryos. One conclusion we may well reach is that conditions that wouldn't satisfy serious handicap under the Abortion Act may nevertheless be suitable for PGD."*

*Bioethicist - Interest group*

### Question 6: Where do you feel the boundaries for PGD lie?

There is no intention following this discussion to produce a list of conditions that are not appropriate for PGD. However, the purpose of asking this question was to find out which conditions people thought should never be tested for using PGD. The HFEA guidance states that PGD should only be available where there is a significant risk of a serious genetic condition being present in the embryo and therefore PGD would not be licensed for cosmetic conditions where there were no medical consequences.

The views on this were quite diverse. Some people felt that the boundary has been passed and PGD is already available for too many conditions. Another group of respondents felt that PGD should not be allowed for conditions that are easily treated or for cosmetic, non-medical traits or for the positive selection of physical traits. Some people specifically said that the lower penetrance inherited cancer conditions such as the ones under discussion here should not be tested for using PGD while others drew the line at behavioural conditions such as Asperger's. One person referred to a recent Nuffield Council on Bioethics report on behavioural genetics which said that PGD should not be allowed to select for positive personality traits such as intelligence.

There were also some people that felt no condition should be ruled out (no absolute boundaries should be drawn) and that it should be up to the patients or the people seeking treatment to decide.

"PGD should never be permitted for cosmetic or cultural reasons [...] or for easily surgically treatable conditions. Nor should it be used to treat late onset or treatable, or potentially treatable, conditions"

*Member of the public*

"The conclusion that was argued was that PGD is totally unacceptable for behavioural or social conditions as it was felt they were more parental preferences. The parents were predestining the child as being well behaved. It would be terrible for PGD to be associated in this way with these conditions."

*Philosopher (bioethics)*

"Specific learning difficulties like Aspergers, dyspraxia, dyslexia, ADHD, etc, could be future candidates for PGD. This would be highly undesirable. It would look like eugenics or social engineering."

*Member of the public*

PGD should not be used to test for any condition. Screening embryos, with a view to destroying, if certain criteria are not fulfilled, should not be carried out, as it is eugenic in nature

*Member of the public*

"The drawing up of lists and the setting of arbitrary boundaries is inappropriate in our view. [...] Setting boundaries is likely to create suffering and injustice for those who fall on the "wrong" side of the line but who turn out to have a particularly unfortunate version of the presenting condition."

*Patient group*

## 05 Findings of the Choices & boundaries public discussion

The views of those involved in the *Choices & boundaries* discussion varied significantly and no overall consensus emerged on the use of PGD for inherited cancer susceptibility conditions. However, there were some questions where there was agreement, often where there were quite different views on PGD in general. For example, people felt, although for very different reasons, that the availability of PGD should not be determined by current practice in prenatal diagnosis. There was also consensus around the issue of penetrance and significant risk where there was some agreement that penetrance alone was not the only factor that should be taken into account.

At the public meeting there was general support for the use of PGD for inherited cancer conditions. The majority of people at the meeting considered these conditions were serious genetic conditions and did 'fit' the HFEA guidance on the use of PGD. The views of the people that responded to the discussion document were much more varied. There was a significant proportion of people who responded to the written document who did not agree with the use of PGD to avoid passing on an inherited susceptibility to the cancer conditions in question. Amongst this group there were those that disagreed with all PGD and IVF treatments that result in the destruction of embryos as well as those who might agree with PGD in general but felt that PGD for the conditions in question is not appropriate.

The lack of an overall consensus is probably unsurprising as it is almost impossible for compromise or consensus on issues where the views of respondents, and society in general, are so polarised and this highlights the difficult environment in which the HFEA has to make decisions.



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