Scottish Council on Human Bioethics

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Consultation Paper on Choices & Boundaries: Should people be able to select embryos free from an inherited susceptibility to cancer?

Consultation response on behalf of the Scottish Council on Human Bioethics:

The **Scottish Council on Human Bioethics** (SCHB) is an independent, non-partisan, non-religious registered Scottish charity comprising doctors, lawyers, psychologists, ethicists and other professionals from disciplines associated with medical ethics.

The SCHB subscribes to the principles set out in the ***United Nations Universal Declaration of Human Rights*** which was adopted and proclaimed by the UN General Assembly by resolution 217A (III) on 10 December 1948.

The SCHB is grateful to the HFEA for this opportunity to respond to the consultation entitled ***Choices & Boundaries.*** It welcomes the HFEA's intent to promote public consultation, understanding and discussion on the licensing of PGD.

In addressing the consultation, the SCHB has formulated the following responses:

Question 1: We are interested to find out how you feel about using PGD to test for lower penetrance conditions such as inherited breast cancer. To help put your views about this in context, it is important to understand how you feel about PGD for fully penetrant conditions such as cystic fibrosis or Haemophilia. Do you agree with the use of PGD in general. For example, for fully penetrant conditions that are present in the child? Please give reasons for your answer.

SCHB response:

Along with many other like-minded individuals and organisations, the SCHB is of the view that the practice of PGD is fundamentally flawed as it fails to recognise the true nature of, and hence undervalues, human embryos. Following the creation of the embryo, when the genetic composition of the individual is determined, the development of this embryo is a continuous process right through to adulthood. Any attempt to demarcate a point in this process, before which an embryo should be considered a person, is arbitrary. In the absence of clear evidence to the contrary, the precautionary principle dictates that even the earliest embryo should be accorded full protection as a human being. In Germany, for example, the embryo is protected right from the one-cell stage of the fertilised egg (Embryo Protection Act (12.13.1990)[1]). Since PGD anticipates the intentional rejection (and usually destruction) of some embryos, it is clearly not in accordance with recognising such a status, and the SCHB believe it is therefore ethically unsound.

In addition, many maintain that individual totipotent cells (such as those removed for diagnostic purposes in PGD) should themselves be regarded as embryos. This is true, for example, in Germany where the legal definition of an embryo is:

- **"*the fertilised egg from the moment of the fusion of the cell nuclei of egg and spermium, and***

[1] Wolfrum R, Zeller AC, Legal Aspects of Research with Human Pluripotent Stem Cells in Germany, *Biomedical Ethics*, 1999; Vol.4, No.3.

- ***every totipotent cell taken from an embryo since these cells have the potential to develop into a human individual*."[2]**

This means that, according to German legislation, every cell of the 8-cell embryo (third-fourth day of embryonic development) is under the strongest possible protection of the German Embryo Protection Act since every cell is totipotent and legally qualifies as an embryo[3]. In addition, Paragraph 2 of the Embryo Protection Act leaves no possibility of discretion when it states that it is forbidden "*to dispose of an embryo, or to deliver, acquire, or use an embryo for purposes not serving its preservation*"[4]. Elisabeth Hildt summarises this when she explains that in German law "*a totipotent cell derived from a human embryo in its development is considered equivalent to a human embryo, as long as this cell is able to develop into a human being. Thus it is prohibited to destroy either an entire human embryo or a totipotent cell derived from a human embryo*."[5] This means that all biopsies of totipotent cells for research or analytical purposes such as in PGD are forbidden, even if the embryo from which they are taken is not harmed, since the cells used for the analysis and their subsequent destruction may also be considered as embryos.

It is clear that no consensus regarding the ethical nature of the early embryo or totipotent cells has yet been reached internationally (it is illegal in Austria, Italy and Ireland as well as Germany). Given that many respected organisations, and various national legislations, consider the early embryo to be due full protection as a human being, the SCHB regrets that UK legislation regards the early embryo as so readily dispensable.

In view of the value that the SCHB believes should be attached to human embryos, another issue associated with PGD is the fate of spare embryos. The SCHB would like to see a study undertaken relating to their prospects and whether they should be discarded, frozen, adopted by other parents, used for research or have any other fate.

Because of the complexity and limited understanding of the effects of gene mutations, most genetic diseases will remain untreatable for the foreseeable future. In other words, the only procedures available to health care professionals to address many genetic disorders remains the use of PGD and prenatal diagnosis (PND). However, 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. This would result in such disorders being considered as rare or 'orphan' diseases by governments and the pharmaceutical industry. 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.

Question 2: The HFEA guidance to PGD centres states that PGD should only be available where there is significant risk of a **serious genetic condition**. Given the lower penetrance, later age of onset and potential treatability of inherited cancer conditions, do you consider them to be *serious* genetic conditions? Please give reasons for your answer.

SCHB response

Whilst the SCHB is opposed to the use of PGD, it is of the view that the seriousness of the genetic conditions for which PGD is permitted must surely be considered in the context that human embryos will certainly be destroyed in carrying out PGD.

The SCHB is particularly concerned that the proposed extension of PGD, to mere susceptibilities to e.g. late-onset cancers, is but the first step down a slippery slope which will see PGD approved for progressively less serious conditions. In consultations such as this it

[2] Wolfrum R, Zeller AC, Legal Aspects of Research with Human Pluripotent Stem Cells in Germany, *Biomedical Ethics*, 1999; Vol.4, No.3.

[3] Wolfrum R, Zeller AC, Legal Aspects of Research with Human Pluripotent Stem Cells in Germany, *Biomedical Ethics*, 1999; Vol.4, No.3.

[4] Wolfrum R, Zeller AC, Legal Aspects of Research with Human Pluripotent Stem Cells in Germany, *Biomedical Ethics*, 1999; Vol.4, No.3.

[5] Hildt E.; Preimplantation diagnosis in Germany; *Biomedical Ethics*; 1996, Vol.1., No.2.

seems that fears of a slippery slope tend not to be given their due weight, perhaps even dismissed as reactionary. But the recent case where abortion was justified on the basis that a cleft palate was deemed to represent a "serious handicap"[6] clearly illustrates that such fears are well-founded.

Question 3: The HFEA guidance to PGD centres states that PGD should only be available where there is significant risk of a serious genetic condition. Does the penetrance of the condition affect whether or not you consider it to confer a significant risk? In your opinion what would be the lowest penetrance – in percentage terms – that would confer significant risk? Please give reasons for your answer.

SCHB response:

The SCHB is of the opinion that any answer to this question would be completely subjective.

It seems to the SCHB entirely inappropriate to consider destroying an embryo only because there is a possibility that it may be affected by a genetic condition.

Question 4: The HFEA guidance to PGD centres states that the views of the people seeking treatment should be taken into account when considering whether to offer PGD. There needs to be a balance between the views of those people who would seek to use PGD to avoid passing on a condition and the views of wider society that may have ethical concerns about them doing so. In your opinion, how much emphasis should be placed on the views of those people seeking treatment? Please give reasons for your answer.

SCHB response:

As soon a couple asks a third party, such as the state, for assistance in the field of human reproduction, this third party has a responsibility and therefore also a say in the procreative process. There is no 'right' to have a child and if a third party, such as a government which represents the views of the general public, does not agree with a procedure, it does not have a duty to comply.

Thus, it is not only those seeking treatment who are best placed to judge the seriousness of a condition. Society should have the final say whether or not a procedure should be implemented.

It is generally recognised that those directly affected by a medical condition feel its effects most acutely, and clearly their views must be given substantial weight. On the other hand, it is understandable that such people are likely to consider primarily their own interests rather than wider implications of their actions. But, for the good of society, it is essential that decisions of this nature take full account of relevant ethical considerations. It is for this reason that any decision to permit PGD for a particular condition should not lie exclusively with those requesting the treatment. Very likely it is not possible to quantify how much say those people seeking treatment should have. Perhaps for each condition for which PGD is sought, the issue should be submitted for consideration to a group comprising people directly affected by the condition, medical practitioners with experience of working with affected people, and impartial professionals drawn from *inter alia* medicine and ethics. And it should be noted that some of the most passionate objections to the use of embryo selection come from disabled persons who find it highly offensive that society should judge their lives as not worth living.

The SCHB is particularly concerned that when the choice is left to those requesting treatment then it tends to progressively devalue the embryo, especially as in most cases of using PGD a significant number of embryos remain unused and usually are ultimately destroyed. Such a development took place in the 'saviour sibling' cases such as the Hashmi couple, who fought for the right to have a tissue-matched IVF baby to save the life of their older son. In this case,

[6] Curate wins abortion challenge - 1 December 2003 - BBC: http://news.bbc.co.uk/2/hi/health/3247916.stm

six IVF cycles were undertaken and a significant number of embryos created but without any success[7]. In the Nash case, though the procedure was eventually successful with the birth of a baby boy who was a match for his older sister, 30 embryos were created and four pregnancies attempted for the birth of one child.[8] There is a very real concern that PGD may enable parents, in the future, to enter into a kind of 'embryonic creation and destruction relentlessness', where ever more embryos are created and destroyed with the aim of having an unaffected child or saving the life of one of their existing children.

Question 5: The HFEA guidance to PGD centres states that the use of PGD should be consistent with current practice in prenatal diagnosis. Do you agree, with respect to lower-penetrance conditions, that the availability of PGD should be determined by current practice in prenatal diagnosis? Please give reasons for your answer.

SCHB response:

The SCHB is concerned that the extent to which prenatal diagnosis is performed is not known in the UK because centralised records are not kept. This is a serious deficiency in the regulation of practices with eugenic implications. So far as this consultation is concerned, given that it is not possible to know how the current HFEA guidelines relating to PND are being worked out in practice, it limits useful comment on whether similar guidance would be appropriate for PGD.

In order for society to be better informed concerning developments in the use of PGD and PND, the SCHB believes it is important that adequate information relating to the practice of PND and PGD be made publicly available. This information should give the nature of the genetic disorders being selected out, and the number of embryos and foetuses being destroyed for each disorder. Without this, it is not possible for society to give an informed opinion on any possible future increases in the number of genetic conditions being included in screening programmes.

It has been suggested that the issues raised by the use of PND and PGD are different[9] and that whereas selective termination following PND is applied to a foetus that has already implanted and is developing in the womb, PGD is used to select which embryos to implant. In other words, it has been implied that whereas PND would be used to end a life, PGD would, in effect, be used to choose which life to start. Hence, the moral prohibitions which apply in the case of PND, do not apply in the same way in the use of PGD.
The SCHB, however, takes issue with the above view. It would, instead, like to indicate that the ethical nature of PGD should first be examined before any discussions are considered concerning its use. In many countries such as in Italy, Austria, Ireland and Germany, PGD is prohibited and any health care professional undertaking such a procedure would be committing a criminal offence.

Question 6: The HFEA wants to know where you feel the **boundaries** for the use of PGD lie. Considering penetrance, age of onset and treatability, what type of condition do you think should never be tested for in embryos using PGD? Please give reasons for your answer.

SCHB response

The SCHB is of the view that any boundaries for PGD will, ultimately, be completely arbitrary and will come under pressures to go down the ethical slippery slope.

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[7] Hashmis fail in 'saviour sibling' attempt, Bionews 9 July 2004, http://www.bionews.org.uk/new.lasso?storyid=2180

[8] Genetic testing of embryos raises ethical issues, CNN.com, 27June 2001, http://archives.cnn.com/2001/HEALTH/06/27/embryo.testing/

[9] Genetics and human behaviour: the ethical context, Nuffield Council on Bioethics, 2002, para: 13.66

The present HFEA consultation on PGD for lower-penetrance disorders is a very good example of an organisation sliding down this ethical slope towards full-blown eugenics.

Once tests are available, there is pressure from medical staff to encourage parents to use the tests as a matter of course. This has already taken place for PND where parents who choose not to have their child tested – because they would not abort the child whatever the result, as they recognise the intrinsic value of human life, regardless of dis/ability – may be regarded as, and made to feel, abnormal. And the same is occurring as PGD becomes more readily available.

On the other hand, as the technology develops and selection becomes more commonplace, many parents will not only want their children free of serious genetic disorder, but also free of minor defects, and then of characteristics that are of no health significance whatsoever.