

No to Eggsploitation: The Case Against Payments for Egg Donation

March 2011

Summary

This briefing makes the case against HFEA proposals to increase compensation payments for egg donors. We argue that increasing payments above current levels will create financial incentives to donate. This would violate the international consensus against the commercialisation of human tissue, which has always governed blood and tissue donation in Britain. In particular, it is against the spirit of the EU Tissues and Cells Directive. It will create a form of exploitation ('eggsploitation'), in which poor women and students with large debts will be induced to take significant health risks, and inevitably, some will be harmed, as has happened in Eastern Europe over the last ten years.

We show that the risks of egg donation are greater than the HFEA acknowledges, and that there is a lack of adequate monitoring of the most well known risk, Ovarian Hyperstimulation Syndrome.

The HFEA has argued that increasing compensation would help to overcome the shortage of donors in Britain. However, there are many problems with this argument. Firstly, it is wrong to change ethical rules in order to achieve pragmatic goals, and we question why the supply of eggs should be expected to meet the demand. Secondly, only IVF clinic staff and the HFEA support the idea; there is no call for increased compensation from donors, parents and the public at large, and donor-conceived people are strongly opposed to the idea, because they do not want their 'donor parent' to have been motivated by financial gain. Thirdly, there is no evidence that increasing compensation will actually succeed in increasing the number of altruistic donors: evidence from

Spain, whose approach the HFEA wants to copy, suggests that most donors there are motivated by financial gain. Allowing compensation payments to donors will also price the NHS out of the market and make it harder for less well off infertile women to access IVF.

We review several aspects of the HFEA's behaviour and arguments and show that over the last decade there is a consistent pattern of bias in favour of free-market approaches. In this latest case, it is obvious that this ideological bias rather straightforwardly serves the commercial interests of the IVF industry, which is concerned about the loss of egg donation business to Spain and other EU countries, due to the shortage of donor eggs in the UK. The current cuts in welfare and impending increases in student debts, introduced by a right-wing government will also help in the realisation of the industry's plans.

In HGA's view the trend towards financial compensation for egg donors has already gone far enough. Rather than looking for loopholes in the EU Directive, Britain should stick to its spirit, not merely its letter. The shortage of donors should be addressed by campaigns to recruit more altruistic donors, not by removing basic ethical safeguards, which are there to protect vulnerable people. There is no doubt that more donors can be found if more money is made available for recruitment campaigns, and if clinics follow up properly on donor's offers.



1. Introduction

This briefing covers the issues raised by proposals by the Human Fertilisation and Embryology Authority (HFEA) to introduce compensation for women who donate eggs for other women for fertility treatment. THE HFEA launched a review of its policy in this area in 2009, just three years since its last comprehensive report (the SEED report¹) on the issue in 2006. It has argued that the donor shortage and the associated problem of 'fertility tourism' (couples travelling abroad for fertility treatment) justify revisiting the question of payments to tissue donors. In July 2009, the new Chair of the HFEA, Lisa Jardine, gave an interview to The Times², in which she stated that it might be appropriate to simply pay women for their eggs in order to boost the number of donors. In fact, Jardine was unaware of the EU Tissues and Cells Directive (2004/23/EC), which prohibits this.

Why is this an important issue? In brief, the concern raised by those proposals is that they go against the ethical principle that parts of the human body should not be traded as commodities like any other type of goods, which has traditionally governed blood and organ donation in Britain. This is not merely a theoretical concern: the abuses and exploitation of poor, mainly Third World people involved in the international black market for human organs are well known and there are many efforts by governments and other bodies to curb the trade.

In the case of eggs, an international trade developed in the early 2000s, with clinics in Eastern Europe and Cyprus supplying many British and other Western European 'fertility tourists'. Two factors contributed to this phenomenon: the opening up of cheap flights to the region, and the fact that donors were white, and often blonde. There have been many media reports about the harm suffered by the

donors, who were often given excessive doses of hormones by the clinics, in order to maximise the number of eggs that could be extracted. Many donors were hospitalised due to side effects of the hormones, and some suffered permanent damage to their health and fertility³.

The harm to women caused by the European egg trade shows that concerns about compensation payments are not merely theoretical

The HFEA has its own, not very reassuring, role in this story. A British IVF centre, the Bridge Clinic in London, established a connection with the GlobalART clinic in Bucharest, which was set up specifically to take advantage of the large pool of young, poor women. The HFEA sent a team to inspect the Romanian clinic, and decided that its standards were acceptable; it seems that it was unaware of the clinic's practice of paying donors. Following complaints from a Romanian lawyer representing two of the donors, who had suffered as a result of the hormone injections⁴, the clinic was shut down by the Romanian authorities. But although the most extreme abuses have now been curbed within the EU, there are still reports of the continuation of this 'eggsploitation'⁵.

The EU Tissues and Cells Directive, which was passed partly in order to curb the international organ black-market, prohibits anyone from buying and selling human tissue for profit. This means that, although IVF clinics can make a profit on their services, they cannot do so for simply supplying eggs. They can cover their expenses and staff costs for supplying eggs, but they cannot charge a "mark-up" on eggs. The Directive allows donors to be reimbursed for the direct expenses and 'inconvenience' of donation, with national authorities in the member states setting the level of compensation. Thus, the Directive bans direct payments for eggs, but contains a potential loophole: if the amount of compensation for inconvenience of donation is set at a high level, this can function as a financial incentive. In 2006, the HFEA decided that whilst donors could be reimbursed for expenses, and loss of earnings up to £250, compensation for inconvenience was not appropriate since it could act as a financial incentive.

The HFEA has now changed its mind and is proposing to copy Spain, where the authorities have allowed clinics to pay women 1,000 Euros in 'compensation' for what the EU Directive calls the 'inconveniences' of donation; this has served to greatly increase the supply of donor eggs there, making Spain the preferred destination for British women who cannot receive egg donation in the UK because of the shortage of eggs here (see below). As we discuss below, there plenty of evidence that donors in Spain are primarily donating in order to get the compensation money. The Czech Republic is the only other EU country that permits significant compensation of donors.

Part of the reason for the existence of 'fertility tourism' from Britain to Spain is the shortage of eggs in Britain for infertile women who need them in order to have a baby. Each year around 1000 women donate eggs, but this is not enough to meet the demand, and as a result women may have to wait two or three years for an egg. This shortage has existed since egg donation began in Britain, but one factor that as least temporarily exacerbated it was the passing of legislation in 2005 which removed anonymity from both egg and sperm donors. The reasons for this change were the demands from people conceived by sperm and egg donation to be able to trace their 'donor parent' when they reached the age of 18. As expected, this initially led to a drop in the number of donors, but the numbers have now risen again, due to recruitment campaigns, and the number of donors is now greater than it was in 2005⁶.

In this briefing, we will refer to the HFEA's policy proposals in favour of donor compensation as firm plans. The HFEA, of course, insists that it has not made up its mind on these issues and is simply consulting stakeholders and the public. However, there are many reasons for doubting this, not least of which is Lisa Jardine's statements in 2009. The HFEA was clearly embarrassed by her remarks, but tried to insist, implausibly, that Prof Jardine's personal views did not indicate any particular policy preference of the HFEA. In mid-2010, the HFEA was forced to issue a statement to counter the impression in media reports that it had already made its mind up⁷. There are many aspects of the way that it has conducted the review so far, such as inadequate research in certain key areas, culminating in an extremely biased consultation document (see below), which have

made its intentions very clear. Finally, to those experienced in observing the HFEA, this pattern is no surprise: it typically decides policy before launching consultations; on one occasion it granted provisional licences to researchers before the consultation about the new research was even launched. This behaviour has attracted criticism, not merely from pressure groups, but from academics, many times in the past.

2. The HFEA understates the risks of egg donation

What is involved in egg donation? Firstly, the woman's ovaries are shut down by hormone injections. Then she is given or self-injects hormones (Follicle Stimulating Hormone, FSH) to stimulate the growth of ovarian follicles, plus a gonadotropin-releasing hormone (GnRH) agonist to block the normal surge of luteinizing hormone (LH), which could cause the woman to ovulate before the physician retrieves the eggs. She subsequently self-injects the hormone human Chorionic Gonadotropin (hCG, similar to LH) to effect egg maturation. When the eggs are ready, the woman is brought into surgery, where she receives intravenous sedation, after which a probe is placed in her vagina. A hollow needle emerges from the probe, and penetrates through the back of the vagina and into the ovary, where under the guidance of ultrasound technology, the eggs are collected. In addition to the significant risks described below, there are many side effects, such as tiredness, mood swings and headaches, which make the process stressful over a period of weeks.

This process of 'superovulation' involves taking complete control over the woman's natural cycle, in order to induce her ovaries to produce 10 or more eggs. A normal cycle is controlled by a set of finely tuned feedback mechanisms designed to produce only one mature egg per month, so the body's complex system is being forced to do something very unnatural, and this requires large hormone doses. It is not surprising that these would have potentially dangerous effects on the body.

Ovarian Hyperstimulation Syndrome

The most important short-term risk is Ovarian Hyperstimulation Syndrome (OHSS), which is a purely iatrogenic (resulting directly from medical intervention) condition, not seen in women who are not undergoing hormonal stimulation. In brief, this happens when the overstimulated ovaries secrete molecules which induce blood vessels to become leaky, releasing fluid into the 'third space' between organs, particularly in the abdomen. This leads to two sets of problems. Firstly, the fluid released causes abdominal swelling, which affects the functions of many organs, causing vomiting and diarrhoea in moderate cases. In the most severe cases it compresses the lungs, causing breathing problems. Secondly, the loss of fluid from the blood can lead to thrombosis and strokes, which can be fatal.

It is very difficult to get reliable figures for the frequency of OHSS. There is no national system for monitoring numbers and severity of cases, and estimates of the frequency vary very significantly between different studies. The HFEA only records numbers of cycles cancelled due to OHSS, which will be significantly less

than the total number of cases. The Royal College of Obstetricians and Gynaecologists (RCOG) says that up to 33% of women suffer mild symptoms, whilst 3-8% of IVF cycles are affected by moderate or severe cases⁸, which require hospitalisation and emergency management. Some studies have found up to 8% severe OHSS⁹. However, IVF doctors and the HFEA quote much lower figures (see below)). This lack of agreement indicates how little is really know about the risks of OHSS. The number of deaths is also unclear, as the HFEA's own review by Professor Adam Balen¹⁰ acknowledges; recent data led him to conclude the number may be higher than previously thought, and that there may be 1 or 2 OHSS deaths per year in Britain.

There is even less adequate research on risks to donors than for IVF patients. One study on egg donors found a 1% risk of severe OHSS¹¹. The only other study,

which is more recent, found that 11.6% of 155 egg donors in the USA had to be hospitalised for OHSS¹². As noted above, the real world has been the laboratory, with many cases of harm reported in the media, from Eastern Europe, Korea and the USA. In the case of Eastern Europe, and Cyprus, it is clear that many of these clinics applied

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excessive doses of hormones. In some cases, clinics paid donors a bonus if they produced larger numbers of eggs¹³. But it should not be assumed that British clinics will necessarily treat their donors much better than those in Eastern Europe. In, Professor Balen's review, he notes that: 'I am aware of anecdotal reports that some centres "push women hard" with high doses of stimulation if they are either donating oocytes or sharing oocytes (eggs)' and notes that 'such practice would be inappropriate'¹⁴. It is surprising that, in a scientific paper, a senior academic would criticise his colleagues in this way, and it can be assumed that he would only do so if he was very confident that the reports are well-founded. In a recent article on adverse effects of IVF¹⁵ three IVF specialists agreed with his concerns: 'Deaths are too rare to identify specific substandard procedures or centres, but market pressures can conflict with best and safest practice. Ovarian Hyperstimulation Syndrome may arise from a reluctance to abandon cycles because of financial payment structures, lack of appropriate cycle monitoring, and competition within the Human Fertilisation and Embryology Authority's "league table."

Egg donors would appear to have one factor indicating increased risk, and another reducing it, compared to most IVF patients. The predisposing factor is age: younger women, such as students, who are the most likely egg donors, are at increased risk of developing OHSS. On the other hand, it is thought that donors' OHSS is likely to be less severe than IVF patients, because it appears that the establishment of a pregnancy increases the severity of OHSS. Since, however, only 20 to 30% of IVF patients become pregnant in any cycle, this relative difference may be fairly minor.

There is clearly a need for more research on the frequency of OHSS, but this will

require a much better monitoring system in routine IVF. For egg donors, US women's health groups have recently been campaigning for a national registry¹⁶, and this would obviously make sense in the UK.

Other Risks

In addition to OHSS, short term risks of egg extraction includes the normal risks associated with a minor operation: infection, bleeding and anaesthetic complications. In the USA women's health campaigners, Our Bodies Ourselves have raised major concerns about side-effects from a drug called Lupron, which is used to shut the ovaries down prior to hormonal stimulation¹⁷.

The long-term risks for egg donors of hormonal treatments are even more poorly understood and researched. One significant concern is infertility, for which there is some evidence¹⁸. In some cases, this may be due to scarring of the ovaries in the egg retrieval process.

A more important worry is cancer of the ovaries, endometrium and breasts, possibly occurring many years after the hormone treatments. Various studies¹⁹ and numerous anecdotal reports²⁰ have indicated an increased risk of these cancers in women who have undergone IVF, whilst others have shown no increase²¹. It is generally acknowledged that not enough time has elapsed for it to be certain that any cancers linked to IVF hormonal injections would have appeared by now, so the jury must remain out on this issue.

Inadequate data, downplaying the risks

This lack of adequate safety data is a typical example of the situation in the field of assisted reproduction. After 30 years of IVF, studies are only beginning to come forward in the last few years on its risks to children, and it is routine for IVF doctors to introduce new techniques, with much less evidence of safety than that needed to market a new drug, for example. This may be because of the general emotional climate surrounding IVF and, in many countries, a lack of regulation. In our view, another factor is simply the fact that the people at risk are women. For many years practically no attention was paid by the pharmaceutical industry and medical researchers to the specific risks drugs pose to women, with many safety trials simply excluding them. There is also a history of the use of hormones in women without adequate safety evidence, the most well known example of which is diethylstilboestrol (DES). Introduced in the late 1940s as a drug to prevent miscarriage, it was apparent by 1953 that it was ineffective in doing so. Nonetheless its use continued until 1971, when a study showed that it was linked to vaginal cancers in the children of women who took DES. A similar history of enthusiastic promotion for decades by doctors, followed by findings of increased risk of cancer and strokes has attended Hormone Replacement Therapy.

Whilst the level of risk is not clear, the HFEA's presentation of those risks is absolutely inadequate. The HFEA website quotes the risk of OHSS as 1-2%, which suggests that it is only counting severe OHSS, although even that is lower than the figures quoted in its own review. Why is moderate OHSS excluded? The

HFEA web pages 'for donors' do not even mention risk, and the page on risk in the 'for patients' section of the site is buried several layers down. The draft consultation document on egg donation does not even mention the words 'risk' or 'OHSS'. If the body tasked with regulating IVF, which is also supposed to be the reliable source of information for the public, cannot adequately present information on risks, can we expect commercial IVF clinics to do better when giving

"..despite the accumulation of almost 20 years of IVF data on volunteer donors, the HFEA is proposing compensation for a risk whose extent and gravity remain unknown..... Such a naive and coercive policy.." information to donors and patients? It would seem not: recently, one clinician speaking at a public event, quoted the risk of OHSS as $0.2\%^{22}$.

In summary, the risks of egg donation for women are uncertain, but they are clearly considerable, and it is scandalous that they are downplayed by the responsible bodies. There are a variety of views on how acceptable they are, and whether

young women who are not IVF patients should be asked to take them at all. In a recent letter to the Sunday Times, two London IVF doctors say that, 'Egg donation requires a complex medical procedure whose long and short-term risks in volunteer egg donors have never been evaluated. Thus, despite the accumulation of almost 20 years of IVF data on volunteer donors, the HFEA is proposing compensation for a risk whose extent and gravity remain unknown..... Such a naive and coercive policy is only intended at increasing the recruitment of egg donors. '23. Most of their colleagues would disagree with that assessment, and would argue that if the woman is highly motivated to donate in order to help others, she should be allowed to decide to take that risk. However, the situation is different if women are entering into this process with the main aim of making money, because they are poor or have large debts. In our view, it is guite unethical for such vulnerable people to take these risks, and the whole social process that pushes them in this direction, and will inevitably cause a proportion of them to suffer damage to their health, is absolutely unacceptable. Again, the gender dimension cannot be ignored: part of the vulnerability of those people is because they are women.

3. The principle of non-commercialisation and why it matters

Since blood and tissue transplantation have become part of mainstream medicine, there has been a strong consensus that donation should be governed by the principle that parts of the human body should not be the source of financial gain. This position is reflected in many international policy documents and the guidelines of professional bodies²⁴, and is the fundamental basis for the EU Tissues and Cells Directive. What is the philosophical basis of this consensus?

The principle of non-commercialisation of human tissue depends partly upon the idea that human tissue has a special ethical status, even when removed from the body, and cannot be treated as just another commodity. Clearly, some things have an intrinsic value, which is separate from their cash value - examples might include ecosystems and human beings. It is partly because human body parts belonged to a particular person that they have their own intrinsic value. That is why, for example, the parents of those children whose organs were removed without consent at the

Alder Hey Hospital in Liverpool were very anxious to have those body parts returned to them, so that they might be buried. The parents' feelings can be labelled as 'irrational', but they show the importance of other types of value than the cash price. The special status of human tissue, which depends on the special status of human beings, has been part of almost every culture, and is what underlies legal bans on trading in human material in many countries. It is widely felt that that special status is very important and must not be degraded by reducing human material to the same status as ordinary goods.

It seems particularly important to keep a clear separation from the free market in the sphere of reproduction, where the human cells are actually being used to create a new person. This is why donor-conceived people are generally vehemently opposed to any payment for egg or sperm donation (see below).

According to the principle of non-commercialisation, donation of tissue to another person must be governed by the ethics of gift-giving. The donor acts altruistically without hope of any direct or immediate benefits to themselves. But it is a mistake. which springs from the liberal-individualistic mindset which has become so common in our society, to think that this act of gift-giving happens purely because the donor is an especially nice, kind and self-sacrificing person. Rather, donation is part of a social web of reciprocal altruism and obligation, sometimes referred to as "the gift economy", which encourages and is sustained by a social climate of mutual help and support. The ethic of reciprocal altruism has accompanied blood and tissue donation in Britain since they became possible, and has dictated that blood donors get no more than the proverbial cup of tea. There have been no campaigns by blood or kidney donors asking for compensation or payment for their donations. These values are far more consistent with those of a socialised medical system, such as Britain's National Health Service, and run absolutely counter to free market values, where the provider of goods or services only does so because s/he expects to receive the full and complete value of their product (plus a profit margin).

The Consequences of a Free Market.

Because of the shortages of tissue for donation, it is sometimes suggested that it would be better to abandon the principle in favour of giving people financial incentives to donate. However, it is only necessary to observe some of the negative consequences of allowing the free markets to govern tissue donation to see why this is not a good idea. The most well known of these problems is the black market in kidneys that exists in various parts of the world, in which poor and desperate people from third world countries supply their organs to wealthy people from industrialised countries. The donors often suffer severe health consequences, and are unable to access the necessary medical services to enable them to deal with the health consequences of donation. They often receive relatively paltry sums of money for their organs, with the brokers making huge profits. These problems arise because of the large differences in power between the donor and recipients, and the free market system effectively results in a new form of exploitation of the poorest people.

Similar problems are evident in international commercial surrogacy, which often also includes egg donation. Surrogacy has become a \$2bn industry in India, with tens of thousands of women servicing the international demand for babies. Generally, Western couples undergo IVF, under the auspices of what have been referred to as 'reproductive outsourcing agencies', which then courier frozen embryos to India. When the baby is born the couple flies in and collect it. The surrogates are often coerced into becoming a surrogate by their husbands, even though surrogacy is regarded as a form of prostitution in India. At some clinics, there are reports that the pregnant women are housed and fed in large dormitories, not unlike battery chickens and their liberty is restricted during the pregnancy. The overall phenomenon is known as 'fertility tourism', but, at least in reference to India, a better term would be 'fertility colonialism'.

In the case of egg donation, we have already seen the damage that can be done in a commercial system. The Cypriot government estimates that each year one woman in 50 between the ages of 18 and 30 sells her eggs, and amongst the island's approximately 30,000 Eastern European immigrants the figure may be as high as 1 in 4^{25} .

The clinics in Eastern Europe and Cyprus that extract eggs from donors, aim to 'harvest' as many eggs as possible, some-

times by applying excessive doses of hormones. Many of the donors have suffered severe health consequences as a result of these clinics' methods, sometimes leaving them infertile, whilst the Western European recipients go on to have a baby. One story

a 'profoundly exploitative and unethical' trade. Suzi Leather, HFEA Chair, 2006

gives an indication of the methods of the clinics in Cyprus: Carmen Pislaru, a Romanian immigrant, whilst still in hospital recovering from the birth of her fourth child was approached by her doctor, asking whether she wanted to sell her eggs²⁶. 'He knew I was in a desperate position. I had no money and no way to support my family.' Concerned about the risks of egg donation, Pislaru refused, but the doctor called her every week for the next month, only relenting when she gave him some names of her friends.

In Spain, clinics have a better reputation than those of Eastern Europe. However, one recent report indicates the way in which business efficiency trumps concern over women's health. The Institut Marques, a Spanish clinic, has its own office in London to recruit customers, and in order to ensure a steady supply of eggs, rather than waiting for a customer to appear before beginning hormone treatment of the donor, it keeps a rolling pool of women on the hormones, thereby risking their health, even though in some cases their eggs are not even used, due to lack of a recipients²⁷.

As noted above, there are reports that British clinics also, 'push women hard' with high doses of hormones. There have been suggestions that there are connections between these clinics and the criminal gangs that traffic women for prostitution from Eastern to Western Europe²⁸, and that in Cyprus, the women who come over to donate their eggs also work in the sex industry during their stay in Cyprus²⁹.

The trade has been widely condemned as exploitative, including by a resolution of the European Parliament in 2005³⁰, and by Allan Pacey of the British Fertility Society: 'It's all a bit convenient' he said. 'In the UK, we have a shortage of donors, but is the ethical answer to this to go to a country where money talks?'³¹. Likewise, the chair of the HFEA, Suzi Leather, said in 2006 that the trade was 'profoundly exploitative and unethical'³²

Other negative consequences of allowing a free market to operate can be seen in the USA, where the majority of donors are women from lower social classes, who may receive a few thousand dollars for their eggs. But there is also a thriving market in eggs from University students, with women from Ivy League universities and are perceived to be beautiful and athletic etc, being able to get as much as \$50-100,000 for their eggs. This highly offensive eugenic aspect is the logical result of a free market system in which a "superior" product has a higher cash value.

Finally, a further example from the USA illustrates the dangers of offering cash for parts of the body. In the 1970s and 1980s, the US blood supply system suffered problems of contamination with dangerous viruses, which came from the oftendestitute drug users who used the payments that were offered for blood donations as a major source of income.

Biomedicine and real-world politics

Over the past 30 years, as developments in biotechnology and biomedicine have made human tissues medically valuable, scientists and corporations have become increasingly keen to acquire them. As scientific understanding and technology penetrates to deeper levels in organisms, and dissects out the elements of complex biological wholes, each element becomes available for manipulation and for ownership and commodification. (IVF is a good example: once the basic process of extracting eggs and sperm and growing embryos in the laboratory was developed, a huge range of new possibilities for manipulation and combination, such as surrogacy, genetic selection and cloning became possible.) This has led

women's bodies have been especially targeted by these industries, because of their vulnerability, due to women's lower social status to new forms of exploitation and oppression: aside from the exploitation of Third World people in the organ trade, examples include the wholesale patenting of human genes and patenting of human cells taken from indigenous peoples without consent. The feminist bioethicist, Donna Dickenson, in her book, Body

Shopping³³ argues that women's bodies have been especially targeted by these industries, because of their vulnerability, due to women's lower social status and dependency upon men. She details one of the worst cases, in which Korean scientist, Hwang Woo Suk, obtained literally thousands of eggs for his cloning research by coercing junior lab assistants and paying other women, using high hormone doses that led to many cases of Ovarian Hyperstimulation Syndrome.

These experiences show that the concern about exploitation is not some

theoretical construct, thought up by opponents of progress. There is now plenty of experience from the real world to show that if financial incentives are offered, exploitation, of a particularly nasty kind, will result. Especially in the current financial climate, in which student debts have been drastically increased, and huge cuts in welfare benefits are about to bite, there can be no doubt that there will be a large pool of young women in Britain, keen to make money from egg donation. In order to reduce their debts and have enough money to live on, there has been a very worrying trend in recent years for students to work part time in the sex industry. There is no reason to doubt that young women in financial difficulties would jump at the chance to essentially sell their eggs.

These social processes are an essential part of the background for any consideration of the ethics of compensating egg donors, yet the HFEA ignores them entirely in its consultation document, preferring an apparently depoliticised account of the issues. It mentions the idea of 'altruism', which arises as a consequence of the regime of non-commercialisation, but which lacks its political dimension. Thus it succeeds in giving the impression that altruism is something unfairly imposed upon donors, for no particular good reason. The nearest the consultation document comes to referring to these processes of exploitation and imposition of risk upon vulnerable people is the rather vague statement that, 'When we last considered donor compensation, in 2005, we had concerns that offering

compensation for the physical inconvenience or risk of donation may encourage some people to donate without thinking sufficiently about the consequences' (emphasis added).

At the end of the HFEA's consultation web page is a section about the possible 'equality impact' of the proposed increase in compensation. It is ironic that despite the fact that the health risks of

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the proposed changes will fall disproportionately upon poorer women, the 'equality impact' provides no opportunity for this to be taken into account, because while there is anti-discrimination legislation for women, disabled people and older people, there is nothing to prevent harm or discrimination against people due to their socioeconomic class.

4. Boosting Donor Numbers and Ethics

Since mid-2009 when the HFEA Chair, Lisa Jardine first signalled the reopening of the public debate on egg donation, the HFEA's key argument in favour of increasing compensation for egg donors has been that this will boost the number of egg donors. As we note in section 5, there are very good reasons for believing that, if the donors to be recruited are altruistic, rather than commercial, it is quite unlikely that there would be any increase in the number of donors. But there is also a fundamental question about whether ethical rules should be changed in order to meet pragmatic goals of this kind. The HFEA seems fundamentally confused about this point: in its draft outline of the consultation document³⁴ it makes the rather extraordinary remark that, 'The two extremes are to maximise donor supply or to

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have an ethically perfect situation (neither of these scenarios are satisfactory ...)'.

A former HFEA member, Walter Merricks, has recently made this point forcefully³⁵. He notes that, "There are also 'shortages' of babies available for adoption, of kidney donors, and surrogate mothers. But it is regarded as unthinkable that deliberate steps should be taken to reduce these shortages, for instance by paying women to bear babies to be given up for adoption, or by offering prisoners early release in exchange for organ donation."

Why do we expect that the supply of eggs 'should' meet the demand? This expectation, which also applies to organs for

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transplantation, has been created by the media and the medical profession, but there is in fact no reason to expect that people will be ready to undergo risky and invasive medical procedures in order to produce an adequate supply of necessary tissue. Human tissue is rightly scarce, but the existence of transplantation procedures and IVF has created the false hope and expectation that there 'should' be enough tissue to help everyone. In essence, the technological tail is wagging the dog, and is driving changes to established ethical principles, in order that the expectation of enough tissue is fulfilled.

Rather than offering financial sweeteners in order to induce donors to donate, we would do a lot better to strengthen existing efforts to recruit more altruistic donors through publicity campaigns. This approach has been shown to be effective in practice. For example, although, as expected the number of donors decreased sharply in 2006, after the removal of donor anonymity, recruitment campaigns have now succeeded in restoring donor levels to more than those in 2005. Laura Witjens, the Chair of the National Gamete Donation Trust recently stated that the limiting factor in increasing donor numbers is simply the availability of sufficient funds³⁶.

As Merricks notes, most IVF in the UK is in the private sector, and it is simply unprofitable for them to run a donor recruitment programme. Perhaps a more ethical way of reducing the donor shortage would be to regulate the prices IVF clinics charge, and to force them to recruit donors, rather than placing the whole burden for doing so upon a small charity (the National Gamete Donation Trust) that is vulnerable to cuts in Government funding. But whatever the methods employed to boost donor numbers, it is not acceptable to jettison well established and vital ethical rules in order to do so.

5. The HFEA's Fig Leaf: 'removing disincentives' for altruistic donors

The intention of the HFEA to introduce compensation for donors has been clear since the interview given by its chair, Professor Lisa Jardine to The Times in July 2009. The HFEA is currently attempting to circumvent the Directive's clear prohibition on creating financial incentives for donors, by arguing that increased

compensation would remove an important disincentive for donors who are fundamentally altruistic, rather than creating incentives for donors whose primary motive is for financial gain. It theorises that altruistic donors may feel that their actions are not being 'properly recognised', and this acts as a disincentive to donors who are otherwise keen to donate.

In our view, this distinction is unconvincing, both in theory and in practice. Certainly, this distinction will not affect egg sharers, who currently make up 40% of the total number of donors, and is unlikely to affect the very significant number of donors who are friends or relatives of the infertile woman. The main point is that in practice, if the HFEA decides to allow compensation, it will be creating a new situation in which young women who may never previously have thought of donating will be made aware that cash is available, and it is inevitable that, for some, this will act as a powerful incentive to donate. The HFEA admits that "...it is important to bear in mind that different people will be incentivised by different amounts of money – what would be a removal of a disincentive to some, may constitute an incentive to others." This is clearly true, particularly with some of the larger figures, such as £1,500 – 2,000, being touted by IVF industry spokespeople. The National Gamete Donation Trust recently noted , that such sums of money constitute 6 months' income for a person on Income Support.

Furthermore, it is not necessary to cite the obvious way in which poor women are induced to donate in an openly free market arrangement such as the USA: the most relevant examples for the UK are Cyprus and Spain (where donors are paid up to 1,000 Euro in compensation; this is the destination for most UK couples who go abroad for egg donation). Note that Cyprus, although it has become the "Wild West" for fertility treatment in Europe is an EU country, and is therefore bound by the terms of the Directive. Thus, payments to donors there are officially "compensation for inconvenience", rather than straightforward payment for eggs, vet the payments of a few hundred pounds are clearly enough to induce many women, particularly from Eastern Europe to donate. There is very little pretence that donors are doing so for any reason other than money³⁹. Likewise, in Spain, this compensation has obviously succeeded in increasing donor numbers, but the evidence suggests that this is simply because the compensation is acting as a straightforward financial incentive. Most donors in Spain are either students or immigrants, often from Eastern Europe⁴⁰, and they make very little pretence of donating for altruistic reasons⁴¹. Some of these donors are invited to undergo up to four ovarian stimulation cycles in a year, which is very dangerous. It is telling that Spanish IVF clinics reported a dramatic leap in the number of young women coming forward to donate at the beginning of the current financial crisis in 2008⁴², a similar effect to that seen in the USA.

Thus, it is almost certain that despite the HFEA's unconvincing fig leaf of "removing disincentives" the effect of allowing significant compensation for donors will be to increase the numbers of exactly those donors who the HFEA says it wants to avoid recruiting i.e. those who are primarily interested in cash, but who will learn to tell IVF clinics that their motivations are altruistic.

Would it work?

The HFEA's research provides very little evidence that their target group - altruistic donors who are holding back, because they want to be "recognized" with a cash payment - even exists. The only group that provided any support for its existence were IVF clinic staff. Throughout the debate on this issue over the last year, no donor has come forward to publicly argue for compensation.

What do donors themselves think? Mysteriously, despite having more than 18 months to conduct research into this issue, the HFEA has succeeded in interviewing exactly two donors, whose evidence on this point was highly equivocal. One thing, however, is certain: there is no outcry from donors in favour of compensation, which has prompted this consultation. On the other hand, we know from the HFEA's last review of this issue in 2006, that many of those who gave evidence questioned whether financial incentives for altruistic donors would work⁴³. In their report to the Authority at the end of 2009, HFEA staff noted that, in practice, donors often refuse even reimbursement of their expenses, and do not

'To think that my donor might have been motivated by money and have no concern for my welfare makes me feel awful²⁴⁶ wish to have their donation associated with money⁴⁴.

A crucial group which opposes payments to donors is those most intimately affected: the people conceived by egg/sperm donation. As with donors, the HFEA seems to have

made little effort to seek out donor-conceived people (it interviewed two). However, one quote recorded by its staff gives a sense of the depth of feeling on this question amongst donor-conceived people: asked how she would feel if she knew that her donor had been paid, she replied, 'Horrible, just horrible'⁴⁵. Rachel Pepa, a donor conceived person, wrote in the Guardian: 'To think that my donor might have been motivated by money and have no concern for my welfare makes me feel awful'⁴⁶. Another HFEA internal document notes that some donor-conceived peoples argued for the removal of the existing reimbursement for expenses and loss of earnings, an option that does not appear in the consultation document. Astonishingly, the HFEA claims that donor-conceived people are a 'hard to reach group'⁴⁷, and that because of the 'lack of evidence on their views, it is hard to reach firm conclusions'. In fact, the views of donor-conceived people are very well known, and were recorded in the HFEA's own SEED report of 2006.

The strong, often vehement opposition of donor-conceived people to any payment for donors will also affect donors' attitudes. Since the removal of donor anonymity in 2005, there is now the possibility that donors may be contacted by their offspring, 18 years hence, and this is likely to make donors even more cautious about accepting money.

As the HFEA's internal report⁴⁸ also notes counsellors and parents tend to oppose compensation for donors for the same reasons, citing concerns about the effect of this on children.

More evidence came from a public opinion poll conducted by the HFEA on the

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general issue of compensation⁴⁹. The largest group of respondents (35%) thought that donors should receive no compensation and only 10% agreed that donors should be compensated for discomfort or inconvenience. Whilst 28% of people perceived the availability of compensation as a theoretical motivator for donation, when asked what would prevent them from personally donating, only 3% said that inadequate compensation is one of the main reasons not to donate. This is the most relevant statistic for the HFEA's argument about removing disincentives. Much larger proportions cited 'impact on the 'donor' (37%), 'There is not currently conclusive body of evidence about how to donate' (20%).

These findings suggest that it is very unlikely that the HFEA's hope, that compensation would act effectively to remove disincentives and thereby 'There is not currently a conclusive body of evidence which indicates donor numbers would increase if compensation to donors was more generous' HFEA report 2010

boost altruistic donor numbers, would be realised. In concluding its review of the evidence, the HFEA admits that, "there is not currently a conclusive body of evidence which indicates donor numbers would increase if compensation to donors was more generous"⁵⁰. In fact, the only evidence that altruistic donor numbers would increase is the views of IVF clinic staff, who do not appear to be a 'hard to reach' group for the HFEA.

6. Constructing A Slippery Slope

Throughout the first 12 years of existence, the HFEA stuck firmly to the principle of non-commercialisation of human tissues, often comparing egg donation to the blood donor system in Britain. It recognised that it is socially and ethically undesirable to induce financially-stressed young women to take the risks of egg donation. By the early 2000s, these fears about risks to women were being realised in Eastern Europe, and the EU, concerned about the exploitative international trade in human organs, was moving towards banning commercial trade in human tissue, but ironically the HFEA began to move in the opposite direction.

In 2002 it permitted IVF clinics to offer 'egg sharing' arrangements whereby women receive a discount from the cost of their private IVF treatment, if they give some of their eggs to women who need donor eggs. The HFEA allayed the concerns of those opposed to commercialisation in two key ways. Firstly, the donors were themselves undergoing IVF and were not therefore being induced to take risks that they otherwise would not take. Secondly, it was argued, these women are receiving a benefit in kind (access to IVF treatment) rather than cash. This, the HFEA said, was qualitatively different from cash and would not set a precedent for payment for eggs or for other tissues. This position was confirmed in the 2006 SEED report.

By 2009, however, we find the new Chair of the HFEA, Lisa Jardine, arguing that, in fact, there is no difference between egg sharing and paying women cash after all, and that what the egg sharers are getting <u>is</u> a financial benefit after all. Thus,

say Jardine and her supporters in the IVF industry, there can now be no objection to cash payments to donors. More recently an HFEA spokesperson even suggested that since egg sharers are now receiving \pounds 3,000 - \pounds 5,000 maybe egg donors should now receive similar sums. This suggestion went far beyond what even IVF industry spokespeople had dared to suggest.

This history is a classic slippery slope, and we find it hard not to believe that it was consciously planned. When you wish to overcome an ethical obstacle, the first step is to breach the rule in a small way. Opponents can be reassured by arguing that this is a special case, and does not set a precedent for the thing that everyone fears. Some time later, when the first exception has become accepted practice and would be hard to reverse, it can then be argued that the first step has already established that the rule no longer applies, and that it is therefore illogical and even discriminatory not to abandon the rule entirely. This is the pattern of evolution of policy on many different issues in the ethics of genetic and reproductive technologies, even while philosophers continue to insist that arguments about 'slippery slopes' are logically incoherent and just scaremongering. It is deeply dispiriting to see this cynicism repeated over egg donation.

If the principle of cash compensation is established, we will no doubt begin to hear that it is illogical not to simply pay for eggs. Once that was established, people would start to argue that life-saving organs are much more important than treating infertility, and that if market incentives are allowed for eggs, then why not for organs too? Given the fact that the organ trade already exists, and that calls to legalise it are already being made, it doesn't seem too far-fetched a prediction that legalising the sale of eggs would lead to a market in organs, too. In the face of all this, it is crucial to defend ethical principles, such as non-commodification, and to ensure that we do not open the door to further abuses.

7. Justice

One aspect of this issue, which has been sadly neglected in the current debate, is the question of justice, one of the four principles of bioethics that students cover in 'Bioethics 1.0.1'. Simply put, justice requires that medical benefits be made available to all, not just to privileged wealthy elites.

There is every reason to be concerned that allowing significant compensation payments to egg donors will create inequality and injustice. Although the problem is acknowledged by the HFEA in internal documents⁵¹ it gets no mention in its consultation document. In Britain, despite recommendations from the National Institute for Clinical Excellence (NICE) that the NHS should offer IVF to all women who need it, IVF is not available on the NHS in many regions. 80% of IVF comes from private clinics, which charge £3,000 - £5,000 per cycle. The British IVF industry has been criticised by no less a luminary than Lord Winston for overcharging, compared to other countries⁵², and is it certain that many infertile women never end up with a baby, simply because they cannot afford IVF. In the current round of cuts in public services, we are already seeing NHS IVF services being shut down as non-essential.

Adding £1,000 or more to the IVF bills of women who need egg donation can only worsen inequality of access. In what remains of NHS IVF services, which often cannot afford to reimburse expenses and loss of earnings under the current system⁵³, it seems unlikely that available funds will cover compensation. The result will be the same as has already been seen in Spain and, of course, the USA, where the market reigns: public hospitals are priced out of the egg donor market⁵⁴ and the less well off women who need donor eggs will be denied their last chance to find one. Meanwhile, private IVF will become even more expensive, but the clinics will continue to make large profits. All this is typical of the changes driven by neo-liberal economic and social policies.

8. 'Fairness'

In its consultation document, the HFEA suggests that it is unfair that, although egg donors are not paid, the private IVF clinics are making a profit. It is sometimes also suggested that denying payment to women is an example of the sexist demand that women should always be self-sacrificing and altruistic. It is curious to see the HFEA, a body not well known for its stance against IVF corporate exploitation, using this argument as a central plank of its case for donor compensation. In fact, the argument has very little substance.

The first point is that, as noted above, the EU Directive prohibits IVF clinics from making a profit directly from supplying eggs, so in that respect clinics are treated in the same way as the donor. However, it is true that the IVF industry makes large, perhaps excessive, profits from treating women using donor eggs.

Another way of looking at this issue is to ask: would we feel the same about egg donation in the NHS? Clearly NHS staff, like their private sector colleagues, are highly trained professionals who must be paid for their work. Uncompensated egg donation seems much more consistent with

the ethics of socialised medicine than private medicine. The example illustrates the fact that the problem is not inadequate compensation of donors, but the ethics of for-profit medicine. In essence, the argument that it is unfair to donors not to

the problem is not inadequate compensation of donors, but the ethics of for-profit medicine

pay them is merely a slightly nicer-sounding form of the free-market philosophy, which is driving the whole move towards donor compensation. It is certainly not a standard practice in bioethics to directly compare the treatment of patients with that of doctors. The example can be pushed further: if 'fairness' is the key principle and it is not fair to pay donors in the NHS, but is fair to pay them when their donation is in the private sector, the result is to create an obvious case of real unfairness.

Up till now, as we have noted above, donors and the public prefer the ethic of gift giving and altruism. There is no call from donors for compensation: such calls generally come from right-wing think tanks or over-enthusiastic transplant surgeons. The claim of the HFEA to know better, to be more on the side of the

donors than the donors themselves rings very hollow.

Although it is true that an aspect of sexism is the demand that women be altruistic, this is a coincidence, rather than the basis of the policy that egg donors are not paid. In fact, in this case, it applies equally to men, who are also, rightly, not paid for sperm donation. The ethic of non-commercialisation became established for blood and organ donation long before egg donations were even possible, and men have espoused it equally.

9. Conclusion

The evidence and arguments presented in this briefing demonstrate that the HFEA's plans to allow significant compensation payments to egg donors are likely to produce a number of harmful social consequences, if the payments are large enough to create a financial incentive. The most important of these is the inevitable harm to the health of egg donors. As past experience has shown, this will fall predominantly upon poor and indebted women, and this is a completely unacceptable form of exploitation. The plans will breach the international consensus against commercialisation of human body parts.

The HFEA has placed great emphasis on tackling the shortage of donors in the UK, by possible increases in compensation payments. However, we and others argue that it is not fundamentally acceptable to change ethical rules for such purely pragmatic purposes, especially when there are other ways to increase the number of donors. Moreover, there is no evidence, other than the belief of IVF clinic staff, that the measure would be effective in boosting altruistic donor numbers, as HFEA internal document admit. Neither is there any perceptible demand from donors or parents for payments to donors, and the public is highly unenthusiastic, strongly preferring the traditional ethic of altruism. Most important of all, donor-conceived people strongly oppose compensation payments.

As we noted in section 3, following the scandal involving the Romanian IVF clinic, that was first inspected by the HFEA and then closed down by the Romanian authorities, the HFEA Chair was obliged to strongly condemn the European egg trade. The British Fertility Society spokesperson asked, rightly, 'In the UK, we have a shortage of donors, but is the ethical answer to this to go to a country where money talks?' Now, it seems that the HFEA has found a solution to this problem: it will import the 'money talks' regime to the UK.

Sadly, there is little evidence that the HFEA cares either about eggsploitation or even for basic standards of fairness in conducting the consultation. From Lisa Jardine's opening shots, it has been clear that the HFEA intends to follow the Spanish model, and is willing to twist arguments and evidence in order to do so. Its bias is apparent in many way: its systematic understatements of risk to women; its engineering of slippery slopes over a period of years; its failure to seek out evidence from donors, parents and especially shockingly, its failure to include the views of donor-conceived people; its emphasis on the utterly misleading principles of 'fairness' between donors and clinic staff, whilst failing to even mention the

principles of non-commercialisation of human tissue. Academic critics have recently made further criticisms of the HFEAs consultation process⁵⁵, which have forced the HFEA to issue a rebuttal⁵⁶. The most insidious aspect of bias is the depoliticisation of the issues in the consultation document: since notions such as exploitation and the targeting of women's bodies for commodification are banned, the reader receives no real indication of these concerns. The document is a perfect example of the truism that depoliticisation, in the name of a spurious 'neutrality', always serves the interests of the powerful over the weak. Those who are regular observers of the way the HFEA behaves will be used to this; however, the HFEA has outdone itself on this occasion, managing to completely ignore and

In this consultation, the link between the erosion of ethical principles and the business interests of the IVF industry is palpable.

marginalise the key ethical issue. It may be that this is connected to its impending abolition. It seems to be behaving in a way that some American presidents do, in the period between losing an election and having to leave office, using the opportunity to take irrevocable steps in the interest of their party.

We therefore make no apology for identifying this consultation process as part of the normal process

whereby business interests manipulate public policy in accordance with their ideological dogma and in the interests of their bottom line. As has also been noted by others⁵⁷, the fingerprints of the IVF industry are all over this consultation. This is reflected in HFEA comments about the problem of reproductive tourism: it warns women about possible dangers to themselves in going abroad (such as possible poor treatment, including the implantation of multiple embryos, and the anonymity of donors, which may impact upon the child). Yet it has been strangely silent on the real ethical problem raised by reproductive tourism, i.e. the exploitation and risks suffered by donors. This focus on the disadvantages to customers of going abroad is consistent with the primary purpose of this whole exercise, which, in our view, is to help the British IVF industry's bottom line, by encouraging its clients not to go abroad, rather to deal with the egg shortage per se.

More generally, the thinly-disguised enthusiasm for financial incentives as the best way to change behaviour, and the distain to even mention exploitation, are typical of the capture of the HFEA by free-market philosophies. In recent years this has been noticeable in its general libertarian individualism and pragmatism on ethical issues and the resulting erosion of established ethical safeguards. Here, the link between this erosion and the business interests of the IVF industry (over which the HFEA is supposed to be a critical watchdog) is palpable. The current economic context for this HFEA initiative, in which a neo-liberal government is pushing through cuts in welfare and increasing student debts, will push young women into taking serious health risks, and in which public IVF services are being shut down thereby forcing infertile women into the arms of the IVF industry, not accidentally, completely reinforces the industry's interests.

In HGA's view the trend towards financial compensation for egg donors has already gone far enough. Rather than looking for loopholes in the EU Directive, Britain should stick to its spirit, not merely its letter. The shortage of donors should be addressed by campaigns to recruit more altruistic donors, not by removing

basic ethical safeguards, which are there to protect vulnerable people. There is no doubt that more donors can be found if more money is made available for recruitment campaigns, and if clinics follow up properly on donors' offers. But there is no reason to create an expectation that supply 'should' meet demand.

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