Subsidized IVF: the development of ‘egg sharing’ in the United Kingdom

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Egg sharing is an arrangement in which a woman is offered free or reduced-cost assisted conception treatment in return for ‘donating’ oocytes for the treatment of another woman, the cost of her treatment being subsidized by the recipient of her oocytes. Egg sharing has been developed for a variety of reasons: to ameliorate donor oocyte shortages, to avoid potential health risks to non-patient donors and, given the limited availability of publicly funded assisted conception treatment in the UK, to make treatment more readily available to individuals on lower incomes, thus expediting treatment by reducing waiting lists. This paper outlines the development and current status of egg sharing in the UK through analysis of responses to a consultation on payment to gamete donors initiated by the Human Fertilisation and Embryology Authority (HFEA) and the HFEA’s Guidance for Egg Sharing Arrangements.

Key words: egg sharing/Guidance for Egg Sharing Arrangements/Human Fertilisation and Embryology Authority

Introduction
Legal and regulatory provisions in the UK prevent the operation of a commercial market in human gametes and limit to £15, in addition to expenses, any payment that may be made to gamete donors. These have meant that a woman who is unable to produce her own oocytes has been obliged to rely on an altruistic donor to access assisted conception services, or to seek treatment abroad where commercial practices are permitted. In 1992, the UK regulatory body, the Human Fertilisation and Embryology Authority (HFEA), issued directions permitting the provision of ‘treatment services and sterilization in exchange for ovum donation’ (Human Fertilisation and Embryology Authority, 1992), thus paving the way for egg sharing. Egg sharing is seen as a means of providing both an additional source of scarce donor oocytes and reduced-cost treatment to the female ‘donor’, and so provides more ready access to services to those on lower incomes. In addition, it may be argued that a woman who is already receiving treatment is not exposed to any additional risks that might be experienced by a non-patient donor, although the precise nature of these risks remains contentious (Ahuja and Simons, 1996, 1998; Ahuja et al., 1996, 1997, 1998, 1999, 2000; Marina et al., 1999; International Federation of Fertility Societies, 2001; Sauer, 2001).

The principal advocates of egg sharing in the UK have been Ahuja and his colleagues (Ahuja and Simons, 1996, 1998; Ahuja et al., 1996, 1997, 1998, 1999, 2000), who have also conducted the only published survey of the experiences of women in the UK who have participated as donors in an egg sharing programme (Ahuja et al., 1998). Of the 144 women responding to this survey, 35 had been successful with their own treatment and 79 had been unsuccessful. However, the authors concluded that these women’s experiences vindicated the practice of egg sharing:

‘Though unsuccessful and frustrated, most donors felt a profound satisfaction that they might have given a recipient the chance to have a child’ (Ahuja et al., 1998, p. 2673).

Nevertheless, egg sharing remains controversial, considered by some as analogous to ‘paid donation’, in a context in which the HFEA was opposed to any payment for gamete donation (Deech, 1998a). Indeed, the HFEA (undated) described egg sharing as an ‘unacceptable’ practice, while Johnson articulated the HFEA’s position that it should be ‘phased out’ (Johnson, 1997). In 1998, having previously determined that all payment to gamete donors should be discontinued, the HFEA instituted a Consultation to determine how this could best be achieved (Human Fertilisation and Embryology Authority, 1998a). The HFEA also used the Consultation to seek views about egg sharing. Responses to the Consultation indicated little support for the withdrawal of payment to donors, and in the face of opposition, this policy was abandoned by the end of the year (Deech, 1998b). At the same time the HFEA announced that egg sharing should be ‘regulated, not banned’, noting that it had been ‘influenced by the argument that egg sharers are not motivated by money, but by the desire for a baby’ (Human Fertilisation and Embryology Authority, 1998b).

Interestingly, the HFEA, which had previously referred to ‘paid’ egg sharing (Human Fertilisation and Embryology Authority, 1998a), used this opportunity to provide a more acceptable gloss to the practice by reconceptualizing it as ‘compensated’ egg sharing. However, at its meeting in July 1999 the Authority agreed that treatment centres should be advised that ‘allowing egg-sharing to continue did not mean that the HFEA had given the practice its ethical approval’ (Human Fertilisation and Embryology Authority, 1999). Given
that publicly available information relating to the HFEA’s decision on egg sharing was limited to the 1998 press release (Human Fertilisation and Embryology Authority, 1998b) and to the web-site reference to the HFEA’s meeting of July 1999 (Human Fertilisation and Embryology Authority, 1999), further information about the change in policy was sought directly from the HFEA. The response from the chair of the HFEA, indicated that the Authority had:

‘Two main reasons to permit [egg sharing], in addition to our underlying philosophy of facilitating the provision of infertility treatment. The first was that since donation was legitimate, egg sharing had an advantage over straight donation, in that it avoided the necessity for a woman to take a course of drugs specifically to donate; she would be taking them in any case for her own treatment, and we have some concerns about the effect of the drugs. The other reason was that a scheme that provided a clear benefit to each woman justified consideration, and we could see arguments for accepting it provided that the right kind of safeguards were in place (clear information, agreements, counselling and separate consideration of donor and recipient)’ (Ruth Deech, personal communication, 16 October 2001).

When it announced that egg sharing would be permitted, the HFEA promised to issue guidance to centres. This was produced initially in 2000 as a free-standing document, drawn up by the Authority’s Code of Practice Committee and representatives of the British Fertility Society and the Royal College of Obstetricians and Gynaecologists and following a feasibility study involving a number of treatment centres (Human Fertilisation and Embryology Authority, 2000a). It was subsequently incorporated within the HFEA’s revised Code of Practice (Human Fertilisation and Embryology Authority, 2001).

HFEA Consultation on the Implementation of Withdrawal of Payments to Donors

In its 1998 Consultation on the Implementation of Withdrawal of Payments to Donors (Human Fertilisation and Embryology Authority, 1998a), the HFEA invited comment on whether ‘paid egg-sharing schemes’ should be allowed to continue, terminated immediately or phased out over time. A total of 148 responses were made publicly available and these were used as the basis for analysis. These responses were from patients who had received treatment using donated gametes (unspecified), patients who had specifically undergone donor oocyte treatment, patients who had not utilized donor treatments, donors (including those specified as oocyte donors), professionals working in treatment centres, other health care professionals, professional associations, patient support groups and other individuals who wished to contribute to the Consultation. Some individuals fell into more than one category (e.g. patient/donor; patient/worker in licensed treatment centre; donor/worker in licensed treatment centre). Centres responding to the Consultation included both those that recruited their own donors (sperm, oocyte or both) and those that did not do so.

No statistical significance can be attributed to these responses, given the self-selected nature of those participating in the HFEA Consultation. They do, nevertheless, indicate the existence of widely divergent views on egg sharing; responses clearly failing to give an unambiguous mandate for an outright ban, despite the HFEA’s own previously declared opposition. More importantly, perhaps, the responses identify key policy and practice issues that need to be considered, given the HFEA’s subsequent decision to permit egg sharing.

Responses to the Consultation indicated an almost equal division between support for (67, including one response: ‘not sure—on balance feel it should be allowed’) and opposition to (68, including one response: ‘undecided—but definitely more no than yes!’) egg sharing. This question was not answered in 10 returned questionnaires. Replies in two of the remaining responses were ambiguous and in the final, corporate, response, it was noted that the respondents had been ‘unable to reach a majority view’. Of responses opposed to egg sharing, 38 considered that it should be ended immediately and 27 suggested dates for phasing out between 1999 and 2003.

Of the 52 responses that could be attributed to a licensed treatment centre (although it was unclear to what extent these responses represented a ‘team’ response or the views of a single respondent, and if so, who), 22 supported egg sharing and 30 opposed it.

The gender of a large number of respondents who indicated direct experience of assisted conception services, either as a donor or as a recipient, was not specified. Consequently, it is not possible to gauge the extent of these respondents’ direct personal experience of oocyte donation or egg sharing. While, it is evident that the majority of donors and patients contributing to the HFEA Consultation endorsed egg sharing, as indicated in Table I, the sole respondent claiming direct personal experience of egg sharing was clearly opposed to it:

‘When I went for my shared egg schemes I was so ready to get pregnant that I did not fully realize what I was giving away. When I did not become pregnant, I badly wanted my eggs back. This caused me much pain and unhappiness. Feeling that I was not pregnant but my recipient may have my baby. This caused me depression and nearly split my family up. If you are donating without the light at the end of the tunnel, e.g. getting pregnant, you are giving your eggs away because you wish to, not because you feel you have to. Their (sic) is a need for people to donate eggs and sperm, but this must be done for the right reasons and not for gain. Shared egg donation can do more harm than good as was my case and many others’.

Of the four national service user groups (Issue; Child; DC-Network and Daisy Network) that responded to the Consultation, one supported egg sharing, two opposed it and the fourth (which responded by means of a letter rather than completing the HFEA’s questionnaire) made no specific mention of egg sharing.

Additional comments made by respondents to the Consultation highlighted the following key themes. These have been broadly categorized as responses endorsing egg sharing, those rejecting egg sharing and, finally, those that urged caution and suggested safeguards if egg sharing was to be practised.

Responses supporting egg sharing endorsed claims previously evident in the literature. Egg sharing was seen as providing an additional source of oocytes for women requiring
donor oocytes and reduced reliance on donors who would not otherwise be undergoing IVF treatment and consequently incurring potential risks to their own health. Indeed, given the unknown risks, some respondents questioned the ethics of using non-patient donors at all. One described egg sharing as ‘virtually the only legitimate source of oocytes at present. Healthy women who do not need ovarian stimulation should not be asked to donate’. Egg sharing was also perceived as making available cheaper treatment for women on lower incomes and consequently reducing waiting times for treatment for both donor and recipient. In the current context of donor oocyte shortages and the limited access to publicly funded treatment under the National Health Service (Kennelly and Reisel, 1998), several respondents commented that egg sharing represented the only means by which some people might access treatment. Other arguments in favour of egg sharing to emerge from these responses included a view that egg sharing puts to ‘good use’ embryos that might otherwise be destroyed or ‘wasted’ and others that emphasized potential benefits to both donor and recipient(s). Several respondents contemplated the potentially undesirable effects of banning egg sharing, such as accessing potential donors via the Internet or increasing pressure on friends or family members to donate. A number of respondents explicitly or implicitly challenged the HFEA’s conceptualization of ‘paid’ egg sharing. Responses arguing that egg sharing was intrinsically different from ‘paid donation’ were exemplified by the following comment:

‘I find it offensive that gametes should be sold by a donor for money or monies worth... . Egg sharing must obviously be regarded as entirely different. In essence there are two women sharing the same problem of infertility... . For these two women to come together to help one another seems to me something that we should be encouraging and should not be sweeping aside as though it were some sordid commercial trade... .’

Given that the HFEA Consultation document had set out the Authority’s own opposition to egg sharing, unsurprisingly, most responses endorsing the Authority’s stance reinforced the ethical, psychological and practical considerations that had been outlined by the Authority. These included the argument that egg sharing is indistinguishable from paid donation; in this context it would be inconsistent to allow egg sharing while banning overt payment. (Given the eventual outcome of the Consultation, the converse also appears to be borne out—that it would be inconsistent to prohibit egg sharing while allowing overt payment. However, it is clear that a number of respondents supporting egg sharing would not see any inconsistency in banning explicit payment to donors but permitting egg sharing). Opponents equated egg sharing with the commodification both of body parts and of children. One respondent wondered how egg sharing squared with welfare of the child requirements and how it would be possible to explain the circumstances of their conception to children born following egg sharing. Other concerns were expressed about the possibility of women being coerced into participating in egg sharing and the extent to which women were able to make an informed choice. The potential risk of women being subjected to excessive drug regimes to ensure superovulation and the production of a large number of oocytes was noted. Respondents warned of the psychological vulnerability of infertile women as potential oocyte donors and the particular emotional problems for donors whose own treatment is unsuccessful. Some considered that these could be exacerbated if the donor was unaware of the outcome of the recipient’s or recipients’ treatment. The point was made that a donor may reduce her own chance of success by giving away her oocytes and may later wish that she had retained them for her own use.

Concerns were expressed about the availability of appropriate counselling and/or information about the implications of egg sharing for both donors and recipients. The possibility that recipients may receive less than optimum treatment because of the donor’s own fertility difficulties, was also

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*a+1 not answered.*
recognized. One respondent questioned the resources expended on egg sharing and that its development might detract from more legitimate activities of ensuring affordable treatment for non-NHS patients and increasing the availability of NHS treatment: ‘Make treatment cheaper and [egg sharing] wouldn’t be necessary’.

Other responses that, in general, supported egg sharing, also indicated possible problems. They nevertheless considered that these difficulties could be avoided by the implementation of safeguards such as ensuring that no pressure was put on patients to consider egg sharing, that both donors and recipients were fully informed of the potential consequences of egg sharing before proceeding and that adequate counselling was available.

**HFEA Guidance for Egg Sharing Arrangements**

According to the HFEA, the Guidance for Egg Sharing Arrangements (Human Fertilisation and Embryology Authority, 2000a, 2001) operates around two general principles:

An explicit written agreement between the treatment centre and the donor, and between the treatment centre and the recipient(s), in addition to the statutory consent;

Where the donor provides an insufficient number of oocytes to proceed with the egg sharing arrangement, her treatment will not be compromised. Where the donor does not provide enough oocytes for egg sharing she should be given the option of keeping all her oocytes for her own treatment at no additional cost to her and with no further commitment.

Concerns raised both by the HFEA itself in advance of the Consultation, and by respondents to the Consultation, on the ability of prospective donors to give genuine consent, appear to lie behind two provisions in the Guidance: access to an ‘impartial’ nurse and increased emphasis on implications counselling. The HFEA recommends that both the donor and recipient should ‘have access to an individual, such as a nurse, who would be available to provide impartial support throughout the egg sharing treatment cycle’. The person providing support for the donor should be different from the person providing support for the recipient(s) and, although the role of the ‘impartial’ nurse is not further elaborated, this support is seen as additional to the provision of counselling (Human Fertilisation and Embryology Authority, 2001, para 3.34). Counselling on the implications of egg sharing is also promoted more rigorously by the HFEA than for any other treatments (Human Fertilisation and Embryology Authority, 2001, para 8.31). The Guidance: ‘strongly recommends that all couples contemplating participation in an egg sharing arrangement receive implications counselling’ (Human Fertilisation and Embryology Authority, 2001, para 8.31—my emphasis) and that ‘counselling equivalent to that provided for gamete donors should be given to an egg provider and her partner’ (Human Fertilisation and Embryology Authority, 2001, para 8.33—my emphasis).

According to the Guidance, implications counselling must be offered to both oocyte donors and recipients and should cover the following issues: (i) the implications of not knowing whether ‘the other couple’ has succeeded or not (the explicit reference in the Guidance to ‘couples’ suggests that its authors did not consider that either a donor or recipient might be without a partner); (ii) the implications for the donor remaining childless; (iii) the implications for the recipient of using oocytes provided by a sub-fertile donor and (iv) the implications of the possible existence of similarly aged half-siblings resulting from the treatment.

**Discussion**

Since this paper has focused on the development of policy towards egg sharing in the UK, there has been insufficient space to undertake any detailed discussion of the ethics of egg sharing. Nevertheless, it is important to acknowledge that the authorization of egg sharing has not closed the ethical debate. In 1999, Johnson, by this time no longer a member of the HFEA, published a detailed critique of the ethics of ‘paid egg sharing’ (Johnson, 1999). More recently, Lieberman has not only described the HFEA decision on egg sharing as ‘handled badly’, but also criticizes centres providing egg sharing (Lieberman, 2001):

‘Egg sharing violates the principle that human cells, tissues and organs should never be sold or used commercially in exchange for treatment purposes. I am more convinced than ever that the centres that undertake this activity are more concerned with the financial advantages than the welfare of the egg providers’ (Lieberman, 2001, p. 12).

Despite such reservations, a number of UK licensed treatment centres are engaged in egg sharing. Murray and Golombok (2000) reported that 13% of clinics in their study (presumably seven centres) did so. Following the HFEA’s authorization of egg sharing, the author undertook a telephone survey of all licensed centres providing treatment with donated oocytes (64) listed in the HFEA’s Patients’ Guide to IVF Clinics (Human Fertilisation and Embryology Authority, 2000b). Of these, 25 (39%) indicated that they currently offered egg sharing. Several other centres indicated that they were actively considering doing so, following the HFEA’s clarification of the status of egg sharing.

As the HFEA has authorized egg sharing, it is now under an obligation to ensure adequate protection for people embarking on egg sharing and those who are conceived following egg sharing and maintenance of necessary clinical standards.

For those considering egg sharing, either as a recipient or donor, the HFEA appears to have adopted a paternalistic approach, epitomized by its ‘strong’ recommendation concerning implications counselling and restricting disclosure of information about treatment outcomes. However, it may be argued that these measures both go too far and do not go far enough. The limitation on disclosing information about treatment outcomes in particular takes insufficient account of available empirical evidence (see below).

The HFEA’s counselling recommendations are presumably a response to concerns to ensure the availability of adequate counselling, but come very close to mandating the receipt of counselling, when the Human Fertilisation and Embryology
Act itself merely obligates the provision but not the receipt of counselling. Of the four specific issues highlighted by the HFEA to be addressed in implications counselling, only the possibility of the donor remaining childless could be regarded as an unavoidable risk. Such risk is, of course, inherent in any form of assisted conception treatment, although it is compounded in egg sharing where the donor is also undergoing treatment. While the HFEA's response to deny both the donor and recipient information about the outcome of the other's treatment was undoubtedly motivated to protect those whose own treatment was unsuccessful, its consequences remain doubtful. In the only reported study of the views of donors in an egg sharing programme, Ahuja et al. note: 'clear evidence that unsuccessful egg share donors, after reflection, remain sanguine about their own choices' (Ahuja et al., 1998).

It may equally be argued that uncertainty about the outcome of the other party's treatment could represent an equal or even greater psychological burden, both for donors and recipients. There is evidence that some oocyte donors at least would like to know the outcome of their donation (Bromwich, 1990; Schover et al., 1991, 1992; Rosenberg and Epstein, 1995; Söderström-Anttila, 1995; Fielding et al., 1998; Kalfoglou and Gittelsohn, 2000). While the only currently available information about the views of egg share donors indicates that just 8% wished to know the outcome of their donation (Ahuja et al., 1998), it would surely be preferable for donors and recipients to be given a choice as to whether they learned the outcome of the treatment of the other party, rather than impose a patronizing and paternalistic approach that allows choice to no one. Then, if research and/or clinical evidence subsequently reveal that donors experience psychological harm by receipt of such knowledge, this should indicate the need for more effective preparation and counselling or even call into question egg sharing as a matter of principle, rather than simply providing justification for the concealment of treatment outcomes.

Where the HFEA might have been expected to exercise greater stringency, or at least have indicated an intention of doing so in the light of experience and further evidence, is in the area of clinical practice. Treatment quality, especially where oocytes from a 'sub-fertile' donor are used, is a function of the centre's ability to assess oocyte quality and its use of 'sub-optimal' oocytes in treatment and should be subject to norms of clinical excellence. What is lacking from the Guidance is any indication by the HFEA that the number of available oocytes may affect treatment quality. Consequently, the HFEA should be considering specifying a minimum number of viable oocytes that must be available to both donor and recipient for an egg share cycle to proceed rather than leaving this to the discretion of individual centres. Other issues raised by respondents to the HFEA Consultation, but not addressed in the Guidance, relate to the need to ensure that donors are subjected neither to inappropriate pharmacological regimes in order to maximize oocyte production, nor to inappropriate inducement. The authorization of egg sharing provides a further argument in support of the incorporation of patient feedback into the HFEA's inspection process.

The apparent concern to protect the presumed (although not necessarily the confirmed) interests of donors whose own treatment is unsuccessful appears to have dominated HFEA policy-making. Consequently, the HFEA has failed to acknowledge other possibilities: that even donors whose treatment had failed might want to know the outcome of their donation (Anonymous, 1999) and that those whose treatment had succeeded might wish to inform their children of the existence of half-siblings and that those born as a result of such treatment themselves might at some point wish to learn whether or not they had half-siblings.

Concerns about the interests of people born as a result of egg sharing need to be located within a wider context concerning the outcomes of assisted conception treatment. Self-evidently, we do not know what people born as a result of egg sharing will feel about the nature of their conception, their donor, their parents, the professionals providing the service, or themselves, and to what extent their experiences and perceptions will be similar or different to those of others born following different types of donor-assisted conception. It is only in recent years that the personal consequences of decades of secretive and anonymous donor insemination have begun to be systematically articulated (for an overview, see Blyth, 2002) and even so there is no consensus on how these messages should be received and acted upon (see, for example, Broderick and Walker, 1995). Awareness and interpretation of the impact of various assisted conception techniques on the people whose very existence they are responsible for are likely to assume greater significance in the future.

Egg sharing appears set to become a particular, and possibly unique, feature of regulated assisted conception services in the UK. Despite the HFEA's efforts to distance itself from the ethical debate (Human Fertilisation and Embryology Authority, 1999), by giving egg sharing the benefit of any doubt, it nevertheless has a responsibility to monitor egg sharing practice closely and to develop policy in the light of experience. This should include giving greater weight to the experiences of those who participate directly as donors and recipients and of those born as a result of egg sharing. If this experience indicates that egg sharing has an intrinsically deleterious impact on any of these parties, the HFEA should not hesitate to abandon its current policy and withdraw approval for egg sharing.

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References


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