Donor Motivation in the UK

Objective

The objective of this review is to identify the repertoire of perceptions, concerns, views and understandings that donors consider as part of the process of deciding whether or not to donate.

Since egg donation became a possibility in the early 1980s, the debate surrounding the manner in which women should be encouraged to donate has been a source of a large variation in opinions. Immediately compared to the organ and blood donation campaigns it was quickly realised that, due to the consequences both for a potential child born, and for the donor themselves, gamete donation should be distinguished from these other two forms of donation. As a consequence, donor motivations will inevitably differ among these categories.

Altruism

Given the recent advances in organ and tissue donation, it seems appropriate to many authors to revisit the current received wisdom that altruism seems to govern organ and tissue donation in British culture. However, before judging if altruism still needs to be seen as a *conditio sine qua non* for every system of organ or tissue donation, there is a more important question to be answered: *what is altruism*?

A brief review of the literature teaches us that there is no straightforward or generally accepted definition of the concept of altruism. The term is applied with a broad brush to describe both unconditional and reciprocal acts of giving. If there is no consensus as to the nature of an altruistic act at all, then this has to be kept in mind when studies or surveys refer to “altruistic motives” for donation.

An example:

In a recent concept analysis, **Smith**[1] argued that altruism displays four critical attributes:
-a sense of personal responsibility for another person’s well-being
-a sense of compassion for another
-a sense of empathy
-an uncalculated selfless commitment to the needs of others.

Sticking to this analysis, Smith goes on to identify the consequences of acting altruistically:
-a vicarious pleasure in the welfare or happiness of others
-a sense of relief when another’s needs have been met

[1] **Smith A.** An analysis of altruism: a concept of caring. Journal of Advanced Nursing. 1995. 22. 785-790.

-good equated with caring for others
-the exclusion of self may result in disequilibrium in relationships if only others are legitimized as the recipients of care
-care of self may be considered selfish.

Arguing from the presumption that altruism is almost impossible to define, the important question will be *which kind of altruism* needs to be seen as the prerequisite for a donation model in British culture. This kind of judgment however falls outside the scope of this review.

An example:

In the 70's, Titmuss[2] claimed that blood donation in the U.K. is the closest approximation to the abstract concept of a 'free human gift' where there are no immediate rewards and donations are made with no prior knowledge of the recipient's age, gender, ethnic group or religion. He further states that because the recipient is anonymized, the donor is not strictly responding to a social expectation or a moral enforcement of a return gift. However, Titmuss concedes that that there is no such thing as an act of complete and spontaneous altruism, for he recognizes that blood donors are still fulfilling an act of self-love. In fact, he claims that the self is realized with the help of anonymous others. In the words of Swales: "altruism becomes, according to his view, a special form of self-interest, but one which is shared with other members of a beneficent society". For Titmuss, this kind of altruism, what he called 'creative altruism', is the only acceptable kind of donation, as it's free from human exploitation, commercialization or risk.

Still, the most common used definition of altruism will in many cases be the one that is applied. In this, altruistic donors are those who donate not in return for any reward but simply in order to give this gift to another. In the case of egg donation for example, altruistic donors are typically those who have experienced motherhood themselves and would like to share this opportunity with another, or women who have come across infertility in their lives either through family or friends, and so realise the struggles that such women face.

Some international considerations

Payment

The notion of altruism, as a necessary prerequisite for donating any kind of tissue or blood, has always been applied to justify the UK's strict position that payment for donation needs to be prohibited. The donation of organs, blood, tissue (eggs and sperm) or embryos is regulated in such a way that no money can be changed hands at all except to compensate for the reasonable expenses or loss of earnings.

[2] **Titmuss R.** The Gift Relationship: from Human Blood to Social Policy. Allen and Unwin. London. 1970 - **Titmuss R.** The Gift Relationship: from Human Blood to Social Policy. (New edition.) (Oakley A. and Ashton J. eds.) London school of economics and Political Science. London. 1997.

The reference to expenses or loss of earnings makes it clear that any such payments are not to be seen as payment for the donated materials itself, or even compensation for the inconvenience of donation, but simply to cover financial costs which are directly attributable to the donation.[3]

Though the EU Tissue and Cells Directive[4] also demands that attempts should be made to promote altruistic donation, it allows **inconvenience payment** for donation. Article 12(1) of the Directive states: "Donors may receive compensation which is strictly limited to making good the expenses and inconveniences related to the donation. In that case, Member States define the conditions under which compensation is paid." The HFEA however decided that donors should only be compensated for the losses associated with donation such as travel expenses and loss of earnings.[5]

In the United States, where gametes have been commercialised, gamete donors are reimbursed for expenses, time, risk and discomfort and is typically about $2000 per donation.[6] Much higher sums have reportedly been paid to models and Ivy League students and graduates.

Donor motivation in the context of the HFEA's regulatory remit

Motivations egg donation for treatment

Fielding et al.[7] and Power et al.[8] pointed to the fact that the small financial compensation that was paid before the Regulations of 2004 came into force, was unlikely to motivate women to donate, implying that women are more likely to donate their eggs for altruistic reasons. Now that only expenses and loss of earnings are compensated, this presumption looks even more appealing.

Due to the unpleasant and intrusive nature of egg retrieval, women who donate altruistically, or as non-patient donors are often relatives or friends of the recipients of their eggs. This means that they are one of the motivations would be to help someone they are close to. These findings were also acknowledged

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[3] **Jackson E.** Medical Law: Text, Cases and Materials. Oxford University Press. Oxford. 2006. 744. - **The Human Tissue Act 2004**.

[4] **The EU Tissue and Cells Directive.**

[5] **HFEA.**

[6] **Steinbock B.** Sperm as Property in **Harris J., Holm J. and Holm S. (eds.)** The Future of Human Reproduction: Ethics, Choice and Regulation. Clarendon Press. Oxford. 1998. 150-161..

[7] **Murray C. and Golombok S.** Oocyte and semen donation: a survey of UK licensed centres. Hum. Reprod. 2000. 15. 10. 2133-2139. - **Fielding D., Handley S., Duqueno L. et al.** Motivation, attitudes and experience of donation: a follow-up of women donating oocytes in assisted conception treatment. J. Community. Appl. Social Psychol. 1998. 8. 273-287.

[8] **Murray C. and Golombok S.** Supra. - **Power M., Baber R., Abdalla H. et al.** A comparison of the attitudes of volunteer donors and infertile patient donors on an ovum donation programme. Hum. Reprod. 1990. 5. 352-355.

by the NGDT (National Gamete Donation Trust)-survey[9]. This survey also stated that many clinics (82%) involved felt that some donors had been under pressure to donate.

Another factor that needs attention according to van den Akker[10] is the socio-cultural fact that women are 'supposed to' nurture and care for babies, and not relinquish them – which is how egg donation may be perceived by some people.

According to Schover et al.[11] another motivation or reason for women donating oocytes is to cope with previous losses.

Lessor et al, in a study on the characteristics of egg donors in the US, where commercial egg donation is allowed, developed the following donor profile: "The typical donor tends to be 26 years old, married with one or two children, holds religious or spiritual beliefs, has 2 years of college, works at least part-time in a white collar job, and is a person with high energy who has additional interests. Incidence of dysfunction in family of origin or family of orientation (abandonment, abuse) is unremarkable".[12]

In the UK, Ahuja et al have also formed a similar profile from their research where they found that the majority of participants in the study were "middle class, married, Caucasian women who had benefited from tertiary education."[13] Many other studies have created a similar profile, with a picture emerging more and more of middle-class, late twenties or early thirties woman possibly with children.[14] This donor profile can lead us to conclude altruism is a main factor of egg donation, whether or not financial incentives are in operation. **Kalfoglou and Gittelsohn** also show that although many begin the donation process attracted by the prospect of financial reward (in the US), their altruistic sentiments increase over the course of the donation.[15]

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[9] **Murray C. and Golombok S.** Supra. - **NGDT-survey**.

[10] **van den Akker O.** A review of family donor constructs: Current research and future directions. Hum. Reprod. 2006. 12. 2. 91-101.

[11] **van den Akker O.** Supra. - **Schover L., Rothman S. and Collins R.** The personality and motivation of semen donors: a comparison with oocyte donors. Hum. Reprod. 1992. 7. 575-579.

[12] **R. Lessor, N. Cervantes, N. O'Connor, J. Balnaceda and R.H. Asch**. An analysis of social and psychological characteristics of women volunteering to become oocyte donors. 1993. 59. Fertil Steril. 65.

[13] **K. Ahuja, B. Mostyn, and E. Simons.** Egg sharing and egg donation: attitudes of British egg donors and recipients. 1997. 12. Human Reproduction. 2845, 2846

[14] **Human Fertilisation and Embryology Authority** "Statistics on Egg Donor Demographics 2004-5 and 1994-5" http://www.hfea.gov.uk/AboutHFEA/HFEAPolicy/SEEDGuidanceandDirections/Graphs_showing_demographics_of_egg_donors_2004_05_Jul_Jun_1994_95.pdf (last visited 29th April 2006) showed that on average half of all oocyte donors are women with children and that the majority of donors were in their early thirties.

[15] **A.L. Kalfoglou and J. Gittelsohn** "A qualitative follow-up study of women's experiences with oocyte donation" (2000) 15 Hum Reprod 798.

Abdalla et al.[16] found that few oocyte donors revealed information about themselves on the HFEA records, and in general, past research has shown that a minority of oocyte donors are happy with identifying information being disclosed to offspring, although there are exceptions, as Purewal[17] mentions. These results are backed by findings by van den Akker relying on studies by Walker et al.[18], Robinson et al.[19], Schover et al.[20], Soderstrom-Antilla[21], Abdalla et al.[22], Lindheim et al.[23] and Kalfoglou and Gittelsohn[24]. A study by Sauer and Paulson[25] was the only one that showed something different – when 66% agreed with open donation.

The 2004 Regulations, abolishing anonymity, are likely to have an influence on the donation of eggs. The removal of donor anonymity will have a different effect on known donors than on donation in general due to the fact that the donor is known to the parents already. This group of donors is more accustomed already to having a lack of anonymity. However, the most significant concern is that of coercion. This is already a significant factor in known donation. It could be argued that there can be no greater coercive force than that of family pressures.

Sperm donation for treatment in the UK

A survey carried out by the HFEA in 1993[26], as part of its consideration of the issue of payments to gamete donors, found out that the large majority of semen donors were young single students who were primarily motivated by payment. Daniels and Hall[27] also pointed out that these men would not donate if payment

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[16] **Purewal S. and van den Akker O.** British women's attitudes towards oocyte donation: Ethnic differences and altruism. - **Abdallah H., Shenfield F. and Latarche E.** Statutory information for the children born of oocyte donation in the U.K.: what will they be told in 2008? Hum. Reprod. 1998. 13. 1106-1109.

[17] **Purewal S. and van den Akker O.** Supra.

[18] **van den Akker O.** Supra. - **Walker A., Gregson S. and McLaughlin E.** Attitudes towards donor insemination – a post Warnock survey. Hum. Reprod. 1987. 2. 745-750.

[19] **van den Akker O.** Supra. - **Robinson J.N., Forman R.G., Clark A.M., Egan D.M., Chapman M.G. and Barlow D.H.** Attitudes of donors and recipients to gamete donation. Hum. Reprod. 1991. 6. 307-309.

[20] **van den Akker O.** Supra. **- Schover L.R., Collins R.L., Quigley M.M., Blankstein J. and Kanoti G.** Psychological follow-up of women evaluated as oocyte donors. Hum. Reprod. 1991. 6. 1487-1491.

[21] **van den Akker O.** Supra. - **Soderstrom-Atilla V.** Follow up of Finnish volunteer oocyte donors concerning their attitude to oocyte donation. Hum. Reprod. 1995. 10. 3073-3076.

[22] **van den Akker O.** Supra. - **Abdallah H., Shenfield F. and Latarche E.** Supra.

[23] **van den Akker O.** Supra. - **Lindheim S., frumovitz M. and Sauer M.** Recruitment and screening policies and procedures used to establish a paid donor oocyte registry. Hum. Reprod. 1998. 13. 2020-2024.

[24] **van den Akker O.** Supra. - **Kalfoglou A. and Gittelsohn J.** A qualitative follow up study of women's experiences with oocyte donation. Hum. Reprod. 2000. 15. 798-805.

[25] **van den Akker O.** Supra. - **Sauer M. and Paulson R.** Oocyte donors: a demographic analysis of women at the University of southern California. Hum. Reprod. 1992. 7. 726-728.

[26] **Murray C. and Golombok S.** Supra. - **HFEA survey 1993**.

[27] **Murray C. and Golombok S.** Supra. - **Daniels K.R. and Hall D.J.** Semen donor 12, recruitment strategies – a non-payment based approach. Hum. Reprod. 1997. 12. 2330-2335.

was removed. These findings were further supported by Gazvani et al.[28], McLaughlin et al.[29] and by the NGDT-survey[30].

However, it has been pointed out by Golombok and Cook[31], Cook and Golombok[32] and Fielding[33] that the wish to be paid and the wish to help an infertile couple are not mutually exclusive, and that many men take both considerations into account when they decide to donate. The NGDT-survey pointed to the fact that payment was the main motivation for students while altruism was the primary motivation of older men.

Though the statistics gathered before the legal change regarding anonymity were somehow mixed, sperm donors were largely supportive of anonymity. However, multiple studies reported that there were exceptions. Some studies identified that more sperm donors would be happy with the possibility that their offspring would attempt to contact them later in life than is generally assumed. (Daniels and Taylor[34], Rowland[35], Leeton and Harman[36], Walker et al.[37], Daniels[38], Power et al.[39], Mahlstedt and Probasco[40], Robinson et al.[41], Kirkland et al.[42], Purdie et

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[28] **Murray C. and Golombok S.** Supra. - **Gazvani M.R., Wood S.J., Thomson J.M. et al.** Payment or altruism? The motivation behind gamete donation. Hum. Reprod. 1997. 12. 1845-1846.

[29] **Murray C. and Golombok S.** Supra. - **McLaughlin E.A., Day J., Harrison S. et al.** Recruitment of gameter donors and payment for expenses. Hum. Reprod. 1998. 13. 1129-1132.

[30] **Murray C. and Golombok S.** Supra. - **NGDT-survey**.

[31] **Murray C. and Golombok S.** Supra. - **Golombok S. and Cook R.** A survey of semen donation. Phase I: the view of UK licensed centres. Hum. Reprod. 1994. 9. 882-888.

[32] **Murray C. and Golombok S.** Supra. - **Cook R. and Golombok S.** A survey of semen donation: Phase II – the view of donors. Hum. Reprod. 1995. 10. 951-959.

[33] **Murray C. and Golombok S.** Supra. - **Fielding D., Handley S., Duqueno L. et al.** Supra.

[34] **van den Akker O.** Supra. - **Daniels K.R. and Taylor K.** Secrecy and openness in donor insemination. Politics Life Sciences. 1993. 12. 155-170.

[35] **van den Akker O.** Supra. - **Rowlamd R.** attitudes and opinions of donors on an artificial insemination (AID) programme. Clin. Reprod. Fertile. 1983. 2. 249-259.

[36] **van den Akker O.** Supra. - **Leeton J. and Harman J.** Attitudes towards egg donation of thirty-four infertile women who donated during their in vitro fertilisation treatment. J. In Vitro Fert. Embryo Transf. 1986. 3. 374-378.

[37] **van den Akker O.** Supra. - **Walker A., Gregson S. and McLaughlin E.** Supra.

[38] **van den Akker O.** Supra. - **Daniels K.** Semen donors: their motivations and attitudes to their offspring. J. reprod. Nf. Psychol. 1989. 7. 121-127.

[39] **van den Akker O.** Supra. - Power **M., baber R., Abdalla H., Kirkland A., Leonard T. and Studd J.W.** A comparison of the attitudes of volunteer donors and infertile patient donors on an ovum donation programme. Hum. Reprod. 1990. 5. 352-355.

[40] **van den Akker O.** Supra. - **Mahlstedt P.P. and Probasco K**. Sperm donors: their attitudes towards providing medical and psychosocial information for recipient couples and donor offspring. Fertile. Steril. 1991. 56. 747-753.

[41] **van den Akker O.** Supra. - **Robinson J.N., Forman R.G., Clark A.M., Egan D.M., Chapman M.G. and Barlow D.H.** Supra.

[42] **van den Akker O.** Supra. - **Kirkland A., Power M., Burton G., baber R., Dtudd J. and Abdalla H.** Comparison of attitudes of donors and recipients to oocyte donation. Hum. Reprod. 1992. 7. 355-357.

al.[43], Ahuja et al.[44], Daniels[45], Sauer et al.[46], Fidell and Marik[47] and Daniels[48]). The presumption that anonymity is necessary in order to protect the continued availability of donated sperm has been undermined by several studies which have indicated that a significant proportion of donors, especially among those who donate during their late twenties and thirties, would be willing to be identified. Ken Daniels describes two studies carried out in the UK, one study involved older donors 53% of whom would not mind if their offspring were able to trace them; the other study involved students, only 18pc of whom would continue to provide sperm if their offspring could learn their identity.[49]

Evidence from countries in which children can gain access to identifying information about the gamete donor, such as Sweden, suggest that is has not dramatically depleted the supply of donated gametes, but rather that it alters the profile of donors, from students to men with families of their own.[50]

Egg sharing for treatment in the UK

Studies by Rapport[51], Pennings[52], Blyth[53], and Ahuja et al.[54] show that the motivation for women to share their eggs is in fact multidimensional. Factors, amongst others, involved in the decision as whether to share or not are the reduced cost and waiting time, thoughts about 'giving away your own genes', the parenthood of the recipient couple, the opening of registers, the resemblance to blood and sperm donation, the outcome of the recipient's treatment, the idea of helping someone and the idea of having a common interest.

However, though it is definitely true that motivations to donate vary, Rapport argues that the idea of motherhood is obviously the predominant theme from

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[43] **van den Akker O.** Supra. - **Purdie A., Peek J., Irwin R., Ellis J., Graham F. and Fisher P.** Identifiable semen donors – attitudes of donors and recipient couples. NZ Med. J. 1992. 12. 105. 27-28.

[44] **van den Akker O.** Supra. - **Ahuja K., Mostyn B. and Simons E.** Egg sharing and egg donation: attitudes of British egg donors and recipients. Hum. Reprod. 1997. 12. 2845-2852.

[45] **van den Akker O.** Supra. - **Daniels K.** The controversy regarding privacy versus disclosure amomg patients using donor gametes in assisted reproductive technology. J. Assist. Reprod. Genet. 1997. 7. 121-127.

[46] **van den Akker O.** Supra. - **Sauer M. Gorrill M., zeffer K. and Bustillo M**. Attitudinal survey of sperm donors to an artificial insemination clinic. J. Reprod. Med. 1989. 34. 362-364.

[47] **van den Akker O.** Supra. - **Fidell L. and Marik J.** Paternity by proxi: artificial insemination with donor sperm in **Offerman-Zuckerberg J.** (ed.) Gender in Transition. Plenum. New-York. 93-110.

[48] **van den Akker O.** Supra. - **Daniels K. and Lewis G.** Donor insemination: the gifting and selling of semen. Soc. Sci. Med. 1996. 42. 1521-1536.

[49] Daniels K. The Semen Providers (Emilys book 827).

[50] Emilys book 828.

[51] **Rapport F.** Exploring the beliefs and experiences of potential egg share donors.

[52] **Pennings G.** Subsidized in-vitro fertilization treatment and the effect on the number of egg sharers. RBM Online. 2006. 13. 1. 8-10.

[53] **Pennings G.** Supra. - **Blyth E.** Patient experiences of an 'egg sharing' programme. Human Fertility. 2004. 7. 157-162.

[54] **Pennings G.** Supra. - **Ahuja K., Mostyn B. and Simons E.** Supra.

which all others develop. Although there is a strong empathic concern and sympathy for another woman's plight, it is the personal desire to achieve motherhood, which is complicated by a number of external factors, which drove their involvement in the process of egg sharing. Lengthy NHS waiting lists, rationing of NHS treatment, costly private treatment and the sense of time not being on their side were predominant in the motivation process. All of this means that it is ill-advised to see egg sharing as a purely altruistic act. Rapport concludes by stating that if there were no rationing of NHS services, it is doubtful whether women would continue to egg share.

Pennings analysed the data on egg sharing in Belgium which showed that since full reimbursement for six IVF-cycles was introduced, the numbers of egg sharers dropped approximately 70 per cent. The category of dropouts still contains two groups: a group who shares oocytes purely for financial reasons and a group whose altruism is not strong enough to share after reimbursement is provided. Although these data show that a large number of donors are mainly motivated by the reduced cost for IVF, it cannot be concluded that money is the only motive to share.

When Blyth asked his respondents if they would contemplate sharing their eggs with another woman, even without any financial advantage to themselves, ten out of 12 women who had shared stated that they would. Ahuja too stated that the financial position of the donors is seldom a major consideration for participation in an egg-sharing programme. He argues that egg sharing donors are not the put-upon poor, but a well-educated middle class group of self determined women who are capable of addressing the issues involved in egg sharing. Most donors, he argues, make a distinction between cash incentives which they reject and the treatment benefits, which they respect and need. They merely use these benefits to make a commitment to give hope to the childless as well as to themselves. Therefore, they think of themselves as acting altruistically. Ahuja then uses this donor profile to conclude that their informed consent is not in jeopardy because of the payment in kind. Though the accuracy of this last presumption is outside the scope of this paper, the clear empirical Belgian evidence shows that the treatment benefit nevertheless operates as a huge motivation for donors.

The above mentioned evidence points to the fact that egg sharing motivation is clearly multidimensional. It shows that egg sharers' motivations are in many cases supported by altruistic feelings but the fact that a lot of egg sharers would drop out if they could access NHS funding shows that the treatment benefits are of huge importance as well.

Spare embryo donation for treatment in the U.K.

An Australian study by de Lacey[55] illustrated that when patients begin IVF treatment they are informed about cyropreservation of embryos and are encouraged to consider options for their outcome if they are not used in their own pursuit of a family. The couples and women interviewed in this study indicated that at this point their intention was to donate them to another couple who, like themselves, were having problems in achieving pregnancy. However, after completing their family, or, as in the case of the childless couple, deferring their treatment, they all changed their minds.

The reason for this change of mind is that their initial intentions were altruistic, at the level of an idealistic plan, i.e. to do a nice thing to couples in similar situations. However, this decision could not be experienced as a truly serious decision with moral ramifications until later. At a later point in time, the decision was much harder than they imagined and fraught with moral ramifications. This conclusion was backed by studies by Svanberg et al.[56], McMahon et al.[57], Laruelle and Englert[58] and Bangsboll et al.[59]. Apparently, parenthood was the main factor changing the status of the embryos and the way parents thought about them. In fact, they started looking at the embryos as a virtual persons rather than clumps of cells. This feeling was intensified by the fact that these embryos represent complete genetic relatedness to the donors, unlike sperm and oocytes. As a consequence of the fact that they wanted to act in the best interests of these "children", they started doubting about the prospective parents. Many regarded donation as child relinquishment. This had also struck other researchers (Van Hoorhis et al.[60], Soderstrom-Antitila et al.[61], Kahn[62] and Widdows and MacCallum[63]). Another concern regarding donation was that they would always be wondering about where the child was.

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[55] **de Lacey S.** Parent identity and 'virtual' children: why parents discard rather than donate unused embryos. Hum. Reprod. 2005. 20. 6. 1661-1669.

[56] **de Lacey S.** Supra. - **Svanberg A., Boivin J. and Bergh T.** Factors influencing the decision to use or discard cryropreserved embryos. Acta. Obstet. Gynaecol. Scand. 2001. 80. 849-855.

[57] **de Lacey S.** Supra. - McMahon **C., Gibson F., Cohen J., Leslie G., Tennant C. and Saunders D.** Mothers conceiving through in vitro fertilisation: siblings, setbacks and embryo dilemmas after five years. Reprod. Technol. 2000. 10. 131-135.

[58] **de Lacey S.** Supra. - **Laruelle C. and Englert Y**. Psychological study of in vitro fertilisation-embryo transfer participants' attitudes towards the destiny of their supernumary embryos. Fertil. Steril. 1995. 63. 1047-1050.

[59] **de Lacey S.** Supra. - Bangsboll **S., Pinborg A., Yding Andersen C. and Nyboe Andersen A.** Patients' attitudes towards donation of surplus cryoperserved embryos for treatment or research. Hum. Reprod. 2004. 19. 2415-2419.

[60] **de Lacey S.** Supra. - Van **Hoorhis B., Grinstead D., Sparks A., Gerard J. and Weir R.** Establishment of a successful donor embryo program: medical, ethical and policy issues. 1999. 71. 604-608.

[61] **de Lacey S.** Supra. - **Soderstrom-Antilla V., Foudila T., Ripatti U. and Siegberg R.** Embryo donation: outcome and attitudes among embryo donors and recipients. Hum. Reprod. 2001. 16. 1120-1128.

[62] **de Lacey S.** Supra. - **Kahn J.** 'Adoption' of frozen embryos a loaded term. CNN.com/health.

[63] **de Lacey S.** Supra. - Widdows **H. and MacCallum F.** disparities in parenting criteria: an exploration of the issues, focusing on adoption and embryo donation. J. Med. ethics. 2002. 28. 139-142.

As de Lacey suggests, in accordance with a previous study by Elford et al.[64], the change of mind by childless couples may also be due to the fact that they are not able to live with the possibility of their genetic child being raised elsewhere. Mind however that de Lacey's study did only involve one childless couple.

de Lacey concludes that the altruistic intentions of the participants remained strong but conflicted with other moral values about family and kinship. Or, as Cooper[65] suggested, intentions to donate were choices made 'in the abstract', but when couples have 'real, living examples of what an embryo can become' the dynamics of the decision are very different.

Spare embryo donation to research in the U.K.

A study by Choudhary et al.[66] identified some factors influencing the donation of fresh embryos to research. It was stated that couples with previously failed fertilisation were less likely to consent to embryo research and that couples of ethnic minority origin were also less willing to consent to research. The scope of this study regarding donor motivation was rather limited as it didn't tell why couples choose or decline to donate their spare embryos to research.

Haimes and Luce[67] argue that only the ongoing Wellcome Trust-funded study[68], on the views of IVF patients who have been asked to provide 'spare' embryos for embryonic stem cell research and for the research to assess the effects of PGD on embryo development, can provide important empirical to address this apparent gap in literature.

The Public Consultation on the Stem Cell Bank[69] did not provide quantitative data, but generally concluded that there was support among the wider public for the donation of embryos to research that would otherwise be destroyed. This is confirmed by a study by McMahon et al.[70]. A researcher at the consultation forum even stated that 70pc of the couples agree to donate mainly because they reason that they wouldn't be getting their treatment unless someone had done research.

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[64] **de Lacey S.** Supra. - **Elford K, Lawrence C. and Leader A.** Research implications of embryo cryopreservation choices made by patients undergoing in vitro fertilisation. Fertl. Steril. 2004. 81. 1154-1155.

[65] **de Lacey S.** Supra. - **Cooper S.** The destiny of supernumerary embryos? Fertil. Steril. 1996. 65. 205-206.

[66] **Haimes E. and Luce J.** Studying potential donors' views on embryoniv stem cell therapies and preimplantation genetic diagnosis. Hum. Fert. 2006. 9. 2. 67-71. - **Choudhary M., Haimes E., Herbert M., Stojkovic M. and Murdoch A.** factors influencing couples' decisions to donate fresh spare embryos for research. Hum. Repro. 2004. 19. 2091-2096.

[67] **Haimes E. and Luce J.** Supra.

[68] **Wellcome Trust-funded study**.

[69] **The Public Consultation on the Stem Cell Bank**.

[70] **de Lacey S.** Supra. - McMahon **C., Gibson F., Leslie G., Saunders D., Porter K. and Tennant C.** Embryo donation for medical research: attitudes and concerns of potential donors. Hum. Reprod. 2003. 18. 871-877.

Although it was clear that those who have benefited from IVF treatment feel an obligation to help others in the same situation by donating spare embryos to research, this feeling of almost being obliged to help future infertility treatment does not necessarily extend to ES cell or other embryo-based research. (Potential donors were especially concerned about the creation of embryo for research only, CNT and fetal stem cells.)

Peter Verbeke
Policy – September 2006

Annex A