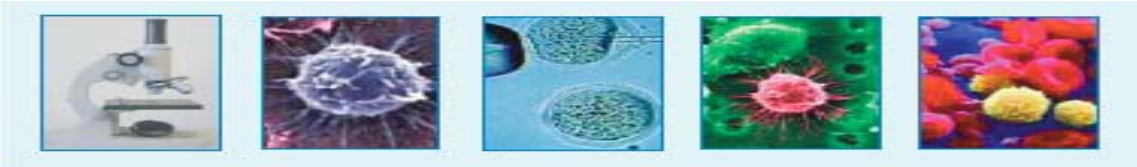

Share Your Views About Donating Eggs For Stem Cell Research

A Summary

Prompted by the *Human Fertilisation and Embryology Authority's* public consultation about the possible use of women's eggs in research, we organised and ran a public debate as part of our project "Talking About Stem Cells: The Social Dynamics of Public Engagement in Stem Cell Research". We chose a question and answer format, with four panellists who helped to facilitate the debate by addressing questions posed by the audience either prior to the event or during the evening itself. The focus was on the issues raised by the two possible sources of donated eggs for research: from women undergoing IVF treatment in 'egg-sharing' schemes, or from women who are not undergoing IVF treatment. The debate was held at Our Dynamic Earth, Edinburgh, and attended by over 90 people.

Overall, this was a successful and lively debate, allowing people to learn about the complex issues that using human eggs in research generates. However, we felt at the end that we had just begun to get to grips with the issues, as the time passed so quickly. Also, the event was not quite as participatory as we had hoped – there was less time for debate from the floor - it did highlight the importance of gaining a broad spectrum of views not just those on the panel. Additionally, it has provided us, the research team, with much food for thought in terms of designing subsequent participatory dialogues for our project.

In this summary, we provide brief outlines of the opening statements of the four panellists, which were framed as a response to a question that had been sent in from an audience member 'What are the panel's views on the HFEA consultation on egg donation?'. We then try to cover the main issues which were discussed during the rest of the debate.

Donna Dickenson's Opening Response

Donna is pleased that the consultation is going ahead, especially as it focuses on the use of eggs within cloning techniques rather than the status of the embryo, which usually dominates public debates concerning stem cell research.

She began her answer by highlighting the case of Professor Hwang from South Korea, who has unsuccessfully attempted to create cloned human embryos using women's eggs. Hwang claimed to have produced stem cell lines that had been extracted from a cloned embryo, which, if possible, could be valuable in the treatment of disease in the future. Although he claimed that he had created eleven stem cell lines, he had, in fact, created none. Donna also pointed out that Hwang's unsuccessful research used (and wasted) around 2200 human eggs, and she is surprised that the issue of where these eggs came from was not raised at the time, but is glad that the HFEA is raising it now.

With regard to the issue of women donating eggs for research, either as non-patient donors or through egg-sharing arrangements, Donna feels that the available evidence is not favourable. The anecdotal evidence of the risks faced by women undergoing egg extraction is mounting

up in a worrying way. For instance, there are serious side-effects caused by the use of the drug which is used in shutting down the woman's menstrual cycle; the hyper-stimulation of the ovaries is linked to the risk of ovarian hyper-stimulation syndrome, which is estimated to occur in between 0.5 and 5 percent of cases; and there is also a risk in the actual extraction of the eggs.

Donna argues that the donation of eggs to research is different to women donating eggs to help other women have a child. Women who donate their eggs to research do not receive any clinical benefit and there are not the same regulatory controls as with clinical trials. Instead, Donna considers women to be the suppliers of raw materials where doctors may actually cause harm to their patients. Rather than asking the question of whether women should be allowed to donate eggs for research, Donna turned the question around and doubted whether allowing doctors to extract eggs to be used for research was the right thing to do.

Overall, Donna thinks that the debate is not being driven by women clamouring to donate but rather by the speculative benefits of stem cell research and an international competition for research teams to succeed in that area. Although she has concerns over women not undergoing IVF donating eggs, she is particularly worried with the practice of 'egg sharing', which is when a woman undergoing IVF treatment does not have to pay so much, in return for a proportion of her extracted eggs. She believes it is better to label the practice 'egg barter', that it is a form of commodification, that women do not want to egg 'share', and that it is discriminating against women who cannot afford to pay the full cost of IVF.

Harry Griffin's Opening Response

Harry notes that the HFEA's consultation document is impressive but that there are some things missing from it and the debate more generally. He is concerned about the confusion between stem cell research and stem cell therapy in general and therapeutic cloning in particular. He stated that stem cells for therapy and research will mainly come from embryos which are surplus to requirements from IVF treatments. With regard to therapeutic cloning, only two centres have been licensed in the UK to perform cell nuclear replacement: the Roslin Institute and Newcastle University. As such, stem cell research which requires donated human eggs is a relatively small subset of the activities which make up stem cell research as a whole. He feels that this needs to be stressed, as, in the HFEA's document, not enough time is spent explaining the broader context. Harry thinks that to both the casual and expert reader, it may appear that egg donation is crucial to the future of stem cell research when, in actual fact, this is not the case.

Harry also thinks there is a certain casualness in phrases in the document such as 'researchers suggest that the efficiency of the CNR technique could be improved by using recently collected eggs'. Meaningful statistical data needs to be produced to support this claim, which would then help to produce a more robust public consultation. Furthermore, the document needs to set the scene by explaining what the alternatives to the proposed research may be. For example, immune rejection can be prevented by other means than through the production of immune identical stem cells for patients.

Diane Beeson's Opening Response

As with Donna, Diane is pleased to be taking part in a debate which didn't concentrate on the moral status of the embryo. She thinks there are many important social issues surrounding

research cloning and egg donation which need to be examined. In her opinion, the most important of these is the threat to women's health posed by the increasing demand for women's eggs.

Diane explained that she is a representative of an international organisation called *Hands off our Ovaries* which is calling for a moratorium on egg harvesting for research purposes. Diane is concerned about the damage being done to women through the global market in human eggs and thinks that the industry is very poorly regulated. She is also worried about the pressure being put on women who want fertility treatment to 'share' their eggs and the amount of hormones being given to women during IVF procedures.

Although Diane is a supporter of stem cell therapy, she is also sensitive to the history of hormonal abuse of women. This is why she is calling for a moratorium because, until we get better data about the short- and long-term effects of drugs used in egg extraction, she considers the idea of informed consent a sham. This is also why she is a supporter of the move towards minimal stimulation IVF and 'natural cycle' IVF, which, in her view, lessen the risks to women undergoing IVF. She said that she believes enough in biotechnology to hold out for a biotechnology that respects the health of all people and does less harm than good.

Daniel Brison's Opening Response

Daniel began by saying that he supports much of what Harry Griffin had said. He also agreed with Diane Beeson on the need to take the risk of ovarian stimulation seriously and thinks that the IVF field in the UK is making a concerted effort to minimise the effects of it.

He explained that in the stem cell centre of which he is a co-director, the eggs they use are left over from IVF treatments, not ones that are donated specifically for research. Furthermore, in the UK, scientists are nowhere near making a therapeutic stem cell line that can be used for transplantation purposes. However, the UK government has spent a lot of money in order to provide the kind of stem cell laboratory facilities that will make transplantation possible. He felt that it was important to note that this money is coming from the taxpayer and government and not from commercial sources.

In agreement with Harry, Daniel is disappointed in the narrow focus of the consultation. He argued that there are plenty of ways of obtaining eggs for stem cell research and embryos for stem cell lines and the HFEA's document focuses too closely on the drive to obtain fresh eggs to make cloned embryos for patient specific stem cell lines. It needs to be acknowledged that stem cell research does not require fresh eggs and that it can use discarded eggs and embryos which introduce no extra risk to the patient.

He also feels that it is important to recognise that, in the UK, each IVF centre employs an independent nurse to gain consent for donation and that the clinician and scientist do not have a role to play in this part of the process. This helps to ensure informed consent, prevents any undue pressure being placed on patients and minimises the possibility of what happened in South Korea with Professor Hwang. Daniel also notes that it was the international stem cell community that first raised questions about the sources of the human eggs in Hwang's research and these enquiries subsequently revealed Hwang's research findings as fraudulent.

Overall, Daniel thinks it is important to discuss whether we need to use fresh eggs in stem cell research and, if there is a need, asks whether it is ethically more acceptable to obtain them from non-patient donors or through egg sharing procedures. In his opinion, the latter was less ethically acceptable and that more consideration should be given to women donating eggs altruistically for research.

Issues

The Drugs used in Ovarian Stimulation

One audience member thought that too much emphasis was being placed on the side effects of the drugs during stimulation. They felt it is important to note that the majority of patients do not have any problems during stimulation and that women should not be put off from having IVF treatment because they are so worried about the side effects of drugs. Moreover, it was noted that the drug used in the UK was not the same as the controversial one used elsewhere.

In response, it was argued that there is a need to distinguish between taking drugs for IVF in which the risks were acceptable because the woman would receive a clinical benefit and taking drugs for research purposes in which the clinician is imposing risks without offering benefits. It was also noted that we don't yet know what the risks are and, therefore, there was a need for a moratorium on egg donation for research until we have further information. It was also pointed out that this lack of information made the movement towards 'natural cycle' IVF and minimal stimulation IVF all the more exciting.

The Role of the Clinician and the Scientist

It was argued that it is important to note that the clinician and the stem cell scientist are not the same person and that the clinician would never allow a woman to be exposed to unnecessary risk for the sake of the research, as he or she has no direct interest in it. However, it was also argued that, although they may not be the same person, they are part of the same social and professional network and their loyalties to each other may be greater than their loyalties to the patient.

The Ethics of Altruism and Informed Consent

A question was raised on the ethics of altruism and whether, if altruism had been established and informed consent given, would the opinions of the panellists change. In reply, it was argued that what made altruism ethical was whether there was informed consent. There is no systematic collection of data concerning the impact and risks of ovarian stimulation and, therefore, informed consent is not possible at the moment, as not all the information required is provided. Moreover, there has been no real effort to attempt to collect it and deception and manipulation of data often took place within IVF. An example was provided of the mother of the first test tube baby who had not been informed of the experimental nature of the research, although there was some disagreement amongst the panel on this.

However, it was argued that if this information is provided and women still want to donate, the issue remains whether anyone should circumscribe that right to decide. It was noted that part of informed consent is also understanding that not all the risks can ever be known and that, so long as this is communicated, altruistic donation remains possible. And in this

context, we need to credit people with being able to take responsibility for their own actions. The point was made that we have to consider not only the ethics of the harm caused to women-as-donors but also the harm caused to patients who may benefit from this form of research if it is not carried out.

On a slightly different point, it was noted that women are not rushing to donate altruistically and that, even if they did, it would not necessarily be the case that we should accept their generosity. An example was given of people wanting to donate their hearts for heart transplantation when this was clearly not in their best interests. Furthermore, it was argued by some that the standard of informed consent in the UK is considered quite weak when compared to that of the US. In the UK, there is a paternalistic standard in which informed consent is measured by what a reasonable doctor would reveal, not what a reasonable patient wants to know. Therefore, with egg donation for research purposes, it would be a worrying thing to rely solely on informed consent.

The Time Span of Stem Cell Research

It was argued that the clinical objectives of current research in cell nuclear replacement are 20 to 30 years into the future and are by no means imminent. Members of patient groups considered this news as refreshing as they are used to being told that a cure is just around the corner. At the same, however, they found the news to be disappointing. It was also argued that scientists have a duty to be realistic in their claims about research and potential therapies.

Commercialisation and International Competition

Worries were raised regarding the patenting stampede for the commercial by-products of women's ovaries. Concerns were also raised about the balance between the need to protect women and the need to maintain the UK's research position with regards to international competition. However, one audience member was glad that people are more interested in protecting women than international competition.

It was pointed out that donors could not benefit financially and that the informed consent process does not allow donors to place any conditions on their donation, such as what kind of specific research it can be used for. The idea that there should be some possibility for donors to be able to state what they wished their donation to be used for was aired, although this does raise the question of whether donations would remain altruistic if there are conditions attached to them. Regarding financial benefits, it was argued that a form of benefit sharing or charitable trust needs to be set up so that public benefit is also taken into account, as well as the needs of commercial organisations and funders.

The Use of Fresh Eggs in Research

It was posited that it was not yet known whether fresh eggs were needed for cell nuclear replacement (creating a cloned embryo) and that this was a hypothesis that needed to be robustly tested before expanding their use in research by asking women to 'egg share' or donate their eggs as a non-patient donor.

Regulation

A further issue considered was that some international stem cell banks may not accept stem cell lines that originate from 'egg sharing'. This is because they may consider the woman as having been coerced rather than donating 'altruistically'. It was argued that this was another reason not to allow 'egg sharing', as it would prevent patients from around the world benefiting.

Concern was raised about the purpose of, and rationale behind, the research being carried out at Newcastle. In particular, the discrepancies concerning the number of eggs used in their research and the ability of the HFEA to deal with these issues was raised by one audience member as being worrisome. It was agreed that scientists need to be much sharper in how they justify their research and that there are some loopholes in the way that this whole area is regulated. It is hoped that the upcoming merger of the regulatory authorities in the UK would be able to plug some, if not all, of these gaps. It was argued that, on the whole, the HFEA does a good job in difficult circumstances but that on the issue of egg sharing it definitely came to the wrong decision by issuing a license to the Newcastle group, at least before the current consultation took place.

The international reaction to decisions made by the HFEA in the UK needs to be taken into account. It was argued that people looked to Scotland and the UK as world leaders in this area and that decisions by the HFEA are used elsewhere to justify procedures by less judicious scientists than in the UK. On this topic, it was noted that scientists are choosing to work in the UK because it has a very robust system for regulating the field and for allowing full and open ethical debates, making it a much more comfortable field in which to work.

We were unable to deal with all the questions raised by the participants and hope that this debate was just the start. If you have any comments on the issues raised or on the event itself, we would like to invite you to send us your thoughts either in writing or by email to the address at the bottom. Alternatively, you could share your views on our online discussion forum at www.talkingstemcells.ed.ac.uk.

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