

Ready or not? A role play on taking stem cells to the clinic

Facilitator's Debriefing Notes

The decision today was not whether we should research with embryonic stem cells or not, it was whether there is enough background work and evidence provided to determine whether this clinical trial should go ahead. I think you did really well because you did discuss the issue of stem cells, embryonic stem cells and whether to use them or not. But then you also discussed whether there was enough scientific evidence to be able to go ahead with the clinical trial. That was very much what the committee based their decision on.

Before you complete the feedback form, I would just like to ask you a little bit about what you thought about this process.

First of all, do any of you have any comments about the biographies?

Did you research the stakeholder that you were assigned to gain more scientific background on the character? Or did you just read your biography sheet? (Show hands) Where did you find additional information?

Does anyone have any comments about their biographies?

Did you think the decision-making process became easier with the discussion?

Did you have to draw on your own views of the subject matter?

Were there feelings about the implication of being part of a clinical trial that do not sit well with you?

Was anyone questioning the use of humans as guinea pigs?

What would have helped as the interested member of the public? If there was a bit more on the profit, or the concerns about making money, would that have influenced your views? Or, do you feel you had enough to get your teeth into as it was written?"

The profit motive is interesting in that some companies that want to use cells to develop cellular therapies are not actually doing it from an ethical point of view, or even a humanitarian point of view. They might be doing it from the point of view of making money.

Do any of you have any questions about the science? About being a scientist? About the international competition between laboratories?

Scientists can find out about what scientists in other countries are doing. But country pride and competition will always exist. There was the case of a Korean scientist who seemed way ahead of everyone. It seemed as though he was way ahead of everyone, the UK, the US. He was getting amazing results but the data turned out to be false. So there is a competition element but there's much more of a collaborative element, so the creators of this Role Play are part of a big consortium, EuroStemCell where many laboratories in many European countries are working together for the greater good. They're sharing knowledge; there is tight collaboration with the Canadian stem cell network and the Scottish stem cell network too. Much of the work is collaborative; most of it is sharing data. There is some competitiveness too.

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Possible student Q: Has there been any case in which a clinical trial like this has been brought forward to a particular committee and then, because it's been refused there, been taken somewhere else and been said that that's okay?

It's likely, it probably has happened because in Europe there's a European-wide organisation that regulates clinical trials but then there's another one in the United States. What may or may not be okay for a European committee may be okay for an American one so it is possible that a company may take their trials over to the States. Or it may even be faster, the decision may be reached quicker in the States or in Europe so a company could decide what to do. And anyway, they would always have to present a proposal. If they wanted to use for example NHS hospitals, patients in NHS hospitals, the proposal would have to have a list of all the partners involved, not only the company but all the hospitals and the doctors and everything involved, and everyone would have to give their agreement. So then to move it to another country, it means you have to set everything up again.

Also important to keep in mind is the idea of potential. These embryos have massive potential, the potential to become any one of us, but that's theoretical potential. You have to also think of actual potential. What is the actual potential of an embryo that has been created by in vitro fertilization (IVF)- where perhaps 10 embryos are created in a laboratory to help a couple with a specific type of infertility difficulty? A clinic may opt to use the best of these embryos to try to implant to help a couple have children. Possibly, the couple may be happy with the first child or two or three if the procedure of implantation and subsequent foetal development is successful. The others are usually frozen, because the embryos can be used later if the couple wants to try implantation again in order to try to have children in the future. If the couple decides that they do not want to try to have any more children, they can opt to donate their embryos to another couple or they can donate the embryos to scientific research. To the dismay of the researchers, the embryos that arrive to research institutes are the 'inferior'. To summarize, the best embryos will be used by the patients; the clinic makes many embryos, approximately 10 of them because the procedure is involved for the woman. She must take strong hormone injections to force her body to release several eggs at one time which is not normal; not only is this procedure quite stressful on a woman's body and health it is also expensive. With IVF treatment, the clinics opt to make a many embryos so that the most viable, healthy-looking embryos can be selected for implantation.

Legally scientists are only allowed to work with human embryos younger than 14 days old. But stem cells are extracted from the 5-7 day old blastocyst created in a fertility clinic. You're not allowed to use these embryos beyond 14 days, which is the time when the primitive streak forms. Have you heard of that? It is when 3 germ layers embryo cells form and that happens on around day 14. But that's legally, there's still a lot of debate about when life starts.

You don't have to be a pro-life, to have to agree with pro-life position to think that an embryo is special enough that you don't do research on it. We're talking about the option of what people who were having IVF could do with their spare embryos after their treatment; if they don't want to use them. They could get rid of them because they just think that an embryo is a unique life, or they could donate it to another couple who are trying to have children. So there are many options that they have to run up and think about, it's not just kind of throw it away or send it to scientists. And there may be all sorts of reasons why people would come to their decision. They may say no to stem cell research but it might not be that they're pro-life. The fact that they're creating embryos as part of IVF would suggest that they don't think that every life begins at conception like many pro-life characters do.

Would you feel comfortable doing embryonic testing on an embryo that was your own?

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Thank you all again very much for today. I think we've had a great time and it's been very interesting. I only hope that you've had a good time as well and that I think from the questions, from the debate itself and from the questions you've been asking now, I think you have taken something from this role-play. Is that true?

The intention was to make you think a little bit and to make you think about these issues in a fun way. The creators would very much like to hear your views on the role-play itself. Is there anything that you think should be changed, that we should improve? You have web address for EuroStemCell in the notes. It would be great to know –'I didn't like this' or 'I think this should be better' or 'I really enjoyed this'. So any input you give can only make it better. It would be really useful.

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