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The Social Dynamics of Public Engagement In Stem Cell Research

Stem cell research (SCR) attracts considerable public interest and media attention. It is a controversial area of science in some ways, not least because some sources of stem cells involve the use of human embryos, eggs and fetuses. Because the social and ethical issues associated with SCR are great, there are also calls for more public debate about concerns and encouragement to bring scientists together with patients and the wider public to discuss the promises and limitations of the research and the social and ethical issues that surround it.

This project is a major contribution to this field and had two main aims. These were to:

- . •Investigate views and concerns about SCR
- . •Explore the scope for increasing public engagement in the developing field

We conducted the research in two distinct but interrelated stages:

Stage I used a tried and tested social science approach to exploring the views of different people – focus groups. In 18 group discussions we focussed on different issues relating to SCR such as sources of stem cells, applications, uncertainty and public engagement. We involved scientists and clinicians working in the area and specialists who were not directly interested in stem cells. We also spoke to the wider public including those who may be particularly interested in SCR because of their experience of illness or disability and people who maybe had not thought about this type of research before.

Stage II involved eight public engagement events of different size and format. Participants included some from stage I. Stage II involved bringing together a diverse range of people, whereas in stage I we kept similar people together. We tried to create a stimulating but comfortable environment within which people could discuss issues and learn from each other. Examples of the topics of these engagement events included the regulation and commercialisation of SCR; the different sources of stem cells and what people thought about using women's eggs for research purposes. We used different formats for these events, based on methods that try to be deliberative, allowing people to think carefully about issues before coming to an opinion. We had talks, question and answer sessions, small group discussions, ballots and games, all aiming to facilitate debate.

Nearly 300 people participated in our project, 30 of whom came to more than one event. We recorded and analysed what people said, and this gave us about 100 hours of transcripts to analyse. What did we find out?

About *sources of stem cells* we found that most people did not object to the use of human material such as cord blood, embryos or fetal tissue, even if they might express some discomfort about this. One reason is that such use might be of benefit and the material would otherwise go to waste. That said, people still had some concerns that related more to the people from whom the material is sought. The first priority must always be the wellbeing of the woman, in the case of donation of eggs or embryos or fetal tissue, and the mother and

child in the case of cord blood. People were also worried by what they feel is a transgression of what we understand and accept as being natural (e.g. in relation to the use of animal-human embryos).

Trust in science was a recurring theme in the research, especially from the wider public who expressed some unease about how SCR may proceed – that you might not really know how well this is being regulated and a feeling that some things might just get done anyway. Scientists too were concerned about lack of trust and what they saw as a lack of public understanding about the extent of regulation in science.

There was much discussion about the role of the *public and private sector* in SCR and unease was expressed about commercialisation and profit. However, there was also an understanding that the future development of new therapies, for example, would require private sector investment. Those involved in innovation were concerned that there are not enough resources for the development of stem cell therapies. It seems that commercialisation raises emotive issues, where some are troubled by what they see as profit at someone else's expense.

The focus group discussions alerted us to people's concerns about how SCR is *hyped up*, particularly in the media, and to how this can raise false hopes. Scientists too were concerned about such hype, even though scientists also work with the media. Through one of our engagement activities, a small group of scientists and patients worked together to discuss problems with over blown media stories and the impact these may have on people with illnesses or disabilities. A draft set of recommendations has been drawn up from this.

As far as increasing the scope for public engagement, this project certainly did manage to include a diverse range of people, to discuss a complex area of science that has significant social and ethical concerns associated with it. We used different techniques to try to encourage people to talk to and learn from each other, so that no one group (for example those with specialist knowledge) would dominate the events. How successful were we?

SCR is a controversial area and some people have strongly held beliefs and views; the events sometimes enabled expression of these, but not always. It was difficult to engage people who might not have any prior interest or knowledge of SCR. However, we did have quite a diverse range of people involved. We found that many people wanted information so that they could discuss issues more fully. We were able to provide this through these events, sometimes at the venue and sometimes in advance.

The research has had some significant impacts. For example, our event on using women's eggs in SCR coincided with the HFEA's consultation, enabling the research team to provide an evidenced based submission. We developed a role-play activity for schools, which is now widely available for teachers. We have also shared our knowledge with others in government and the research councils as they plan their own public engagement programmes.