

the social science stem cell initiative



The Social Dynamics of Public Engagement in Stem Cell Research

The project has two key aims:

- to investigate views and concerns about Stem Cell research
- to explore the scope for increasing public engagement in the developing field

In order to achieve these aims, the project is composed of three main stages: (1) twenty focus groups comprised of diverse scientists and publics; followed by (2) another round of focus groups in which there will be a mixture of participants from the first round; and (3) nine public engagement events. Running alongside these focus groups and events, educational activities concerned with issues surrounding stem cell research (SCR) are to be developed.

We are presently at the end of the first stage of the project and have embarked on the second stage by running two public engagement events. In addition, we have recently completed an overview of the theory and methodologies surrounding public engagement and have convened an advisory board meeting in order to discuss the issues surrounding public engagement and the initial themes identified from the first round of focus groups. Furthermore, our scientific communications officer has developed and successfully trialled a role-play exercise based on a clinical trial committee's decision-making process.

We have completed 18 focus groups and have identified a number of issues which will feed into the next stages of the research. The most important of these was overwhelming support for further opportunities for engagement, which bring together scientists and diverse publics in non-threatening environments. Yet, as expected, this did not necessarily mean an unquestioning acceptance of the value of a wider public's input into debate, whether expressed by scientists, patient groups or indeed publics themselves. Moreover, the focus group dialogues rejected a discourse that prioritised scientific expertise, while concurrently recognising a need for information to inform debate. The management of this ambivalence and tension will be a key task for the project as it develops.

The two public engagement events have been prompted by the recent HFEA's consultation exercise on donating eggs for research. The first of these was an online forum which allowed interested parties to comment and discuss on all aspects of donating human eggs for stem cell research. The second of these events was a related public debate. Over 90 members of the public came to pose questions and discuss issues with a panel comprising Daniel Brison (Scientific Director at a Regional IVF Unit), Diane Beeson (Sociologist and Women's Health Activist), Donna Dickenson (Medical Ethicist) and Harry Griffin (Director of Roslin Institute).

In the immediate future, we will complete the analysis of the data from the first round of focus groups and consequently produce articles for journals such as Sociology, Social Science & Medicine and Public Understanding of Science. We will also begin to plan the other public engagement events. The aim of these will be both substantive and methodological. At a substantive level, we wish to create opportunities for participants to enter into dialogue on the complex issues which have emerged from the focus groups. At a methodological level, we wish to contribute, both analytically and practically, to the development of participatory and dialogic public engagement techniques.

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