

## **Evaluation of the ESRC Stem Cells Initiative**

**Professor Donna Dickenson, Emeritus Professor, University of London;  
Honorary Research Fellow, University of Bristol; Research Associate,  
University of Oxford**

### **Executive Summary**

The ESRC Stem Cells Initiative (SCI) comprised a total of fifteen awards in three separate stages over the period 2004-2009, with a total budget of just over £3 million (in pre-FEC terms). Calls were made in responsive mode for the first round, with a deadline in November 2003. Six projects were funded in May 2004, for a total of around £1 million, with start dates in late 2004 and early 2005. A decision was then taken to concentrate the remaining funding on capacity-building and awareness-raising activities (CBAR), with two substantial awards being made to ESRC Genomics Centres in the first CBAR phase, together with a smaller award for the ESRC Genomics Forum. Five ‘translational’ fellowships and a post-doctoral fellowship were also funded under Phase II CBAR. The ESRC also appointed an Initiative Co-ordinator, Professor Andrew Webster, whose role was to promote network collaboration and dissemination activities. It should be emphasised that this role was different from that of a full-fledged Programme Director.

The evaluation of the SCI was undertaken by Professor Donna Dickenson, who is Emeritus Professor of Medical Ethics at Birkbeck, University of London, and who also holds honorary posts at the Centre for Ethics in Medicine, University of Bristol, and the HeLEX Centre (Health, Law and Emerging Technologies) at the University of Oxford. She has academic qualifications in political science, international relations and philosophy, along with experience of designing an ESRC programme proposal, ESRC refereeing and ESRC/MRC panel membership.

Professor Dickenson examined:

- all project End-of-Award reports, with comments from referees, assessors and rapporteurs, and, where available, nominated publications and original applications
- yearly and final reports to the ESRC from the SCI Co-ordinator
- minutes and other documentation of the Troika, the ESRC liaison body for the Initiative
- minutes and other documentation from the commissioning panels for each stage of the Initiative
- documentation from the ESRC Research Priorities Board and its successor, the Strategic Research Board
- developments in stem cell science and public policy over the lifetime of the SCI, through review of the literature base, coverage in online journals and specific topic searches.

She also devised and administered two separate questionnaires: one for research users from industry, academia, the voluntary sector and biomedical science, and the other for SCI principal investigators. (A total of 21 questionnaires were returned.)

Finally, she conducted lengthy semi-structured interviews with 11 individuals mentioned in EoA reports or suggested by the ESRC, including Professor Webster.

The academic quality of several SCI projects was extremely high, either 'outstanding' or 'good' verging on 'outstanding'. Those in this category forged new collaborations with research scientists, ethicists and clinicians, engaged in innovative ethnographic research, studied risk and regulation in translational medicine, collected data from the wider UK bioeconomy, considered the global framework of stem cell research and often achieved impressive levels of publications. Interesting and sometimes surprising results were obtained on such issues of considerable policy importance as the way in which biomedical scientists actually 'dampen down' rather than 'play up' public expectations of rapidly available stem cell therapies.

Unfortunately, this high level was not uniform across the Initiative. At least three projects were problematic because they were not fully cognisant of important scientific and medical developments, and because that weakness in their evidence base might have had adverse ethical implications, which the researchers did not seem to have considered. Other weaknesses identified by rapporteurs in these and some other projects included absence of genuine innovation, lack of relevance to industry, unwillingness to alter initial assumptions in light of evidence, difficulty in getting reasonable numbers of papers together, uncertainty of focus, lack of an overall intellectual project beyond the preparation of academic papers and a sense among some users that interdisciplinary collaboration benefited social scientists more than biomedical scientists.

While SCI award holders were generally very positive about their experience, and particularly about the contribution of the Co-ordinator, there was often a disparity between their views and the less sanguine opinion of research users, both academic and non-academic. Although many award holders engaged with relevant governmental and public bodies, achieving concrete impacts with policy-makers and developing innovative means of dissemination, the level of outside awareness of the SCI was lower than expected, even among academics and funding bodies. Engagement with non-academic users was often viewed with some cynicism in those users' feedback, and in some cases with strong criticism, although others reported positive experiences and were proactive in seeking out involvement with the SCI. There was some sense among other academics and voluntary sector representatives of being excluded, even though many events were open to all.

The management of the Initiative was quite unusual, with considerable autonomy devolved, formally or informally, to the Genomics Centres. Because he was not a Programme Director, the Co-ordinator felt there was a certain amount of ambiguity about the extent to which he could ensure comparable levels of dissemination activities by the component projects, since he had no formal management function. However, there was very high praise from many SCI award holders for the way in which Professor Webster fulfilled a difficult brief.

Future funding possibilities relevant to stem cell research must be viewed in the specific context of existing ESRC investments and UK governmental reviews, as well as in the broader context of the global bioeconomy and the strategic challenge of regulating new biotechnologies. In the former context, a follow-up review of the Pattison Report by the Department of Business, Industry and Skills, and a follow-up review of the UK National Stem Cells Network by RCUK, are both taking place in a scientific context which no longer expects imminent therapeutic breakthroughs but which offers other opportunities for industry. Stem cell 'patent density' is also relevant to the current situation for regenerative medicine and could form an important subject

for the international Open Research Area as a whole. The proposed abolition of the Human Fertilisation and Embryology Authority and the Human Tissue Authority, together with changing relationships between universities, government and patient groups, also give rise to important questions about how governance of this area will be structured. The rise of health 'tourism' and the phenomenon of 'philanthrocapitalism' also call for further research, which might be conducted under the frameworks of the new ESRC Rising Powers Initiative and in co-operation with other research councils, particularly the MRC.

The Stem Cells Initiative achieved much in the face of tough odds. Not only is stem cell science difficult for social scientists to understand; its development over the course of the Initiative altered radically, although that unpredictability was itself predictable and might have argued for retaining a larger proportion of funding for another open project call at a later stage. Many award holders and the Co-ordinator did extremely well to develop close relationships with biomedical scientists and clinicians, to trace commercial and public relationships with and reactions to stem cell science, and to keep abreast of scientific developments. These scientific and clinical collaborations worked best when SCI research teams were themselves interdisciplinary, where possible including social science, ethics, law, clinical medicine and biomedical science.

Where there were difficulties, they should not be attributed solely to individual award holders, but also to the way in which prior decisions about the structure of the Initiative were taken. While the umbrella initiative could certainly have added value, the value added was undermined somewhat by the fact that the Co-ordinator was not appointed at the very start and that there were no formal management structures.

Recommendations include:

- **Alternative dissemination strategies** as operated by another major grant-giving body, which offers support from a central media and public relations executive to help its award holders reach specific publics
- **Administrative ESRC support in establishing policy and advisory groups** for projects, together with **specific incentives for their members**, such as joint publications or regular updates on new literature and developments
- **Genuine, two-way interdisciplinarity, where relevant**, including clearer and less academic terminology for the benefit of non-social scientists and elimination of the sense of social science 'territoriality' criticised by some respondents
- **Enhancing impact among user groups with reduced budgets** by ensuring that nominated articles and other publications do not appear solely in subscription-only journals, that summaries and position papers containing actual data are sent out more widely, and that funding is made available for patient group and activist representatives to attend final project conferences
- **Sharing findings and scientific background information more systematically**, so that all network members have equally good levels of scientific accuracy, with power delegated to the Co-ordinator to require award holders to attend briefing meetings and with ESRC programme officers sharing findings with their opposite numbers in other research councils.