Institution: The University of Edinburgh

Unit of Assessment: UoA5: Biological Sciences

Title of case study:

05. Patients', policy-makers', educators' and the public's understanding of stem cell research is increased through in-depth engagement.

1. Summary of the impact

Impact on society, culture and creativity; health and welfare; practitioners: Extensive public engagement with a broad target audience has increased understanding of the hopes and hypes generated by stem cell research at UoE and elsewhere, and has provided resources for practitioners to deliver high-quality public engagement and science education.

Beneficiaries: Educators, teacher trainers, science communicators, journalists; patients; students; officials in the European Commission, the European Parliament and by extension constituents.

Significance and Reach: This programme has promoted informed decision-making among non-specialists and public acceptance of stem cell-based research and future therapies in Europe (compared for instance to the USA). The project is focused on Europe, but participation is world-wide. 767,000 unique visitors have accessed the *www.eurostemcell.org* website. The educational tools have been used by 11,000 pupils, and engaged 20,100 participants at festivals and science centres. More than 740,000 individuals world-wide have viewed the films (>240,000 confirmed online, film showings and DVD; estimated >500,000 TV audience).

Attribution: The programme reflects a range of stem cell research, substantially based on underpinning research carried out at UoE led by Professors Austin Smith and Ian Chambers. The outreach programme is led by Professor Clare Blackburn. Leadership, management, content identification, content format, editorial input, and evaluation of the outreach programme are all led at the University of Edinburgh.

2. Underpinning research

The impacts reported result from basic research into stem cell biology carried out at the University of Edinburgh from the 1990s to the present day.

The underpinning research was the discoveries by Austin Smith and UoE colleagues of the key mechanisms that regulate the two cardinal properties of embryonic stem cells, the ability to 'self-renew' and to differentiate; the use of this knowledge to develop novel methods for selecting undifferentiated stem cells and specific differentiated progeny cell-types; and for growing these cells in culture using a completely defined culture medium [1, 2, 3, 4]. This led to the derivation of embryonic stem cell lines from rats in 2008 [5]. Smith and colleagues also demonstrated that cells could change identity as a result of cell fusion [6], negating prominent claims that some adult stem cells could generate any cell type in the body upon transplantation.

The 1994-2003 UoE research led to the award of the first large-scale EC-funded pan-European stem cell research consortium (EuroStemCell, 2004-2008, €12M). Clare Blackburn developed and led a substantial programme of training and science communication for this project (budget of €0.8M), which draws extensively on the UoE research and on the advances and discoveries made subsequently in the field of stem cell research both at UoE and elsewhere. The underpinning UoE research was fundamental to many subsequent advances in stem cell biology and regenerative medicine which feature in the public engagement programme.

Key personnel at UoE: Professor Austin Smith (1990-2006); Profesor Ian Chambers (1991-present); Professor Clare Blackburn (1997-present).

3. References to the research

1. Mountford, P., Zevnik, B., Düwel, A., Nichols, J., Li, M., Dani, C., Robertson, M., Chambers, I.,

and Smith, A. Dicistronic targeting constructs: reporters and modifiers of mammalian gene expression. Proc Natl Acad Sci U S A. 1994 91: 4303-7. DOI: 10.1073/pnas.91.10.4303. **256 citations at 19/09/13.**

2. Niwa, H., Miyazaki, J., and Smith, A.G. Quantitative expression of Oct-3/4 defines differentiation, dedifferentiation or renewal of ES cells. Nat Genet. 2000 24: 372-6. DOI: 10.1038/74199. **1756 citations at 19/09/13.**

3. Chambers, I., Colby, D., Robertson, M., Nichols, J., Lee, S., Tweedie, S. and Smith, A.G. Functional expression cloning of Nanog, a pluripotency sustaining factor in mouse embryonic stem cells. Cell. 2003 113: 643-655. DOI: 10.1016/S0092-8674(03)00392-1. **1564 citations at 19/09/13.**

4. Ying, Q.-L., Nichols, J., Chambers, I., and Smith, A.G. BMP induction of Id proteins suppresses differentiation and sustains embryonic stem cell self-renewal in collaboration with STAT3. Cell. 2003. 115: 281-292. DOI: 10.1016/S0092-8674(03)00847-X. **1014 citations at 19/09/13.**

5. Buehr, M., Meek, S., Blair, K., Yang, J., Silva, J., McLay, R., Hall, J., Ying, Q.L. and Smith, A. Capture of authentic embryonic stem cells from rat blastocysts. Cell. 2008 135:1287-98. DOI: 10.1016/j.cell.2008.12.007. **287 citations at 01/05/13**

6. Ying, Q.L., Nichols, J., Evans, E.P. and Smith, A.G. Changing potency by spontaneous fusion. Nature. 2002 416: 545-8. DOI: 10.1038/nature729. **1124 citations at 19/09/13.**

4. Details of the impact

EuroStemCell led directly to the present large-scale, high-impact programme of communication and public engagement in stem cell research and regenerative medicine throughout the REF period. The materials and activities described below extensively feature the UoE research of Austin Smith and colleagues. Without these research outputs, the EuroStemCell grant with its major outreach component would not have been awarded and the establishment of *www.eurostemcell.org* and the associated films and educational materials would not have been possible. The UoE research constituted a series of major advances, including clarification of a critical controversial issue by providing one of the breakthroughs that negated reports which had misled clinicians and patients into believing that transplantation – for instance of blood stem cells – could directly repair damaged heart, muscle or nervous system tissue [6]. UoE was thus in a unique position to ensure that this important scientific understanding reached the public domain.

Impact on society, culture and creativity; and on awareness of health and welfare. ***www.eurostemcell.org*** is a major information portal that provides trusted, accurate and up-to-date information on stem cells and regenerative medicine for European citizens. It delivers information in the form of fact sheets, FAQs for patients, and commentaries on a wide range of topics in stem cell biology, regenerative medicine and related societal issues written in plain language and reviewed by experts prior to publication. Multilingual functionality was added from 2011 (English, French, German, Italian, Spanish, and Polish; these 6 languages make the site accessible to >80% of Europeans). Social media channels are now integrated into all communications to provide supplementary dissemination platforms, extending the reach of public engagement.

In the REF census period the website received 1,010,468 visits (767,006 unique) from >200 countries. Website traffic has grown during the period, with 333,624 visits in the year Aug 2012 - July 2013. 95% of respondents to our 2011 website evaluation felt that it provides reliable information and 86% would recommend the site to others. It is a trusted information source for a wide range of specialist and non-specialist audiences. The website is routinely used by European Commission Research Directorate Scientific Officers to inform answers given by the Commissioner for Science and MEPs to parliamentary questions [a]. From May 2010-31 July 2013, 463 patient enquiries were responded to. Our Twitter account (twitter.com/eurostemcell) has 2,847 followers, including journalists (@RogerHighfield), patients and patient groups (@MichaelJFoxOrg, @ParkinsonsUK, @PatientsLikeMe) and educators (@hrogerson, @tesScience, @ViciaScience).

We have developed a **stem cell outreach toolkit**, 14 extensively-tested, downloadable resources and activities with full instructions for use, available to educators and science communicators (http://www.eurostemcell.org/stem-cell-toolkit). For example the dialogue event based partly on [6],

"**A Stem Cell Dream",** was used at Bergamo Scienza science festival, Italy (October 2011), attended by over 300 members of the public (http://www.eurostemcell.org/story/400-attend-stem-cell-dream-bergamo-scienza). In March 2011 interactive sessions on stem cells at the Science Museum London "Lates" event were attended by thousands of adults and in March 2012 almost 2000 people took part in EuroStemCell events at the Centre for Life in Newcastle ScienceFest. We have produced a graphic short story **"Hope Beyond Hype",** as a tool for engaging audiences, including the hard-to-reach youth audience, with the process through which a new basic science discovery must go to become part of a new therapy. This was released online in 2012 and has had >120,000 read-views. It is highlighted by patient organisations including Parents Project, MS Society and Parkinson's Foundation [b] and educational resource sites including the National STEM Centre [c], and is a recommended resource on the European teacher resource website http://www.scienceinschool.org/2013/issue26/spinal. We have distributed a **physical outreach kit** of resources to over 30 research centres across Europe and have trained >230 scientists for public engagement. Within the REF census period, the outreach kit has been used at >17 science and cultural festivals and at least 5 science centres, reaching over 20,100 members of public.

In 2006 we produced four **short documentary films** about our stem cell research, *"Stem Cell Stories".* We subsequently produced two further films – the **feature-length documentary** *"Stem Cell Revolutions: vision of the future"* (2011) and the **short educational film**, *"Stem cells, the future: an introduction to iPS cells"* (2012). These films address UoE research [2-4,6] and other findings and were generated through a partnership between UoE scientists and film-makers (including UoE's Edinburgh College of Art). The films have won multiple awards including best documentary for *Stem Cell Revolutions*, Vedere La Scienza Science Film Festival, Milan, March 2012. The eurostemcell.org film pages have received 176,000 views from 127 countries. Our YouTube film channel has had >100,000 views and has 369 subscribers (http://www.youtube.com/eurostemcell). We have also distributed >800 copies of the Stem Cell Stories DVDs, which have been used in schools and in activities with patients [d]. We developed online accompanying lesson resources to match curriculum requirements. An online synchronised viewing and discussion of the film '*Stem cells: the future'* was co-ordinated in Scottish Schools in December 2012. 38 secondary school science classes (>600 students) participated. The film has been used in 4 UK teacher-training events (ASE (Association for Science Education) Liverpool 2012, ASE Reading 2013, ASE Scotland 2013, SSERC (Scottish Local Authorities' Schools Education Research Centre) 2013).

'*Stem Cell Revoutions*' has toured to 30 venues throughout the UK reaching a collective audience of >1500 (at August 2013). Screenings are followed by an extended Q&A session with an expert scientist and/or clinician to promote deep engagement with stem cell research and regenerative medicine. The film has also screened at 11 international science festivals and events in Europe, Japan, New Zealand and Australia. In audience surveys at 16 UK screenings (>550 questionnaires) respondents were asked about the potential impact of the film on their future behaviour. 85% were more likely to discuss the topic of stem cell research with colleagues/friends; over half were more likely to go to a public meeting (52%) and nearly a third (31%) also reported that they were now more likely to provide a written opinion in a public consultation.

Impact on practitioners and services: We have developed a toolkit of educational materials, activities and other curriculum-relevant resources for use in different educational contexts, for 11 years old upwards, that fit with the curriculum objectives of 5 European countries and the International Baccalaureate. Two of our tools **"Ready or Not? A role play on taking stem cells to the clinic"** and **"All About Stem Cells"**, drawing particularly on work in [6], have been included by the Scottish Government agency Learning and Teaching Scotland in their recommended resource for teachers of post-16 school students studying biology [e]. **"All About Stem Cells"** was used at the European Molecular Biology Laboratory International Teacher Training course, 'Stem Cells at the Forefront'; 93.3% of the participants said they would be very likely to use the resource in their classrooms. **"Discover Stem Cells"** is an interactive lesson for students aged 12-14 supported by guidance material. 250 kits have been distributed to teachers and researchers in 5 countries. A Spanish translation is used in the schools programme at the Seville Science Centre *Casa de la Ciencia*, and a German version in teacher training workshops run by the Max Delbruck Centrum fur Molekulare Medizin, Berlin. In the REF census period, these tools have been delivered to over 29,300 school students Europe-wide including the annual UniStem event in Italy. Elements of the

educational Toolkit have been used in at least 10 CPD events to 160 teachers in the UK and across Europe. SSERC has endorsed our films for use in secondary schools and "*A Stem Cell Story*" has been incorporated into a lesson plan published by Oxford University Press, and is recommended by Scottish government agency Learning and Teaching Scotland as a tool for National Qualifications support.

We deliver training events for science communicators/public engagement practitioners, e.g. a discussion session at the 12th International Public Communication of Science and Technology Conference (Florence, Italy, 2012) attended by approximately 60 public engagement practitioners and social scientists (http://www.eurostemcell.org/story/whats-best-way-help-researchers-and-patients-communicate); and a workshop on designing public engagement tools for use by researchers at the British Interactive Group (BIG) conference, York, UK in 2012.

Impact on public awareness through press and media: ***www.eurostemcell.org*** influences the representation of stem cell science and scientists in the media. Its function as a coordinating force for communication of stem cell biology and regenerative medicine in Europe has made it a point of contact for press and broadcast media specialists including the Science Media Centre (SMC) and the Wellcome Trust. An example is our coordination, with SMC, of a major press briefing around the European Advocate General's advice to the European Courts of Justice on the patentability of procedures related to the use of human embryonic stem cells [f]. This was attended by science journalists resulting in extensive print (the Independent, Guardian, Times, Telegraph, FT, Daily Mail, Daily Mirror, Metro and New Scientist) broadcast (BBC News) and online media coverage.

Impact on commerce: Distribution, streaming and TV rights for the feature '*Stem Cell Revolutions*' are licensed to SDI Productions Ltd, to market personal and educational copies as downloads or DVDs worldwide, as part of the Virtuous Circle programme funded by Creative Scotland, which aims to establish a sustainable documentary industry in Scotland. 199 downloads were sold for private and educational (multi-viewer) use in the 12 months to August 2013 [g]. An important component of the film's distribution is the website stemcellrevolutions.com, built by SDI Productions Ltd to collect viewer information for science documentary audience building, and for online sales and distribution. The film is also embedded on more than 25 other websites through a blogger outreach programme. To August 2013, stemcellrevolutions.com has received 17,110 visits (11,888 unique visits) and 42,854 page views. The site has 713 Twitter followers, 2,494 Facebook 'likes' and 973 emailable supporters. The film has received 32,925 player loads and 6,591 previews from 79 countries. SDI Productions have licenced the film for broadcast on TV to ARTE (France and Germany) and for distribution (DVD, TV, internet) in Japan and in the Czech Republic [g].

5. Sources to corroborate the impact

The Tiny URLs provide a link to archived web content, which can be accessed if the original web content is no longer available.

[a] Use of the website by EC officials can be corroborated by the Principal Scientific Officer, DG Research & Innovation.

[b] Parkinson's Disease Foundation website referencing this resource: http://www.parkinsons.org.uk/content/stem-cell-story or http://tinyurl.com/o88n38q

[c] Educational use can be corroborated by the Educational Technology Lead, Myscience, National Science Learning Centres and National STEM Centre, York

[d] Outreach with patients can be corroborated by the Leukaemia and Lymphoma Research Regional Manager, Scotland.

[e]. The materials produced by the Scottish Government agency Learning and Teaching Scotland using EuroStemCell resources are available as pdf downloads at Education Scotland: http://www.educationscotland.gov.uk/resources/nq/h/nqresource_tcm4670037.asp?strReferringChannel=nationalqualifications&strReferringPageID=tcm:4-672951-64 or http://tinyurl.com/q8s7qdo

[f] Corroboration of role in press events can be provided by The Science Media Centre, London.

[g] Film sales can be corroborated by the Producer of Marketing and Distribution, Scottish Documentary Institute Productions Ltd, Edinburgh.