EUROSTEMCELL Report Summary

Project ID: 241878
Funded under: FP7-HEALTH
Country: United Kingdom

Final Report Summary - EUROSTEMCELL (European Consortium for Communicating Stem Cell Research)

Executive Summary:

Introducing EuroStemCell

Who we are

The European Consortium for Communicating Stem Cell Research (EuroStemCell) was established in 2010 and united more than 90 European stem cell and regenerative medicine research laboratories, through partnership with:

- Five major EU Framework 6 and 7 stem cell projects
  - OptiStem, NeuroStemCell, ESTOOLS, EuroSystem and BetaCellTherapy
- The European Clinical Research Infrastructures Network (ECRIN)
- Eight internationally recognized European stem cell research centres, in Edinburgh, Sheffield, Cambridge, Galway, Lund, Barcelona, Bonn and Milan

We now work closely with ten other EU-funded stem cell projects established since 2010 – CardioCell, HEALING, REDDSTAR, STELLAR, HumEn, ThymiStem, NeuroStemcellRepair, PluriMes, Visicort and MERLIN. Through these projects we are widely connected throughout the European stem cell research community, and in the next iteration of EuroStemCell, due to begin in February 2015, we broaden our partnership to include connections - via research centres, consortia, networks and hubs - to more than 400 stem cell and regenerative medicine labs and SMEs across Europe.

EuroStemCell brings scientific experts into partnership with clinicians, ethicists, social scientists, policy makers, regulators, educationalists and science communicators. We also work closely with teachers and patient representatives. Through this partnership, 187 individuals have written, reviewed and translated content for the EuroStemCell website. Many more have been involved in the development and testing of resources.

Our project team, based in Edinburgh, brings together a range of science communications expertise – from schools engagement and training to resource development, science writing, filmmaking and event management.

Our goals

EuroStemCell aims to address the need for trusted, high quality information on stem cells tailored for citizens and stakeholders across Europe and beyond; to establish a model for widespread dissemination of research outputs to European publics; and to share best practice based on our experiences.

We have established a coordinated platform for collation, dissemination and archiving of information on stem cells and regenerative medicine. Our structured approach to reaching European citizens focuses on three major dissemination routes: the web, enhancing capacity for direct public engagement, and provision of resources for educators.

The project’s centrepiece is our multilingual website, www.eurostemcell.org. With the input of leading stem cell experts, we have developed the site as a premier, multilingual European reference point for stem cell information and discourse in Europe - Europe’s stem cell hub.

We’re here to help European citizens make sense of stem cells

We provide reliable, independent information and road-tested educational resources on stem cells and their impact on society
Project Context and Objectives:
Communicating stem cell research

Stem cell research is one of the most promising and exciting areas of biomedical science, with potential to revolutionize the way we understand and treat many debilitating diseases and injuries. Basic research is advancing rapidly, and stem cell therapies are moving at increasing speed towards the clinic. Some new treatments are being tested in clinical trials, but only a few stem cell treatments have been thoroughly established as safe and effective, and many scientific questions remain. The future wellbeing of many thousands of people may be enhanced by knowledge acquired through stem cell research and its applications. Meanwhile, this research is constantly confronting society with new ethical and social dilemmas.

Assessing the risks and potential of stem cell research and potential therapies – at an individual and societal level - requires access to reliable information, supported by effective engagement with the broadest possible community. The views of all stakeholders must inform decision-making around issues of public interest, including tissue and organ donation and clinical trial participation, and the development of appropriate regulatory frameworks for new research and therapies.

But communicating stem cell research presents significant challenges. The field is fast-moving, the terminology complex, and debates often heated. It can be hard for the outsider to assess the credibility of new claims. Misinformation is a real issue, not least from unscrupulous operators offering ‘miracle cures’ that have little or no scientific foundation and have not been medically evaluated.

EuroStemCell has approached the challenge of communicating stem cell research across three distinct strands - information, education and conversation.

Information addresses the need for reliable and up-to-date factual information about a fast moving and contested area of research.

Education addresses a core target audience for this project – educators and their pupils/students. This audience was prioritized for its potential to widely disseminate information (a “multiplier effect” where educators cascade information to their students, and students to their parents) and, in the case of young people, as the future decision-makers and potential recipients of emerging stem cell technologies.

Conversation underpins everything that we do. In any new initiative, we start by listening to our stakeholders. We are responsive to feedback, and always looking for or creating space where dialogue and discussion about stem cell research can take place. Information by itself is not enough. Resources work best when supported by opportunities to discuss, ask questions, interact and converse.

Together, these three themes form the basis of our engagement strategy.

Project Results:

1.2.1. Information

In the first 18 months of the project, we established a core infrastructure for collating, managing, structuring, disseminating and archiving stem cell information - from research developments and clinical progress to commercial, ethical and societal factors. We also developed collaborations with a wide and growing network of experts both within and beyond the EuroStemCell partners, to capture the latest scientific and policy developments. This allowed us to develop extensive, accurate and up-to-date factsheets, commentaries, interviews and other content, published on eurostemcell.org. This work also provided a strong foundation of scientific information for our other activities, such as development of educational resources.

In months 18 to 36, we focused on two major areas - content, and translation.

• We consolidated and further developed existing content types, and increased their visibility to key audiences. Additionally, we have produced new website content in a range of formats for differing audience needs - fact sheets, FAQ, commentaries, interviews, research updates, research spotlights and blogs. We monitor the news and take a feature- and commentary-type approach to hot/emerging topics, and also act as a contact point for journalists seeking expert input on press stories. A
significant focus for content development has been disease research and clinical trials. We have developed multilingual, accurate and accessible fact sheets and FAQs on research in specific disease areas, have published news updates summarizing the aims of selected clinical trials and have collated links to patient organizations and other reliable websites with information on clinical research. All clinical trials related content is collated on one page of eurostemcell.org. We have also developed new content visualization tools, including a European Stem Cell map.

• EuroStemCell aims to provide accurate information to European publics and therefore an essential component of the project is multi-linguality. Six European languages, English, French, German, Italian, Polish and Spanish, cover the 1st and 2nd languages of 80% of the European population. In months 18-36 we have committed substantial effort to translating website content into these six languages; all six are now represented on the website.

In months 37 to 60, we have continued our focus on content and translation, responding to audience needs as identified in evaluation work completed, and trends identified via other forms of audience interaction (e.g. patient enquiries). Many of the information gaps identified have been filled; the top ten areas of research patients ask us about are now served by fact sheets. We also now have a much more complete range of content in our six site languages.

1.2.2. Education
In months 1 to 18, we collated, developed, tested, published and promoted a suite of stem cell and regenerative medicine resources for direct public engagement and for educators, which together comprise a stem cell toolkit available online with full instructions for use, in 6 languages. We complemented this Toolkit with a fully searchable directory of third party resources on stem cells and regenerative medicine, collated by us into a single user-friendly database. Together, our Toolkit and Resource Directory constitute a ‘one-stop-shop’ for public engagement and education resources in this field and, to our knowledge, the world’s leading collection of this type.

In months 18 to 36, we expanded our Toolkit with several curriculum-relevant resources for educational use, including two new educational films – on iPS cells, and on how genes control cells.

We also worked with the Association of Science and Discovery Centres to build relationships and run events with science centres throughout the UK.

In months 37 to 60 we have consolidated the tools and their translation, formed them into physical kits for teachers and researchers involved in public engagement and disseminated these kits to over 150 research institutes and schools across Europe, where they are now being used with schools students, European citizens and other stakeholders. We have also added two new tools to the kit, namely the sporty stem cell animates and an offline version of the Hope Beyond Hype comic containing flash animation activities.

1.2.3. Conversation
Information and resources by themselves are not enough to foster meaningful engagement, and work best when supported by opportunities to discuss, ask questions, interact and converse. Through the EuroStemCell website, social media channels, events, resources and the EuroStemCell toolkit we have created space, support and opportunity for dialogue about stem cell research and regenerative medicine to take place: between scientists, clinicians and other specialists, media, writers, and European citizens.

Increasingly, we also stimulate conversations reflecting on the practice of communicating stem cell research, extending to other science communicators, educators and scientists involved in outreach. We are linking to and sharing best practice with other stem cell organisations as well as critically evaluating the impact of dissemination activities and building the evaluation outcomes into both our resource development and our ongoing dissemination programme.

1.2.4. Collaboration and endorsement
We have established and built upon internal and external collaborations – with our own partners, with external organisations and with other EC-funded Framework projects. Many of our partners are involved in writing and reviewing content for our website, or participating in events we run. We also consult partner representatives about key decisions via work package meetings. We have collaborated with The Node, EMBO, the Science Media Centre in the UK, teacher training and educational resource organisations in several countries, and stem cell networks worldwide, including the ISSCR and Stem Cells Australia.

1.3. MAIN RESULTS ACHIEVED SO FAR

1.3.1. Information:

1.3.1.1. Sharing the latest science

Months 1-18:

• We developed an active and functional infrastructure for collation and structuring of stem cell information, using a variety of techniques to keep up to date with the latest scientific developments.
• We established clear editorial guidelines for producing materials and structuring information into a wide variety of formats including factsheets, FAQs, interviews, commentary articles and blogs.
• We published our first 10 non-technical fact sheets on different aspects of stem cell research and regenerative medicine - from embryonic stem cell ethics to GMP manufacturing, cancer stem cells and reprogramming.
• We published 11 commentaries via [www.eurostemcell.org](http://www.eurostemcell.org), including in-depth coverage of the on-going European Court of Justice case about patenting of embryonic stem cell-based technologies. We reported scientists’ concerns about this case, and its ethical, legal and biotechnology sector implications, and opened a moderated comment stream to enable open discussion of this issue. We also collated the widespread media coverage of the case. More than 500 concerned individuals took the opportunity, made available through [www.eurostemcell.org](http://www.eurostemcell.org), to express support of the scientists’ position.
• In collaboration with The Node, we produced a monthly version of Erin Campbell’s image blog, bringing the beauty and detail of recently-published stem cell images to a general (non-scientist) audience.
• We developed a series, “what your taxes pay for”, that provides concise annual progress reports from other stem cell projects funded by the European Commission.
• We performed the development work required to enable the website to become multilingual; a significant number of resources have already been translated into one or more languages (prioritised according to demand).

Months 19-36:

• We have continued to grow the informational content on our website and have added 249 discrete informational pieces to the site during this second project period. We now have 24 fact sheets for non-specialists on the site.
• We have collaborated with the Science Media Centre (SMC), London, UK, to raise awareness of key issues and to develop a briefing sheet on stem cell research for all UK journalists; we helped the SMC gather quotes from scientists about the recent Nobel Prize award to John Gurdon and Shinya Yamanaka.
• We have developed our provision of evidence-based clinical trial information, including an interactive version of the Hope Beyond Hype graphic story, and integrated information on clinical research where relevant across the site. A variety of clinical trials related content can be found on a single dedicated page on the website ([www.eurostemcell.org/clinical-trials](http://www.eurostemcell.org/clinical-trials)).
• [Eurostemcell.org](http://www.eurostemcell.org) is now available in six European languages (English, French, German, Italian, Polish and Spanish) and translation of content is ongoing. 400 discrete articles, resources and other content items have been translated so far.

Months 37-60:

• A total of 233 new pieces of informational content have been added to the website in this period, including blogs, commentaries, fact sheets, FAQ, research spotlights and interviews.
• Seventy discrete content items have been translated in this period, with a particular focus on fact sheets, the highest traffic area of content on the website.
• We have responded to hot topics and information needs as they emerged, including the STAP and Stamina cases and related issues, public perceptions of stem cell research, and how patients can participate in research.
1.3.1.2 Archiving
Following discussion at the mid-term meeting and among partners, archiving is not now considered a core activity for the project. We have nevertheless continued to make our established infrastructures available to FP6/7 projects who wish to use it, and this has resulted in the addition of several articles to the website (as blogs, press releases and research spotlights) covering the research of such consortia, and dynamic archiving of public engagement tools within our Toolkit, resource directory and YouTube channel.

1.3.2. Education

1.3.2.1. Resources for public engagement

Months 1-18:
• We launched our stem cell toolkit and the first seven tools – a set of extensively tested, downloadable resources and activities. These tools cater for a variety of audiences and settings, come with full instructions and are provided in a format that allows them to be adapted to suit local needs.
• Four of these tools were translated into one or more of the languages French, Italian, Spanish and Portuguese.
• We developed and populated a new Stem Cell Resource Directory cataloguing public engagement and/or educational stem cell resources from across Europe. The directory is fully searchable and users can vote and comment on resources, and submit stem cell videos, websites, lesson plans, presentations and other resources.
• We acted as advisors for a group of Swedish students developing a stem cell iPad app, and have licensed footage from our films to a Hungarian production company and to the Museum of Science & Industry in Tampa, Florida.

Months 19-36:
• We have developed a number of new educational resources, bringing the total number of tools in our stem cell toolkit to 14.
• We have made the Stem Cell Stories DVD set available in 10 languages
• We have developed a new short film for release in Autumn 2013, “Cell Fate: stem cells, genes, proteins and the journey to specialisation”, introducing a general audience to the concept of complex gene networks and how they work in both normal and malignant cells and is being developed.
• We have produced a short film explaining how neurons can be grown in the laboratory, to be used as a core component of a new engagement tool on neurological repair.
• We have completed and released a short film on iPS technology, which has already been used at many educational events.

Months 37-60:
• We have developed one new educational resource and redeveloped another, bringing the total number of tools in our toolkit to 15
• We have made the Stem Cells: The Future DVD available in 7 languages
• We have completed and launched the film Cell Fate: Journeys to specialisation, making it available in 6 languages.
• Our interactive comic Hope Beyond Hype was included in a large touring exhibit on stem cells that will reach a large audience of non-specialists in North America and Europe.

1.3.2.2. Resources for educators

Months 1-18:
• We performed an extensive analysis of secondary education science curricula in 5 European countries, plus the International Baccalaureate, to identify where the science and ethics of stem cells and regenerative medicine can be used to illustrate specific learning objectives.
• We developed and tested a series of curriculum-relevant educational resources for schools, and made them available in our
online Toolkit. Feedback from teachers was very positive and two of these tools – ‘Ready or Not? A role play on taking stem cells to the clinic’ and ‘All about stem cells’ – were included by the Scottish Government agency Learning and Teaching Scotland in their recommended resource for teachers of post-16 school students studying biology (see http://www.ltscotland.org.uk/nationalqualifications/resources/h/nqresource_tcm4670037.asp). A Spanish translation of the tool ‘Discover stem cells’ also became part of the schools programme at the science centre Casa de la Ciencia, Seville.

Months 19-36:
• We have developed and piloted two new lessons for 12-14 year olds and added them to the online toolkit.
• We have held over 40 events for high schools, reaching an estimated 11,200 students.
• We have run teacher training for over 140 teachers and formed strategic alliances with teacher training providers to support future work in this area.
• We have shared our materials via key teacher networks and are developing increasing links with relevant organisations for reaching educators via a combination of online and print materials to extend reach, e.g. to policy makers, public engagement practitioners, patients and doctors, other scientists.

Months 37-60
• We have consolidated our toolkit and developed a physical box of resources for educators and researchers undertaking public engagement and outreach activities.
• We have held over 94 events for high schools reaching an estimated 40,014 school students.
• We have run professional development training for over 1324 biology teachers and strengthened our strategic alliances with teacher training providers.
• We have continued to share our materials via key teachers and public engagement networks and are continuing to build links with relevant organisations for extending our reach to educators. Our success in this area is indicated by a 161% increase in downloads of the resources from the website compared with Period 2.

1.3.3. Conversation

1.3.3.1. Direct public engagement

Months 1-18:
• Through the schools debating competition Debating Science Issues, we facilitated stem cell science & ethics workshops at 18 secondary schools in the West of Ireland and 14 stem cell debates throughout the Republic and Northern Ireland.
• Our tools were used in teacher training at EMBL’s Monterotondo campus for ‘Stem Cells at the Forefront’ - 3 days of lectures, laboratory experience and hands-on practical experience.
• EuroStemCell’s “All about stem cells” educational resource was used in a workshop for high school students as part of the large-scale Italian high school event, UniStem.
• 7 scientists and science communicators took our Discover stem cells tool to 11 classes of 12-14 year olds.
• We used the feature-length science documentary “Stem Cell Revolutions: a Vision of the Future” as the centre-piece of a stem cell road show which has toured 12 cities throughout the UK, reaching an aggregated audience of >900. EuroStemCell was closely involved in production of the film and in promotion and hosting of the road show, which won Best documentary at the Vedere la Scienza science film festival in Milan and was screened ‘in competition’ at the ScienceTeller festival in New Zealand.

Months 19-36:
• EuroStemCell partners participated in at least 154 public engagement activities with over 72,000 individuals from a range of audience groups and in 13 countries.
• Our tools continued to be used widely in schools events and teacher training (detailed above under ‘1.3.2.2 Resources for educators’) and we expanded our reach significantly both within and beyond school audiences. Our tools were used at major
science festivals, in science centres, universities, a large-scale sporting event and as part of Researchers’ Night 2012.

Months 36-60
- EuroStemCell partners participated in at least 365 public engagement activities with over 199,135 individuals from a range of audience groups and in 13 countries.
- Our tools continue to be used widely especially with school, community, family and general public groups. We have again significantly expanded our reach across all key EuroStemCell stakeholder groups. Our tools have been used at music festivals, national sporting events, European Researchers Night, International Science Days, science centres and science festivals.

1.3.4. Awards
- The film Cell Fate: Journeys to specialisation was selected for inclusion in the Goethe Institut Science Film Festival http://www/goethe.de/ins/th/prj/wif/fes/enindex.htm
- EuroStemCell was a finalist in the National Co-ordinating Centre for Public Engagement Engage Competition and a case study of the project will be presented on the NCCPE website as an example of best practice to others,
- EuroStemCell nominated one of our Italian partners, Prof Elena Cattaneo for Stem Cell Person of the Year 2013 and were delighted when she was awarded this recognition.

1.3.5. EuroStemCell in numbers
To date, 180+ scientists, science communicators and other experts in their fields have written, reviewed and translated content for the website. The website has received more than 1.2 million visitors in the final two years of the project, up 230% on the previous 24 months.

More than 40 stem cell videos are now freely available on our YouTube channel, which has 1,100 subscribers. We have posted more than 3,000 tweets and have 5171 followers on our Twitter account, @eurostemcell. We have 2,189 Facebook likes – growing audiences across all social media channels.
We have responded to 759 direct enquiries from patients, their families and caregivers in this period, on clinical trials, unproven treatments, umbilical cord blood banking and prospects for therapy in a variety of diseases, and many more from event organizers, recruiters, media, students and job seekers. We have engaged in face-to-face conversations with over 199,135 citizens.

1.3.6. Evaluation
Evaluation is embedded in our on-going activities, and all our educational tools and materials are piloted and/or tested with user groups during development. We have also carried out a dedicated evaluation of eurostemcell.org, the findings from which were used to optimize the website and guide subsequent actions within the project. More recently, we have commissioned two further pieces of research - one to analyse the cooperation across the partnership in EuroStemCell and develop a series of best practice guidelines, and the other, a stakeholder evaluation of the EuroStemCell project as whole. These two pieces of research are described in more detail under WP4 Theme 2. We have also performed a number of smaller scale evaluations; these are also listed below and available on request. The findings of the evaluations will be disseminated as part of an online guide to best practice.

Potential Impact:
EXPECTED FINAL RESULTS & THEIR POTENTIAL IMPACT AND USE

The EuroStemCell project aimed to develop both a comprehensive information and resource centre, and to evaluate and refine best practice methodology for dissemination of new scientific outputs. These aims have been achieved and, together, constitute the first coordinated effort to deliver effective communication of stem cell research to relevant stakeholders and publics and show the way forward for future efforts in this field, including via the new H2020-funded EuroStemCell project.

1.4.1. Impact on science
Stem cell research is a diverse and growing field, encompassing many different scientific disciplines. EuroStemCell provides a
hub, a central focus for the sector in Europe. Scientists can visit the site to monitor relevant policy news and developments in other, related areas of research. It facilitates rapid knowledge sharing between European research groups and out to a wider European audience, via web-based resources. EuroStemCell also raises the profile of stem cell research in Europe generally, which in turn raises awareness of career openings in Europe for talented young scientists.

By actively fostering communication between stem cell scientists within Europe and internationally, EuroStemCell has significantly contributed to establishing an internationally visible presence for the European stem cell community.

In the wider field of communicating life sciences, EuroStemCell is developing best practice for information management and science communication.

1.4.2. Economic benefits
The EuroStemCell network represents 82 leading stem cell laboratories and 11 SMEs across Europe, and reaches out to many more in the global stem cell community. The project enables partners to minimise duplication of effort, pool resources and maximise impact of public engagement activities and resources. It provides road-tested tools and resources to help ensure success of public engagement efforts. And as Europe’s hub for stem cell research, it acts as a point of focus for those outside of the sector (public, media, politicians, regulators etc.) and can help to filter and efficiently respond to enquiries and requests for information at the personal and policy development level. The Horizon 2020 iteration of EuroStemCell commenced in January 2015 with an expanded partnership representing 31 separate research and network entities within the European stem cell research community. The FP7 EuroStemCell project has therefore catalysed development of a much larger network of scientists, which will continue to act collaboratively to disseminate research findings and engage people with stem cell research. This minimises duplication of effort in development of effective approaches and resources for outreach, and also enhances impact through co-ordination.

1.4.3. Impact on society
Thanks to the close and enthusiastic involvement of many European scientists working at the highest level internationally in this field, we can ensure scientific accuracy in all project outputs. The information and resources we produce are reliable and authoritative - countering misinformation, promoting informed decision making and supporting increased public awareness and understanding of stem cell research and the issues it raises. We are pioneering a collaborative approach to public engagement: collating and coordinating public engagement materials and activities across a whole European scientific community, and building capacity for high quality engagement and dissemination within that community. By mobilising and engaging the stem cell research community, we’re helping European citizens, whatever their interest in the topic, to make sense of stem cells.

List of Websites:

Project Co-ordinator contact details:
Professor Clare Blackburn
The University of Edinburgh
Telephone: +44 (0) 131 651 9563
Fax: +44 (0) 131 651 9501
Email: c.blackburn@ed.ac.uk
Project website: www.eurostemcell.org

Related information

<table>
<thead>
<tr>
<th>Result In Brief</th>
<th>Stem cell communication tailored for citizens and stakeholders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Documents and Publications</td>
<td></td>
</tr>
</tbody>
</table>