

Communicating stem cell research

Information | Education | Conversation
2010–2015

Report on the activities of EuroStemCell

a project funded by the European Commission's
Seventh Framework Programme (FP7)

www.eurostemcell.org

Introducing EuroStemCell

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.

EuroStemCell is a partnership of:

- 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. 187 individuals have written, reviewed and translated content for the EuroStemCell website, and 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



400



EuroStemCell now has connections to over 400 stem cell and regenerative medicine labs and SMEs across Europe

Communicating stem cell research

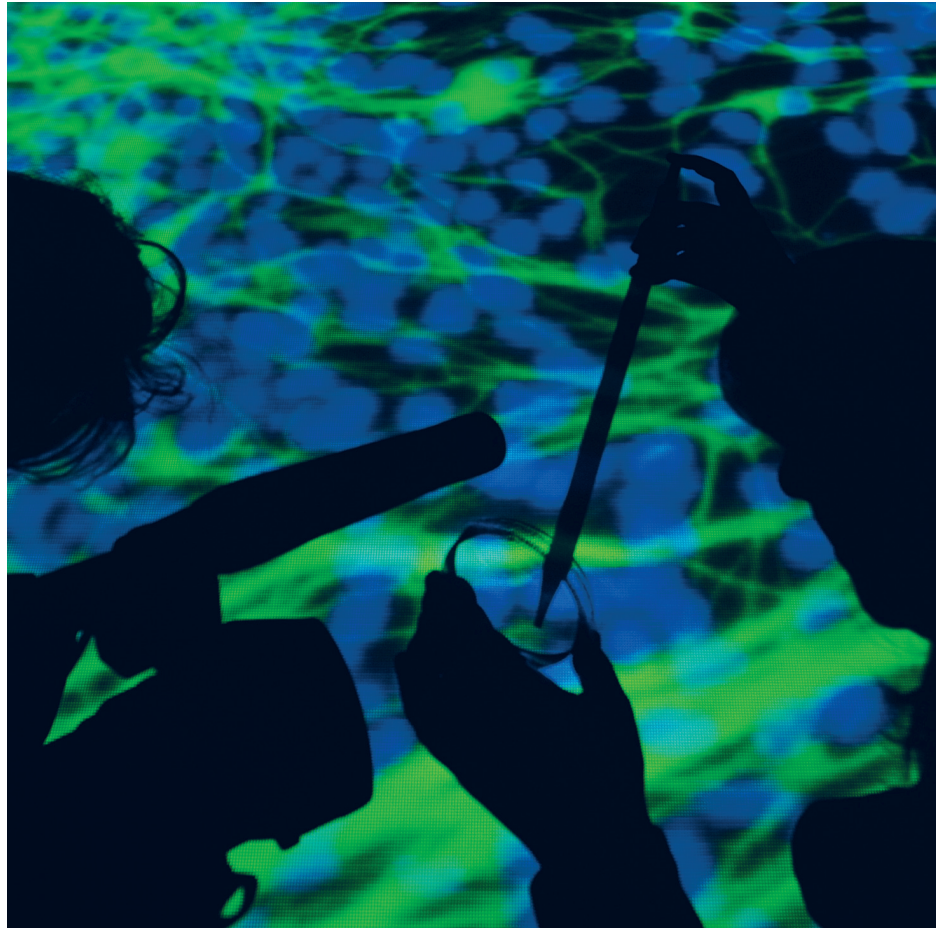
Stem cell research is one of the most promising and exciting areas of biomedical science, with potential to revolutionize the way we understand and treat many debilitating diseases and injuries.

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 prospects 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. This report details our approach, and the results we, and others, have observed.

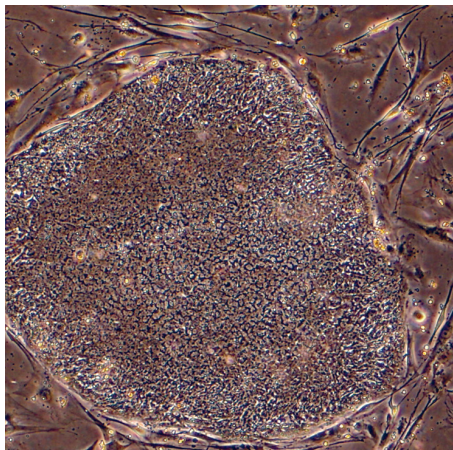
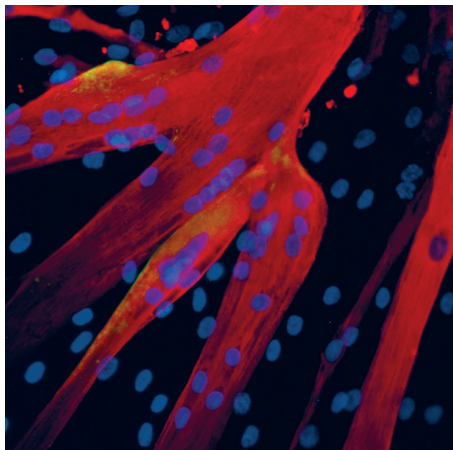


Stem cell information

EuroStemCell has established a core infrastructure for collating, managing, structuring, disseminating and translating stem cell information – from research developments and clinical progress to commercial, ethical and societal factors.

We collaborate with a wide and growing network of experts both within and beyond the EuroStemCell partnership to capture and communicate the latest scientific and policy developments.

The result is extensive, accurate and up-to-date content published on eurostemcell.org. As well as making reliable information readily available to the public, this work provides a strong foundation of scientific information for other activities, such as development of educational resources.



Above: Image by Christian Unger, Centre for Stem Cell Biology, University of Sheffield

Since 2010, we have developed, published and in many cases translated the following information resources on the EuroStemCell website:

254 

254 news stories and blog posts

32 

32 expert-reviewed, non-technical fact sheets in English (a total of 146 including translations). 17 of these address specific diseases and the prospects for stem cell therapies in those diseases.

43 

43 short format FAQ (a total of 209 including translations)

25 

25 in-depth commentaries, on topics like embryonic stem cells, cancer stem cells, stem cell patents, stem cell tourism, peer review, funding, clinical translation, patient needs, cell replacement therapies, commercialization and regulation.

19 

19 research spotlights, taking a closer look at individual scientific papers

13 

13 interviews with scientists and other stem cell specialists

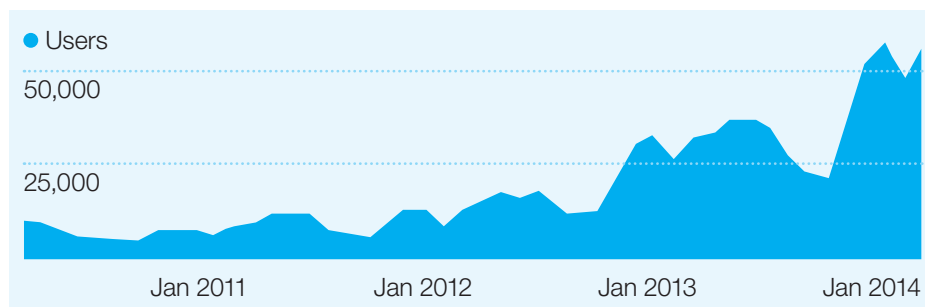
39 

39 newsletters, reaching more than 3,000 subscribers every month



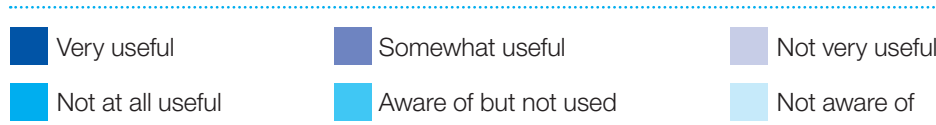
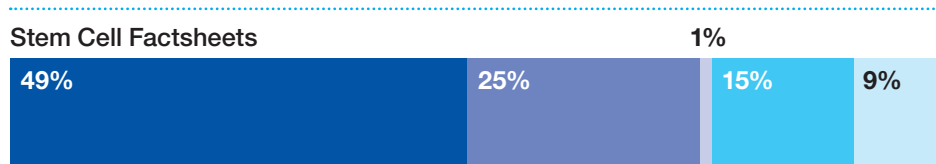
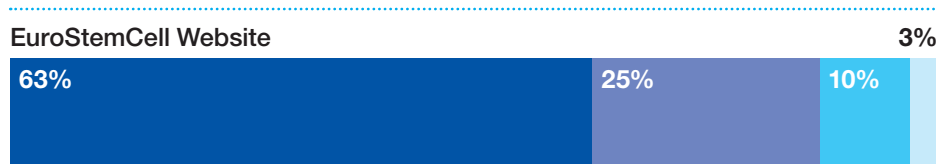
We also worked with publisher Elsevier to produce a comprehensive analysis of trends, growth and development in the stem cell field, published in report form (print and online) and presented at the World Stem Cell Summit 2013.

Our website has reached more than 1.6 million unique visitors since 2010, and its audience grows year-on-year:



"I have read the information you offered and am so much more enlightened and educated in this field. I will tread very gingerly."
 Email from patient with hearing loss, February 2013

A significant majority of stakeholders polled in our 2013 evaluation of public engagement activities found our website (88%) and fact sheets (74%) to be very or somewhat useful:



"[the website] has provided me with factual information for discussing stem cell research with our local branch of Parkinson's UK."
 Charity worker surveyed as part of our stakeholder evaluation, October 2013

"The credibility of the information and resources produced by... EuroStemCell is a major success factor in engaging all types of stakeholders."
 Stakeholder evaluation, October 2013

Our stem cell toolkit and fully searchable resource directory constitute a one stop shop for public engagement and education resources relating to stem cell research and regenerative medicine.

Stem cell toolkit

We have developed, tested, packaged and in many cases translated 16 downloadable stem cell tools and resources, suitable for classroom, science centre, open day, festival and general outreach or education use. Tools have been extensively tested, can be customized, are free to download or use online, and come with full instructions.

Tools included in the toolkit are:

Films

- Stem cell stories
- Stem cells: the future – an introduction to iPS cells
- Stem cell revolutions
- Cell fate: journeys to specialization

"Fantastic, it kept year 11 transfixed and really got discussion underway."
Teacher, Scotland



Deborah Richmond
@debrichmond

Some great resources from @eurostemcell here <http://www.eurostemcell.org/films> including a fab 15 min introduction. Great for GCSE and extension KS3.



RETWEETS 4 FAVOURITES 2

6:12 AM – 7 Jun 2013

Hands-on activities and games

- Start with a stem cell: posters and group games

"I have seen first-hand how the resources have been used to improve understanding at family events and in schools. Their suitability for and impact on young people is very impressive!"
University lecturer

Discussion and debate

- Stem cell dream discussion event
- Debating science issues debate competition
- Ready or not? Role play

"This is a superb role play! Really well resourced and structured, with plenty of supporting material! The debate that this activity will generate will certainly engage your learners and will help them consider all aspects of stem cell research and respect other people's views, feelings and opinions. An outstanding resource and very relevant to today's world and issues."

Alessio, Science Subject Lead at TES

Online interactives

- Hope Beyond Hype graphic story and interactive
- Sporty stem cells – animates



Sci Museum Learning
@SM_Learn

@eurostemcell's comic is a great teaching tool <http://ow.ly/nMCoe>
Try running a student competition for their best science comics



FAVOURITE 1

1:20 PM – 12 Aug 2013

School lessons and activities

- Introducing stem cells
- Discover stem cells
- CSI: cell science investigators
- Stem cell treatments and ethics
- All about stem cells activity cards

"The students were enthusiastic and in a short time were involved in the activity, even the students that usually pay less attention to the lessons participated with commitment."

Teacher, Italy



tes Science
@tesScience

This lesson by @EuroStemCell is really useful. Something to bookmark for the new year – <http://ow.ly/nzRHm>



RETWEETS 2 FAVOURITES 5

12:20 AM – 5 Aug 2013

"I liked that as many as 10 people were involved in the discussion and that all possible views were represented. It was very interesting and encouraged a deeper understanding of bioethics."

In July 2013, the Biology teaching specialist at the UK's National STEM Centre selected the lesson materials for listing on the widely used National STEM Centre e-Library for teachers. In February 2014, The Guardian's Teacher Network chose to feature Discover Stem Cells in its article, "How to teach... stem cell research", which listed our materials as a useful resource for "understanding stem cells". Several of our resources have been recommended by Scottish government agency Learning and Teaching Scotland as a tool for National Qualifications support.

Training for teachers and scientists

Supporting our educational resources, and maximizing their reach, we have delivered teacher training and CPD through the Association for Science Educators (UK), the German Stem Cell Network, Stem Cells Australia, and the Irish Science Teachers' Association, as well as public engagement training workshops to scientists throughout Europe, in collaboration with partner projects HumEn, PluriMes, OptiStem, EuroSystem and ThymiStem and the Hydra stem cell summer school (271 students over 5 years).

Keen to improve our practice we initiated a project to explore a model of good practice in providing teacher CPD through additional funding from The Wellcome Trust (£30,000). The project provided CPD for 377 science teachers from over 200 Scottish high schools along with kits of EuroStemCell resources, together with 69 trainee teachers from 5 training establishments. Evaluation of our model of working showed a positive swing in confidence and knowledge in teaching about stem cells, and has shown positive effects on pupils taught by teachers who attended one of our workshops.

"Overall, excellent CPD, which was truly helpful and enabled me to teach a new area of the course with confidence and with engaging resources."

Our success has led to an invitation by Education Scotland in 2015 to present our CPD work, as an example of exceptional practice, at a day for government, industry and education on 'Engaging with Scottish schools to promote STEM' and our model will be used across other science areas.

Distribution and dissemination

Almost 300 print kits of Discover Stem Cells in five different languages have been distributed to educators and scientists throughout the UK and Europe. We have delivered public engagement training workshops using our lesson materials to 89 researchers from across Europe. Continuing professional development workshops for science teachers from the UK (>200), Germany (37) and Spain (15) have also taken place using the lessons as an example resource.

UniStem Day

EuroStemCell tools, expertise and dissemination channels have also been part of the annual UniStem day, the largest stem cell dissemination event in Europe. Led by the University of Milan, this large scale event connects thousands of high school students throughout Europe with researchers, in a day of stem cell talks, activities, music, movies and more.

"This is probably the most comprehensive suite of resources available anywhere in the world and the formats are innovative and engaging. Well done!"

Public engagement practitioner



20,000 

High school students connected with stem cell researchers as part of UniStem Day 2014

Conversation: sharing and engaging

Information and resources by themselves are not enough to foster meaningful engagement. They work best when supported by opportunities to discuss, ask questions, interact and converse.

Through the EuroStemCell website, social media channels, events and resources, we have created spaces where dialogue about stem cell research and regenerative medicine can take place: between scientists, clinicians and other specialists, media, writers, and European citizens.

Online

Complementing informational content, the EuroStemCell website includes guest blogs, interviews and commentaries where individual perspectives on aspects of stem cell research can be expressed. Topics addressed include funding, peer review, patenting, clinical translation and stem cell tourism. We also provide opportunities for site visitors to comment, vote and interact. We have received and responded to more than 400 comments via the website, and thousands of enquiries via our contact form (including more than 1,000 from patients and their caregivers about clinical research and stem cell treatment possibilities). Often, these initial questions and comments are the spark for something new: our FAQ and fact sheets are developed based on the questions we are most often asked, and many collaborations – with researchers, students, patients and organizations – have been kicked off with a question.

Direct engagement

Through events, exhibits and screenings EuroStemCell has staged, or supported our partners to run and resource, we have engaged more than 90,000 non-specialists worldwide since 2010, in direct, face-to-face conversations about stem cell research and regenerative medicine. Many of our resources are designed to foster dialogue.

“We made use of some of the activities in the Outreach kit for scientists and the blood stem cell exhibit, during our event. They worked well with families in a drop-in situation.”

Non-clinical researcher

Social media

Social media provide supplementary spaces for conversation, and the opportunity for us to engage directly with a wide range of audiences. We regularly receive questions and comments via our Facebook page. Our videos on YouTube have been viewed more than 270,000 times, and our channel has more than 1,000 subscribers. We have run a session on stem cells and social media at the Hydra summer school 2014, and were invited to contribute to a Voices column in *Cell Stem Cell* on social media.

On Twitter, we have posted 2,950 tweets, amassed 5,171 followers, made many new connections, and supported several scientists in their first steps in social media, with guidelines, training, advice and the opportunity to ‘guest tweet’ for a day or at an event. We look for hashtags and events that create space for stem-cell-related interactions. During #brainweek we connected with artists, neuroscientists, patients, and charities, while #ASEchat lets us speak directly with teachers. Twitter interactions generate real world opportunities too, like a recent invitation to run a teachers’ workshop. Completing the circle, participants tweeted from the workshop, and a teacher asked about a resource pictured, resulting in a stem cell conversation that extended all the way from New Zealand to a UK classroom.

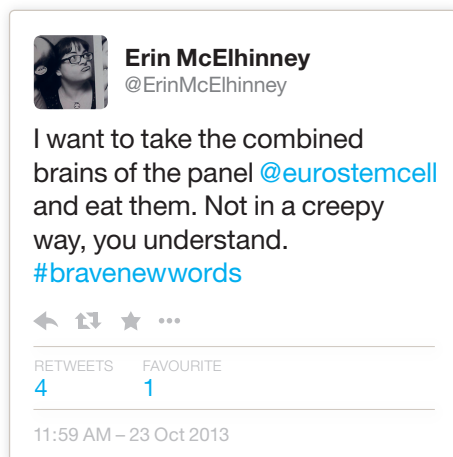


Creative conversations: writing competition, event and publication

We ran a stem cell writing competition in 2013, inviting entries in three genres – poetry, imaginative science writing and graphic non-fiction – and capturing the imagination of entrants in 18 countries. Winning entries were celebrated at an event in Edinburgh, Brave New Words, described this way by writer Barbara Melville in her blog:

“Last Wednesday night, in a room of 80 readers, writers and the curious, we talked about the importance of public engagement, the possible dumbing down in science documentaries, and the responsibility of fiction writers.”

And more graphically by another audience member, via Twitter:



We also produced a publication, distributed digitally and in print, of competition winners and runners up.

Using film to stimulate discussion

We have been closely involved in the production and distribution of feature length science documentary, ‘Stem Cell Revolutions: a Vision of the Future’, featuring Nobel prizewinners Shinya Yamanaka and Sir John Gurdon.

The film was broadcast on ARTE in France and Germany, won best documentary at the Vedere la Scienza Festival 2012, and screened in competition at the Science Teller Film Festival in New Zealand.

This film was also the centrepiece of a stem cell roadshow which toured 12 cities throughout the UK, reaching an aggregated audience of over 900 people (mainly adult audiences), and a schools tour in Australia in collaboration with Stem Cells Australia, targeted at schools and teachers in four Australian centres and reaching more than 550 students.

“Students were excited about the possibilities of the research and were able to imagine themselves in the shoes of the people on screen, doing the same great work. They were worried or curious about the implications of the discoveries and were pleased to have the scientists to talk to about it.”
Teacher, Melbourne



I enjoy learning about science **Very educational**
I feel that I have a better understanding of ethical issues
I feel that DSI has improved my knowledge of biomedical science and my confidence in my public speaking
Increased my communication skills
I have gained confidence
It has boosted my interest in science and scientific issues
It is an excellent experience and opportunity
I now have a better understanding of science and what I'd like to do as a career in science
I learnt a lot I feel that I have been given a confidence boost
I am a lot more informed
It has given me huge amounts of confidence, research skills and passion for science
It has helped me understand scientific terms more easily
DSI links in to all aspects of life **Very helpful and interesting**
It has helped my understanding of science
I've learned many new words
I have learnt a lot of new facts
I feel that I have gained a better knowledge of stem cell research since DSI
It makes me more aware
It has been an excellent experience and improved my skills
DSI has given me good insight into science as a career
It has opened my mind to many different scientific topics
I now have more of an interest in biomedical science
I have gained confidence in public speaking
I have gained more knowledge, confidence and experience
Made science fun and exciting
It brought science to a personal level that interested me

5,171

Twitter followers

2,189

Facebook likes

1,100

YouTube subscribers

Policy and media

In 2011 we reported scientists' concerns about the case heard by the European Court of Justice on the patenting of embryonic-stem-cell-based technologies, and its ethical, legal and biotechnology sector implications. We opened a moderated comment stream to support open discussion of this issue, worked with the UK's Science Media Centre to brief journalists and collated the widespread media coverage of the case. More than 500 concerned individuals took the opportunity, made available through eurostemcell.org, to express support of the scientists' position.

We have also worked with the UK Science Media Centre (SMC) to develop briefing notes for journalists on human stem cells, which are widely distributed to journalists and used by the BBC Academy and College of Journalism in their training. And we supported the SMC in a briefing for journalists on mesenchymal stem cells and the Stamina case (September 2013).

"I have to say your site is proving incredibly useful!"

Robin Bisson, Science Media Centre

EuroStemCell worked with partner OptiStem and the UK Office of the European Parliament to run a panel and discussion event in February 2013 in London, around the amendment of the Clinical Trials Directive. We secured the participation of the Rapporteur for this amendment, MEP Glenis Wilmott. The event was fully booked, and 65 high level delegates – industry, funders, national regulatory bodies, journalists and other policy makers – attended.

We've reported developments and helped to brief stakeholders across other hot topics, including the Stamina case in Italy and the 'One of Us' European Citizens' Initiative.

Sharing best practice: examples

We presented the EuroStemCell project and shared our educational tools with scientists and communicators at the International Society for Stem Cell Research 9th Annual Meeting's Satellite Symposium, 'An informed society – How to participate in public science education and why it matters', in June 2011.

We have provided guidance and interview input to several groups of students developing stem cell projects, including a group in Belgium developing an information tool about stem cell regulation, and a group in Sweden developing a stem cell iPad app.

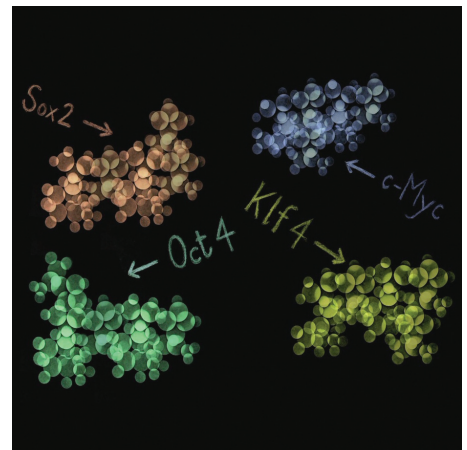
We ran a discussion session at the International Public Communication of Science and Technology conference in 2012, exploring how best to communicate with patients about research.

We presented learning from the EuroStemCell project to other science communicators at the British Stem Communicators Network Conference, 2015.

Our sharing of best practice in public engagement extends beyond stem cells to other research areas. For example we presented the EuroStemCell project and toolkit at the conference of FP7 project PLACES (2012) in a panel on science in society, and provided a talk and training to the GENIE network in 2014.

The EuroStemCell team also teaches and hosts placements from the University of Edinburgh MSc in Science Communication, training the next generation of science communicators.

And we have advised other European projects on their communication and public engagement strategies – including a new project proposed in the field of neurodegenerative diseases and based on the EuroStemCell model.



"Great insights into how outreach can address all types of publics – all ages, all places."

Peter Meister, founding member GENIE

Continuing the conversation

EuroStemCell has already helped many European citizens – and people and organizations around the world – to make sense of stem cells. Feedback received and evaluation completed suggests that our approach is working.

The information and resources we produce are reliable and trusted, 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.

But our work is not yet done!

Our Stakeholder Evaluation (2013) concluded that EuroStemCell had “created a strong platform on which to strengthen existing impacts and build new ones,” and identified the following opportunities for future work:

- further promotion amongst all stakeholder groups
- helping and supporting stakeholders to develop on-going, longer-term dialogues with non-specialists
- strengthening links with policy makers through resources and events developed specifically for them
- developing an explicit, facilitated networking strand of activities to build upon contacts made, with a specific focus on developing new collaborations and projects
- translating and adapting all materials for overseas use
- ongoing, standardised evaluation of all activities, resources and impacts

All of these opportunities are addressed in the continuation of our work, funded under the EC’s Horizon 2020 – Research and Innovation Framework Programme (2015–2018) and kicking off in February 2015.

“I’m a 13 year old who loves biology! My amazing biology teacher, Mr Campbell, told my class that Euro Stem Cell is a great website/twitter for information about stem cells and he was correct as always! I am learning about stem cells just now and this website is a huge help. I followed you on twitter so I can get the latest updates on stem cells! Overall, what a fantastic website and I’m impressed! Will be using this a lot!”

“I am in the process of joining a local independent research institute as a volunteer on its stem cell research oversight committee. I came across your organisation in the course of my efforts to educate myself about stem cell research. I quickly discovered some of the articles on stem cell biology and ethical issues associated with stem cell research, and found these to be a very useful introduction to the field. The site is well organised, easy to explore and has many useful links. I expect to be returning to it frequently over the next few years.”

unsolicited feedback received by email



Meet the team

The work described in this report was developed and delivered by:



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