

20 EMRC Newsletter European Medical Research Councils (EMRC)

May 2012

Editorial

Despite this year being the last one for EMRC, the standing committee is keeping to its reputation and is extremely active again this year in science policy and strategy actions towards biomedical research.

The first half of the year has already seen the publication of the position paper of the EMRC Expert Group on a European Academic Proposal for a Revision of the Clinical Trials Directive (2001/20/EC) (http://www.esf.org/researchareas/medical-sciences/publications.html). This paper is an excellent summary of the many constructive discussions that took place between EMRC and the European Commission as the Directive was being drafted. It also takes into account important issues that fall outside the realm of the Directive but are key to reducing the red tape burdening investigator-driven clinical trials in Europe. The Directive is now in the hands of the European Parliament and it is expected to be voted on by the end of 2012 or early 2013. Many new hurdles could potentially emerge during the legislative process and all will have to keep a close eye on the progress. We have also published a followup paper on the Science Policy Briefing published less than a year ago on 'Health Research Classification Systems - Current Approaches and Future Recommendations' which underlines concrete implementation steps (more information on page 2 and at www.esf.org/hrcs and http://www.hrcsonline.net/).

Many important workshops and conferences have also been held since January. Besides a successful EMRC Standing Committee meeting held in Strasbourg (FR) in April, the Forward Look on personalised medicine has mobilised a lot of attention. A 'Big Picture' workshop was held in February in Dubrovnik (HR) at the invitation of the Croatian EMRC representative and Forward Look instigator Professor Krešimir Pavelic. Following the two previous workshops on technologies and diseases, personalised medicine was discussed here in a broad societal context. This led to the formulation of recommendations that were discussed in depth by more than 60 participants at the final Stakeholder Conference held in April in Rome (IT). The report and its recommendations are now being finalised. For the important issue of open access in biomedical research, an expert workshop was held in Madrid (ES) in March, kindly hosted by our member organisation CSIC. There again a draft report with tangible recommendations was debated in depth and will lead to a paper publication. Both of these publications are expected to be published in the autumn.

These two reports are only two of many yet to be published before the end of the year with the others addressing medical research education, implementation of medical research in clinical practice, and neurosciences. EMRC plans this way to finish its existence with a firework of publications aiming to help biomedical sciences in Europe and set its successor at Science Europe for a bright future.

Finally, this is my last EMRC newsletter before I leave the ESF this summer. When I made the decision to move from biotech research into science management, I had great hopes of making a difference in my new field. Today, when I look back at what we have achieved together during the 3 years I have been at the head of the biomedical sciences unit, I can only be proud of the legacy we are leaving behind to promote innovative biomedical research and its clinical application towards the improvement of human health. None of this could have taken place without the unfailing support of our core group members, our standing committee members, our contacts and all the experts and participants we called upon and who willingly gave up their precious time. I cannot leave, of course, without saying a very special thank you to my team at the ESF for their commitment and dedication, and for making our time in the office pleasant and often fun. My last words, however, are reserved for Lotte, our Chair, as she too will soon leave EMRC. I would like to thank her on behalf of EMRC for her profound dedication and tireless involvement. During her term, the strength of her leadership helped EMRC to become a beacon for biomedical research in Europe and beyond. On a more personal level, I am deeply grateful for her unconditional support and for her capacity to be a manager, coach, and mentor while also remaining a colleague and peer. Lotte personifies the profound respect I have encountered from all of you for what I do and for who I am today as a science manager. Thank-you for making me proud of my work. I wish you every success in your personal and professional endeavours and I truly hope our paths will soon cross again. Merci!



Stephane Dr Stephane Berghmans, DVM PhD

On behalf of EMRC, I would like to express our most sincere appreciation and thanks to Dr Stephane Berghmans for his hard work and commitment to EMRC over the past three years. His continued efforts in striving to strengthen the conditions for biomedical research in Europe and globally with the final aim of better health and wealth for patients and societies has been crucial to the success of EMRC. We wish Stephane good luck for the future and again, a very grateful thank-you from EMRC.

Lotte **Professor Liselotte Højgaard**, MD DMSc EMRC Chair

Highlights

Forward Look

iPM – Personalised Medicine

The Forward Look activity on personalised medicine was launched in 2011, chaired by Stephen Holgate, Medical Research Council, School of Medicine, University of Southampton (UK); Aarno Paalotie Director of the Finnish Genome Center, University of Helsinki (FI) and Senior Group Leader, Wellcome Trust sanger Institute (UK) and Barbara Prainsack, Deputy Director, CBAS, Sociology and Communications, Brunel University (UK). Different issues in the area of personalised medicine were discussed: technological developments and integration of existing and novel technologies, disease-specific challenges and opportunities with respect to personalised medicine and the broader context of personalised medicine - new methodological approaches for randomised clinical trials, the role of the patient at the centre of healthcare, clinical phenotyping and diagnostics pathways in personalised medicine and the impact of personalised medicine on the healthcare system and health economics. The final report will be published this autumn and the recommendations could be discussed at an international implementation meeting in late autumn 2012.

Science Policy Briefings

FLIP – Implementation of Medical Research in Clinical Practice

The report of our Forward Look, 'Implementation of Medical Research in Clinical Practice' was launched in May 2011 with dissemination to over 2000 organisations and individuals throughout Europe and it has been extremely well received. However, it was recognised that further action was needed to ensure implementation of the report's recommendations. An implementation expert group was set up and chaired by Liselotte Højgaard and three working groups were set up in the areas of: public and patient involvement; primary care practice; and knowledge generation transfer. The results of their discussions will be published in a Science Policy Briefing in the autumn of 2012.



HRCS: Health Research Classification Systems – Current Approaches and Future Recommendations

This SPB, chaired by Dr Ian Viney (MRC, UK) was published on 14 November 2011. Professor Liselotte Højgaard, EMRC Chair, strongly encouraged all Heads of ESF Member Organisations

(MOs) to implement the Health Research Classification System (HRCS) developed by the UK Clinical Research Collaboration (UKCRC) in their organisations. Twentythree MOs and two non-MOs have endorsed the SPB and are ready to support the HRCS use.

The SPB was presented in November 2011 at the G8 Heads of Research Assessment meetings and the European Research Council (ERC) workshop, "Assessing the performance of ERC-funded projects, impact assessment and ex-post evaluation of results". It was circulated to the MO Fora experts of, "Evaluation of Publicly Funded Research" (co-chaired by Dr Viney), "Best Practice in Peer Review" and "Evaluation: Indicators of Internationalisation".

A workshop that took place on 22 November 2011 in London (UK) to discuss the implementation of the recommendations including next steps and milestones led to the publication of a follow-up paper (http://www.esf. org/fileadmin/FlipBooks/HRCS_FollowUp_Report. html). To the best of our knowledge, DFG (DE), F.R.S.-FNRS (BE), Health Research Unit of the Academy of Finland, Croatian Academy of Sciences and Arts (HR) and FCT (PT) have started discussions on the potential implementation of HRCS in their organisation or even started testing it. Dr Viney has accepted to take care of the next implementation steps.

HRCS publications and more information: www.esf.org/hrcs and http://www.hrcsonline.net/ MO Fora: www.esf.org/activities/mo-fora

Position Paper



Revision of the Clinical Trials Directive (2001/20/EC)

EMRC published this position paper in January 2012 as a result of discussions with many different expert groups. EMRC is now closely following this on-going issue and invites you to send us any information you have on any on-going activity in this area.

Research Networking Programme

REMEDIC – Regenerative Medicine

One of the most important scientific activities of the RNP REMEDIC in 2012-2013 will be a large final conference on regulations, rules and standards in regenerative medicine to be held in May 2013. National regulatory hurdles are still a major problem in marketing advanced therapies in Europe. The aim of this conference is to bring together European regulators, e.g. EMA, national regulators, academia, company representatives, representatives of tissue banks and also young scientists in order to advance the field of regenerative medicine and provide an incentive to tackle regulatory problems in Europe. A large part of the budget for 2012-2013 (70,000€) is dedicated to this activity.

A kick-off meeting took place in Frankfurt (DE) on 4 June 2012 with the aim of discussing the format, ideas, structure and topics for the conference. Participants were representatives of the REMEDIC Steering Committee, EMA, and the Alliance for Advanced Therapies.

Events 2012

- RNP REMEDIC Kick-off meeting on Regulatory Issues Frankfurt (DE), 4 June 2012
 - http://www.esf.org/remedic
- RNP REMEDIC 10th World Congress of the International Society for Adaptive Medicine Bucharest (RO), 7-10 June 2012
 http://www.esf.org/remedic
- FORWARD LOOK Personalised Medicine (iPM) Scientific Committee meeting London (UK), 11 June 2012
 - http://www.esf.org/iPM
- RNP ESF-ELN European LeukemiaNet Workpackage Meetings at 17th Congress of EHA (European Hematology Association) Amsterdam (NL), 14 June 2012
 http://www.esf.org/esf-eln
- Forward Look The Future of Science in Society
 Workshop 3: Reflecting on Research as a Profession
 Vienna (AT), 18-19 June 2012
 http://www.esf.org/science-in-society
- http://www.esf.org/science-in-society
- RNP EUCCONET
 Workshop on Dissemination, engagement
 and impact getting research understood and used
 Edinburgh, Scotland (UK), 25-26 June 2012
 http://www.esf.org/eucconet
- RNP EUCCONET
 Workshop on Metadata and documentation
 for the survey life-cycle
 - Edinburgh, Scotland (UK), 25-26 June 2012
 - http://www.esf.org/eucconet

- RNP REFLECTION Summer School Leuven (BE), 1-13 July 2012
 http://www.esf.org/reflection
 - RNP REFLECTION Steering Committee meeting Leuven (BE), back to back to Summer School event
 http://www.esf.org/reflection
 - RNP TRACE
 Steering Committee meeting
 Vienna (AT), 4 July 2012
 http://www.esf.org/trace
- EUROCORES EuroEPINOMICS
 Data Analysis meeting
 Luxembourg (LU), 5-6 July 2012
 http://www.esf.org/euroepinomics
- RNP Euroglycoforum 4th Euroglyco Steering Committee meeting Madrid (ES) 24 July 2012
- RNP FFG

The 3rd Young Investigator Workshop on "Biobanking, New Technologies, Complex genetic Traits and Personalised Medicine" Tartu (EE), 27-29 August 2012 ► http://www.esf.org/ffg

- EW11-010 Physics of Cancer Varenna (IT), 13-15 September 2012
- RNP FFG Workshop on Dynamics of Cell Signal Systems Oslo (NO), 27-30 September 2012
 http://www.esf.org/ffg
- 12-393 Molecular Biology and Innovative Therapies in Sarcomas of Childhood and Adolescence Pultusk (PL), 29 September-4 October 2012
 http://www.esf.org/conferences/12393
- EMRC 61st Standing Committee meeting Prague (CZ), 4-5 October 2012
 www.esf.org/emrc
- RNP REFLECTION Master Class
 Lübeck (DE), 4-6 October 2012
 http://www.esf.org/reflection
- RNP ERNI-HSF Workshop on Orienting of Attention: neural implementation, underlying mechanisms and clinical implications Tübingen (DE), 2-3 November 2012
 http://www.esf.org/erni-hsf
- EW11-012 Gene-Environment interactions and the distribution of Periodontitis in Europe Aarhus (DK) 26-27 November 2012
- RNP EUCCONET

Conference organised jointly with the International Society for Longitudinal and Lifecourse studies on Childhood and Beyond: tracing cohorts across the lifecourse

Paris (FR), 29-31 October 2012

http://www.esf.org/eucconet

ESF

The European Science Foundation (ESF) is an independent, non-governmental organisation, the members of which are 72 national funding agencies, research performing agencies and academies from 30 countries.

The strength of ESF lies in its influential membership and in its ability to bring together the different domains of European science in order to meet the challenges of the future.

Since its establishment in 1974, ESF, which has its headquarters in Strasbourg with offices in Brussels and Ostend, has assembled a host of organisations that span all disciplines of science, to create a common platform for cross-border cooperation in Europe.

ESF is dedicated to promoting collaboration in scientific research and in funding of research and science policy across Europe. Through its activities and instruments, ESF has made major contributions to science in a global context. ESF covers the following scientific domains: Humanities; Life, Earth and Environmental Sciences; Medical Sciences; Physical and Engineering Sciences; Social Sciences; Marine Sciences; Materials Science and Engineering; Nuclear Physics; Polar Sciences; Radio Astronomy; Space Sciences

EMRC

The European Medical Research Councils (EMRC) is the membership organisation for all the medical research councils in Europe under the auspices of the ESF. EMRC's mission is to promote innovative medical research and its clinical application towards improving human health. EMRC offers authoritative strategic advice for policy making, research management, ethics and better health services. In its activities, EMRC serves as the voice of its Member Organisations within the European scientific community. EMRC disseminates knowledge and promotes the socio-economic value of medical research to the general public and decision makers.

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