



A 2015 marked by project meetings and developments

ExPO-r-Net partners have been particularly busy in the past months, both in making progress in the achievement of the project's deliverables and milestones, and in raising awareness on our overall objective to prepare the creation of a European Reference Network (ERN) for paediatric oncology.

The last **ExPO-r-Net Executive Committee (ExeCom) Meeting** in 2015 took place last 29-30 September 2015 at the Childhood Cancer Research Institute (CCRI) in Vienna, Austria. The aim of this biannual meeting was both to enhance internal communication among partners as concerns the results achieved so far and the next steps forward in the achievement of the project's objectives, but also to show how the future system could work to the European Commission.

Before and after the ExeCom Meeting, two smaller **ExPO-r-Net Working Meetings** took place on 7th August in Vienna, Austria, and on 10th October in Cape Town, South Africa.

During all these project meetings, **updates** have been given from the groups on very rare tumours, Wilms tumour, retinoblastoma and haepatoblastoma, on the feedback from Chafea about the first Interim Report of the project, on the developments as concerns IT/e-Health tools for paediatric virtual tumour boards (VTBs), on the questionnaire circulated in Eastern European countries, on the Survivorship Passport initiative and on all aspects related to the creation of VTBs in Europe.

Importantly, the European Commission informed partners about different aspects:

- all EU Member States now have at least one **National Contact Point (NCP)** in place where people can find out more about their patient rights and options, and can look for answers to questions on seeking healthcare abroad, e.g. is referral needed, will patients be reimbursed, are preventive measures covered, etc. Each NCP has its own dedicated, multilingual website, and support is provided by the Commission (more information [here](#));
- a tender calling for an institution to evaluate IT solutions to be used within VTBs as communication tools, which will be made available free of charge for all future ERNs. As ExPO-r-Net partners are currently testing an **e-Health interoperability architecture**, they have been thus involved in this process, and Ruth Ladenstein offered close cooperation with the European institutions to make sure that newly established IT-solutions are suitable for paediatric oncology.

In this framework, Günter Schreier from AIT recently presented this e-Health integrated system – which also includes the case consultation forum developed by CINECA – on 10th

December 2015, during the Lisbon e-Health week, within the session “Towards a European interoperability roadmap for sharing data in the framework of the operation of ERNs”.

Finally, we are glad to inform ExPO-r-Net partners that **the next biannual Executive Committee meeting will take place on 3-4 March 2016 in Lund, Sweden.**

ExPO-r-Net profiled at all levels

Project Coordinator Professor Ruth Ladenstein took part in several **international events** where ExPO-r-Net was presented since last summer: at the meeting “Cross-Border Healthcare in Europe” on 1st July in Brussels, Belgium; at the workshop “Realising Rare Disease European Reference Networks” on 2nd July in Brussels, Belgium; at the [European Cancer Congress](#) (in particular at the ECCO Oncopolicy Forum and during the SIOPE Session) 25-29 September in Vienna, Austria; as one of the main speakers at the “[SIOPE-MAC launch of the European Cancer Strategy for Children and Adolescents](#)” and at the Data Protection event, on 18th and 19th November at the European Parliament in Brussels, Belgium; and at the financial workshop “How to prepare the final financial report” on 7th December in Luxembourg. During these meetings, the paediatric oncology community proved to be highly visible, used to working together, and well interconnected. -

One of the major events where the work performed within the project has been showcased was the **2nd ERN Conference** (8-9 October 2015, Lisbon, Portugal), where the ExPO-r-Net project proved to be progressing well in awareness raising among other successful aspects. Prof Ladenstein made a general introduction on the project and – in spite of other concurring congresses taking place in the same period – several partners could attend this high profile meeting, including Project Manager Barbara Brunmair, Adela Cañete, Jerzy Kowalczyk, Günter Schreier and Piotr Czauderna. The Conference was useful and informative as concerns some specific aspects of the future ERNs’ structure that needed some clarification – e.g. sustainability of the networks, cooperation with EU Member States in their concrete implementation, and communication to parent and patient groups. The European Commission is currently negotiating aspects related to reimbursement with EU Member States, as the work performed by specialists within VTBs will be probably on a voluntary basis at the start of ERNs, with the expectation that this will change in the future.



IMPORTANT: National Designation

Each centre that intends to participate in the PO-ERN needs a national designation; **if such a designation is not given, a centre is not eligible to become a full ERN-member.**

Therefore we urgently recommend our envisaged ERN partner centres to contact your national ERN contact points and inform them about your interest in a national designation for the ERN application. The national designation process is not an EU-wide process, but differs between the individual member states.



More information: please find [here](#) a list of national contact points provided by the EU.

Future Events: Save the Date

- **ExPO-r-Net Biannual Meeting**
3-4 March 2016 in Lund, Sweden

Project Acknowledgement

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1. Display the following EU logo (available [here](#))
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Changes in Contact / Organisation

Dear ExPO-r-Net partners, please inform us about any news from your Work Package, as well as about any change in your contact / organisation details.

Please do not hesitate to widely disseminate to interested colleagues.

Please do not hesitate to contact expornet@ccri.at or office@siope.eu for more information.



SIOP Europe
the European Society for Paediatric Oncology

Avenue E. Mounier 83

B-1200 Brussels

Belgium

Tel: +32 2 775 02 12

Fax: +32 2 775 02 00

www.siope.eu



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