



**E-Blast**  
June 2015

## **First Annual Report Submitted**

In May 2015, ExPO-r-Net successfully submitted the first annual report due to the EU funding agency CHAFEA. The report consists of a technical part describing project activities and a financial part on the status of the budget. It consolidates inputs received from all Work Packages and describes achievements in the first year of the project.

We are delighted that all deliverables expected for completion in this first period have been duly finalised, and the vast majority of milestones achieved. In particular, the **Plan for cross-communication, knowledge transfer and activity integration** is now available, and its implementation already ongoing.

Congratulations on this successful submission – we look forward to further progress through all mutual efforts!

### **More information:**

- Deliverable 2: [Plan for cross-communication, knowledge transfer and activity integration](#)



## **Workshop on Future Priorities**

On 21 May 2015, a number of Work Package leaders met in Brussels, Belgium, to discuss how to best advance the project in the next 6 months.

The focus of the meeting was on the following most immediate priorities:

- Roadmap initiation: Bottom-up identification of Hubs of Coordination (HoC) on very rare tumours that will support respective study groups and function as tumour boards for national and/or cross-border advice.



Here, participants worked on the first possible prototypes of Paediatric Oncology European Reference Networks (PO-ERNs) in the fields of Very Rare Cancers and Retinoblastoma.

- Evaluation questionnaire: exercise to identify centres in Eastern European countries that

fulfil the requirements of the European Standards of Care for Children with Cancer and may become twinning partners interacting with HoC in shared cross-border health care models.

Template questionnaires were analysed by the workshop participants to produce a final draft of targeted questions. The expected outcome of the questionnaire is a list of centres that can effectively interact with a PO-ERN. Results will also support decisions on whether treatment can be done in the home country or requires cross-border transfer of the patient. The European Standards of Care for Children with Cancer underpin the initiative.

- IT solutions for tumour boards: the features and costs of IT e-health tools for a tumour boards' forum, case consultation and exchange of clinical data were discussed.

Participants agreed that a comprehensive comparison among the available IT tools is needed to effectively balance the criteria of interoperability, flexibility and cost for a possible choice within the project.

- Paediatric Tumour Board Questionnaire: WP5 (Paediatric Oncology tumour board ERN based on e-Health/ICT concepts for sharing and providing expert advice) outlined two questionnaires targeting respectively Paediatric Oncology Units & European Paediatric Oncology Groups.

The best way to reach all European Paediatric Oncology Units with this questionnaire will be by getting into contact with:

- the Chairs of the NaPHOS (National Paediatric Haemato-Oncology Societies)
- the Chairs of the ECTG (European Clinical Trial Groups)
- Very Rare Tumours (VRT) webpage: the details of the future webpage dedicated to inform families and the public on VRT has been discussed.

It will be built in collaboration with SIOPE and integrated in the ExPO-r-Net website with links to the SIOPE and ENCCA websites.

A Doodle has been sent to hold the next workshop with WP leaders over the summer.

**More information:**

- [European Standards of Care for Children with Cancer](#)



**ExPO-r-Net at the  
6<sup>th</sup> CCI Europe Meeting**

On 8 - 10 May 2015, ExPO-r-Net was presented to parents, patients and survivors at the 6th CCI Europe Regional Meeting in Malmö, Sweden. Both SIOPE and CCI covered the project in respective contributions to the programme, highlighting its objectives to reduce inequalities and empower patients. Thus, CCI speaker Anita Kienesberger described ExPO-r-Net as a 'favourite' of CCI Europe, as it is set to optimise cross-border access to the best possible care.

**More information**

- [CCI Europe webpage](#) (formerly ICCCP)



## **National-level mobilisation**

In addition to presence at international conferences and events, ExPO-r-Net is also showcased at national venues.

Thus, the ExPO-r-Net information material (brochure and bookmark) were distributed to participants at the UK Childhood Cancer Conference, 15 May 2015 in London, UK. This multi-stakeholder event focused on fostering innovation and dialogue on research, effective treatments, and better outcomes for children with cancer.

ExPO-r-Net information was also available at the Congress of the Italian Association of Paediatric Haematology Oncology (AIEOP) on 24 – 26 May 2015 in Lecce, Italy.

Partners are invited to promote the project at other national-level events by referring to the Communication resources available on the project website.

### **More information**

- [ExPO-r-Net Communication resources](#)
- [UK Childhood Cancer Conference](#)
- [AIEOP Congress](#)

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## **FUTURE EVENTS: SAVE THE DATE**



### **Policy symposium on Cross-Border Healthcare**

*1 July 2015, Brussels (BE)*

ExPO-r-Net Coordinator Prof. Ruth Ladenstein will speak about the project at the International symposium 'Cross-Border Healthcare in Europe: Promoting Equal Access to Quality Care' on 1st July 2015 in Brussels, Belgium. The event will focus on the policy implementation aspect in relation to the EU Directive on Cross-Border Healthcare.

### **More information**

- [Symposium: Cross-Border Healthcare in Europe](#)



### **ExPO-r-Net Biannual Meeting**

*29-30 September 2015, Vienna (AT)*

The next ExPO-r-Net Biannual Meeting will take place from the **early afternoon of Tuesday 29<sup>th</sup> September (from 2pm to 7pm, lunch available from 1pm) to the full day of 30<sup>th</sup> September 2015 (from 8am to 3pm)** at the Children's Cancer Research Institute (CCRI) in Vienna, Austria.

More information will be soon made available by the ExPO-r-Net Project Management Team.



## **2<sup>nd</sup> EU ERN Meeting announced:** **8 - 9 October 2015, Lisbon (PT)**

Following the ERN launch event in June 2014, the European Commission DG Health and Food Safety will hold its **2nd Conference on the European Reference Networks on 8-9 October 2015 in Lisbon, Portugal**. ExPO-r-Net has been invited to present and participation details are being finalised.

This second EU-level conference will look at the implementation aspects including the establishment and evaluation of ERNs. The event will also consider the next steps towards the European Commission call to establish actual European Reference Networks, provisionally scheduled for the end of 2015.

### **More information**

- [2nd Conference on European Reference Networks \(ERNs\)](#)

***Please do not hesitate to widely disseminate to interested colleagues.***

Please do not hesitate to contact [expornet@ccri.at](mailto:expornet@ccri.at) or [office@siope.eu](mailto:office@siope.eu) should you need more information on ExPO-r-Net.



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