



**E-Blast**  
September 2015

## 2<sup>nd</sup> Workshop on Future Priorities

7 August 2015, Vienna (AT)

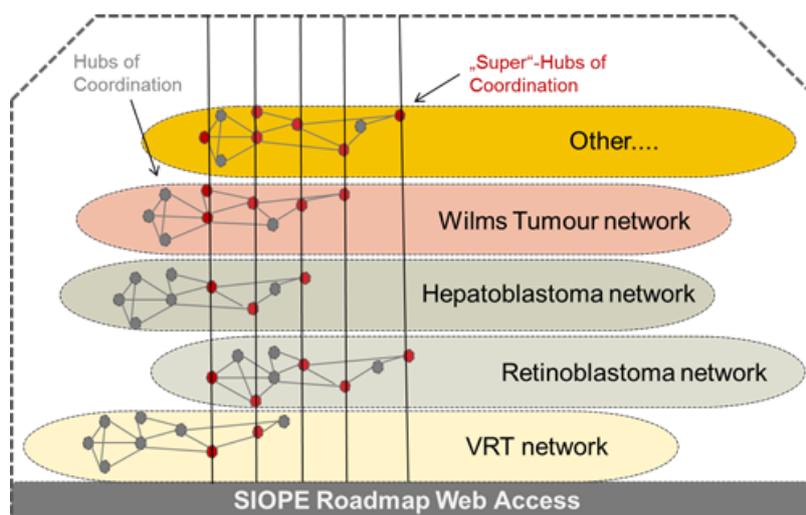
On August 7<sup>th</sup> 2015, several work package leaders and collaborating partners met at the 2<sup>nd</sup> ExPO-r-Net workshop in Vienna, Austria. The aim of the meeting was to take stock of the progress and anticipate readiness to apply for an official European Reference Network (ERN), for which the call is expected in December 2015/January 2016.

The focus of the meeting was on specific priorities as follows.

- ERN roadmap

A roadmap identifying paediatric oncology networks is under preparation. As a start, it includes networks on very rare tumours, retinoblastoma, haepatoblastoma and Wilms tumour.

The workshop began with an update on the progress and challenges of these individual networks during the preparation of the roadmap. Going forward, the goal is to have one ERN with several sub-networks therein (figure).



The ERN roadmap will be instrumental in identifying Hubs of Coordination (HoC) based on advice and support from the project community, including in particular on the prior existence of cross border healthcare settings. As a direct consequence of identifying HoCs in several fields, “Super-Hubs” uniting networks with natural synergies will assert themselves. These

“Super-Hubs” will be particularly large centres with the capacity to engage in multitasking across several fields. The ExPO-r-Net roadmap will formulate the process of defining the ERN, its network components, as well as the qualification of centres.

- Self-assessment questionnaire for Eastern European centres

Another focus of the meeting was the self-assessment questionnaire evaluating the standards of care in Eastern European centres and their potential eligibility to cooperate with the Paediatric Oncology (PO)-ERN. A first pilot with seven (7) centres was done in July 2015 to check if the questionnaire is fit for purpose, and the results were presented at the meeting. An additional questionnaire for parent organisations participating in site visits will support the evaluation.

- Survivorship Passport

Translations of the Survivorship Passport as well as its guidelines and a coding manual are ongoing. It will be important to pursue the translations, provide a homogenous layout and define IT solutions for data storage and transfer.

A presentation of the Survivorship Passport website and online app will be performed during the European Cancer Congress in Vienna during the following timeslots:

- Sunday 27<sup>th</sup> September 2015, from 12h00 to 16h00 – SIOPE Lounge
- Monday 28<sup>th</sup> September 2015, from 11h00 to 12h00 – SIOPE Lounge

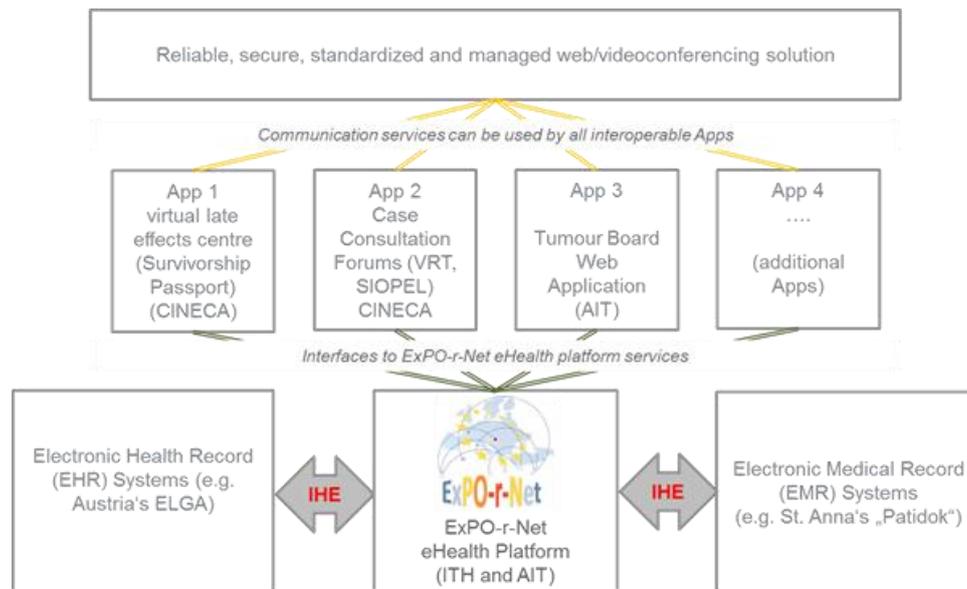
- Questionnaire on virtual tumour boards (VTBs) in Europe

The questionnaire was distributed in Europe via the NaPHOS and ten (10) sets of answers have already been received. Detailed information on the results will be given at the 3rd biannual ExPO-r-Net ExeCom meeting. Other issues of VTBs were also addressed including liability, informed consent, and VTB request- and answer-forms. Another important aspect of VTBs is the need for financial compensation.

- ExPO-r-Net IT-interoperability architecture

A demonstration of an interoperable IT-infrastructure for the ERN was given at the meeting. By implementing standardized cross-enterprise tumour board workflow definitions from IHE (Integrating the Healthcare Enterprise), the presented infrastructure is fully compatible with standard eHealth-applications and should be able to implement any user-adapted application, e.g. the CINECA case consultation forum (figure). The idea is to prepare the prototype of an ExPO-r-Net IT infrastructure which can be adopted by any future ERN. The same infrastructure can be adopted by any future ERN.

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## **European Reference Networks workshop for Rare Diseases**

2<sup>nd</sup> July 2015, Brussels (BE)

The aim of the workshop was to support rare disease stakeholders in preparation for the first Call to establish ERNs, which is expected in December 2015/January 2016. The event gathered participants with experience of coordinating networks dedicated to specific disease areas requiring highly specialised expertise to deliver optimum clinical care to patients across Europe. EU officials were also present to answer questions and provide updates. By addressing ERN implementation aspects, the workshop provided a possible taste of the second official ERN Conference and associated workshops taking place in Lisbon this October (8-9th).

Importantly, EU officials at the workshop announced a contract with Adobe Connect, which will be used as a communication tool for ERNs. For further development of ERN IT structures, like virtual tumour boards, Ruth Ladenstein offered close cooperation with ExPO-r-Net to make sure that newly established IT-solutions are suitable for the paediatric oncology field.

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

1<sup>st</sup> July 2015, Brussels (BE)

This meeting gathered national authorities, researchers and other stakeholders working on care organisation and delivery. It focused on aspects of cross-border healthcare such as reimbursement and patient rights.

The presented findings highlighted that, even though the impact of cross-border healthcare on total health expenditure is relatively low, there are persisting issues that require attention. Thus, a policy framework is needed to address the structural imbalances in EU health care systems, promoting equal access to quality care for all. This has to include a right to reimbursement for health care treatment abroad (Regulation (EC) No 883/2004 & Directive 2011/24/EU) and focus on the transfer of expertise and pooling of resources to support

greater efficiency through cross-border cooperation.

The event provided the opportunity to showcase the ExPO-r-Net project in a presentation of its forward-looking goals and activities to reduce inequalities in survival by improving the quality of healthcare across Europe, with particular focus on countries with low (annual) health care expenditures.

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## **European Retinoblastoma Group Meeting**

15<sup>th</sup> June 2015, Paris (FR)

During this meeting, the retinoblastoma group unanimously confirmed their close cooperation with ExPO-r-Net in the development of the ERN roadmap. The communication tool for the retinoblastoma group will be an adapted CINECA case consultation forum as already used by the liver group SIOPEL.

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

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

29-30 September 2015, Vienna (AT)

- **2<sup>nd</sup> EU ERN Meeting**

8 - 9 October 2015, Lisbon (PT)

[Event website](#)

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***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) for more information.



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Co-funded by  
the Health Programme  
of the European Union

*This publication arises from the project ExPO-r-Net which has received funding from the European Union in the framework of the Health Programme (2008-2013), grant agreement nr. 2013 12 07. The content represents the views of the author and is his sole responsibility and it can in no way be taken to reflect the views of European Union bodies. The European Commission and/or Chafea do not accept responsibility for any use that may be made of the information it contains.*