

## Newsletter 3 April 2014

### Workshop on "The Policy and Implementation Context for Cross-Border Patient Registries" Brussels, 27 March 2014



The PARENT JA held a two-day event in Brussels on March 27<sup>th</sup>, with the participation of members from the Associated Project Group, together with Associated and Collaborating Partners, in addition to European Commission representatives (DG Sanco / EuropeanReferenceNetworks, European Social Insurers Platform, EUnetHTA Joint Action2, Health Information and Quality Authority of Ireland).

The event began with a Workshop aimed at gathering input on the "Policy and Implementation Context for Cross-Border Patient Registries", and was followed by a meeting of the PARENT Executive Committee. The participants in the workshop presented their experiences in developing sustainable solutions implemented in their different European countries, and important discussions arose about the interim findings of the WP6 on policy analysis, European and international registries strategies and governance, as well as potential models for sustainable cross-border registry platforms.

Warm thanks to all the participants for their active contribution!

[\(Download Materials\)](#)

#### Highlights and conclusions from the meeting

The feedback drawn from this workshop on the "Policy and Implementation Context for Cross-Border Patient Registries" will be useful for further work, as regards a forthcoming round of Stakeholders' discussions that will culminate at **a follow up PARENT meeting that will be held in June 12-13<sup>th</sup>, in Helsinki, Finland.**

The main highlights and conclusions pinpointed in the meeting are as follows:

Resources such as the ones developed by PARENT are in high demand, among others by European Reference Networks, insurers' organizations and the EU Member States. Guidance regarding to registries, management of data in general and cross-border data exchange is needed, as well as the development of tools for setting up registries (particularly in support of interoperability and data protection aspects). [Read more...](#)



#### Forthcoming Events


Forthcoming Events	
12-14 May 2014	<a href="#">eHealth Forum 2014, Athens, Greece</a>
31 May - 5 June 2014	<a href="#">ISPOR Annual Congress</a>
31 May - 4 June 2014	<a href="#">51th ERA-EDTA Congress</a>
12-14 June 2014	<a href="#">Workshop on "The Policy and Implementation Context for Cross-Border Patient Registries"</a>
30-31 October 2014	<a href="#">HTA 2.0 Europe Conference</a>

#### Partner Member States

Partner Member States	
Croatia	<a href="#">Croatian Institute of Public Health</a>
Finland	<a href="#">National Institute for Health and Welfare</a>
Hungary	<a href="#">National Institute for Quality- and Organizational Development in Healthcare and Medicines</a>
Italy	<a href="#">Ministry of Health</a>
Slovakia	<a href="#">Národné centrum zdravotníckych informácií</a>

#### Partner Member States

Partner Member States	
Greece	<a href="#">National and Kapodistrian University of Athens (NKUA)</a>
Slovenia	<a href="#">National Institute of Public Health of the Republic of Slovenia (NIJZ) Ministry of Health</a>
Malta	<a href="#">Ministry of Health</a>
Spain	<a href="#">Center for Public Health Research / Public Health Regional Authority</a>
Latvia	<a href="#">The centre of Health Economics</a>



Co-funded by the EC - supporting cross-border availability of European patient registries data

[www.patientregistries.eu](http://www.patientregistries.eu) - [www.parent-ror.eu](http://www.parent-ror.eu)