

Main Results of the PARENT Workshops about Patient Registries Brussels, 2-4 December 2013

In December 2013, a three-day event took place in Brussels with the participation of approximately 50 PARENT partners and external registry experts, coming from different European countries and Malaysia. The event began with a meeting of the PARENT Executive Committee and was followed by two major workshops. The first workshop was led by the PARENT WP4 team and was devoted to the Registry of Registries, while the second one had a double focus: the structure of the PARENT Guidelines and Recommendations and the entire PARENT Framework and its different use cases (including advanced functionalities of the Pilot Registry of Registries).

Effective discussions arose during the workshops, and important feedback, opinions and suggestions were collected on the PARENT activities already performed and those planned for the near future within the Work Packages 4 and 5.

The PARENT team was pleasantly surprised by the level of the workshop participants' interest, commitment and enthusiasm, which provided valuable input to help us achieve improved results on the main PARENT objectives.



WP4, Mapping and Analyzing Existing Registries, Workshop

[Link to material](#)

The main objective of the WP4 workshop was to familiarize registry holders and other participants with the RoR environment, their role in it and its use as a tool for efficient registry governance. More specifically the workshop had the following objectives:

1. Familiarizing the participants with the RoR as a registry information tool (registry 'yellow pages') in which the user can BROWSE, SEARCH and COMPARE various EU Member States registries.
2. Sketching outlines of the PARENT Framework and RoR 2.0.
3. Introducing participants to the design idea behind the RoR 2.0 (the RoR as a paradigm for a stakeholder community networking framework for registry assessment, comparison, standardization, support, collaboration, interoperability and integration) as well as getting feedback on the participants' impressions and understandings of the concept to be taken into account as future reference for the framework development.
4. Outlining the idea of a Registry Assessment Tool on the EU level (as this is one of the top priority functionalities envisioned for the PARENT RoR) that will support registries' comparison, evaluation and standardization.
5. Registry comparison and assessment use cases and criteria review, focusing on collaboration and stakeholder participation.



WP5, Methodological and Governance Guidelines for Member States, Workshop

[Link to material](#)

The WP5 workshop was divided into two parts, and began with introducing the structure of the forthcoming PARENT "toolkit" for patient registries, which will be the Methodological guidelines and recommendations for efficient and rationale governance of cross-border patient registries.

The aim of the first part of the workshop was to collect participants' opinions and comments about the toolkit proposed structure, the scope of the chapters, the contents that will compose the final document, approaches to quality assurance, suggestions on the tools and other remarks.

An important topic of discussion was the choice of the definition of registry, to which the guide will adjust its criteria.

A general agreement was the convenience of not forgetting important points in the guidelines, such as: security, storage, separating sensitive data from other data, policy on access rights and sustainable maintenance.

The second part of the workshop was also important for PARENT Work Package 5 activities. It was devoted to the discussion of a PARENT Framework use case (i.e. building a new registry), which is highly connected with the activity and development of the Methodological guidelines and recommendations for efficient and rationale governance of cross-border patient registries.

Very relevant comments were gathered about the overall process, how to plan a new registry, the content design and data elements of a registry, the registry data model phase, the design of a process model, the data sources for registries, the set-up phase, how to run a registry, collection, linkage, controlling, cleaning, storing, analysing data as well as data dissemination and changing or stopping a registry.



Forthcoming Events

20-21 February 2014	V4 Antilope Summit, Bratislava, Slovakia
27-28 March 2014	SPARENT ExCo and WP6 Seminar, Brussels, Belgium
26-30 April 2014	Satellite workshop and conference, Budapest, Hungary
12-14 May 2014	eHealth Forum 2014, Athens, Greece

Partner Member States	
Croatia	<i>Croatian Institute of Public Health</i>
Finland	<i>National Institute for Health and Welfare</i>
Hungary	<i>National Institute for Quality- and Organizational Development in Healthcare and Medicines</i>
Italy	<i>Ministry of Health</i>
Slovakia	<i>Národné centrum zdravotníckych informácií</i>
Greece	<i>National and Kapodistrian University of Athens (NKUA)</i>

Partner Member States	
Slovenia	<i>National Institute of Public Health of the Republic of Slovenia (NIJZ)</i> <i>Ministry of Health</i>
Malta	<i>Ministry of Health</i>
Spain	<i>Center for Public Health Research / Public Health Regional Authority</i>
Latvia	<i>The Centre of Health Economics</i>

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www.patientregistries.eu - www.parent-ror.eu