

An important achievement: the pilot Registry of registries

To help achieving the project main objective, which is to support the European Member States in developing comparable and coherent patient registries, with the aim to rationalize and harmonize their development and governance, several actions has been accomplished hitherto:

- Literature review
- Best practices research
- A questionnaire to collect data from European patient registries was created and surveyed, available at:
 - <http://dnndefault6.blink.hr/questionnaire>

By the end of May 2013, information from over 120 European registries had been received. After analysing the results of the questionnaire, a pilot Registry of Registries (RoR) v. <http://ror.nahundi.net> was created and it has been launched by the end of October 2013 with the following goals: \B7

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The questionnaire surveyed for the Registry of registries (RoR)

The purpose of [the questionnaire](#) was to gather information on existing patient registries, for the state-of-the-art analysis and input to create the pilot Registry of Registries (RoR).

A very important feedback was received from the respondents, recruited from the list of APGs as well as from the country members, who provided their national contacts for registries.

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What is PARENT?

PARENT Joint Action (www.patientregistries.eu) is a response to poor cross-border availability of health data for public health and research. It is a key joint activity performed by the European Commission together with some Member States aimed at improving cross-border use of data from patient registries.

The PARENT project began on May, 2nd, 2012, will end on April, 30th, 2015 and was created to bring added value by providing the European Member States with recommendations and tools for implementation of interoperable and cross-border enabled patient registries.

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Benefits that PARENT JA will bring to the European community

PARENT will give a response to poor cross-border availability of health data for public health and research, by improving cross-border use of data from patient registries, what will bring important benefits to the European community, such as [EU1](#) :

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Partner Member States	
Croatia	Croatian Institute of Public Health
Finland	National Institute of Health and Welfare
Hungary	National Institute for Quality- and Organizational Development in Healthcare and Medicines
Italy	Ministry of Health
Slovakia	Národné centrum zdravotných informácií
Greece	National and Kapodistrian University of Athens (NKUA)
Latvia	The Centre of Health Economics

Partner Member States	
Slovenia	National Institute of Public Health of the Republic of Slovenia (NIPH)
	National Health Information Center
	National Institute of Public Health of the Republic of Slovenia (NIPH)
	Ministry of Health of the Republic of Slovenia
Malta	Ministry of Health, the Elderly & Community Care
Spain	Center for Public Health Research / Public Health Regional Authority

PARENT JA future activities

3-4 December: PARENT meeting on the Pilot Registry of Registries (RoR) in Brussels

24-25 March: Seminar in Helsinki

28-29 April: Satellite workwhop in Budapest