Newsletter 5
December 2014

Two and a Half Years of PARENT Joint Action

Two and a half years have passed since the PARENT Joint Action began. During this time, we the PARENT JA team have been working hard and continue to give our best, aiming at providing the European community with better tools for the creation and governance of patient registries and expecting our contribution will be significantly useful for cross-border information transfer.

Main results of the Seminar "Cross-border registries at your service" Helsinki, 12 June 2014

The PARENT JA WP6 carried out a seminar in Helsinky with the participation of 32 attendees, among Associated Partners, Collaborating Partners, Stakeholders and some members from the Associated Projects Group, in addition to two European Commission representatives (DG SANCO).

The seminar "Cross-border registries at your service" had the aim of presenting the JA initial proposals on policy-focused actions necessary for advancing cross-border use of registry data. The colloquium was organized in four parts: panel discussion, introduction of policy action proposals, group work discussion and synthesis of feedback. Read more…

(Download Materials)

"Methodological Guidelines and Recommendations for Efficient and Rational Governance of Patient Registries"

This useful guideline, to which a large number of experts have contributed with their work, will be soon available. It consists of approximately 180 pages and is now in the process of being updated, developing some particular chapters, removing overlaps of some others and giving coherence to the whole work. Once finished, it will be submitted to an external editor and we expect that the edited version will be available by late January or early February of 2015.

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"Interviewing for Best Practices in Interoperability"

This document presents the results of a series of structured interviews that were conducted in 19 European countries for the purposes of the Patient registries initiative (PARENT).

Although these interviews were first conceived as a follow-up to the questionnaire that was used as a basis for the inclusion of patient registries into the Registry of Registries, they also provided the PARENT JA with a comprehensive overview of the patient registries existing in the EU. It was soon recognized that a more detailed view into common registry practices and operation would further improve understanding by providing qualitative data together with the previously collected information on patient registry metadata, governance, establishment and operating conditions and data sharing protocols. Read more…

Mrs. Marija Magajne

The new European Coordinator of the PARENT JA, Marija Magajne was introduced during the ExCo meeting held in Brussels in October '14.

Mrs. Magajne substituted our former coordinator Dr. Matic Meglic, whom we congratulate for his new job.

PARENT JA was Presented in the Framework of Other Projects	
EUROCAT Registry Leaders Meeting, Belfast (United Kingdom)	Zurriaga, O.
Spanish Epidemiological Association (SEE) Meeting, Alicante (Spain)	López-Briones, C.
Gastein & EPH conferences and exhibition (Austria)	López-Briones, C.
EUnetHA HTA 2.0 Europe event, 30-31 October, Rome (Italy)	KHaranikas, H., Doupi P.
European critical care (IT, SLO, HR), Trieste (Italy)	Pristas, I.
EXPAND project, WP3 Workshop, Brussels (Belgium)	Doupi P, Pajic, V.
eHealth Networking meeting, Brussels (Belgium)	Zaletel, M.
heath economics seminar "Priorities debate and consequences for helth economic analysis (NMA, NBH, Medical devices industry), Oslo (Norway)	Pajic, V, Doupi, P.
HTA professionals meeting, Amsterdam (Holland)	Pajic, V.

Partner Member States	
Croatia	Croatian Institute of Public Health
Finland	National Institute for Health and Welfare
Hungary	National Institute for Quality- and Organizational Development in Healthcare and Medicines
Italy	Ministry of Health
Slovakia	Národné centrum zdravotníckych informácií

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

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