

Newsletter 7 - July 2015

PARENT – IHE Europe meeting, 9th June 2015, Zagreb

In early June, the PARENT JA organised the seminar “Interoperable Patient Registries in the EU”, in Zagreb, Croatia, gathering a large number of European experts on health registries and informatics. Eight presentations in all were conducted during the morning and afternoon sessions, beginning with four presentations by the PARENT JA Work Package (WP) leaders on their respective areas.

Session 1



After the introductory welcome from the Croatian Ministry of Health and Croatian Institute of Public Health high level representatives, the PARENT JA coordinator, Mrs. Marija Magajne, introduced the goals and milestones that the PARENT teams have achieved so far. Then Ivan Pristaš (CIPH, WP4 Leader) presented the findings of previous in-depth analyses on patient registries, the new PARENT Framework, the second version of the Registry of Registries (RoR-v2), and the assessment tool developed by the WP4 team, which is still being tested. This tool should be a valuable one in current and future efforts for improving visibility and interoperability of individual patient registries, as well as for giving better insights into the patient registry landscape in the EU area.



The third presentation was held by Metka Zaletel (NIPH, WP5 Leader), who explained the purpose and envisioned role of the PARENT Methodological guidelines, which will soon be available online in several forms (including a Wiki page).

The final PARENT JA related presentation was held by Persephone Doupi (THL, WP6 Leader), and dealt with policy issues, legal and regulatory requirements, as well as collaboration opportunities concerning the interoperable use of patient registries in the regional, national and international contexts.

Session 2

The second half of the seminar focused mainly on the currently employed technical and semantic standards initiatives, experience and efforts made to improve registry semantic interoperability.



Charles Parisot and Alexander Berler, representing IHE-Europe, gave an extensive overview of the role of IHE profiles in creating dynamic and applicable templates for assuring registry semantic and technical interoperability, regardless of the individual technical challenges related to a registry's specific national and thematic context. Following this, Vedran Boškic presented IHE-Adria, the newly formed regional affiliate of the aforementioned IHE-Europe organization.

Igor Ljubli, representing the Croatian Health Insurance Fund, gave an overview of the Croatian experiences in various projects closely related to PARENT JA, such as epSOS, EXPAND, IN3CA and JASeHN, all of them improving various aspects of e-Health in the EU.

The session concluded with a presentation by Annika Sonne Hansen, from SemInte Denmark, who spoke about the current and possible implementations of SNOMED CT, an international standard in clinical terminology and its use implications and experiences in patient and quality registries' projects in Sweden and Denmark.

[Download materials](#)



Cross-border Patient Registries iNiTiative PARENT Joint Action

Final Event

Date: 22nd and 23rd October 2015

Location: Valencia, Spain



Overview of the event agenda

Our final and most important happening is planned as a two day event that, in addition to the presentation of the final PARENT deliverables, will cover important topics related to the project, such as the role of patient registries in public health policy planning, their applications in medicinal products and medical devices lifecycles, issues in improving patient registry interoperability and secondary use of data, and proposals for sustainable patient registry cross-border collaboration. Presentations and discussion panels will count on eminent experts and representatives of various European institutions.

Other forthcoming events

"PARENT Joint Action: tools and actions to promote EU-wide utilization of patient registries"

PARENT JA Workshop in the 8th European Public Health Conference 14-17 October 2015, Milan, Italy

PARENT JA Dissemination & Collaboration activities

MIE2015 Workshop (short text provided)

Information Paper for EC RD Expert Group (short text & .pdf for linking provided)

Partner Member States

[National Institute of Public Health of the Republic of](#)

Croatia	<u>Croatian Institute of Public Health</u>	Slovenia	<u>Slovenia (NIJZ) Ministry of Health</u>
Finland	<u>National Institute for Health and Welfare</u>	Malta	<u>Ministry of Health</u>
Hungary	<u>National Institute for Quality- and Organizational Development in Healthcare and Medicines</u>	Spain	<u>Center for Public Health Research / Public Health Regional Authority</u>
Italy	<u>Ministry of Health</u>	Portugal	<u>Direcção-Geral da Saúde</u>
Slovakia	<u>Národné centrum zdravotníckych informácií</u>	Greece	<u>National and Kapodistrian University of Athens (NKUA)</u>

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