EU Patient Registries as eHealth assets: addressing interoperability on all levels

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Abstract The lifecycle of medical data and information spans primary data sources to long-term repositories such as patient registries. The latter are yet to take full benefit of the progress in eHealth, facing considerable interoperability challenges that are even more crucial in a cross-border environment. The EU-funded Joint Action PARENT (Cross-border patient registries initiative) has produced in a period of three years a comprehensive analysis and set of tools to support EU-patient registries interoperability on all levels and complement the advancements achieved in the area of EHRs. Key results and deliverables of the Joint Action will be presented for discussion and feedback from workshop participants.

Keywords. medical records, registries, eHealth interoperability standards, public health, health information exchange.

Introduction of the topic

Directive 2011/24/EU on the application of patients’ rights in cross-border healthcare (1) or, for short, cross-border healthcare Directive has set the target of developing guidelines ensuring “effective methods for enabling the use of medical information for public health and research”. Patient registries are repositories of medical information which, due to their sheer number and large volume, present significant potential for research, innovation and public health improvements in the EU. Interoperability and cross-border cooperation between EU patient registries has been identified as a central issue due to their diversity, Member States’ specific needs and differences in legislation, complexity of the health domain, and lacking level of standardization across registries.

Concerted and sustained research, policy and deployment actions have thus far successfully promoted the interoperability of data generated during the provision of healthcare services. Ensuring the interoperability of existing data collections in the context of their secondary use is the essential next step, closing the circle in the added value generated by eHealth tools and applications (2).

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1. Aim of the discussion

The EU-funded Joint Action PARENT (Cross-border patient registries initiative) (3, 4) has specifically focused at improving the quality, reliability and cross-border usability of EU-patient registry data. By addressing all levels of interoperability (political, legal, organizational, semantic and technical) through a variety of activities, the partners and collaborators of the Joint Action have strived to pave the way for eHealth-enabled patient registries.

Bringing forward the findings and products of this work to the medical informatics community has a two-fold aim:

a. to provide valuable feedback and insight for future work in the area of patient registries
b. to increase awareness and activate dialogue on the necessity of working along the whole continuum of health data: from the patient and point of care, to public health and other patient data repositories.

2. Contribution from each speaker

Persephone Doupi will give a short introduction of PARENT Joint Action and discuss EU policy developments in the context of the cross-border healthcare Directive implementation opening the path and increasing the demand for patient registry data use.

Ivan Pristaš will provide a comprehensive overview of the patient registries currently existing in the EU and their common practices and operations based on the results of questionnaires and interviews undertaken by WP4 of PARENT Joint Action.

Haralampos Karanikas will outline the current strategy landscape regarding the utilization of health data resources in EU Member States.

Vanja Pajić will introduce the PARENT Joint Action Framework supporting the assets developed by PARENT to promote IT-enabled, higher quality patient registries, including the Registry of Registries (www.parentror.eu).

Metka Zal tel will present an overview of the “Methodological Guidelines and Recommendations for Efficient and Rational Governance of Patient Registries” developed by PARENT Joint Action and proposed for endorsement by the eHealth Network.

3. Expected results

By exploring all facets of interoperability in the context of patient registries and secondary use of health data, the workshop aims to address topics of interest to a variable audience including: researchers, system developers, healthcare service provider and patient representatives, regional, national and EU policy makers.

Participants, through their active engagement in the workshop, will gain:

• Understanding of the EU legal, regulatory and policy framework surrounding the secondary use of registry data;
• Knowledge of EU Member State strategies and approaches to health data and pertinent infrastructures;
• Familiarity with the features and purpose of use of the assets developed by PARENT Joint Action;
• Awareness and understanding of the shared interoperability challenges and opportunities between EHRs and patient registries’ initiatives.

References


