

## PARENT Joint Action: Increasing the Added Value of Patient Registries in a Cross-Border Setting

Matic Meglič<sup>a</sup>, Persephone Doupi<sup>b</sup>, Ivan Pristaš<sup>c</sup>, Yannis Skalkidis<sup>d</sup>, Metka Zaletel<sup>a</sup>, Andrej Orel<sup>e</sup>

<sup>a</sup> National Institute of Public Health, Ljubljana, Slovenia

<sup>b</sup> National Institute for Health and Welfare, Helsinki, Finland

<sup>c</sup> Croatian Institute of Public Health, Zagreb, Croatia

<sup>d</sup> National and Kapodistrian University, Athens, Greece

<sup>e</sup> Andrej Orel, Ljubljana, Slovenia

### Abstract

*Patient registries are poorly interoperable and as a result data exchange or aggregation across organizations, regions and countries for secondary purposes (i.e. research and public health) is difficult to perform. PARENT Joint Action aims to provide EU Member States with a set of guidelines, recommendations and tools to support setting-up, management and governance of interoperable patient registries, thus helping EU Member States to drive down cost and interoperability risks of patient registries as well as improving secondary use of registry data in a cross-border setting.*

**Keywords:** Knowledge Management, Health Information Management, Semantics, Patient Registries, Cross-border

### Introduction

The directive on the application of patients' rights in cross-border healthcare promotes collaboration between member states (countries) and exchange of information to enable continuity of care and patient safety across borders. This goal can only be achieved by standardization of methods and tools used in different countries.

There are unmet needs in the field of patient data collection and data dissemination. Policy makers are seeking for new health indicators and improved analytical health data that would provide input for health technology assessment and evidence based policy creation. Now, there are several different patient registries held in Member States at national and regional level, and more are being planned and established. Due to insufficient harmonization, the richness of available data does not lead into full utilization of these data for supporting EU common goals in providing better healthcare for the citizens. Interoperability of those registries would – while taking into account personal data protection - enable sharing important data and existing knowledge between countries. This would result in higher quality of care and patient safety.

### Methods

The overall objective of the PARENT Joint Action is to support EU member states (countries) in developing comparable and interoperable patient registries with the aim to rationalise and harmonise their development and governance. The Joint Action objective is also to support EU member states in provid-

ing objective, reliable, timely, transparent, comparable and transferable information on the relative efficacy. This information should be effectively exchanged among the relevant national authorities.

The so-called two-fold actions will serve to achieve the general objective on a long term. In the beginning a comprehensive set of recommendations and specific guidelines to support EU member states in methodology, development, implementation, governance and improvements of national and local patient registries will be developed. Following that, activity plans, business model and policy proposals to ensure cross-border collaboration and proposals for future activities to support cross-border health care directive will be drawn.

### Results

The results of the project are distributed across particular work packages. Every project of this kind shares coordination and project management endeavours as well as dissemination with coordination and liaison to concurrent EU projects such as EAR EFORT, EUCERD Joint Action, EUnetHTA, eHGI, ePSOS, SemanticHealthNet, EHR4CR and others.

Work on evaluation of the joint action is focused on the assessment of the project's performance against the objectives defined in the overall project PARENT and specified according to the objectives and deliverables of the particular core thematic related to the main objective of the PARENT joint action project.

One of the most important project objectives is to assess the current situation of health registries (electronic as well as traditional) and analyse their impact on national healthcare systems including reviewing the existing literature from the field of interest and identifying country level registries best practices and applied research methodology.

Once the data about existing registries are collected and a basic analysis is performed general guidelines for joint registries are to be chartered. These activities include development and upgrading of the existing knowledge and practice according to mapping and analysis of existing registries together with development of guidelines for setting up registries.

The Directive 2011/24/EU on the application of patients' rights in cross-border healthcare represents and makes the foundation for actual implementation of joint health records and the PARENT Joint action.