



The RARE-Bestpractices project: a platform for sharing best practices for the management of rare diseases

RARE-Bestpractices is a four-year project (January 2013-December 2016) funded by the Seventh Framework Programme of the European Union (FP7/2007-2013) under Grant Agreement n° 305690.

The National Centre for Rare Diseases (CNMR) of the Istituto Superiore di Sanità acts as a coordinator, bringing together a team of high level of experts in the area of clinical practices guideline, systematic review, health technology assessment, health policy, rare disease epidemiology and public health. The project includes 14 partners across Europe: Jamarau (UK), Karolinska Institutet (SE), Healthcare Improvement Scotland (UK), London School of Economics and Political Science (UK), Consiglio Nazionale delle Ricerche (IT), EURORDIS European Organisation for Rare Diseases (FR), Associazione per la Ricerca sull'Efficacia dell'Assistenza Sanitaria Centro Cochrane Italiano (IT), Universitaetsklinikum Freiburg (DE), Bulgarian Association for Promotion of Education and Science (BG), Fundación Canaria de Investigación y Salud (ES), Universiteit Maastricht (NL), The European Academy of Paediatrics (BE), University of Newcastle Upon Tyne (UK), Instituto de Salud Carlos III (ES).

The project aims to improve the clinical management of rare diseases by undertaking the following activities which carry significant implications for the timely translation of research results into practices. These are:

- 1) create standards and transparent reliable procedures for the development and evaluation of clinical practice guidelines for rare diseases
- 2) identification of available notations for graphic representation of processes within CPG to improve user understandability and implementation.
- 3) build a comprehensive public database of high quality clinical practice guidelines, ranging from diagnostic tests and treatments to organization of care, to help professionals, patients, policy makers with the best and most up to date information;
- 4) produce mechanisms to identify and prioritize rare diseases clinical research needs to optimize as well as redefine the clinical research agenda taking into consideration both patients' and clinicians' needs and interests.
- 5) define to what extent conclusions from cost-effectiveness analyses for pharmaceuticals are accounted for and implemented in best-practice guidelines across a range of countries.

Core activities will be complemented by training events organized to support stakeholders in developing and evaluating guidelines for rare diseases.

To help shape its strategy and support its activities RARE-Bestpractices has set up an Advisory Board of international experts representing European and extra-European organizations/agencies all with strong commitment in basic, clinical research on rare diseases such as National Institutes of Health - Office of Rare Diseases Research (NIH-ORDR) and public health. The Advisory Board is also composed of experts representing global networks e.g. the Guidelines International Network (G-I-N), which supports evidence-based health care, and Pan America Health Organization/World Health Organization (PAHO/WHO) a health agency working to improve health and living standards of the countries of the Americas.

More information on RARE-Bestpractices project is available at www.rarebestpractices.eu