

## PROMOTING IMPLEMENTATION OF RECOMMENDATIONS ON POLICY, INFORMATION AND DATA FOR RARE DISEASES

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**RD-ACTION works towards an integrated, European approach  
to the challenges faced by the rare disease community.**

**By supporting the development of European and national policies,  
RD-ACTION brings together efforts to improve knowledge on rare diseases  
and orphan drugs, and support the rare disease community.**

A 3-year  
European Joint Action  
(June 2015 – May 2018)

34 beneficiaries  
30 collaborating partners  
40 countries

**rd-action.eu**

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the Health Programme  
of the European Union

## 3 OBJECTIVES

1

Support the development and sustainability of the Orphanet database, the biggest global repository of information on rare diseases.

2

Contribute to solutions to ensure the appropriate codification of rare diseases in health information systems across Europe.

3

Work on priority issues for people living with rare diseases by implementing the actions identified in the *EU Council Recommendation on an action in the field of rare diseases*.

Ensure the sustainability of these actions and support the work of the European Commission Expert Group on Rare Diseases.

## Coordination 1

Facilitate and ensure the efficient implementation of actions foreseen, based on effective cross-talk between work packages.

RD-Action is coordinated by the Orphanet team at the Inserm, France.

## Evaluation 3

Evaluate the actions and activities of the Joint Action and set up a sustainability plan for databasing activities in this area after the end of the project.

## Steering, maintaining and promoting the adoption of Orphacodes 5

Develop a toolset to assist European countries in implementing the specific coding system for rare diseases, Orphacodes, in a standardised and interoperable way.

This should improve the codification of rare diseases and hence their traceability in health care systems.

# 6 ACTIVITIES

WP1  
Coordination

WP2  
Communication

WP3  
Evaluation

WP4  
Orphanet

WP5  
Orphacodes

WP6  
Policy Development

**i** European projects can be divided into “work packages” (WP).

A work package can be thought of as a sub-project, which, when combined with other work packages, form the completed project<sup>1</sup>.

**RD-ACTION is composed of 6 WP.**

<sup>1</sup>[http://ec.europa.eu/chafea/management/Fact\\_sheet\\_2010\\_03.html](http://ec.europa.eu/chafea/management/Fact_sheet_2010_03.html)

## 2 Communication

Disseminate disease-related information and improve the two-way information flow between national and European levels.

Ensure the appropriation of the EU-level regulatory framework and policy at national level.

Facilitate the integration of EU developments in national systems through European national workshops.

Promote sustainable health systems for rare diseases.

## 4 Orphanet, the European database for Rare Diseases (RD)

Produce a sustainable European database of information and data on rare diseases, Orphanet, including the nomenclature and classification of RD (interoperable with other resources), an encyclopaedia of RD and a directory of expert resources in 40 countries.

Engage the rare disease community in contributing to Orphanet content through an open, web-based platform.

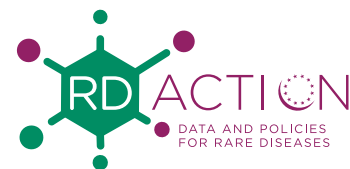
Produce compiled data needed to support rare diseases codification and policies.

## 6 Policy Development for Rare Diseases and Integration

Support the development of new policy guidance in the field of rare diseases, on a broad range of topics, for delivery to the Commission Expert Group on Rare Diseases, the Member States, and all relevant stakeholders.

Develop the ‘State of the Art of Rare Disease Activities in Europe’ into a dynamic, web-based resource, to inform rare disease stakeholders.














# PARTNERS
















## DESIGNATED PARTNERS

 Medical University of Vienna (MUV)	 Medizinische Hochschule Hannover (MHH) Deutsches Institut für Medizinische Dokumentation und Information (DIMDI)	 Instytut Pomnik - Centrum Zdrowia Dziecka (IPCZD)
 Federal Public Service Health (FPS Health) Scientific Institute for Public Health (WIV-ISP)	 Országos Tisztifőorvosi Hivatal Szemmelweis Egyetem (SE)	 Directorate-General of Health (DGS)
 Bulgarian Association for Promotion of Education and Science/Rare Diseases Institute	 Health Service Executive (HSE)	 University of Medicine and Pharmacy "G.R.T.Popa" Iasi Orphanet Center
 Croatian Alliance for Rare Diseases	 Ospedale Pediatrico Bambino Gesù (OPBG) Istituto Superiore di Sanita (ISS-CNMR) Regione del Veneto	 Faculty of Medicine in Bratislava (UniBA FoB)
 Coordination Center for Rare Diseases in University Hospital in Motol (NKCVO)	 Center For Disease Prevention and control of Latvia	 University Medical Centre Ljubljana (UKC Ljubljana)
 University of Tartu (UT)	 Vilnius University Hospital Santariskiu Klinikos (VULSK)	 Centro de Investigación Biomédica en red (CIBER)
 Rinnekoti Foundation Norio Centre (Rinnekoti)	 Leids Universitair Medisch Centrum (LUMC)	 Karolinska University Hospital (Karolinska)
 Institut National de la Santé et de la Recherche Médicale (INSERM) Direction Générale de la Santé, Ministère des Affaires Sociales, de la Santé et des Droits des Femmes (DGS) Assistance Publique - Hôpitaux de Paris (APHP)	 The Norwegian Directorate of health (HDIR) Norwegian National Advisory Unit For Rare Diseases (NKSD)	 University of Newcastle (UNEW) UK Department of Health (UK PHE)
		 European Organisation for Rare Diseases (EURORDIS)

## DESIGNATED COLLABORATING PARTNERS

 Austrian Health Institute (GÖG )	 Fehlbildungsmonitoring Sachsen-Anhalt an der Medizinischen Fakultät der Otto-von Guericke-Universität Magdeburg	 Directorate of Health (Ministry of Health)
 Ministry of Health Medical University Sofia	 Institute for Research of Regulatory policies (INERP)	 Ministry for Energy and Health (MEH)
 Croatian Institute of Public Health (HZJZ)	 Pécsi Tudományegyetem (PTE)	 Poznan University of Medical Sciences
 Ministry of Health (MoH CY)	 Landspítali University Hospital Ragnar	 Instituto de Salud Carlos III Fundación para la Investigación Sanitaria y Biomédica de la Comunidad Valenciana
 Robert Koch Institut (RKI) Universitätsklinikum Frankfurt (UKF)		

## COLLABORATING PARTNERS

 Ministry of Health	 University Hospital of Aarhus	 Mc Gill University
 Center of medical genetics and primary health	 Foundation for Genetic and Rare Diseases (GeRad)	 Belgrade University
 Office Population Health Genomics, Department of Health Government of WA Garvan Institute of Medical Research	 Institute for Rare Diseases, Institute of Medical Genetics The Chaim Sheba Medical center	 CMU Institute of Medical Genetic
 Institute of Health Information and Statistics of the Czech Republic	 Institut National d'Hygiène, Department of Medical Genetics	 Service de Cytogénétique et de Biologie de la Reproduction, CHU Farhat HACHED, Sousse
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