RD ACTION

DATA AND POLICIES FOR RARE DISEASES

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

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

This leaflet is part of the project/joint action '677024 / RD-ACTION' which has received funding from the European Union's Health Programme (2014-2020).

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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.

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6 ACTIVITIES

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[1].

RD-ACTION is composed of 6 WP.

[1] http://ec.europa.eu/chafea/management/Fact_sheet_2010_03.html

WP1 Coordination

WP2 Communication

WP3 Evaluation

WP4 Orphanet

WP5 Orphacodes

WP6 Policy Development

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

DESIGNATED COLLABORATING PARTNERS

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

COLLABORATING PARTNERS

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

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