EUROPLAN
European Project for Rare Diseases National Plans Development
Coordinated by the Italian National Centre for Rare Diseases
Italian National Institute of Health
2012-2015

EUCERD Joint Action
Co-funded by the European Commission
Executive Agency for Health and Consumers

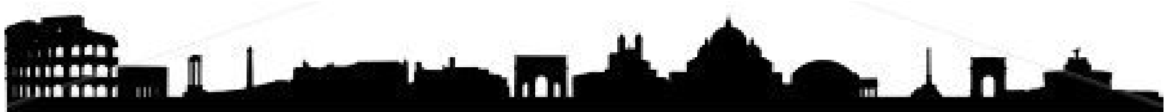
EUROPEAN PROJECT FOR RARE DISEASES NATIONAL PLANS DEVELOPMENT: from 2008 up to now

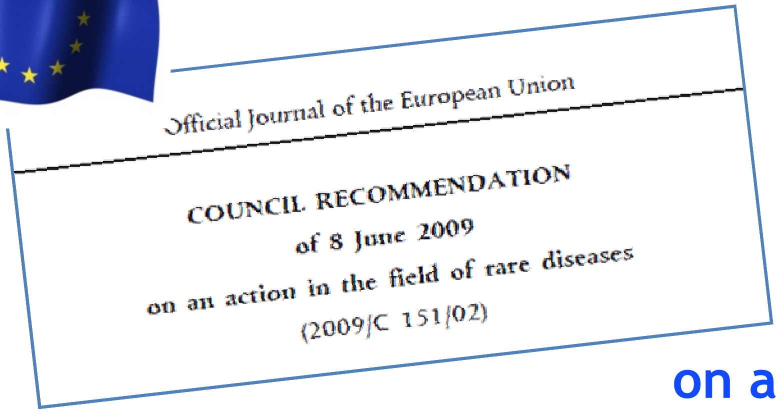
Dr. Domenica Taruscio

EUROPLAN Leader,
Italian National Institute of Health, Rome
Italy

INCEPTION WORKSHOP ON NATIONAL PLANNING FOR RARE DISEASES

10-11 September 2012, Rome, Italy





Official Journal of the European Union

COUNCIL RECOMMENDATION
of 8 June 2009
on an action in the field of rare diseases
(2009/C 151/02)

EUROPLAN originates from..

Council Recommendation of June 2009 on an action in the field of rare diseases (2009/C 151/02)

… that recommends that member States:

a) **ELABORATE AND ADOPT A PLAN OR STRATEGY AS SOON AS POSSIBLE**, preferably by the end of 2013 at the latest, aimed at guiding and structuring all relevant actions in the field of rare diseases within the framework of their health and social systems

a) **TAKE ACTION TO INTEGRATE CURRENT AND FUTURE INITIATIVES** at local, regional and national levels into their plans or strategies for a comprehensive approach

a) **DEFINE A LIMITED NUMBER OF PRIORITY ACTIONS** within their plans or strategy, with objectivs and follow-up mechanisms

a) **TAKE NOTE OF THE DEVELOPMENT OF GUIDELINES AND RECOMMENDATIONS FOR THE ELABORATION OF NATIONAL ACTION FOR RARE DISEASES** by relevant authorities at national level in the framework of the ongoing european project for rare diseases national plans development (**EUROPLAN**).

EUROPLAN 2008-2011

EUROPLAN was a three-year project of the Programme of Community action in the field of Public Health (2003 - 2008). It involved 57 Associated & Collaborating Partners (clinicians, scientist, health authorities, patients' Groups) from 34 Countries and EURORDIS. EUROPLAN main goal was to provide National Health Authorities with a supporting tools for the development and implementation of National Plans and Strategies for rare diseases following the European Council Recommendation on an action in the field of RDs (2009/C 151/02).

Specific objectives of EUROPLAN 2008 - 2011

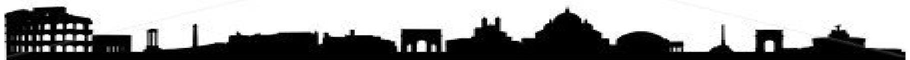
- **Elaborate recommendations** as "tools" to facilitate the development of a national plan or strategy for rare diseases
- **Elaborate indicators** for monitoring national plans/strategies
- **Discuss the recommendations** with stakeholders
- **Disseminate the recommendations**

Results of EUROPLAN 2008 – 2011

- **Report on EU Members States initiatives,** with previous and current experiences on rare diseases (Joint document RTFD/EUCERD-EUROPLAN)
- **Guidance Document containing the EUROPLAN recommendations** for the designing of the National Plans or Strategies for rare diseases
- **Report on indicators for monitoring the implementation and evaluating** the impact of National Plan or Strategy for rare diseases
- **Report on key results of the 15 EUROPLAN National Conferences.**

EUROPLAN 2008-2011

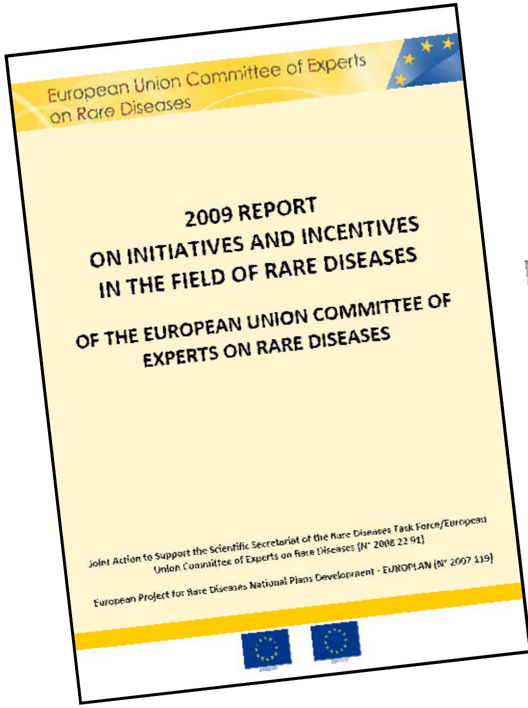
WP	STRUCTURE of the project
WP 1	Coordination of the project. Leader*: Domenica Taruscio, CNMR – ISS (Italy)*
WP 2	Dissemination of the results. Leader*: CNMR – ISS (Italy)*
WP 3	Evaluation of the project. Leader*: Edmund Jessop (UK)*
WP 4	Describing EU Member States initiatives on RD. Leader*: CNMR – ISS (Italy)*
WP 5	Selecting indicators to evaluate the achievements of RD initiatives. Leader*:* *Manuel Posada de la Paz (Spain)*
WP 6	Evaluating selected activities and identifying best practices Leader. Leader*: Jan-Inge Henter (Sweeden)*
WP 7	Preparing recommendations for RD national plan development. Leader*:* *Jolanda Huizer (The Netherlands)*
WP 8	Promoting the recommendations for RD national plan and presenting the Commission Communications on RD. Leader*: Yann Le Cam (EURORDIS)*



EUROPLAN 2008-2011

Results

JOINT REPORT



European Union Committee of Experts on Rare Diseases

2009 REPORT
ON INITIATIVES AND INCENTIVES
IN THE FIELD OF RARE DISEASES

OF THE EUROPEAN UNION COMMITTEE OF
EXPERTS ON RARE DISEASES

Joint Action to Support the Scientific Secretariat of the Rare Diseases Task Force/European Union Committee of Experts on Rare Diseases (N° 2008 22 91)

European Project for Rare Diseases National Plans Development - EUROPLAN (N° 2007 119)

EUROPLAN RECOMMENDATIONS

EUROPLAN
EUROPEAN PROJECT FOR RARE DISEASES NATIONAL PLANS DEVELOPMENT

FUNDED:	EUROPEAN COMMISSION PUBLIC HEALTH PROGRAM 2003-08
PRIORITY AREA:	1. HEALTH INFORMATION (HI 2007).
ACTION:	1.4 DEVELOPING STRATEGIES FOR INFORMATION EXCHANGE AND RESPONDING TO NON-COMMUNICABLE HEALTH THREATS
CONTRACT NUMBER:	101120 - 2007118
PROJECT COORDINATOR:	DOMENICA TARUSCIO (ISS)
MAIN PARTNER:	ISTITUTO SUPERIORE DI SANITÀ (ITALY)
ASSOCIATED PARTNERS:	10
PROJECT PERIOD:	1 APRIL 2008 – 31 MARCH 2011
REFERRING PERIOD:	1 JUNE 2010 – 31 DECEMBER 2010

RECOMMENDATIONS
FOR THE DEVELOPMENT OF NATIONAL PLANS FOR
RARE DISEASES
GUIDANCE DOCUMENT
Guidance_Doc_EUROPLAN_20100601

DOCUMENT AUTHORS	ALL EUROPLAN PARTNERS
REVISION DATE	8 JULY 2010
DIFFUSION LEVEL	PUBLIC DOCUMENT
INTENDED TARGET	PARTICIPANTS OF THE 16 NATIONAL CONFERENCES
KEY WORDS	RECOMMENDATIONS, NATIONAL PLANS, RARE DISEASES

EUROPLAN INDICATORS

EUROPLAN Draft version. Selecting indicators to evaluate the achievements of RD initiatives 1

European Project for Rare Diseases National Plans Development (EUROPLAN)

Selecting indicators to evaluate the achievements of RD initiatives

By WP5: Manuel Posada, Manuel Hens, Maria José Carroquino and EUROPLAN Working Group on Indicators

Rare Diseases Research Institute
Instituto de Salud Carlos III

Madrid March, 29th, 2010

SUMMARY REPORT

of the 15 National Conferences organized by EURORDIS

KEY RESULTS of the 15 EUROPLAN National Conferences

February 25 2011

Preliminary Draft for the EUROPLAN Final Conference (Rome, 25 February 2011)

- **EUROPLAN WP8**
- **Title:** "Promoting the recommendations for rare diseases national plans and presenting the Commission Communications on Rare Diseases".
- **Leader:** EURORDIS

National conferences

National conferences organized by EURORDIS

EURORDIS
Rare Diseases Europe

	Country	City	Date in 2010/11	Organiser
1	BULGARIA	Sofia	28-29-30 May	NAPRD National of People with RD
2	ROMANIA	Bucarest	18-19 June	RONARD Romanian National for RD
3	CROATIA	Dubrovnik	17-18-19 September	Hrvatska udruga bolesnikas rijetkim bolestima
4	FRANCE	Paris	30 September	Alliance Maladies Rares
5	GERMANY	Berlin	13-14 October	ACHSE Allianz Chronischer Seltener Erkrankungen
6	HUNGARY	Budapest	15-16 October	HUFERDIS Rare Disease Hungary
7	POLAND	Krakow	22 October	Polish Cystic Fibrosis Foundation MATIO
8	SPAIN	Burgos	5-6 November	FEDER Federación Española de Enfermedades Raras
9	SWEDEN	Stockholm	11 November	Sällsynta diagnoser
10	ITALY	Florence	11-12-13 November	UNIAMO Federazione Italiana Malattie Rare
11	UNITED KINGDOM	Manchester	16 November	Genetic Interrest Group - Rare DiseaseUK
12	The NETHERLANDS	The Hague	19 November	VSOP Dutch Genetic Alliance
13	DENMARK	Copenhagen	19 November	Rare Disorders Denmark
14	GREECE	Athens	26-27 November	PESPA Greek for RD
15	IRELAND	Dublin	20 January 2011	GRDO Genetic and Rare Disorders Organisation

APPROACH AND SYNERGIES

Approach

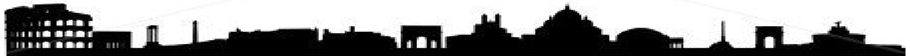
a) **TOP-DOWN:** EU Communication, Council Recommendations

b) **BOTTOM-UP:** Experts (including all stakeholders); EURORDIS – National Conferences

c) **VERY INCLUSIVE:** wide possibility to join activities of the project

Active involvement of all stakeholders (experts, health authorities, Patients' Associations, EUCERD, etc)

Consensus process among experts and stakeholders, through workhshops and National conferences



EUCERD
Joint Action

Co-funded by the European Commission

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Workpackage 4

Support for the implementation of plans or strategies at MS level (continuation of EUROPLAN)”

EUROPLAN

European Project for Rare Diseases National Plans Development
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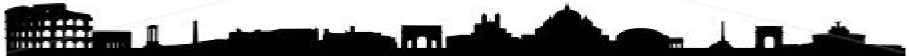
A capacity building network

for the implementation of Rare Diseases National Plans/Strategies

OBJECTIVES

To provide scientific and technical support for the establishment and monitoring of national plans and strategies for rare diseases at member state level:

- To establish an interactive network (mainly policy makers)
- To produce a complete, coherent and feasible operational proposal for NP/NS.
- To support EURORDIS National Conferences.



COORDINATION AND MANAGEMENT

LEADER

- Italian National Centre for Rare Diseases, Italian National Health Institute, Italy

EU ASSOCIATED PARTNERS

- European Organisation for Rare Diseases (EURORDIS)
- Ministry of Social Affairs and Health (MSAH), Finland

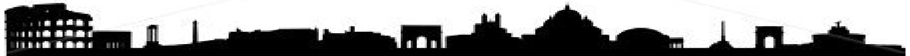
EU COLLABORATING PARTNERS

All EUCERD Members (27 Member States) plus

- Medizinische Universität Wien (MUW), Austria
- Bulgarian Association for Promotion of Education and Science (BAPES), Bulgaria
- Ministry of Health (UCPRA), Czeck Republic
- National Institute for Health Development (OEFI), Hungary
- Hospital Žilina (CDG), Slovakia

NON EU COLLABORATING PARTNERS

- Yerevan State Medical University (NDCA), Armenia
- Georgian Foundation for Genetic and Rare Diseases (GeRaD), Georgia
- National Association of Organizations For Patients with are Diseases “Genetics” (RAOPRD Genetics), Russia



EUROPLAN 2012-2015

-**will ensure scientific and technical assistance** to Countries.

-aims at **establishing an interactive network** among its partners.

- Partners will : work during specific workshops (cooperative learning); use dedicated website for project activities, exchange and share experiences, good practices and scientific evidence. **Capacity building.**

- **Survey:** to identify strengths and critical aspects in developing public health strategies and plans (dr. Rita Ferrelli)

-each participant will contribute to produce an operational proposal for NP/NS, taking into account specific country features (size, GNP, health care system);

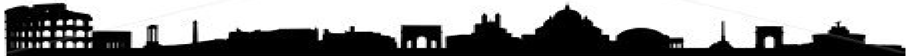
- **EUROPLAN indicators** will be selected for future data collection for a pilot study

EURORDIS conferences are meant to support the process of elaboration of NP/NS by assessing the transferability of EU policy documents in countries that did not organize a EUROPLAN National Conference and countries that did it but need to sustain the process (Dr. Valentina Bottarelli)

CAPACITY BUILDING

Capacity building is a process that focuses on understanding the obstacles that inhibit people and organizations from realizing their goals while enhancing the abilities that will allow them to achieve measurable and sustainable results.

The United Nations Development Programme (UNDP) was one of the forerunners in developing an understanding of capacity building and defined it as a long-term continual process of development that involves all stakeholders (ministries, local authorities, non-governmental organizations, professionals, community members, academics …)



CAPACITY BUILDING

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Kaplan, Allan (Aug 2000). "Capacity Building: Shifting the Paradigms of Practice". Development in Practice. 3/4 10 (10th Anniversary Issue): 517–526

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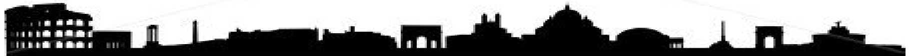
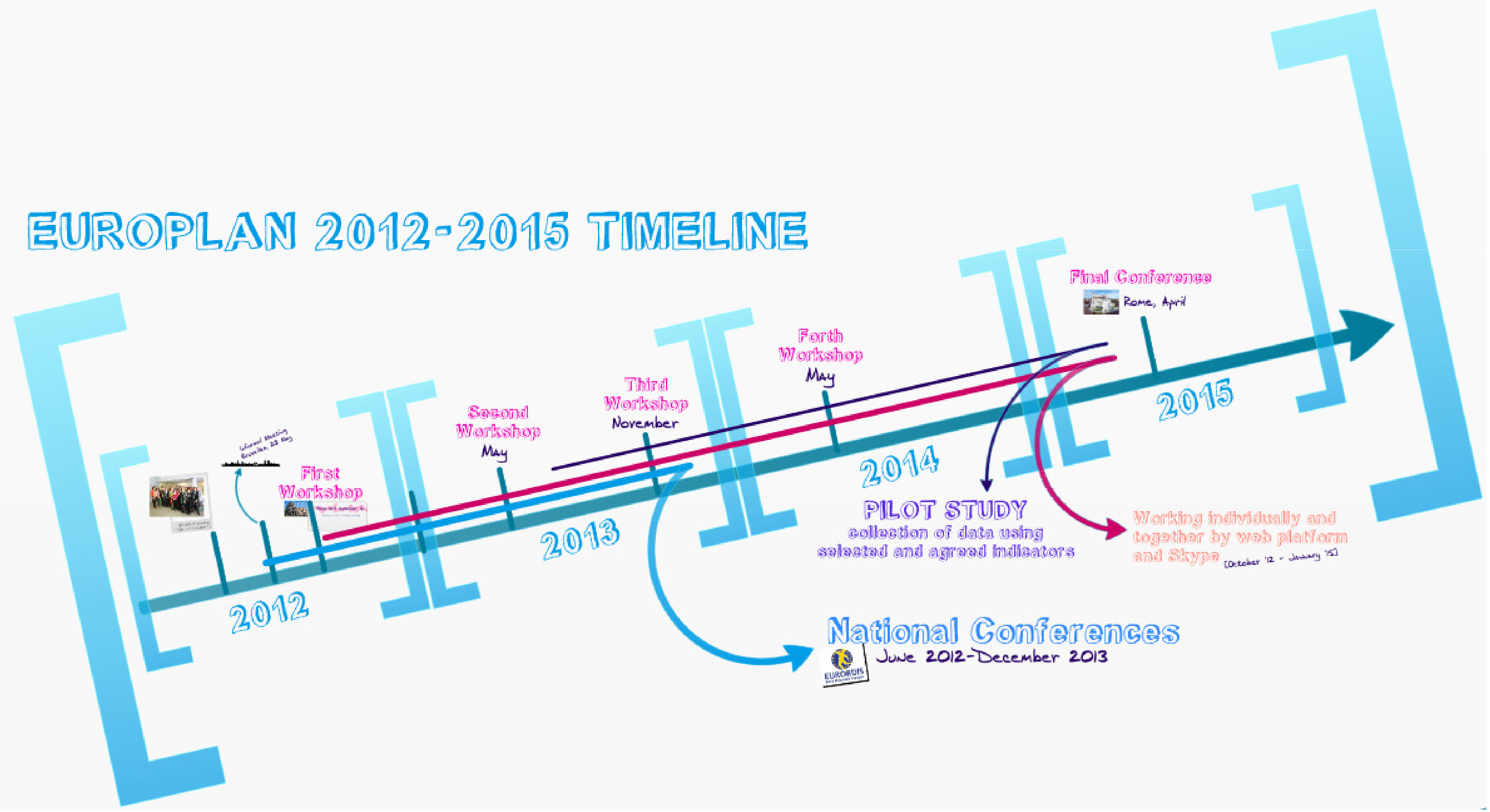


EUROPLAN 2012-2015 TIMELINE



NATIONAL CONFERENCES

BELGIUM - organized by RARE DISEASES ORGANISATIONS (RaDiOrg)

CROATIA - organized by The Croatian Society of Patients with Rare Diseases (Rijetke Bolesti)

CYPRUS - organized by CYPRUS ALLIANCE FOR RARE DISORDERS (CARD)

DENMARK - organized by RARE DISORDERS DENMARK (RDD)

FINLAND – organized by Finnish Rare Diseases Alliance (HARSO)

FRANCE - organized by Alliance Maladies Rares (AMR)

GREECE - organized by GREEK ALLIANCE FOR RD (PESPA)

HUNGARY - organized by RARE DISEASE HUNGARY (HUFERDIS)

IRELAND - organized by GENETIC AND RARE DISORDERS ORGANISATION (GRDO)

ITALY - organized by FEDERAZIONE ITALIANA MALATTIE RARE (UNIAMO)

LUXEMBOURG – organized by Luxembourg Alliance for Rare Diseases and Neuro Muscular Diseases (ALAN)

NETHERLANDS - organized by Dutch Genetic Alliance (VSOP)

POLAND – organized by Polish National Forum for rare diseases therapy – ORPHAN

PORTUGAL - organized by Portuguese Alliance of Associations of Rare Diseases (APADR)

ROMANIA - organized by Romanian National Alliance for Rare Diseases (RONARD)

SLOVAKIA –organized by Slovak Alliance of Rare Diseases (SAZCH)

SPAIN - organized by Federación Española de Enfermedades Raras (FEDER)

SWEDEN - organized by Rare Disease Sweden (Sällsynta diagnoser)

UNITED KINGDOM - organized by Genetic Interrest Group - Rare Disease UK

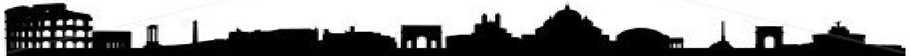
GEORGIA - organized by Georgian Foundation for Genetic and Rare Diseases(GERARD)

RUSSIA - organized by National Association of Organization of Patients with Rare Diseases GENETICS«Genetics») - Russian Patients Union - Rare Disease Working Group

SERBIA - organized by National Organisation for RD Serbia (Norbs)

SWITZERLAND - organized by Alliance for Rare Diseases Switzerland (ProRaris)

UKRAINE - organized by Children with Spinal Muscular Atrophy (CSMA)



RESULTS

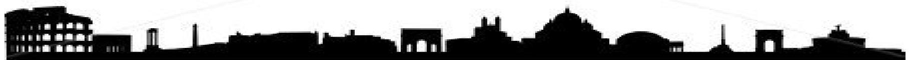
EUROPLAN 2012-2015 deliverables will be:

- Info Pack for organisers of National Conferences
- Operational proposals for National Plan/Strategy
- Final reports of National Conferences
- Final report on Capacity Building

EVALUATION

The achievements of the project will be evaluated by process, outcome and impact indicators.

The project will be assessed also in WorkPackage 3 “Evaluation of the joint action” of EUCERD Joint Action: working for rare diseases.



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