

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

A brief overview



Co-funded by the



DOMENICA TARUSCIO

*Italian National Centre for Rare Diseases
Italian National Institute of Health
Rome, Italy*

INFORMAL MEETING

23 May 2012, Bruxelles

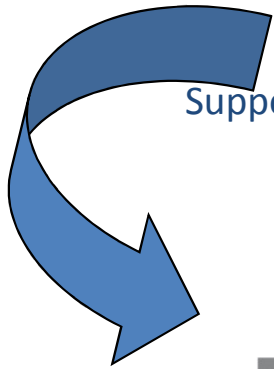


Co-funded by the



Workpackage 4

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



EUROPLAN

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Italian National Institute of Health

2012-2015

A capacity building network

for the implementation of Rare Diseases National Plans/Strategies



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 objectives 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**).

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EUROPLAN 2008-2011

A three-year project of the Program of Community action in the field of Public Health (2003 - 2008), coordinated by Italian National Institute of Health (ISS) - Italian National Centre for Rare Diseases (CNMR).

EUROPLAN involved **57 Associated & Collaborating Partners** (clinicians, scientists, health authorities, patients' Groups) from 34 Countries and EURORDIS.

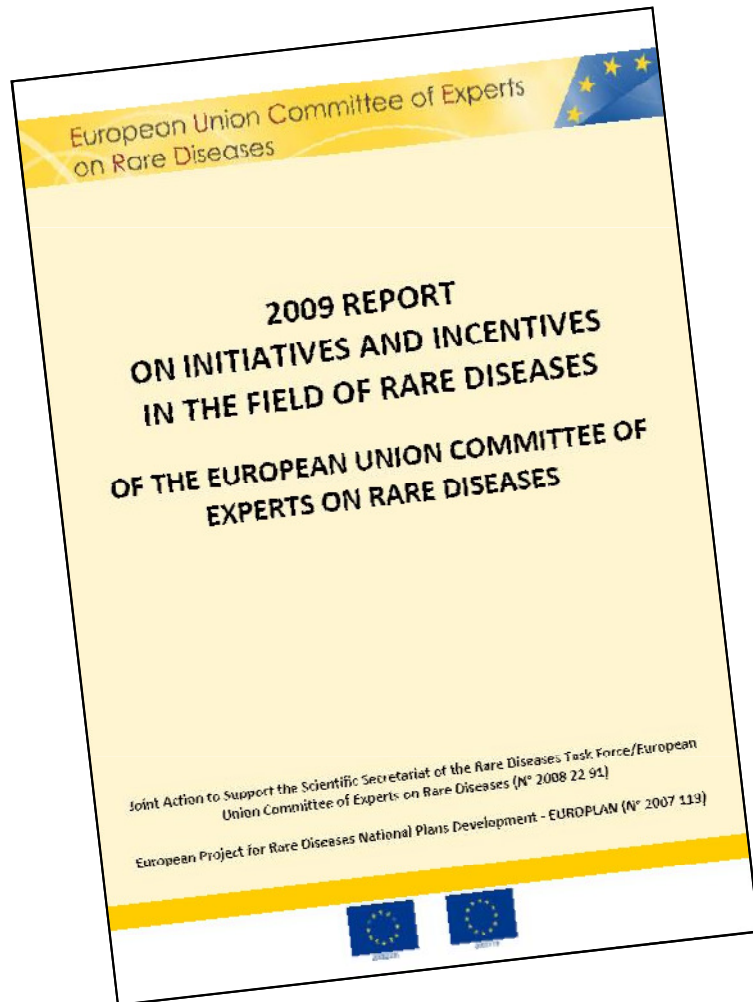
Main goals

- **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**

EUROPLAN 2008-2011

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

*Elaborate recommendations
as tools to facilitate the development of national plans and strategies for rare
diseases*



JOINT REPORT

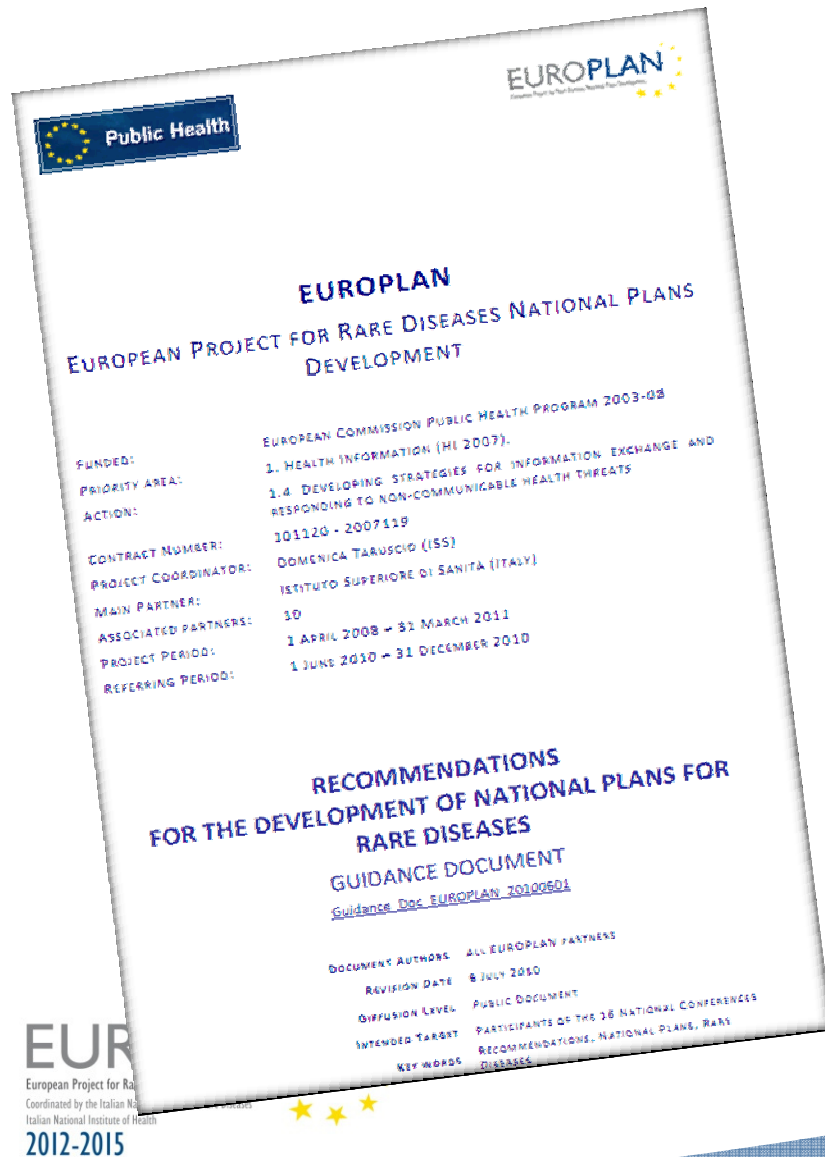
Report on EU Member States initiatives, previous and current experiences on rare diseases
(Joint document RTFD/EUCERD -EUROPLAN)

www.eucerd.eu
www.europlanproject.eu

GUIDANCE REPORT

Guidance Document containing the EUROPLAN recommendations for the designing of the National Plans or Strategies for rare diseases

www.europlanproject.eu



*Discuss the recommendations with stakeholders
(inside each MSs and among MSs)*



REPORT ON INDICATORS

for monitoring the implementation and evaluating the impact of National Plan or Strategy for rare diseases

www.europlanproject.eu

National conferences

National conferences organized by EURORDIS



	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 Interest 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

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SUMMARY REPORT

of the 15 National Conferences
organized by EURORDIS



www.eurordis.org

www.europlanproject.eu

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 in each step of all stakeholders
(experts, health authorities, Patients' Associations, EUCERD, etc)*

*Consensus process among experts and all stakeholders,
through workshops and National conferences*

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Objectives

TO PROVIDE TECHNICAL / SCIENTIFIC SUPPORT
FOR THE ELABORATION
OF NATIONAL PLANS AND STRATEGIES
FOR RARE DISEASES AT STATE LEVEL:

- 1. To establish an interactive network for rare diseases policy makers:** the network will provide technical/scientific assistance & capacity building skills to policy makers in charge of developing a NP/NS.
- 2. To produce a complete, coherent and feasible operational proposal for NP/NS:** through public health networking and sharing experiences, every participant will contribute to produce a operational proposal for NP/NS, according to specific country features (size, GNP, health care system), selecting EUROPLAN indicators for future data collection, and identifying strengths and critical aspects in developing public health strategies and plans.
- 3. To support EURORDIS National Conferences:** EURORDIS identifies and organises National Conferences to support the process of elaboration of NP/NS and assess the transferability of EU policy documents in countries that did not organise a EUROPLAN NC and countries that did it but need to sustain the process.

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Leader

Italian National Institute of Health (ISS) - Italian National Centre for Rare Diseases (CNMR)

Participants

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

EU Collaborating Partners

ALL EUCERD MEMBERS *plus*
Bulgarian Association for Promotion of Education and Science (BAPES)
Ministry of Health of the Czech Republic (UCPRA)
National Institute for Health Development (OEFI) - Hungary
Hospital Žilina (CDG) - Slovakia
Medizinische Universität Wien (MUW) - Austria

Non EU Collaborating Partners

Georgian Foundation for Genetic and Rare Diseases (GeRaD)
Yerevan State Medical University (NDCA) - Armenia
National Association of Organizations of Patients with Rare Diseases «Genetics» (RAOPRD Genetics)
- Russia

TASK 1

M2>M42

EUROPLAN Website

It will be implemented for sharing and disseminating documents and experiences.

It will be regularly updated until the end of the JA.

EUROPLAN team will ensure that EUROPLAN and EUCERD websites will not be duplicated and both websites will be synergistic.

Leader

Italian National Institute of Health (ISS) - Italian National Centre for Rare Diseases (CNMR)

Deliverables

EUROPLAN Website



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TASK 2

M2>M8

Phase 1 - Inception

During the first phase contact persons will be identified by e-mail. Starting from the state of art of NP/NS in the 27 EU MS, we will collect strengths and weakness in developing NP/NS by means of a form that we will circulate among partners. The results will be presented, discussed and shared during the Workshop (ISS, September 10-11, 2012). Moreover, Working Groups will be established during the workshop in order to share available knowledge, experiences and best practices.

Leader

ISS - CNMR

Additional Participants

All MS representatives

Deliverable of Task 4

Report of phase 1



TASK 3

M1>M8

Identifying 20 National Conferences on Rare Diseases

20 National Alliances of RD patients will be selected to organise 20 National Conferences on RD in the EU27 aimed to support the process of elaboration of national plans or strategies in European countries. 9 Advisors will be also selected among engaged patient representatives active within their National Alliances to work with EURORDIS to supervise the organisation of National Conferences.

Leader

EURORDIS

Deliverables

List of National Conferences



TASK 4

M1>M24

Set of guiding documents for organisers of National Conferences

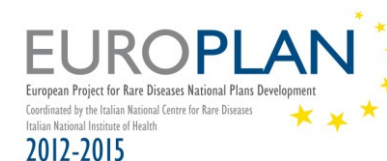
A set of guiding tools and documents, including the common Conference layout and the guidelines reflecting the thematic structure of the EU main documents, will be developed or revamped. They will be collected in an “Info Pack” for Conference organisers and available on the EURORDIS website in the section: “National Rare Disease Policy”.

Leader

EURORDIS

Deliverables

Info Pack for organisers of National Conferences



TASK 5

M9>M16

Phase 2

Working Groups (WGs) will work by e-mail and skype for continuing activities started during the first phase.

Each WG will be coordinated by a moderator.

An interactive methodology (e.g. cooperative learning, problem solving) will be used.

All steps for drafting a NP will be taken into account (from need assessment, to strategic planning, to priority setting, etc.)

A Workshop will be organized to illustrate and consolidate results of each WG.

Leader

ISS - CNMR

Additional Participants

All MS representatives

Deliverables

Report of Phase 2



TASK 6

M4>M36

Support to the Organization of 20 National Conferences on Rare Diseases

EURORDIS will coordinate and supervise the National Conferences and ensure that during all National Conferences the whole body of EU measures on RD is presented and promoted and so is the development of national plans or strategies on RD.

Interim reporting will be ensured to EJA partners on the progress relating notably to the organisation of National Conferences in each country, the development of content material by area and eventual integration and adjustment to new findings.

Leader

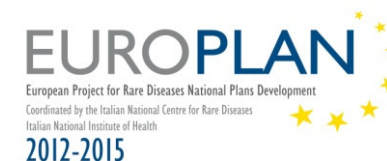
EURORDIS

Additional Participants

EURORDIS National Alliances

Deliverables

- Accomplishment of 20 National Conferences (M24)
- Final Reports in English of the 20 National Conferences (M36)



TASK 7

M17>M22

Phase 3 – Selection of indicators

The aim of the third phase is to identify few, feasible and agreed indicators (selected among EUROPLAN 2008-2011 indicators) for data collection in MS. A grid of indicators will be discussed among WGs.

A pilot study on data collection in MS using the agreed indicators will be performed. WGs will illustrate activities on the elaboration of NP/NS during a workshop.

Leader

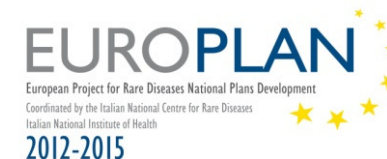
ISS - CNMR

Additional Participants

All MS representatives

Deliverables

Report on Phase 3



TASK 8

M23>M28

Phase 4 – Operational proposal

WGs will produce final NP/NS operational proposals and the pilot study using the selected indicators.

WGs will present the operational proposal of NP/NS during workshop 4.

WGS will illustrate the interim results of the pilot study.

Leader

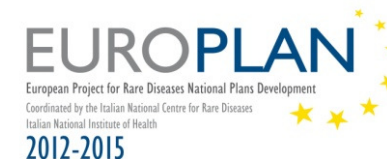
ISS - CNMR

Additional Participants

All MS representatives

Deliverables

- Report on phase 4
- Report of operational proposals for National Plan/Strategies



TASK 9

M29>M42

Phase 5 and Final Conference

WGS will continue the pilot study (collection of data using selected and agreed indicators).
Final Conference: to disseminate WP4 activities to the general public M24-M34 WGS will continue the pilot study (collection of data using selected and agreed indicators).
Final Conference: to disseminate WP4 activities to the general public.

Leader

ISS - CNMR

Additional Participants

All MS representatives

Deliverables

Report on phase 5
Capacity building report for RD NP/NS in EU MS



ISS EUROPLAN TEAM

Domenica TARUSCIO

CNMR-ISS Director

Rita Maria FERRELLI, Amalia Egle GENTILE, Marta DE SANTIS, Giovanni DE VIRGILIO, Antonello NAPOLETANO, Luca ROSI

ISS Researchers

Fabiola GNESSI, Massimo SANNA

Webmaster and dissemination tools

Giorgio VINCENTI, Stefano DIEMOZ

Administrative support

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Thank You!