

# 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



## Workshop objectives

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EUROPLAN

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

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EUROPLAN II WORKSHOP “Key Indicators for National Plans”

25 March 2013, Rome, Italy

[www.europlanproject.eu](http://www.europlanproject.eu)



# EUROPLAN

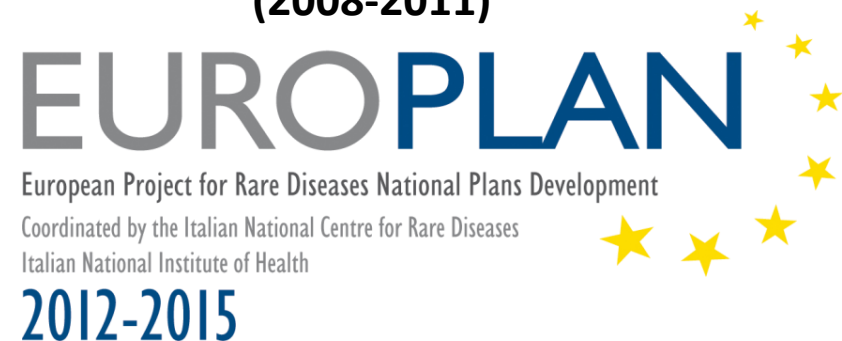
## (European Project for Rare Diseases National Plans Development)

is co-funded by the EU Commission (DG-SANCO)  
to promote and implement national plans or strategies for rare diseases,  
to share relevant experiences within Countries,  
linking national efforts with a common strategy at European level.

**EUROPLAN I**  
(2008-2011)



**EUROPLAN II**  
(WP4 EUCERD JA)  
(2008-2011)



# EUROPLAN I (2008-2011)

A three-year project coordinated by *Italian National Institute of Health (ISS) - Italian National Centre for Rare Diseases*.

It involved EURORDIS, 57 Associated and Collaborating Partners (clinicians, scientist, health authorities, patients' Groups) from 34 Countries.

Its main goal was to *elaborate agreed tools for the development and implementation of National Plans or Strategies following the European Council Recommendation*.



RESULTS



JOINT REPORT



EUROPLAN  
RECOMMENDATIONS

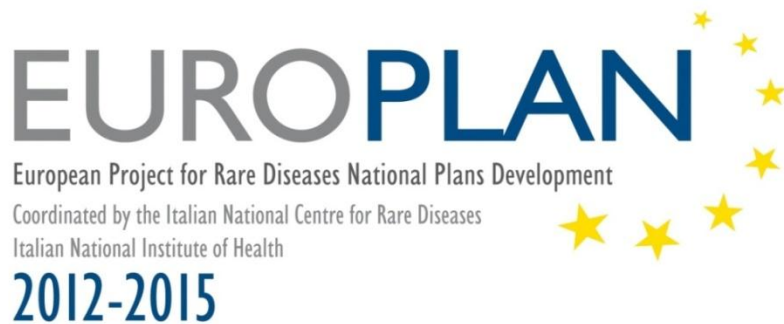


EUROPLAN INDICATORS



SUMMARY REPORT  
of the 15 EUROPLAN  
National Conferences  
organized by EURORDIS

# EUROPLAN II (2012-2015)



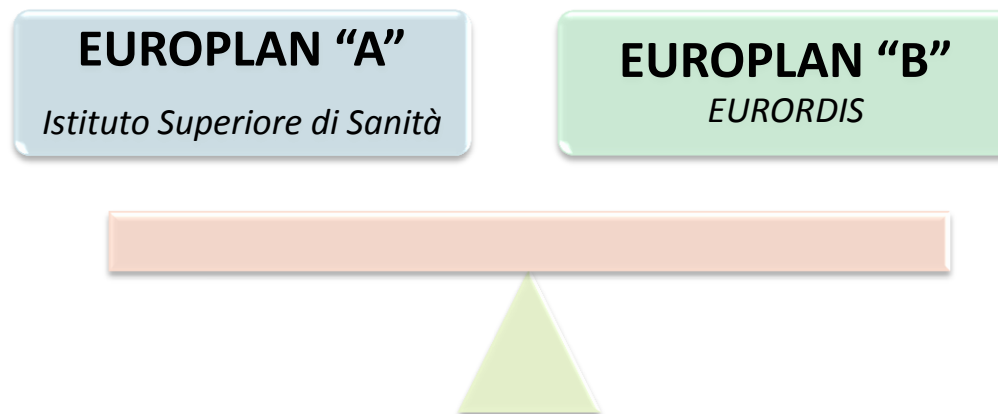
## Continuation of EUROPLAN I :

Workpackage 4 “Support for the implementation of plans or strategies at MS level” of the EUCERD Joint Action.

**TO PROVIDE TECHNICAL AND SCIENTIFIC SUPPORT TO COUNTRIES**

**FOR THE ESTABLISHMENT / IMPLEMENTATION OF NATIONAL PLANS AND STRATEGIES**

- Establishing an **interactive network involving public health policy-makers**
- improving **capacity building competencies**
- and **sharing experiences**
- **supporting the EURORDIS National Conferences.**



## LEADER

Italian National Centre for Rare Diseases, Italian National Health Institute (ISS), Italy (*EUROPLAN "A"*)

## EU ASSOCIATED PARTNERS

European Organisation for Rare Diseases (EURORDIS) (*EUROPLAN "B"*)

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), Czech 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

*plus* Croatia and Norway



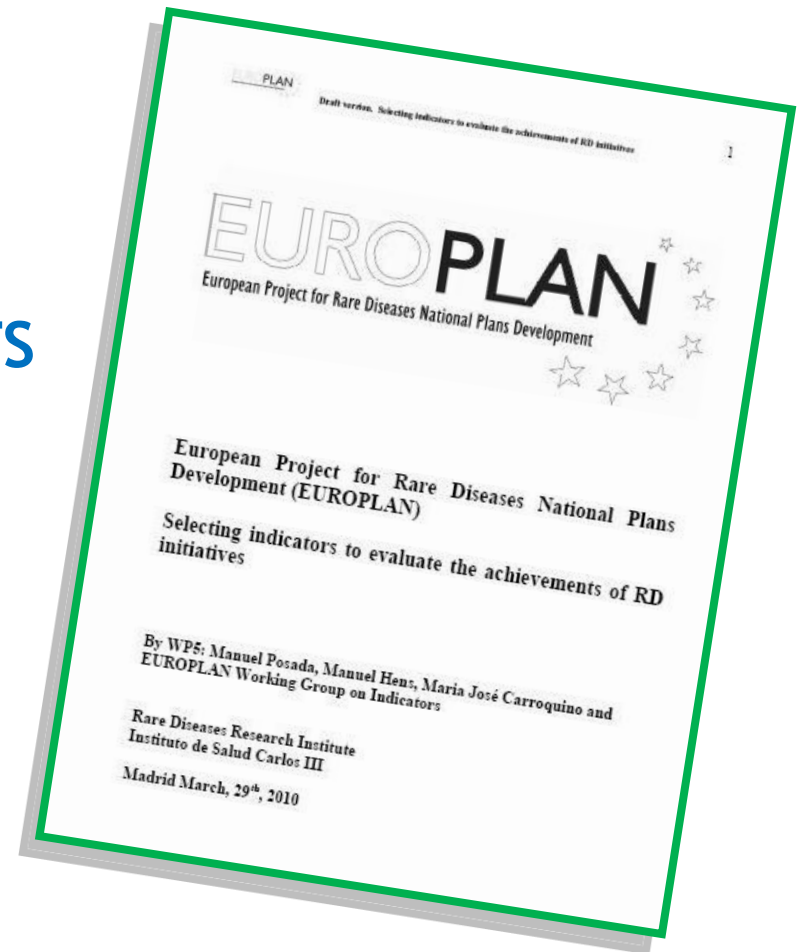
## THE ACTIVITY ON INDICATORS

### FROM THE DOCUMENT

“SELECTING INDICATORS  
TO EVALUATE THE ACHIEVEMENTS  
OF RD INITIATIVES”

EUROPLAN 1 (2008-2011)

**59 INDICATORS**



# INDICATORS

carried out by EUROPLAN “A” (ISS) and EUROPLAN “B” (EURORDIS)

*...towards*

**EUCERD  
Recommendations**

*EUCERD Recommendations on Core Indicators for Rare Disease National Plans*



**EUCERD RECOMMENDATIONS ON  
CORE INDICATORS FOR  
RARE DISEASE NATIONAL PLANS**