



# **An EUCERD Recommendation on Indicators for Rare Diseases National Plans/Strategies**

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# I. Why a EUCERD Recommendation on Indicators?

- The Council Recommendation for Action on Rare Diseases focuses on National Plans:
  - EU MS to adopt a plan /strategy for RDs by End 2013
  - EC to produce by End 2013 an implementation report
  - EUCERD created to support implementation of Council Recommendation and Commission Communication, including through Recommendations to guide & advice MS and EC

# I. Why a EUCERD Recommendation on Indicators

- A tool to support and guide MSs, EC and EU CERD
- EU DG SANCO co-funded project EUROPLAN 2008-2011:
  - WP 5 → Outcomes: **59 Indicators to monitor the implementation & impact of NP/NS**  
→ a good and comprehensive basis for EU MS
- March 2012-2015: EUCERD Joint Action (EJA)
  - WP 4 → **Revision of the 59 indicators out of EUROPLAN project for data collection in MS**

## II. Why on « core indicators » only?

- ~ 60 Indicators for NP/NS are:
  - difficult to collect systematically for each country and difficult to monitor in 27 MSs on long term,
  - good to select most relevant indicators adapted to the NP/NS of each MS
- A smaller set of core / common indicators are needed:
  - For a good vision across 27 MSs and on long term so to monitor process and progress of common policies on RDs
  - Potentially useful for the EC Report of end 2013
  - Surely useful for the annual EUCERD State of Art of RD

## II. Why a EUCERD Recommendation on Core Indicators for NP/S?

- Objectives:
  - The **overall objective** of the Core Indicators for Rare Disease National Plans and Strategies is to capture relevant data and information on the process of planning, following up and implementing of these plans and strategies
  - To agree on this common core set of indicators and commit to its collection
  - To streamline and align the follow up of the implementation of RD NP/NS amongst EU MSs in areas defined in the Council Reco and guided by EUCERD Recos

# III. EUCERD Joint Action WP 4

## work on indicators

- Initial approach to identify core indicators for NPs for the purpose of supporting the 25 National Conferences – EURORDIS & 9 National Alliances with their representatives in Ministries of Health
- Delphi Method to identify core indicators involving all stakeholders in EUCERD, including answers from the 27 MSs – ISS & EUCERD MSs representatives

# IV. EUCERD 7th Meeting on 31st January

- Presentation in Plenary
- Why a EUCERd Recommendation
- Why Core Indicators only
- Method to select them with support of EUCERD Joint Action
- Structure of this EUCERD Recommendation



# V. Content structure of the Recommendation?

- Background & Methodology & Target Groups
- Objectives & vision & scope
- List of 21 core indicators
- In annex detailed guidance for good understanding and quality collection of data
- Key reference documents

# VI. Experimentation & Revision

- All EUCERD Recommendations adopted by EUCERD so far, are considered as experimental and will need revision based on feedback from field work in MSs
- This EUCERD Recommendation on Core Indicators will be experimented for few years
- It may be revised if needed based on experience gained in the collection and analysis of this indicators
- It may also be revised based on further work to revise the full sets of indicators for national strategies on rare diseases based on actual plans and EUCERD JA / WP 4 EUROPLAN II action in the coming year