



EUCERD Recommendations on Core Indicators for Rare Disease National Plans/Strategies

Executive Summary

On 6 June 2013, during the eighth meeting of the European Union Committee of Experts on Rare Diseases, the *EUCERD Recommendations on Core Indicators for Rare Disease National Plans/Strategies* were adopted by the 51-member EUCERD.

The Council Recommendation on an Action in the Field of Rare Diseases (2009/C 151/02) (8 June 2009) encourages Member States to elaborate and adopt, preferably by the end of 2013, a national plan or strategy for rare diseases. In this context, a number of indicators for national plans/strategies were identified by the EUROPLAN project (2008-2011) for the purpose of monitoring the elaboration and implementation of these plans. These indicators were reconsidered in the scope of the EUCERD Joint Action via a broad consultation of stakeholders in 2013 in order to select a smaller number of indicators which could be reasonably used for the monitoring of these national activities, notably at European level.

The *EUCERD Recommendations on Core Indicators for Rare Disease National Plans/Strategies* thus provides a short list of 21 “core” indicators which are intended to capture relevant data and information on the process of planning and implementation of these plans and strategies on a regular basis. The indicators cover both process and outcome indicators in areas such as background to the plan/strategy (covering the elaboration and preparation stage), content (concerning actions in priority areas relative to the fields identified by the Council Recommendation) and financial support. Each indicator is fully explained in the annex with details of what information should be supplied in each case.

These indicators would provide information at European level notably to the European Commission on the implementation of the Council Recommendation on an Action in the field of Rare Diseases, as well as the annual report on the State of the Art of Rare Disease Activities elaborated by the EUCERD’s Scientific Secretariat. They can also serve as a basis for the elaboration of indicators at national level tailored to the specific actions foreseen in the plans/strategies for the appropriate monitoring of specific measures.

It is intended for this set of recommendations to be revised in the future to take into account the experiences of the Member States in this area.

The target groups of these Recommendations are primarily the EU Member States and the European Commission. Additionally, their dissemination is intended to other actors in the field of rare diseases.

The Recommendations are available on www.eucerd.eu here:

http://www.eucerd.eu/wp-content/uploads/2013/06/EUCERD_Recommendations_Indicators_adopted.pdf