Work Package | WP4: National Plans and Strategies for Rare Diseases
---|---
Deliverable | 20112201D05-00_OTH_EN.PS.pdf
Type of document | Report
Title | Capacity building report for Rare Disease National Plans/Strategies in EU MS
Lead partner | ISS (Istituto Superiore di Sanità)
Date | November 2015

This work arises from the EUCERD Joint Action: Working for Rare Diseases N° 2011 22 01, co-funded through the European Union’s 2nd Programme of Community Action in the Field of Health.

The sole responsibility for the information provided in this document lies with the authors: the European Commission/CHAFEA is not responsible for any use that may be made of the information contained therein.
Deliverable 5

Capacity building report for RD NP/NS in EU MS (continuation of EUROPLAN)

Author(s): Amalia Egle Gentile, Marta De Santis and Rita Maria Ferrelli (Istituto Superiore di Sanità - ISS)
Reviewer(s): Domenica Taruscio (Istituto Superiore di Sanità - ISS)

Approved by the:
☒ WP Leader
☐ Project Coordinator

Keyword List: National Plans, National Strategies, Rare Diseases, Capacity building, Public health, policy

Abstract: The EUROPLAN goal was to support the implementation of National Plans or Strategies to tackle RDs and share relevant experiences within countries, linking national efforts, through a common strategy at a European level. In order to fulfill these objectives, EUROPLAN involved health authorities, clinicians, scientists, EURORDIS and National Alliances, as associated and collaborating partners from several European countries. EUROPLAN collaborated with the other EJA Workpackage as well as European and National projects and initiatives and promoted the knowledge and the dissemination of their activities.

The main results obtained relate to the establishment of network among stakeholders, in particular policymakers of European Countries exchanging information, expertise and experiences. In conjunction with the developed tools, such as the core indicators, the expertise of the network allows for promoting new intervention strategies to support RD patients and families.

In conclusion, EUROPLAN fulfilled the aim to promote the capacity building of RD stakeholders at national and international level, confirming its role as a European and international process more than a project.
Document history

<table>
<thead>
<tr>
<th>When</th>
<th>Who</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>06/07/15</td>
<td>AE Gentile, M De Santis, RM Ferrelli</td>
<td>Definition of the structure and contents of the report</td>
</tr>
<tr>
<td>03/08/15</td>
<td>AE Gentile, M De Santis</td>
<td>Redaction of the first version of the report</td>
</tr>
<tr>
<td>03/09/15</td>
<td>RM Ferrelli</td>
<td>First review</td>
</tr>
<tr>
<td>30/09/15</td>
<td>AE Gentile, M De Santis</td>
<td>Redaction of the second version of the report</td>
</tr>
<tr>
<td>28/10/15</td>
<td>RM Ferrelli, D. Taruscio</td>
<td>Second review</td>
</tr>
</tbody>
</table>
Table of Contents

1. **Introduction** ...................................................................................................................................... 4

2. **Process and activities** ........................................................................................................................ 4

   2.1. To increase interactions among stakeholders and to provide them new skills ......................5

       2.1.1. International level ....................................................................................................................... 5

       2.1.2. National level ............................................................................................................................... 10

   2.2. To answer to priority needs ............................................................................................................ 11

       2.2.1. Creating synergies and exploiting the potential of EU activities and projects ......................12

       2.2.2. Providing informative and educational tools ................................................................................ 13

       2.2.3. Providing up-to-date information ............................................................................................... 13

3. **Conclusions** ..................................................................................................................................... 14
1. **Introduction**

National Plans and Strategies (NP/S) for Rare Diseases (RDs) are the common denominator of current public health policy concerns on RDs across Europe. They conjugate the European objective that aims at ensuring that patients with RDs have access to high-quality care - including diagnostics, treatment and rehabilitation - with the national priorities of selecting specific measures for adoption and implementation.

The objective of EUCERD Joint Action (EJA) Workpackage (WP) 4 “Support for the implementation of plans or strategies at MS level (continuation of EUROPLAN)”, alias EUROPLAN 2012-2015, was providing technical and scientific support to EU Countries with various geographical/economic concerns for the elaboration and implementation of their NP/S for RDs, mainly through capacity building actions. EJA WP4 was coordinated by the Italian National Center for Rare Diseases of the Istituto Superiore di Sanità (ISS), and involved Associated Partners (EURORDIS, the European Organisation for Rare Diseases, and Finland) and Collaborating Partners (EU Member States and Armenia, Georgia, Norway, Russia and Serbia).

EUROPLAN 2012-2015 continued the work carried out in the 3-year project European Project for Rare Diseases National Plans Development (EUROPLAN, 2008-2011), cofunded by the EU Commission (DG-SANCO) and coordinated by the Italian National Center for Rare Diseases of the Istituto Superiore di Sanità (ISS). EUROPLAN 2008-2011 built the consensus definition of operational tools (recommendations and indicators), laying the groundwork for EJA WP4.

EUROPLAN 2012-2015 focused on a more proactive involvement of multilevel stakeholders and a more intensive information exchange among them to aid networking and collaborative decision making.

Information on both ones, EUROPLAN 2008-2011 and EUROPLAN 2012-2015, is available in the EUROPLAN website www.europlanproject.eu.

This report presents the capacity building process and activities carried out in the 3-year EUROPLAN 2012-2015.

2. **Process and activities**

A complex and inclusive process was established to achieve the EUROPLAN 2012-2015 objective: to provide technical and scientific support to EU Countries with various geographical/economic concerns for the elaboration and implementation of their NP/S for RDs, mainly through capacity building actions.

Capacity Building includes all those actions, approaches, strategies, and methodologies that help institutions, organizations and human resources to improve their performance, generate development benefits, achieve their objectives and maintain the results over time.

The European Commission describes Capacity Building as working to develop and strengthen structures, institutions and procedures that help to ensure: transparent and accountable governance in all public institutions; improve capacity to analyze, plan, formulate and implement policies in economic, social, environmental, research, science and technology fields; and in critical areas such as international negotiation.

Capacity Building activities, tailored to each situation, include the training of human resources but are not limited to it. They comprise also technical support and other strengthening efforts directed to:

- Human resource development - the process of providing individuals with the understanding, skills and access to information, knowledge and training that enables them to perform effectively.
- Organizational development, the elaboration of management structures, processes and procedures, within organizations and, as well, the management of relationships between different organizations and sectors (public, private and community).
- Institutional and legal framework development, making legal and regulatory changes to enable organizations, institutions and agencies at all levels and in all sectors to enhance their capacities.

With this in mind, a capacity building process was implemented of wide range of activities, according specific aims, as indicated in the following sections.
2.1. To increase interactions among stakeholders and to provide them new skills

In order to reach this aim, EUROPLAN 2012-2015 worked at:

- **international level:**
  a) [EVENTS] Six events – one meeting, four workshops and the final conference - were organized involving all EUROPLAN Partners;
  b) [INDICATORS] A specific work on Indicators was carried out;
  c) [NP/S RD ANALYSIS] An analysis of National Plans/Strategies for rare diseases was performed;

- **national level:** 24 EUROPLAN Conferences were organised and coordinated by EURORDIS, and 14 Debrief Sessions, were organised by Italian National Institute of Health, EURORDIS and UNEW.

2.1.1. International level

The activities carried out at international level aimed to build a network among stakeholders, in particular policymakers, from several European Countries exchanging information, expertise and experiences. The knowledge of initiatives and “solutions” adopted in other States could be useful to promote new intervention strategies.

a) EVENTS

In the EUROPLAN website (www.europlanproject.eu), specific reports (Annex #1) as well as programme, list of participants, photos and presentations, are available for the events which involved EUROPLAN Partners:

- **Informal Meeting**, 23 May 2012, Bruxelles. Organised back to back with ECRD 2012, with the aim to extend the stakeholder network.
- **Inception Workshop on National Planning for RDs**, 10-11 September 2012, Rome. Aimed to present and discuss the results of a survey, carried out to identify strengths and weaknesses in the definition of NP/S in each Country context.
- **II Workshop “Key Indicators for National Plans”**, 25 March 2013, Rome. Aimed to share and agree the work on the indicators, an important step towards the adoption of the "Recommendations on EUCERD Core Indicators for Rare Disease National Plans/Strategies”.
- **EJA Workshop “EUROPLAN National Plans/Strategies capacity building activities”**, 8 May 2014, Berlin. Organised back to back with ECRD 2014, this event focused on the state of art of NP/S in EU and on the needs expressed during the Debrief sessions.
- **EJA/EUROPLAN Workshop on Rare Disease ERNs and Structural Funds**, 28-29 October 2014, Rome. Organised in collaboration with EJA Coordination team and aimed to share info on ERNs and to explore the financial opportunities of the EU Structural Funds.
- **EJA/EUROPLAN Final Conference “Working for Rare Diseases”**, 15 September 2015, Luxembourg. Organised in collaboration with EJA Coordination team and aimed to show the achievements of the EJA, by exploring progress and remaining challenges in RD field.

b) INDICATORS

In EUROPLAN 2008-2011, through a specific Workpackage on Indicators, 59 Indicators to monitor NP/S were identified across all themes of the Council Recommendation on an action in the field of rare diseases (2009/C 151/02).

In EUROPLAN 2012-2015, there was a new assessment by EUCERD members/patients due because the need to narrow this list down to few Core Indicators, according to criteria of usefulness and feasibility, so that each EU Member States will fill out the same indicators on RD NP/NS.
In order to reduce the complexity of the list, EUROPLAN 2012-15 (as WP4 of the EJA) identified a series of 21 core indicators. The selection of core indicators has been the result of the work carried out in several procedural steps by both teams of EUROPLAN and EURORDIS. The process foresaw two independent methodologies for selecting the “core indicators”:

- Delphi process (carried out by the ISS) with the collaboration of Ministry of Health representatives of 27 Member States (MS), 10 EURORDIS advisors and 4 experts. Participants were asked to select indicators according to two criteria: usefulness and feasibility of data collection. The process took place from 1 December 2012 to 14 February 2013. A satisfactory level of agreement was reached at the first round of the Delphi;
- EURORDIS approach (carried out by EURORDIS) with the participation of 8 EURORDIS advisors in conjunction with their Ministry of Health lead contacts on national plans/strategies.

The drafting group elaborated the first version of the Recommendations, merging the results from the two methodologies and circulated them among Ministry of Health representatives of 27 Member States, 10 EURORDIS Advisors and 4 experts; their comments and amendments were included for the preparation of the second draft, that was discussed and amended during the EUROPLAN Workshop “Key Indicators for National Plans” (ISS, Rome, 25 March 2013). The subsequent drafts circulated among EUCERD members, until adoption. EUCERD adopted the list of 21 core indicators on 6 June 2013, as “Recommendations on Core Indicators for National Plans/Strategies for Rare Diseases”.

Following EUCERD adoption of the core indicators in June 2013, a follow-up study about the use of indicators was deemed necessary for their fine-tuning and for improving their potential to orient policies for RDs. The method was a descriptive study with purposive sample (Bulgaria, Croatia, Italy, Romania and Spain), including (a) survey on the use of core indicators and (b) qualitative collection of lessons to take into account.

This study showed:

- Positive aspects: Collection of important information about development and implementation of NP; Excellent opportunity to share knowledge and comparability among countries; Political usefulness: chance to adapt national RD policies to best examples; Harmonisation of monitoring procedures, criteria and assessment of common RD policies in the 28 EU MSs;
- Problem faced: Quantitative indicators may not reflect qualitative improvements; Binary variables as limited tools for comparing MS different rules and regulations; Low visibility of activities for daily life integration of RD patients; Regionalisation hampering data collection and extrapolation to national level.

The study highlighted indicators usefulness in giving a snapshot of the main areas of concern for national planning for rare diseases and represent an excellent opportunity to share knowledge and comparability among MS. As binary variables, they give at a glance the picture of the Country in relation to the examined issues, but may not be able to give all the related nuances. Qualitative information will be necessary to fill in this gap.

The Analysis Report of Data collected via the Core Indicators (Annex #2; Deliverable 4.7.6) was published in “Annali dell’Istituto Superiore di Sanità. A science journal for public health” as open access article entitled “Exploring the Usability of EUCERD Core Indicators for Rare Diseases” [Ferrelli RM et al, Ann Ist Super Sanità 2015;51(4)].

e) NP/S RD ANALYSIS

In the “Recommendation on an action in the field of rare diseases” (2009/C 151/02), the EU Council recommends that Member States to elaborate and adopt a plan or strategy by the end of 2013 at the latest to guide and structure actions in rare diseases within their health and social systems. In this respect, most of the MS (18) had adopted a NP/S by December 2013. By September 2015, 24 Countries has published a NP/S. However, all Countries are working in this direction, and some have already produced a second document [Fig. 1].
The objective of this study was to analyse the adherence of National Plans/Strategies adopted in Europe with the EC Recommendations areas.

Selection criteria of documents to be included:

- **Document type**: National Plans and National Strategies (published by August 2015). [If available, for the selected States with NP/S, other documents (such as Recommendations) have been included, if necessary. For each included State, all documents (NP, NS and related docs) are available at www.europlanproject.eu.]
- **Language**: English, French, Spanish and Italian.

A table, considering all Council Recommendation areas, has been elaborated for each State, in order to identify parts of the documents relative to the Recommendation.

A double check (two researchers) has been done for each State included in the study and an analysis of data has been performed.

Fourteen EU States have been included:

- 13 Member States (Belgium, Bulgaria, Czech Republic, France, Germany, Hungary, Ireland, Italy, Romania, Slovak Republic, Slovenia, Spain, United Kingdom);
- 1 EEA/EFTA Country (Switzerland)

Note that (a) for United Kingdom: National Strategy, Welsh Plan and Scottish Plan have been included; (b) for Austria: the Austrian Executive Summary in English is not included due to the brevity of the text compared to the original document; (c) The Netherlands: the Dutch Strategy in English is not included because subsequently a plan has been published only in Dutch.

Data analysis highlighted that all Recommendation areas were considered in these NP/S. More specifically area by area, main evidences were the following:

- **Area 1. PLANS AND STRATEGIES IN THE FIELD OF RD**. All considered documents took into account the presence of a panel/committee of experts and indicated objectives of NP/S [Fig. 2].
• **Area 2. ADEQUATE DEFINITION, CODIFICATION AND INVENTORYING OF RD.** National Registry for RD was included in all NP/S. Coding types mentioned most often were ICD (78%) and Orphacode (57%) [Fig. 3].

![Fig. 2. Area 1. NP/S analysis results.](image)

[![Fig. 3. Area 2. NP/S analysis results.](image)](image)

• **Area 3. RESEARCH ON RD.** In all documents Countries fostered participation to research projects on RD. In 79% research needs and priorities were included [Fig. 4].

![Fig. 4. Area 3. NP/S analysis results.](image)
• **Area 4. CENTRES OF EXPERTISE AND EUROPEAN REFERENCE NETWORKS FOR RD.** Centres of Expertise and European Reference Networks were included in all NP/S. In 86% Exchange of expertise and multidisciplinary approach as well as healthcare pathways were considered [Fig. 5].

![Fig. 5. Area 4. NP/S analysis results.](image)

• **Area 5. GATHERING THE EXPERTISE ON RD AT EUROPEAN LEVEL.** Training for health professionals and Orphan Drugs and medicines were included in all NP/S. Social Services were also considered as Specific for RD in 43% and General in 57% [Fig. 6].

![Fig. 6. Area 5. NP/S analysis results.](image)

• **Area 5. EMPOWERMENT OF PATIENT ORGANISATIONS.** Consultation of Patient Organisations, in terms of inclusion in committees, were included in all NP/S, as well as information for Patients [Fig. 7].

![Fig. 7. Area 6. NP/S analysis results.](image)
• **Area 6. SUSTAINABILITY.** The documents took into account general funds (57%) and specific funds (36%) for ensuring the sustainability of NP/S [Fig. 8].

![Fig. 8. Area 7. NP/S analysis results.](image)

In order to facilitate circulation of information about NP/S for RD, EUROPLAN provided unofficial translations in English of NP/S for the following Countries: Austria, Croatia, Finland, Italy, The Netherlands. All documents are available at www.europlanproject.eu.

### 2.1.2. National level

The activities carried out at national level aimed to promote (a) a more effective interaction among all stakeholders in each Country and (b) the knowledge of EU initiatives, projects and opportunities as well as what was done in other Countries.

Reports of the 24 EUROPLAN National Conferences (NC), organised by EURORDIS in collaboration with National Alliances, and further information about are available in the EURORDIS website ([www.eurordis.org](http://www.eurordis.org)) as well as in the EUROPLAN website ([www.europlanproject.eu](http://www.europlanproject.eu)).

**Debrief Sessions** (DS) were specific activities post-National Conferences, organised by ISS, EURORDIS and UNEW (EJA Coordinator), with the objectives (a) to identify and collect needs, challenges and the most pressing issues emerged during the EUROPLAN National Conferences and (b) to identify possible proposals to National Authorities.

DS were attended by representatives from ISS, EURORDIS, UNEW, conference organisers and representatives of Ministry of Health of the Countries hosting the National Conferences.

ISS, UNEW and EURORDIS jointly created Standard Operating Procedures to govern the process of generating and revising both the Summary Table section of each document and the second part containing Proposals of Support. The document produced after the DS, agreed by all participating stakeholders, was composed of two parts:

- A table organised by Areas, the content of which results from the DS, the NC and the latest EUCERD State of the Art Report on Rare Disease Activities in Europe, for each specific Country. The content of this table was not meant to be an exhaustive report of each NC or to provide a comprehensive report of the state of the art of all activities carried out in each Country in the field of RD. It rather summarised the main elements that emerged during each NC.
- A list of Proposals for Assistance of specific interest to the Ministry of Health and to other competent national authorities. The proposals were suggestions in specific areas regarding needs emerged during the course of the DS and should have been considered as suggestions that the recipients could have been accepted if they find them useful. A distinction was made between the main proposals prioritised during
the DS. Preliminary Proposals (PP) expressed basic needs and are considered a higher priority as regard to Complementary Proposals (CP) which, though important, were considered less relevant than the prior ones.

These tables were circulated exclusively among DS participants (Annex #3.1_confidential). Participants, general details (Annex #3) and photos of the Debrief Sessions are available in the EUROPLAN website (www.europlanproject.eu).

DS were organised in:
1. Slovak Republic (28 February 2013, Bratislava)
2. Romania (24-25 May 2013, Bucharest)
3. Finland (21 September 2013, Helsinki)
4. Poland (28 September 2013, Warsaw)
6. Lithuania (14 November 2013, Vilnius)
7. Cyprus (15 November 2013, Nicosia)
8. Luxembourg (20 November 2013, Luxembourg)
9. Serbia (7 December 2013, Belgrade)
10. Italy (28 January 2014, Rome)
11. Croatia (27 and 28 February 2014, Zagreb)
12. Belgium (28 February 2014, Brussels)
13. Spain (Madrid, 20-21.11.14)
14. Denmark (Copenhagen, 23.01.15)

The DS data analysis in 14 EU MS and one non-EU Country provided a clear indication of the specific interests and the needs of the involved Countries in relation to the development and implementation of their NP/S for RD.

Data showed that Registries were a main concern and the top priority in all 14 Countries followed by, in a diminishing degree, by Centres of Expertise/ERNs, Research, Specialised Social Services, Orphacode, Guidelines, OMPs, Helplines, and so on [Fig. 9].

![Fig. 9. Top10 priorities (preliminary and complementary) raised by the analysis of the Debrief Sessions.](image)

2.2. **To answer to priority needs**

Debrief Sessions held at the end of National Conferences represented interesting tools for the collection of relevant data and mapping each Country’s situation with the regard to the current state of art, with the strengths and the weaknesses.

DS data have been useful for the planning of activities to meet the priority needs expressed during the NC and reinforced in the course of the DS.
The data of the 14 DS held during 2013-2014 clearly showed a number of basic priorities that should have been addressed systematically or this activity remains a futile exercise, creating unfulfilled expectations, further demotivating local stakeholders.

A number of actions in support of the expressed needs have been carried by the ISS, and by others, as well as the countries themselves and therefore a monitoring system should be put in place in order to follow up, at planned intervals, the development process in each of the selected fields.

### 2.2.1. Creating synergies and exploiting the potential of EU activities and projects.

The WP4 coordinator, ISS, managed several EU funded projects on RD. Therefore, in the interest of optimising scarce resources and diminishing duplications, has made an effort to create links among the various projects in order to answer, wherever possible, to the national needs in a systematic and coordinated manner. The DS provided the map of prioritised needs and the ISS has linked them to existing resources initiating a number of specific Capacity Building activities as follows:

- **EPIRARE WORKSHOP “National Registries of Rare Diseases”** (4-5 March 2014, Rome): scientific and technical support by EUROPLAN.

- **II International Summer School Rare Disease and Orphan Drug Registries** (15-19 Sep 2014, Rome): EJA WP4/EUROPLAN contributed through:
  - Priority given to EUROPLAN Partners in the participants selection;
  - Funding of 11 MS representatives (EJA WP4/EUROPLAN Partners);
  - Cooperative learning sessions;
  - Funding of streaming online (70 participants from several Countries).

- **II International Courses “Health Care Guidelines”** (23 February 2015, Rome): EJA WP4/EUROPLAN, collaborating with Rare Best Practices project, contributed through:
  - Priority given to EUROPLAN Partners in the participants selection;
  - Funding of 11 MS representatives (EJA WP4/EUROPLAN Partners).

- On the topic of **primary prevention**, EUROPLAN collaborated with EUROCAT (European Surveillance of Congenital Anomalies) elaborating:
  - European recommendations for primary prevention of congenital anomalies: a joined effort of EUROCAT (European Surveillance of Congenital Anomalies) and EUROPLAN projects to facilitate inclusion of this topic in the National Rare Disease Plans. [Taruscio D et al., Public Health Genomics. 2014;17(2):115-23].
  - Analysis of NP/S for RDs in terms of primary prevention. By June 2015, in their NP/S: 11 Countries included this topic, 2 Countries had health CA prevention/promotion in general, 9 Countries don’t specifically address CA Primary Prevention.

![Fig. 10. Overview of Primary Prevention in National Plans/Strategies for Rare Diseases (as of June 2015).](image)
2.2.2. Providing informative and educational tools

The following tools, in terms of informative and educative materials and initiatives, were realised during EUROPLAN 2012-2015:

- **State of the art of rare diseases networks in EU (Annex #4).** In anticipation of the call for European Reference Networks in early 2016, a study has been conducted with the main objective to carry out an inventory of existing and formerly established Networks of rare diseases in Europe, collecting relevant data regarding their set-up and functional status.

- **E-learning materials on Registries issue (on demand).** The digital materials of the International Summer Schools on rare disease and orphan drug registries were collected and made available on-demand (europlan@iss.it).

- **Scientific articles:**
  - Exploring the Usability of EUCERD Core Indicators for Rare Diseases. [Ferrelli RM et al, Ann Ist Super Sanità 2015;51(4)].
  - European recommendations for primary prevention of congenital anomalies: a joined effort of EUROCAT and EUROPLAN projects to facilitate inclusion of this topic in the National Rare Disease Plans. [Taruscio D et al., Public Health Genomics. 2014;17(2):115-23]
  - Romanian EUROPLAN workshops (Medical University, Bucharest, 18-19.07.14 and 24.07.15) – Issues & presentations: European Reference Networks; COMMUNITY project: Towards a shared model of quality assessment for CEs.
  - European Reference Networks. Open Day (3 July 2015, Rome) – Scientific and organisational support by EUROPLAN. This event provided an opportunity for share information about this theme at national level.

2.2.3. Providing up-to-date information

In the field of rare diseases the circulation of information is an essential requisite, from the research to the health strategies, from the good practices to the international project and initiatives. For this reason, EUROPLAN used a specific digital dissemination channels, as website and twitter profile, in order to reach as many people as possible.

The EUROPLAN website (www.europlanproject.eu), launched in 2008, was restyled and it is continuously updated, at least weekly. It contains information and documents about the activities of 2008-2011 as well as 2012-2015, which is linked to the website of the Commission expert group on rare diseases (during the EJA project, also to the EJA webpages), and to the EURORDIS website (www.eurordis.org), in order to align and maximize the dissemination of information among RD stakeholders.

Main aims are:

- promoting EUROPLAN Capacity building activities;
- providing links to useful documentation (as National Plans of RD, EC Recommendations, scientific articles international initiatives and projects etc). All documents are downloadable;
- facilitating contact and networking among different stakeholders;
- disseminating news and events (at national and international level).

The website have around 900 visitors/1’000 sessions per month.

In July 2014, was opened the Twitter profile @EUROPLANproject. It has over 700 followers (as of September 2015), but this number is growing.
The choice of Twitter was due to this social media is an effective channel for rapid and viral communication, used by around 200 million users every months, many of which are professionals.

**EUROPLAN website and Twitter profile will be maintained and implemented by ISS, even after the project officially ends in 2015.**

### 3. **Conclusions**

The EUROPLAN goal was to support the implementation of National Plans or Strategies to tackle RDs and share relevant experiences within countries, linking national efforts, through a common strategy at a European level. In order to fulfill these objectives, EUROPLAN involved health authorities, clinicians, scientists, EURORDIS and National Alliances, as associated and collaborating partners from several European countries.

EUROPLAN collaborated with the other EJA Workpackage as well as European and National projects and initiatives and promoted the knowledge and the dissemination of their activities.

Capacity building in health could be considered as the development of sustainable skills, organisational structures, resources and commitment to health improvement in health and other sectors, to prolong and multiply health gains many times over. This encompasses not only providing skills and awareness, but also creating channels, by means of partnerships, policy and leadership, through which this learning can be transferred into sustainable action (United Nations Development Programme, 2008).

Bearing all this in mind, it is possible to conclude that EUROPLAN fulfilled the aim to promote the capacity building of RD stakeholders at national and international level, confirming it is an European and an international process more than a project.