This first interim report of the EUReMS project gives an overview of the implementation of the project during the first year (July 2011 to June 2012) and includes the deliverables mentioned in the Grant Agreement 2010 12 13.

European Register for Multiple Sclerosis - A tool to assess, compare and enhance the status of Persons with MS throughout the EU.

Prepared by Tsveta Schyns and Elisabeth Kasilingam on behalf of:
European Multiple Sclerosis Platform aisbl
GENERAL INFORMATION

Contract number: 2010 12 13

Proposal title: European Register for Multiple Sclerosis - A tool to assess, compare and enhance the status of People with MS throughout the EU.

Acronym: EUReMS

Starting date: 01 July 2011

Duration of the project: 36 months

Reporting period: 01 July 2011 - 30 June 2012

PARTNER INFORMATION

Main partner: European Multiple Sclerosis Platform AISBL, Belgium

Number of associated partners: 11

- Association of Multiple Sclerosis Societies of Croatia, AMSSC, Croatia
- Dept. of Clinical and Experimental Medicine (former Dept. of Neurosciences), University of Sassari, NeuroSS, Italy
- Deutsche Multiple Sklerose Gesellschaft Bundesverband e.V., DMSG, Germany
- Fundació Institut de Recerca Hospital Universitari Vall d’Hebron, FIRHUVH, Spain
- Karolinska Institute, KI, Sweden
- Neurologisches Rehabilitationszentrum Quellenhof in Bad Wildbad GmbH, NRCQ, Germany
- Polskie Towarzystwo Stwardnienia Rozsianego, PTSR, Poland
- Societatea de Scleroza Multipla din Romania, SSMR, Romania
- The Multiple Sclerosis Society of Great Britain and Northern Ireland, UK MS Society, UK
- Universitaetsmedizin Goettingen - Georg-August - Universitaet Goettingen - Stiftung Oeffentlichen Rechts, UMG-GOE, Germany
- University of Bergen, UiB, Norway

FINANCIAL DETAILS

Total amount of the project: 1.646.503,00 EUR

EC Co-funding: 987.198,00 EUR

Received payment:

First pre-financing payment (30%): 296.159,40 EUR

Remaining payments:

First installment (20%): 197.439,60 EUR; Second installment (20%): 197.439,60 EUR

Balance payment (30%): 296.159,40 EUR
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1. EXECUTIVE SUMMARY

With the general aim of establishing a European wide Platform for systematic collection, exchange and analysis of longitudinal data on Multiple Sclerosis (MS) in Europe, the EUReMS project is set up by an international consortium to address the currently unmet needs of Persons with Multiple Sclerosis (PwMS).

EUReMS is underpinned by the following principles: building on already existing national or regional data collections; involving and combining the expertise of clinicians, researchers and patient organizations; addressing questions at an international level; including highest available expertise concerning its organization and technical solutions; it should ultimately contribute to improve access for PwMS across Europe to evidence-based health care services and offer a cutting-edge research tool to gain further insights into various aspects of MS, e.g. including long-term effect of the services offered to PwMS that is believed to be particularly important in times of economic constraints.

The European Commission through its Communications on health issues has expressed its willingness to tackle more effectively health inequalities faced by EU citizens such as the provision of health services, the design of health promotion and health protection activities, living and working conditions. The Commission intends to provide support to the Member States in identifying successful strategies to reduce health inequalities and in their implementation: by improving data collection and monitoring on health inequalities and by identifying and prioritizing areas of improvement and best practices that can be shared by the Member States. The EUReMS project addresses the current lack of data at an EU level on treatment and care of PwMS. In doing so, the EUReMS will meet the expectation of the general objective of the EU health policies to improve quality of health care and treatment and, ultimately, quality of life of PwMS throughout the EU.

During the First Project Year the EUReMS has achieved the following:

- Kick-off meeting, 4th July 2011 in Luxembourg
- Adoption of the Terms of References for the project time by the EUReMS Consortium
- Launched the web site: www.eurems.eu, in September 2011
- Held the First Consensus meeting with Scientific Advisory Board and Stakeholders, 19th October 2011 in Amsterdam
- WP1: The Steering Committee adopted the EUReMS Consensus Statement, on 14th December 2011
- Launched the Project Partners on line Collaboration Platform in December 2011
- WP2: Identified MS data collection sites in Europe and conducted a Survey using a Questionnaire of 17 MS registers and telephone Interviews to detail information
- Held a Workshop in Barcelona, on 20-21 May 2012 with associated partners, Collaborating partners and Experts to present the Summary of Results from the Survey
- Held Consultations with stakeholders: at the EMSP workshop for MS societies on 19th May 2012, in Barcelona and for sponsoring Industry on the 11th June 2012, in Brussels.
## 2. Specification of the Project:

### 2.1 General Objective of the Project

The general objective of the EUReMS project is to establish a European Platform for systematic collection, exchange and analysis of longitudinal data on Multiple Sclerosis (MS) in Europe by building upon the already existing national or regional MS data collections and involving and combining the expertise of clinicians, researchers and patient organizations.

### 2.2 Specific Objectives of the Project

<table>
<thead>
<tr>
<th>Number</th>
<th>Title</th>
<th>Indicators</th>
<th>WP</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Define the Mission, the Vision and the Objectives of EUReMS.</td>
<td>EUReMS Mission statement validated by all stakeholders</td>
<td>WP1</td>
</tr>
<tr>
<td>2</td>
<td>Establish a core data set for EUReMS that can be extracted from the</td>
<td>Published data mask of EUReMS</td>
<td>WP2</td>
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<tr>
<td></td>
<td>currently existing national and regional MS registers.</td>
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<td>3</td>
<td>Develop statistical methodology and data analysis strategies that</td>
<td>Published results from the test phase of EUReMS</td>
<td>WP3</td>
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<td>will be applicable and appropriate for studies utilizing the EUReMS.</td>
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<td>4</td>
<td>Establish the IT infrastructure for data collection, collaboration</td>
<td>Functional Platform and Register</td>
<td>WP4</td>
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<td></td>
<td>and information on MS across Europe that can be expanded for future</td>
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research and project.

<table>
<thead>
<tr>
<th>WP</th>
<th>Activities</th>
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<tr>
<td>5</td>
<td>Define the ethical principles, procedures and policies for establishing and operating EUReMS and to develop the appropriate tools to communicate and monitor this in an effective way.</td>
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<tr>
<td>6</td>
<td>Ensure a sustainable and a geographical representative Network of high quality data providers to the EUReMS.</td>
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### 2.3 Overview of activities for the period covered in the interim report

<table>
<thead>
<tr>
<th>WP</th>
<th>Activities</th>
<th>Outcomes/Deliverables</th>
<th>Date foreseen</th>
<th>Date of achievement</th>
<th>Level of achievement (measured by indicators)</th>
<th>Justification/Problems encountered</th>
<th>Action to be taken to overcome the problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Identify PwMS’ needs by literature revue, input from MS-ID project and MS Registers</td>
<td>Report (D3)</td>
<td>M4 31.10.2011</td>
<td>M2 18.08.2011</td>
<td>Disseminated on time to the EUReMS Consortium</td>
<td>IP issues concerning publishing the Report have been noted at the Kick-off meeting. Also, due to the level of details and its size, the report was made available only to the Consortium.</td>
<td>The EUReMS Steering Committee has decided to publish, instead of the whole document, the main conclusions of the Report in the format of Consensus Statement.</td>
</tr>
<tr>
<td>Step</td>
<td>Task Description</td>
<td>Document Title</td>
<td>Date of Preparation</td>
<td>Date of Consultation</td>
<td>Notes</td>
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<tr>
<td>1</td>
<td>Draft the EUReMS Consensus Statement</td>
<td>Report (D3)</td>
<td>M6 04.12.2011</td>
<td>M6 04.12.2011</td>
<td>The EUReMS Steering Committee has decided to publish, instead of the whole document, the main conclusions of the Report in the format of a Consensus Statement.</td>
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<td></td>
<td>Organise the first Consensus meeting</td>
<td>Meeting Documents (Annex 4.6)</td>
<td>M4 31.10.2011</td>
<td>M4 17.10.2011</td>
<td>High level of attendance and interest from Stakeholders and the Scientific Community</td>
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<td>2</td>
<td>Identification of different data collection methods across Europe</td>
<td>Questionnaire (Annex 4.10)</td>
<td>M8 01.02.2012</td>
<td>M8 01.02.2012</td>
<td>The Questionnaire was sent to 32 identified contacts for data collection in Europe</td>
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<td>n.a.</td>
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<tr>
<td></td>
<td>Comparison of MS registers</td>
<td>Presentation</td>
<td>M11 21.05.2012</td>
<td>M11 21.05.2012</td>
<td>Detailed comparison of 10 MS Register out of the enquiry to 13 MS registers</td>
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<tr>
<td>Task</td>
<td>Report</td>
<td>Date</td>
<td>Status</td>
<td>Details</td>
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<tr>
<td>Developing of a (test) European data set</td>
<td>Report</td>
<td>M16</td>
<td>In progress</td>
<td>The Survey revealed that MS registers are very heterogeneous in scopes but also in quality of data across the specific areas.</td>
<td>The EUReMS approach will be to apply a Short term Strategy: start with few Registers to compile a core set of items that are commonly collected and cover the first two missions of EUReMS.</td>
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<tr>
<td>Interact with WP 1 and WP 2</td>
<td>Report (Annex 4.5)</td>
<td>-</td>
<td>Participation in the SC monthly teleconferences</td>
<td>n.a.</td>
<td>n.a.</td>
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<tr>
<td>Input to the Consensus Statement</td>
<td>Report (D3)</td>
<td>M6</td>
<td>M6</td>
<td>Participation in the First Consensus Meeting 17.10.2011</td>
<td>n.a.</td>
<td></td>
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<tr>
<td></td>
<td>Activity Description</td>
<td>Methodology</td>
<td>Milestone</td>
<td>Status</td>
<td>Notes</td>
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<td>4</td>
<td>Set up the EUReMS portal for exchange of MS information</td>
<td>First version And specification (D7)</td>
<td>M6 31.12.2011</td>
<td>M5 30.11.2011</td>
<td>In progress, regular updates</td>
<td>n.a.</td>
<td>n.a.</td>
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<tr>
<td>5</td>
<td>Interact with WP 1 and WP2</td>
<td>Report (Annex 4.5)</td>
<td>-</td>
<td>-</td>
<td>Participation in the SC monthly teleconferences</td>
<td>n.a.</td>
<td>n.a.</td>
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<tr>
<td></td>
<td>Recruit members of the EUReMS Network</td>
<td>Stakeholders meeting during the First Consensus Meeting Report (Annex 4.6)</td>
<td>M4 17.10.2011</td>
<td>M4 17.10.2011</td>
<td>High level of attendance and interest from Stakeholders</td>
<td>n.a.</td>
<td>n.a.</td>
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<td></td>
<td>First Concept for Model Contract with Data providers</td>
<td>Presentation at the WP2 Workshop Barcelona</td>
<td>M11 21.05.2012</td>
<td>M11 21.05.2012</td>
<td>In Progress</td>
<td>n.a.</td>
<td>n.a.</td>
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</table>
3. **TECHNICAL IMPLEMENTATION OF THE PROJECT**

3.1 **Activities related to Horizontal Work Packages:**

*WP1: Management of the project*

**Activities undertaken**

**Partnership** – EUREMS project meeting was organised on the same day as the launch of the project on 4th July 2011, in Luxembourg. The meeting was held in the premises of the Executive Agency for Health and Consumers. The meeting brought together all associated partners of the EUREMS project.

**Management structure** – The main governance body of the EUREMS is the Steering Committee (SC) which is composed by member(s) of each partner organizations. The first Terms of References document has been adopted at the Kick-off meeting and regular updates are made upon suggestions from partners and according to the evolution of the project. The Steering Committee has met three times during the first year. (Minutes of the meetings in Annex 4.5)

**Intellectual Properties issues** have been discussed during the first two meetings of the SC and the conclusions have been included in the Terms of references current version.

**Internal communication** – The communication between partners is ensured via monthly videoconferences (WebEx system), and other regular channels (emails and phone calls).

**Communication strategy** – The exchange of information and documents has been facilitated through the EUREMS Portal accessible with password to each partner.

**Project Consultant** – Christoph Thalheim was subcontracted to undertake the Project consultancy tasks of the EUREMS project.

**Problems encountered**

The management team considered that the originally planned email communication with partners would not be optimal as the only path of communication.

**How were problems resolved**

Therefore, from M3 the Coordination team organises monthly videoconferences. Those videoconferences included only the WP leaders at first and, later were extended to all SC members, to monitor and support the progress of the project activities.

**Activities planned for the next period**

The next SC monthly videoconference is foreseen for the 31st August 2012.
The next SC meetings will be held in Lyon on the 10\textsuperscript{th} October 2012 and then during the spring 2013, in Göttingen.
WP2: Dissemination strategy

Dissemination plan available  yes  (please attach as Annex 4.1)

Activities undertaken

Stakeholder analysis / target group identification - Through the contact of the Main Partner (EMSP) and the associated partners relevant stakeholders were identified in the scientific community in the field of MS, among patients’ organisations, other NGOs and also MS related organisations.

The First meeting with Stakeholders was held at M4 during the First Consensus meeting, ECTRIMS in Amsterdam, on the 19th October 2011.

Dissemination content

The Logo and the template for the project presentations were developed at the beginning of the project, together with a EUReMS brochure for dissemination (Annex 4.11) and a banner for external meetings.

The EUReMS project consortium submitted a Poster for the poster presentation held during the ECTRIMS Congress in Amsterdam, October 2011.

An article was published in the Lancet of Neurology (Editorial) on EUReMS, in October 2011 (Reference 1).

Dissemination means

The dissemination of the EUReMS ongoing activities, news and outcomes is ensured via the EUReMS website (www.eurems.eu), periodic emailing of public report (M6 and M12) to Stakeholders, presentations of the project at external meetings – such as the MS event at the European Parliament (April 2012), EMSP briefing and consultation meeting for sponsoring Industry (June 2012), EMSP Annual Congress (May 2012).

The EUReMS brochure has been translated into Polish.

An article on the EUReMS project was published in the Romanian MS Society magazine.

Activities planned for the next period

Please, see Annex 4.1: dissemination plan.
**WP3: Evaluation of the project**

**Evaluation plan available**  yes (please attach as Annex 4.2)

**Activities undertaken**

**Data collection for process evaluation** – A continuous monitoring of the planned activities by mailing and monthly videoconferences with the SC is ensured internally. An External evaluator has been appointed among 5 tenants to the public call published in 2011.

**Analysis of process evaluation data** - At the level of the Main Partner and with the SC at the monthly TCs and the face-to-face meetings.

**Data collection for effect evaluation (baseline)** - As part of the Evaluation plan of the external consultant.

**Analysis of effect evaluation data** - As part of the Evaluation plan of the external consultant (cf. report of the External Evaluator – Annex 4.2)

**Problems encountered**

The appointment of the External evaluator has been delayed since the first selected candidate dropped out.

**How were problems resolved**

The next selected candidate was contacted and was appointed: Sebastian Mariano (Annex 4.2; 4.3).

**Activities planned for the next period**

Please, see Annex 4.2.
3.2 Activities related to project objectives (core work packages)

**Objective 1: Define the aims of EUReMS**

**Methodology applied as planned**

Literature review and input from MS-ID project.

Survey on the Long Term and Short Term Mission among EUReMS project partners, the Scientific Advisory Board (SAB) and Stakeholders (MS Societies and Industry). The final decision of the EUReMS was adopted, as planned, by consensus from the EUReMS Steering Committee.

**Involvement of partners and target groups**

The drafts of the report and the Consensus Statement were discussed by the EUReMS Steering Committee at several consecutive meetings. The drafted Consensus Statement was sent along with a Questionnaire to the SAB and stakeholders – MS Societies, broader Scientific Community at ECTRIMS and with Industry.

**Coordination with other projects or activities**

The First Consensus meeting was combined with the ECTRIMS/ACTRIMS Annual congress, held in October 2011. This allowed gathering and involving highly recognized MS experts from the scientific community and seeking their involvement and also raising awareness on the project to potential users of the EUReMS or potential data providers.

**WPH 1, 2 and 3:** 1) meeting of the Steering Committee; 2) with the Scientific Advisory Board; 3) dissemination at the ECTRIMS (poster presentation).

**WP6:** Building up the EUReMS Network through the organised stakeholders’ workshop.

**Outcomes and deliverables achieved**

The working draft of the Report on definition of PwMS’ needs minimum core and clinical data sets, on characteristics of identified MS registers/datasets and European registry systems for other chronic disease was presented to the Consortium on time (M3).

**Problems encountered**

IP issues concerning publishing the Report have been noted at the Kick-off meeting. Also, due to the level of details and its size, it was decided that the report will be made available only to the Consortium members.

**How were problems resolved**

The EUReMS SC has decided to publish, instead of the whole document, the main conclusions of the Report in the format of Consensus Statement (D3).

**Activities planned for the next period**

This WP is now completed.
Objective 2: Establish a core data set for EUReMS that can be extracted from the currently existing national and regional MS registers.

**Methodology applied as planned**

The Identification of existing MS registers was performed using Literature search through Pub Med and by Cross-check with EMSP (MS Barometer 2011). A list of 32 contacts in Europe was compiled as possible sources of further information on MS data collection.

A Questionnaire for surveying the MS data collecting contacts was drafted and emailed to the contacts. The responders on the Survey (13 out of 32) were contacted for further details. Telephone interviews were held with 7 of the MS registers.

**Involvement of partners and target groups**

The first draft of the Questionnaire was done in collaboration with partner 11 and 2 and in consultations with the WP Leaders. The Interviews were organised and supported by the Main Partner. WP5 (EUReMS Charter) and WP6 (Model Contract with DPs) were discussed in parallel with the Survey results by the WP Leaders.

Collaborating Partners were invited and took part in the Workshop on the WP2 that took place in Barcelona 20-21st May 2012.

**Coordination with other projects or activities**

The Workshop WP2 was organised in conjunction with EMSP Annual Congress in order to enhance participation and dissemination. The first part of the Program was designed to include presentations from related and relevant EU-funded and scoped projects such as the ENCEPP/EMA, HTA/eunethta and ESID.

**Outcomes and deliverables achieved**

**D4 a - Report on currently functional MS databases**

The results from the Survey and the Interviews were presented to the participants of the Workshop WP2 and will be published.

**D4 b - Data mask for the test study of EUReMS**

In preparation for the Workshop, four Working groups were set up to work on the Items addressing each of the four EUReMS Missions: 1) Epidemiological and clinical surveillance; 2) Long-term assessment of treatments; 3) Health Economic and Quality of health care; 4) Patient reported Outcomes and Quality of life.

**Problems encountered**

The results of the WP2 Survey revealed that MS registers are very heterogeneous in scopes but also in quality of data across the specific areas.

**How were problems resolved**
The EUReMS approach will be to apply a Short term Strategy: start with few Registers to compile a core set of items that are commonly collected and cover the first two missions of EUReMS.

**Activities planned for the next period**

The Working Groups WP2 will meet for one day in September in Frankfurt to work on the draft proposal of the EUReMS template and pilot projects. Their Proposal will be send for consultation to the Project partners and presented at the EUReMS meeting at the ECTRIMS in Lyon, 10th October. The final core data set for the test phase should be ready by December 2012.

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**Objective 3: Develop statistical methodology and data analysis strategies that will be applicable and appropriate for studies utilizing the EUReMS.**

**Methodology applied as planned**

Interact with WP1, WP2 and WP4 activities from the beginning of the project.

**Outcomes and deliverables achieved**

**D5 - Presentation on Summary of methodological approaches to the EUReMS Consortium**

**Activities planned for the next period**

**July – Dec 2012:** Address the following issues together with WP2, WP4, WP5 and WP6: how pseudonymization will be performed; Glossary for EUReMS; sources of data acquisition incl. registry data and patient reported outcomes;

**Jan - July 2013:** Supporting other WP in: defining research questions and working hypothesis; defining rules for data acquisition: including criteria for data quality and completeness of datasets; starting the testing phase of the EUReMS.

---

**Objective 4: Establish the IT infrastructure for data collection, collaboration and information on MS across Europe that can be expanded for future research and project.**

**Methodology applied as planned**

EUReMS Portal accesses for project partners and tests. Interaction with WP1, WP2 and WP3 from the start of the project.

**Outcomes and deliverables achieved**

**D7 - Functional EUReMS Collaboration Platform:** Access provided to each partner and to the external evaluator. The Platform is regularly updated and a Manual for user has been shared with the partners.

**Activities planned for the next period**
**Step 1 (July – Oct. 2012):** Together with WP2, WP3, WP5 and WP6: Develop a Glossary for EUReMS terminology; Clarify sources of data collection and Specifications of export frameworks for each register.

**Step 2 (Nov. 2012 – April 2013):** Set-up of a EUReMS register database; Develop a standardized transformation process to merge data of the different registers; Implement an interface for national registers to provide or upload register data exports.

**Step 3 (May 2013 – Oct. 2013):** Develop Standard Operation Procedures for the EUReMS.

**Objective 5: Define the ethical principles, procedures and policies for establishing and operating EUReMS and to develop the appropriate tools to communicate and monitor this in an effective way.**

**Methodology applied as planned**

Develop a concept: ethical and legal issues identified for EUReMS.

**Outcomes and deliverables achieved**

The concept was presented during the SC meeting held in Barcelona, 20-21st May 2012.

**Problems encountered**

The Legal advisor on potential constraints in sharing clinical and data-base information across EU borders still needs to be appointed.

**How were problems resolved**

The Main Partner will facilitate the appointing of the legal Advisor during July - August 2012.

**Activities planned for the next period**

**July - September 2012:** With the help of an external Advisor and together with WP2, WP3, WP4 and WP6, draft the EUReMS Charter.

**October - November 2012:** Consultation and adoption of the Charter by the EUReMS partners.

**Objective 6: Ensure a sustainable and a geographical representative Network of high quality data providers to the EUReMS.**

**Methodology applied as planned**

Recruit and reinforce contacts with members of the EUReMS Network of data providers.
The UK MS Register which opens the way for patient-reported outcomes expressed its interest in collaborating with the EUReMS and could be envisaged as a potential data provider on a longer run. This opportunity will be evaluated and further steps will be taken to concretize this initiative.

**Outcomes and deliverables achieved**

Presentation of the concept on Model Contract.

**Activities planned for the next period**

**July – Oct. 2012:** Second Draft Model Contract

**Oct. – Dec. 2012:** Consult and adopt the Model Contract with the EUReMS partners.

**Jan. - July 2013:** Start conclusion of contracts with Data providers.
4. ANNEXES

4.1. Dissemination Plan
4.2. Evaluation Plan, Evaluation results
4.3. Call for evaluator documentation
4.4. Report of the Kick-off Meeting, 4th July 2011
4.5. Minutes of the SC TCs held between September 2011 and May 2012
4.7. Public report EUReMS M6
4.10 EUReMS Registries survey (WP2)
4.11 EUReMS Brochure

5. REFERENCES

5.1. Lancet Neurology Publication on EUReMS.
5.2. EUReMS Poster ECTRIMS, October 2011
5.3. EUReMS Presentation at the Symposium National MS-Registries in Bergen/Os – Solstrand Hotel 17th-18th April 2012.

6. COPIES OF DELIVERABLES

D3 – Consensus Statement
D5 – Summary of methodological approaches
D7 – SharePoint Feature updates, March 2012