European Union Committee of Experts on Rare Diseases

THIRD MEETING OF THE EUROPEAN UNION COMMITTEE OF EXPERTS ON RARE DISEASES

SUMMARY REPORT

Luxembourg, 24 & 25 October 2011

ABSTRACT

The third meeting of the European Union Committee of Experts (EUCERD) took place on 24-25 October 2011 in Luxembourg. The plenary was preceeded, for the first time, by preparatory meetings by stakeholder groups, a format which will be continued in future meetings.

The first item on the agenda was the unanimous adoption of the EUCERD's first set of recommendations : « EUCERD Recommendations on Quality Criteria for Centres of Expertise for Rare Diseases in Member States ». It was also decided that the EUCERD will start the process to elaborate a EUCERD recommendation on European Reference Networks for rare diseases, along the same lines as the methodology used to elaborate the first set of recommendations.

The EUCERD then was informed about the next steps concerning the implementation of the directive of the European Parliament and the Council on the application of patients' rights in cross-border health care. The EUCERD will closely collaborate with the committee in charge of implementing the Directive. The EUCERD also requested to be informed in a future meeting of the Heath Technology Assessment (HTA) elements of the Directive.

An update on the latest draft of the Road Map for the implementation of the Commission Communication and Council Recommendation on an action in the field of rare diseases for the period 2011-2013 was given. The EUCERD were asked to give any last comments on this version before finalisation as a document of the Commission.

The EUCERD then had the opportunity to hear the results of the call for tender study on a mechanism of knowledge exchange on the clinical added value of orphan drugs (CAVOD) led by Ernst & Young and discuss the EUCERD's implication in the next steps. It was decided that a short EUCERD recommendation on the implementation of the CAVOD process would be written and that a workshop to discuss this will be scheduled in 2012. In addition, a member of EUnetHTA will be invited to the next EUCERD meeting to strengthen collaboration.

Updates were given on the next EU Public Health Programme 2014-2019 and on the contents of the DG Health and Consumers 2012 work plan in the field of rare diseases (RD). RD will continue to be a priority and funding will be available for EU information networks on RD.

DG Research and Innovation activities were presented in the field of RD, including current calls in Framework Programme 7 and the progress made by the International Rare Disease Research Consortium (IRDiRC) to date including the next steps to be made in establishing its governance and adopting a policy document in 2012. EUCERD members were encouraged to take note of the nomination process now open for participation in the Scientific Committees of the IRDiRC which will propose research priorities to the Executive Committee and assess the progress made by research funded by the Consortium.

An update on the EUCERD Scientific Secretariat activities included a discussion of the editorial procedure for the « 2012 EUCERD Report on the State of the Art of Rare Disease Activities in Europe » with the decision taken to consult all Members on the content of the new overview section (Part 1). An update on workshops planned in 2011 by the EUCERD was presented along with a

presentation of the progress made in incorporating RD in the revision of the International Classification of Diseases. All EUCERD members were encouraged to comment on the chapters concerning their speciality available on the site www.eucerd.eu.

The conclusions and consensus reached during the EUCERD workshop jointly held with the EMA on 4 October 2011 on public-private partnership for registries in the field of rare diseases were highlighted in. A number of next steps were discussed, including the process towards establishing EUCERD recommendations in the are of public-private partnerships for registers in the field of RD. It was decided at the workshop that disease registries should be favoured above product registries in the future.

In terms of support for the EUCERD's work from 2012 onwards, the content of the final application for the Joint Action to support the EUCERD, which has been approved and will start in early 2012, was presented with all MS urged to participate in the activities supported by the grant. The tentative schedule for workshops in 2012 was presented to the EUCERD. In order for the workshops foreseen by the Joint Action to be planned effectively, Members planning additional workshops via other EC-funded contracts were asked to make these dates known to the EUCERD Bureau and the EC.

The theme for Rare Disease Day 2012 (29 February 2012) was announced ('Rare but strong together') and EUCERD members were urged to become involved, especially to support their National Alliances for RD and by encouraging public institutions to become 'Friends of Rare Disease Day' and participating in the meeting in Brussels on the 29 February organised by EURORDIS in close collaboration with the EC. The themes of the European Conference on Rare Diseases and Orphan Drugs (23-25 May 2012, Brussels) were also presented and the ways in which the EUCERD will be involved were discussed, as chairs, speakers and at a dedicated «Meet the EUCERD members» networking reception.

The next meeting of the EUCERD will be held on 26-27 January 2012 in Luxembourg.

SUMMARY REPORT

Adoption of the EUCERD Recommendations on Quality Criteria for Centres of Expertise for Rare Diseases in Member States

The recommendations were initially drafted by the EUCERD Scientific Secretariat using the results of previous work on the subject of centres of expertise of the Rare Disease Task Force and the EUCERD as well as the relevant sections of the Cross Border Healthcare Directive, the Council Recommendation on an action in the field of rare diseases and the Commission Communication on rare diseases. This draft was then submitted for comments to the EUCERD prior to a workshop open to all EUCERD members on 8 September 2011 to finalise the text. The finalised text was then submitted to all EUCERD members a month prior to the present meeting for any final comments.

The comments received in this period were discussed with the EUCERD and were proposed for approval. After the approval of several small modifications, the text of the recommendation was adopted as the first recommendation of the EUCERD.

Cross-Border Healthcare Directive: Presentation of the processes at EC level to implement the directive

An overview of the next steps at EC level to implement the directive of the European Parliament and the Council on the application of patients' rights in cross-border health care (otherwise known as the Cross Border Healthcare Directive) was given. The Directive intends to clarify patients' rights to access safe and good quality healthcare in another Member State (MS), and be reimbursed for it, to increase transparency by making mandatory for MS and healthcare providers to make public comprehensive and accurate information on the services, the possible treatment options, the prices, and the quality and safety of the services they provide. The Directive has three main aims: to help patients to exercise their rights to reimbursement for healthcare received in another EU country, to provide assurance about safety and quality of cross-border health care, and to establish formal cooperation between health systems.

Article 12 of the new Directive foresees enhanced cooperation of MS in the area of ERN with a main goal to facilitate improvements in the diagnosis and treatment of certain disease across EU, including RD which requires the concentration of expertise or resources, through the delivery of high quality, accessible and cost-effective health care. The methodology should define the criteria for centres of expertise/reference, for which EU co-operation is the most cost-effective option, and that the development/dissemination of best practices is to the advantage of all MS. The heterogeneity of health care systems in Europe and the broad variety and level of development of models and experiences in centres of expertise/reference and networks means that there is a need to develop a standardised model: the EUCERD recommendations on quality criteria for centres of expertise for RD in MS should be of help for this.

The EC will support MS in the development of ERN and will adopt Delegated and Implementing Acts to do so: the delegated acts will be supported by expert groups and the implementing acts will be supported by a Committee with representatives of each MS. MS should facilitate ERN by connecting providers and centres of expertise throughout their national territory, and by fostering participating in the ERN. Voluntary participation will be in accordance with MS legislation and subject to the fulfillment of required conditions and criteria.

The timeline for the Directive was explained with the 2011-2013 period focused on the legislative process (i.e. the definition of criteria for centres of expertise and ERNs, the exchange of information and expertise on ERN and the publication of criteria for establishing and evaluating ERN) and the 2013-2015 period focused on the deployment process.

The EUCERD will closely collaborate with the committee implementing the directive. It was highlighted that there are existing networks for RD which should be taken into account. It was agreed that the EUCERD should more thoroughly discuss issues surrounding networks and their composition. Members also requested that they be informed in a future meeting of the HTA elements of the Directive.

Format of future EUCERD meetings

The EUCERD expressed their interest to have preparatory meetings by stakeholder groups in the future, and to reflect on the type of group breakout sessions needed. It was also decided to define agendas for these meetings as for the plenary meeting. In addition, all agendas including the plenary agenda) should clearly note whether an agenda point is for discussion, for information or for adoption.

Road Map for the implementation of the EC Communication and Council Recommendation on an action in the field of RD: Future steps

The Road Map, discussed at the two previous meetings, was presented in its current version. Since the previous version, the document has been split into three main parts, as requested by the Committee, to improve the clarity of the information provided: the actions of the EC in terms of implementation, the EUCERD's role in the implementation, and the actions for the implementation financed via Joint Actions in the field of JA.

The EUCERD will play an important role in influencing processes underway and reflecting on the long term future of RD policies, such as the preparation of the 3rd Health Programme 2014-19, the new FP8 (now cllaed Horizon 2020), the revision of the ICD, the World Health Assembly in 2014, etc. The Joint Action for the EUCERD activities has been approved, and many actions, such as OrphaNews Europe are already underway. OrphaNews Europe and the State of the Art of RD Activities reports are extraordinary instruments to promote our work and should be disseminated as widely as possible to reflect what is happening in the field of RD.

The EUCERD was invited to send to the EC their final remarks on the Road Map for 2011-2013 in order to assure that the document is consistent and definitive.

Clinical Added Value of Orphan Drugs (CAVOD): Discussion of the outcomes of the call for tender and next steps for the EUCERD

A detailed overview of the results of the CAVOD study was given. This study concerned the creation of a mechanism of exchange of knowledge on CAVOD:, i.e. to describe the regulatory process followed by an orphan medicine from orphan designation at EU level to reimbursement in the MS; to describe the Health Technology Assessment expertise; to identify the data collection which could be considered as acceptable to establish the relative effectiveness; to propose a format for the Common Assessment Report for CAVOD; to define with stakeholders the most appropriate structure and mechanism for this task; to formulate recommendations for principal tasks of the mechanisms; to propose possible articulation between Common Assessment Reports on CAVOD and the CHMP (Committee for Human Medicinal Products) and COMP (Committee for Orphan Medicinal products) post-marketing obligations whilst adhering to what can be implemented within the current legislative framework on pharmaceutical products; and finally to envisage the potential enlargement of these assessments and mechanisms of cooperation to the broader context of HTAs and to all types of medicines.

Three scenarios and three different direct costs were presented for the CAVOD process (i.e. EUnetHTA, CMD-EMA and EUCERD-EAHC) with the EUnetHTA option shown to present the highest cost-synergies.

Four pilots have been suggested for 2012 which require the support of key stakeholders:

- First Pilot to set up the process for the interaction and information exchange between EUnetHTA and EMA prior to the CHMP opinion
- Second Pilot to run the CAVOD compilation report based on an OMP under final review by the CHMP for the marketing authorisation,
- Third Pilot on the development of the European evidence generation plan with an OMP under reception of a positive opinion of the CHMP including the Risk management plan
- Fourth Pilot to perform a EUnetHTA relative effectiveness assessment with one orphan drug that is already on the market in certain countries and that is about to be reviewed by one member state

The main questions raised by the EUCERD following the presentation included the facility of the implementation of the process and the next steps, including the pilots to be launched.

The next steps for the EUCERD are to formulate a short 2-3 page recommendation for the implementation of the CAVOD process. It was suggested that a representative of EUnetHTA be invited to the next EUCERD meeting to strengthen collaboration with the EUCERD.

EU Public Health Programme: Update on the 3rd EU Public Health Programme and the Sanco 2012 Work Plan

An update on the EU Health Programme and plans for the next Programme 2014-2019 was given. The President of the Commission announced at a press conference on 26 June 2011 the contents for the multi-financial framework (MFF) for the period 2014-2019 (the period of the 3rd Health Progamme). The EC proposes to double the existing resources from the 2nd Programme from 300 to 600 million for the new period, warranted by the implementation of the Cross Border Healthcare Directive and actions in the field of RD. The budget has to be decided on by the Council and the Parliament: the discussions will start in 2012 and the economic crisis may play an important role.

The Sanco 2012 Work Plan will soon be presented. The Work Plan will be essentially similar to the 2011 Work Plan: there will be funding available for EU information networks on RD, a term which is deliberately ambiguous to allow for a wide interpretation in the applications.

DG RTD activities in the field of rare diseases

An update on the activities of DG RTD in the field of Rare Diseases, notably the IRDIRC initiative was given. The International Rare Disease Research Consortium (IRDiRC), established at the initiative of the EC and the US NIH, aims to lead the way with the goal of developing 200 new therapies for RD by 2020 and the means to diagnose most RD by 2020. The 3rd workshop of this Consortium was held in Montreal on 8-9 October 2011. The IRDIRC is open to all research funding bodies with programmes with more that $10 million US over a 5 year period supporting the objectives of the IRDiRC.

The milestones of the IRDiRC were outlined to map the way to the cited objectives and the governance structure was explained.

The next steps are to set up the Scientific Committee: the nomination period will be open from 1 November to 15 December 2011, with a decision on composition by the Executive Committee in January 2012. The Executive Committee will identify names of projects funded from 2010 onwards and their representatives for each Working Group by 1 January 2012. A policy document will be produced after consolidation and consultation of IRDiRC policies and guidelines. An Executive Committee meeting will be held in January 2012 in Brussels to adopt the policy document, to decide on the composition of the Scientific Committees, to decide on the dates and hosting of the first meetings of these Committees, to start the composition of the Working Groups and to agree on the next IRDiRC meetings.

The EC supports RD research via the Health theme of FP7 (2007-2013): in October 2011, 65 projects had received €313 million of EC support in the fields of natural history, pathophysiology, rare Mendelian phenotypes of common diseases, and also the development of preventative, diagnostic and therapeutic interventions. In the current call for proposals in the Health Theme, €108 million is earmarked for the following areas: support for international rare diseases research, clinical utility of -omics for better diagnosis of rare diseases, databases, biobanks and clinical 'bio-informatics' hub for rare diseases, preclinical and/or clinical development of substances with a clear potential as orphan drugs, observational trials in rare diseases, and best practice and knowledge sharing in the clinical management of rare diseases.

Outcomes of the EUCERD/EMA workshop on registries – 4 October 2011

An overview of the outcomes of the recent EUCERD/EMA workshop on the subject of public-private partnering for rare disease registries, held at the EMA in London was presented. The workshop was a very popular initiative and was the fruit of previous work on the subject of registries conducted by the RDTF and Scientific Secretariat of the RDTF/EUCERD, including the RDTF reports on "Patient registries in the field of rare diseases" (2008/2011) and "Health indicators for rare diseases" (2010, 2011), as well as the Orphanet Report "Disease registries in Europe" (2011).

The objectives were to avoid the duplication of work, discuss sustainability issues and tackle the burning issue of a unique source of information by disease, not by product, whilst also dealing with the requests of regulators concerning the clinical utility of new drugs for which data is needed and of which registers are excellent source. As a wide range of high quality data is needed, it is not wise to ask companies to set up data collection for product, without thinking of the wider scope and how to best serve stakeholders.

In conclusion, there was a consensus that it is imperative that fragmentation be avoided: public/private partnership is necessary, and although it cannot be made mandatory, it can be suggested by the EMA at the relevant moment in the process. It was also suggested that technical and methodological support be provided as should rules of conduct for such partnerships. Regulatory frameworks and standards must be assured. Open-access to data should be promoted. Management by academia was identified as a solution to ensuring long term sustainability. In addition, this data must be valorised through the cross-border use of E-Health instruments.

The next steps proposed are to establish a small working group of stakeholders to work on the next steps, in order to move forward and concentrate on future opportunities (i.e. HTA requirements for MS). Liaison with CAVOD plans should be assured with the EUCERD as right forum to discuss issues of clinical utility. The possible opportunity or threat posed by the revision of the data protection legislation must also be carefully considered.

It was proposed that a small working group convene to prepare a first draft of a recommendation for consultation by the EUCERD, with a possible half-day workshop attached before next meeting of the EUCERD in January 2012 to discuss the document, based on the procedure used for the elaboration of the Recommendations for centres of expertise. The EUCERD needs to move quickly on this issue and this document will give a vision of the necessity of this type of partnership, like for CAVOD.

2011 EUCERD report on the state of the art of RD activities in Europe: Dissemination and evolution for next year's edition

Charlotte Rodwell gave an update on the EUCERD report on the State of the Art of Rare Diseases Activities in Europe was given. This year's edition, published in July 2011 covered activities up to the end of 2010. Three distinct 'products' target specific audiences: Part 1 (new this year) is an overview of RD activities in Europe and key developments in 2010 destined for the general public and political decision makers to raise awareness and has been printed and is available in PDF format. Part 2 concerns European Commission and other European Activities and Part 3 concerns activities at

national level: these parts are destined for RD stakeholders to maximize impact of data at EU and country level in the field and are available in PDF format.

The 2012 edition of the report will be produced in the context of the Joint Action to support the EUCERD and will cover up to the end of 2011. This report will have 4 distinct parts: in addition to the 3 parts of the 2011 report, the key developments section will be a separate part of the report and will be developed. A tentative timeline for the production of the report was given.

In order to improve the update of national data, MS representatives were requested to fulfill the role of editor of their national data, which will include elaborating further the updated information provided by the Scientific Secretariat in consultation with national patient alliances, Orphanet country coordinators, MS COMP representative, National plan/strategy coordinators, research agencies, EUCERD members in the country and E-Rare partner institutions. The key developments at national level in 2011 will be extracted for the overview to add to the key developments extracted from the data collected on activities at EC-level.

It was decided by the Committee that the overview section would be sent to all members for their comments and criticisms rather than to create a new editorial board.

Joint Action to support the EUCERD 2011 – Content of the final application

An overview of the content of the final application which has recently been accepted by the EAHC for financing for the total budget requested was presented. All Members were requested to play an active role in this Joint Action through the work packages led by different institutions: as many partners were listed as collaborating partners, but there was limited space and not all names were included, however all EUCERD members can be involved and all MS have expressed their interest to do so.

Further detail on each work package (as outlined in the supporting documentation provided before the meeting) was given.

The workshops planned in the context of the JA will have clear aims and should gather together smaller, expert groups to work outside of the main EUCERD meetings: we need to agree on the tasks and delegate them to these groups. Around 13 workshops are foreseen over the 3 year period of the Joint Action with the possibility of requesting extra ad hoc funding from the EC to respond to questions that should be addressed in other areas. There is the possibility of integrating work into workshops of other EC-funded projects, i.e. Epirare.

Transparency will be ensured by giving feedback from workshops at EUCERD meetings and by feedback from the evaluation team.

All EC-funded projects planning workshops in 2012 should now communicate these details to the Bureau so we can compile and check there is no overlap.

Workshops in 2011

An update on the upcoming ad hoc workshops organised in the context of the current Joint Action to support the RDTF/EUCERD Scientific Secretariat was presented. A one day workshop will be held in Montpellier on 4 November 2011 in the context of the Rare2011 EuroBioMed conference. There will be 3 sessions on key issues: ensuring visibility of rare diseases in health information systems, partnering to optimise the use of patient data to improve clinical research and health care, and improving access to expertise and quality care.

On 1 December 2011 and extra workshop on the classification of genetic diseases will be held thanks to extra financing from the EC. Top experts will be invited to work on this topic in the context of the revision of the International Classification of Diseases. A wider public consultation will be held on the beta draft of the proposal of the Rare Diseases Topic Advisory Group for ICD-11.

The cross-referencing of the Orphanet nomenclature with other classifications will be available online by December 2011: we will communicate with Snomed-CT, MedDRA and MeSH on how they can improve. The Orphanet nomenclature, the model for ICD-11, is available on the new site www.orphadata.org.

In terms of ICD-11, first drafts are available on www.eucerd.eu for: haematology, endocrinology, nutrition, metabolism, immunology, neurology, malformations and pneumology (ongoing). Second drafts are available for: haematology, endocrinology, nutrition, metabolism and immunology.

The other chapters must first be revised by the TAG of the medical specialty concerned: we will add RD to them, but will not touch the structure as done for the chapters where the TAG RD was leading.

Organisation of cooperation between EC-funded projects to ensure resource and knowledge sharing and to optimise outcomes *(Ségolène Aymé and Kate Bushby)*

The rational for cooperation between EC-funded projects in the field of rare diseases was presented: actions are funded by both DG RTD (support to 161 RD registries and networks as tools for research through FP5, FP6 and FP7 calls) and DG Sanco (support to 23 RD information networks through the Public Health Programme calls) which have sometimes some overlap (i.e. data collection, establishing registries for specific diseases), as well as projects funded through the E-Rare ERA-Net (29 consortiums).

The issue of how to collaborate was raised: this is already underway thanks to workshop were experiences were shared. More efforts are being made to disseminate the results of projects widely through OrphaNews Europe, but more could be done by, for example, proposing that all projects funded by DG Sanco should be obliged to publish their work plan at the start of the grant agreement in the newsletter, as well as results when of interest. EC funded projects should also feed into the Orphanet database (as a pre-requisite for finalising the grant agreement) by providing information on guidelines they produce, data on expert centres in their networks, data on diagnostic tests/laboratories in their networks etc.

There is little funding for RD so there is the moral obligation to make the most of every project. There are ways to optimise collaborations at no cost. There is a need to better define competitive calls, especially in the field of public health.

Rare Disease Day 2012

An update on the preparation of Rare Disease Day (RDD) 2012 which will be held on 29 February 2012 was presented. 2012 will see the 5th RDD and the theme will be solidarity with the slogan "Rare but strong together". The aim is to next year pave the way to RDD becoming an international WHO day, so the international dimension will be stressed.

EUCERD Members were encouraged to get involved in the Day, for example by supporting activities at national level by engaging with and supporting National Alliances of Rare Diseases (who are the national coordinators for RDD) and by engaging public institutions such as becoming "Friends of Rare Disease Day" via the website. EUCERD members are also encouraged to participate in the EURORDIS meeting in Brussels organised closely with the Commission on the occasion of the Rare Disease Day which will be held on Wednesday 29 February 2012 at the International Press Centre, Residence Palace.

European Conference on Rare Diseases and Orphan Products 2012 Brussels (23-25 May 2012): Programme, satellite activities and the role of the EUCERD

Organised by Eurordis and co-organised by the DIA, the conference's partners are the EUCERD, EMA (COMP), Orphanet, ESHG, EuropaBio-EBE/EFPIA and NORD. The Members of the EUCERD who will participate as co-chairs and members of the programme committee were listed, as were the advisors to the programme committee.

Day 1 will be a Pre-Conference Day with multiple parallel activities such as satellite workshops. Networking will be organised throughout the 3 days.

EUCERD Bureau members and other members are involved in the programme committee and some will be advisors to programme committee and theme leaders to help develop the programme. The plenary session will include an overview presentation based on Annual Report of the « State of the Art of Rare Diseases in Europe » of the EUCERD prepared in the scope of the Joint Action for the EUCERD. The call for posters (open until 15 January 2012) for the poster board and oral presentations will be widely disseminated to and through EUCERD members. General information concerning the conference can be found on a special website: www.rare-diseases.eu. EUCERD Members are warmly urged to attend the Conference and participation in the "Meet the EUCERD members" networking drinks reception on 24 May.

Next meeting dates

The next meeting will be held on 26-27 January 2012 with the EUCERD Joint Action and Kick Off meeting to be held beforehand on 25 January. The second meeting in 2012 is tentatively scheduled for 20-21 June 2012 with a workshop on 19 June 2012. The third meeting in 2012 is tentatively scheduled for 25-26 October with a workshop on 24 October 2012.

Conclusions

- The next meeting of the EUCERD will have a format with preparatory meetings with clear agendas by stakeholder group, and breakout sessions on various topics within the meeting will be considered.
- All agendas will clearly note if points are for information, discussion or adoption.
- Work will be started on the elaboration of a recommendation on criteria for European Reference Networks for RD.
- A presentation on the HTA elements of the cross-border health care directive will be given at the next EUCERD meeting.
- EUCERD members were requested to send any last minute corrections and comments on the Road Map version 4.0 to the EC.
- A representative of EUnetHTA will be invited to the next EUCERD meeting to strengthen collaboration with the EUCERD.
- The next steps concerning the way forward with the CAVOD process will be determined quickly.
- Nominations for participation in the Scientific Committees of the IRDiRC are now open and the template letter is available on the website of the IRDiRC.
- A drafting group will be composed to work on recommendations for next steps in the area of public-private partnership for registries for proposal to the EUCERD.
- Members should read all *OrphaNews Europe* newsletters, communications sent to them by the Scientific Secretariat/EC secretariat and visit the EUCERD website to keep up to date with meetings and workshops.
- All projects planning workshops in 2012 should communicate these dates to the Bureau and the EC so as to verify that there is no overlap with the workshops planned by the EUCERD in the context of the Joint Action.
- EUCERD Members were encouraged to input on the ICD revisions process for their medical specialties: the drafts are available in PDF format on the EUCERD website.
- EUCERD Members were encouraged to participate in Rare Disease Day 2012 and to become friends of the day.
- EUCERD Members are warmly urged to attend the European Conference on Rare Diseases and Orphan Products (23-25 May 2012 in Brussels) and participate at the “Meet the EUCERD members” networking drinks reception on 24 May 2012.
- Member States who will hold EU presidencies from mid-2012 were asked to follow-up on the invitations sent to the permanent representations concerning the hosting of a EUCERD meeting in their country during the presidency.

- The next meeting will be held on 26-27 January 2012 with the EUCERD Joint Action and Kick Off meeting to be held beforehand on 25 January. The second meeting in 2012 is tentatively scheduled for 20-21 June 2012 with a workshop on 19 June 2012. The third meeting in 2012 is tentatively scheduled for 25-26 October with a workshop on 24 October 2012.