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EUCERD Joint Action – Working for Rare Diseases (EJA)

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Coordinator: Kate BUSHBY, University of Newcastle upon Tyne



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Communication Strategy & Website;

Annual State of the Art report; OrphaNews newsletter

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Abstract: The Dissemination WP elaborated a communications strategy and website (www.eucerd.eu) to promote the activities of the European Union Committee of Experts on Rare Diseases (EUCERD) and the EUCERD Joint Action, as well as to exchange experiences and information concerning initiatives in the field of rare diseases at European level. Three editions of the annual report on the State of the Art of Rare Diseases Activities in Europe, produced with the input of the EUCERD members, were published in July 2012, July 2013, and July 2014. OrphaNews (www.orphanews.org), the newsletter of the EUCERD and the rare disease community, with over 16'000 subscribers was produced at a rhythm of 2 issues per month during the duration of the contract to communicate on the activities of the EUCERD and EUCERD Joint Action.	
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1. Introduction

The dissemination work package was charged with developing a communications strategy and communications tools in order to promote and communicate on the activities of the European Union Committee of Experts on Rare Diseases (EUCERD) and the EUCERD Joint Action, and to promote the exchange of experiences and information concerning rare disease initiatives at European level. These tools included a new version of the existing EUCERD website with private sections for EUCERD Members and EJA partners, the continuation of the publication of the OrphaNews newsletter (previously the newsletter of the EC Rare Disease Task Force before becoming that of the EUCERD in 2010), the creation of executive summaries and Powerpoint presentations to more easily disseminate EUCERD recommendations, and the annual publication of the report on the State of the Art of Rare Disease Activities in Europe, which had been first published in 2010 as an output of the previous RDTF/EUCERD Scientific Secretariat Joint Action (N° 2008 22 91).

2. Presentation of results

The objectives of this WP have been met in due time. The results are presented as follows: communications strategy, website, report on the State of the Art of Rare Diseases Activities in Europe, OrphaNews newsletter, other dissemination activities.

2.1. Communications strategy

Following the Kick-Off Meeting, a common graphic identity for the EUCERD/EUCERD Joint Action and communications strategy was developed for M6 (see Annex). This included a new logo for the EUCERD and derived logo for the EUCERD Joint Action to establish a common graphic identity between the two, and a colour chart to provide graphical cohesion for documentation produced.



Figure 1: EUCERD general logo and EUCERD Joint Action logo

The communications strategy detailed the communications tools available/elaborated to promote the outputs of the EUCERD/EUCERD Joint Action, including the www.eucerd.eu website (see section 2.2.), the OrphaNews newsletter (see section 2.4.), and the annual State of the Art Report (see section 2.3.).

In addition to these channels of communication, EUCERD Members, in particular Member States representatives as collaborating partners of the EUCERD Joint Action, were entrusted with disseminating the outcomes of the EUCERD and EUCERD Joint Action. To facilitate this, as foreseen in the communication strategy, Executive Summaries were produced (http://www.eucerd.eu/?page_id=277) for EUCERD Recommendations, meetings and EJA reports, such as the State of the Art Report, to ease dissemination. In addition, the EUCERD Members were provided with reusable PWP sets concerning the EUCERD's Recommendations so as to promote their dissemination: (http://www.eucerd.eu/?page_id=13).

Other channels of communication on activities included EUCERD meetings and presentations as invited speakers at conferences (see list of communications provided by WP1 and section 2.5.)

The communications strategy also establishes procedures concerning dissemination of information to the EUCERD members, and the policy concerning the language used for documents produced.

A contact database was also established for partners to use when seeking to identify national channels for consultation on specific topics and communication. The database was searchable by name, country, organisation etc. The database was populated with contacts provided by each partner.

Further to the development of this communications strategy, the WP1 Management team launched and managed a EUCERD Joint Action Twitter account: @RareDiseasesEU in May 2013 which has to date 680 followers and follows over 300 relevant Twitter feeds.

2.2. Website

The dissemination WP aimed to develop a new website (www.eucerd.eu) to inform the public about the activities of both the EUCERD and the EUCERD Joint Action. The existing EUCERD website was transferred to a WordPress tool and the site architecture and content was redesigned as scheduled by September 2012, following approval by the partners at the EJA Kick-off Meeting. Two separate private areas, for EUCERD Members and for EUCERD Joint Action partners were included. The website included the following tabs:

- About the EUCERD
- EUCERD Joint Action
- EUCERD Activities
- EUCERD Recommendations
- EUCERD Reports
- Press releases
- Contact
- Other resources (links to national, European and international external resources)



Figure 2: EUCERD website home page www.eucerd.eu

The front page of the website was further overhauled in 2014 due to the end of the EUCERD's mandate. The site now serves as an archive of the EUCERD's activities, reports and recommendations, whilst the dedicated tab concerning EUCERD Joint Action activities remains updated to the end of the Joint Action. Visitors seeking information about the Commission Expert Group on Rare Diseases are redirected to the relevant part of the EC Public Health portal. The communications team has worked in collaboration with the EC website team to ensure that the State of the Art Reports and EUCERD recommendations have been transferred to the Expert Group's new website.



Figure 3: EUCERD Joint Action project area on www.eucerd.eu

The dedicated EUCERD Joint Action section of the website includes a specific page per work package, describing the work package's activities and objectives, and providing links to dedicated workshop pages, reports, deliverables. It also includes a page inventorying all the EUCERD Joint Action workshops, and another providing links to all outputs and deliverables. A dedicated page concerning documents for the EJA partners is provided and is password protected.

Statistics concerning the frequentation of www.eucerd.eu are monitored using Google Analytics, and from July 2013 a dedicated, in-house tool was created to monitor the download of documents such as the State of the Art Report.

The EUCERD Joint Action area of the website continues to be updated as and when workshop reports and deliverables/outputs are made available and communicated to the website team by the Management team.

2.3. Annual report on the State of the Art of Rare Diseases Activities in Europe



Figure 4: The five volumes of the 2014 edition of the State of the Art of RD Activities in Europe report

Since 2010, the publication of an annual report on the State of the Art of Rare Disease Activities in Europe has been supported by the EC, firstly via the RDTF/EUCERD Scientific Secretariat Joint Action (N° 2008 22 91), and from 2012 via the EUCERD Joint Action. This multi-volume report provides information concerning the state of the art of activities at both European and Member State levels, in particular the advances made to date in the implementation of the Council Recommendation on an Action in the field of rare diseases, notably the elaboration and implementation of national plans/strategies for rare diseases at national level. Elaborated with the input of stakeholders at national level and with the help of the members of the EUCERD/Expert Group on Rare Diseases, the report provides a transversal view of the rare disease field and its evolution over the past few years.

The report was published annually during the EUCERD Joint Action (July 2012, July 2013, July 2014) in 5 different volumes (totaling around 500 pages):

- 1) Overview of the state of the art of RD activities in Europe (70 pages)
- 2) Part II: Key developments in the field of rare diseases in the previous year (90 pages)
- 3) Part III: European Commission activities in the field of rare diseases (50 pages)
- 4) Part IV: European Medicines Agency activities and other European activities in the field of rare diseases (30 pages)
- 5) Part V: Activities in EU Member States and other European countries in the field of rare diseases (280 pages)

In addition, the national reports provided in Part V are produced as individual country reports separately, so as to ease dissemination at national level. Some countries, when national financing has been identified, have translated these reports into their national language.

Part I is a general overview, geared to a more general public, whilst Parts II, III, IV and V provide a more detailed report of the situation for stakeholders who wish to learn more about the situation at European or national level.

The detailed means and methodology for the elaboration report is available in each volume of the report. One of the main sources of information for the report is a survey of the articles published in OrphaNews in addition to the collaboration with all EUCERD Members to collect information at national level and European level on initiatives in the field of rare diseases.

The report was widely distributed, both electronically (by mailing and in particular via OrphaNews), and in paper format (uniquely the Part I “Overview” section) each year to all EUCERD/Expert Group Members and to

targeted stakeholders including EU Health Programme Committee Members, EMA Committee on Orphan Medicinal Products members, international contacts in the field including RD patient alliances in non-European world regions, and via EUCERD meetings, EJA workshops, the European Conference on Rare Diseases and Orphan Products, and the European Society of Human Genetics annual conference.

2.4. OrphaNews newsletter

OrphaNews covers both scientific and political news of interest to the rare disease community, including articles concerning the activities of the EUCERD/Expert Group and the EUCERD Joint Action, with spotlight articles on the outputs of the Joint Action already published/to come with the finalisation of the EJA activities following the final conference foreseen in September 2015. The different columns include: reports on the latest developments in the field of rare diseases and orphan drugs, including new syndromes, new genes, basic and clinical research, national and international policy, disease surveillance, clinical trial updates, orphan drug approvals, funding opportunities, ethical, social and legal issues, news from patient associations, upcoming events, and new publications.



Figure 5: OrphaNews newsletter

OrphaNews is suited to, and subscribed to by, all sectors of the rare disease and orphan drugs community including policy makers, scientists, health professionals, patient representatives, geneticists, members of the biopharmaceutical industry and anyone interested in staying informed of important developments and new initiatives in the field of rare diseases and orphan drugs. OrphaNews is a highly subscribed newsletter, with the number of subscribers increasing from 13'000 to around 16'000 during the duration of the Joint Action.

The OrphaNews letter was published at a frequency of two issues per month throughout the duration of the contract as foreseen. The survey of scientific literature and political news is carried out at the INSERM by the Editor of the newsletter and is reviewed by an Editorial Committee at the INSERM on a twice-monthly basis. The draft newsletter is sent for review to the Editorial Board before publication. Until the end of 2013, the Editorial Board was composed of the EUCERD's Bureau and representatives from the relevant European Commission services and EU Agencies, before it was renewed with the establishment of the Commission Expert Group on Rare Diseases to include the Expert Group-nominated stakeholder contact points and European Commission representatives in early 2014.

A tool was made available in M1 to translate the newsletter to other languages if national funding was identified. For the moment, the newsletter is translated into French and into Italian.

2.5. Other dissemination activities

The WP1 Management team maintains a listing of the presentations/posters/articles of EUCERD/EUCERD Joint Action outputs by partners, which includes regular updates to the EUCERD/Expert Group on Rare Diseases. The Joint Action coordinator and the WP leader (and former Chair of the EUCERD) have widely presented the work of the EUCERD Joint Action/EUCERD at meetings and conferences internationally.

One of the main forums for dissemination on the outputs of the Joint Action was the 2014 European Conference on Rare Diseases and Orphan Products in Berlin where a number of talks and posters were presented (the WP6 poster won the poster prize), as well as a dynamic presentation based on the State of the Art Report during the plenary session.

The national conferences carried out within WP4 were also key events to promote the EUCERD's recommendations and activities and the work of the EUCERD Joint Action, ensuring that these European activities impact on national policies (for more information, see the Deliverable report for WP4). Individual EUCERD members, as collaborating partners, also played key roles in disseminating further these results.

3. Critical analysis of results

The WP has succeeded in delivering the results expected. The critical analysis of results and challenges faced is presented by as follows: Communications strategy, website, State of the Art of Rare Diseases Activities in Europe, OrphaNews newsletter, other dissemination activities.

3.1. Communications strategy

The communications strategy and the maintenance of the communications tools (website, newsletter, State of the Art Report, executive summaries etc.) was carried out as foreseen. More detail concerning results of each of these tools can be consulted in 3.2.,3.3 and 3.4. The activities of the EUCERD/EUCERD Joint Actions have been disseminated at many meetings and conferences (see communications list established by WP1), with all partners playing a key role in this activity, in particular the JA Coordinator and the WP2 leader as Chair of EUCERD.

The communications WP had to confront a number of difficulties during the duration of the Joint Action, in particular, the change from the EUCERD to the EC Expert Group on Rare Diseases in 2014. The transitional period and dissolution of the EUCERD Bureau meant that many communications activities were placed on hold whilst the status of the EUCERD Joint Action in relation to the new Expert Group was defined. The communications strategy had successfully worked up to July 2013 to establish a EUCERD 'brand' with a clear link between the Committee and the Joint Action, and the change in name introduced a level of confusion during, and after, this transitory phase.

In particular, the communications leaflet intended to present the EUCERD and the EUCERD Joint Action's role in supporting the committee, was placed on hold in 2013 at the request of the European Commission in the light of the change to the name and status of the Committee. Although preparatory work had advanced on its content, the final publication was not given the green light by the EC. However, an article highlighting the achievements of the EUCERD was published in the Orphanet Journal of Rare Diseases to mark Rare Disease Day 2014: entitled "[The European Union Committee of Experts on Rare Diseases: three productive years at the service of the rare disease community](#)".

It was also foreseen that a visualisation of the road map to the implementation of the Commission Communication and Council Recommendation, planned to be adopted by the EUCERD at one of their first

meetings and foreseen in the communications strategy, was not created as the road map was never formalised/finalised. However, a dynamic Prezi presentation of the RD landscape in Europe is available on the site.

It should be noted that the existence of a separate Europlan website (see 3.2.) and branding was a significant challenge to the cohesiveness of the EUCERD/EUCERD Joint Action communications strategy. Efforts were made by the communications team as far as possible to reduce duplication between the two sites, but such duplication of websites within Joint Actions should be avoided in the future.

In practice, due to the effort required to maintain such a database, instead of using the EUCERD Joint Action database, it was deemed more efficient to solicit recommendations from EUCERD MS representatives to identify relevant contacts at national level for participation in workshops/groups etc.

3.2. Website

At the meetings of the EUCERD, Members gave positive feedback, stating that the website, although simple, was up-to-date, easy to navigate and for information to be found.

The website had on average around 900 visitors per month, with around 1'000 sessions per month (period January 2014-December 2014). The top ten countries visiting the site were from: France, Italy, United Kingdom, Belgium, Germany, Spain, United States, Netherlands, Portugal and Switzerland.

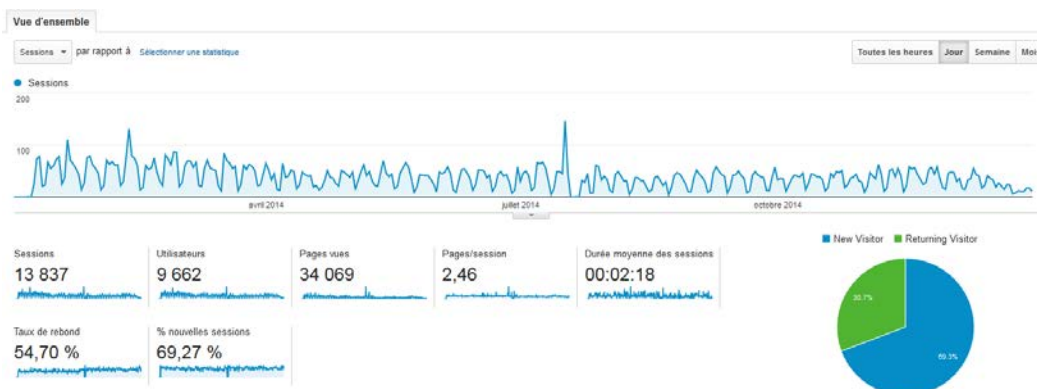


Figure 6: Google Analytics review of the period January – December 2015

The most highly accessed and downloaded documents continue to be the different sections of the annual State of the Art of Rare Diseases reports which amount to around 15'000 downloads (all sections combined) per year.

The monitoring of downloads for the reports produced via the Joint Action, has been complicated by the publication of EJA outputs separately on the EUROPLAN and Eurordis websites, as well as recently for the State of the Art report on the new Expert Group website on the EC's website.

Indeed, one of the challenges of the communications work package has been to avoid the unnecessary reproduction of information across these different websites. The Communications team has endeavoured to reduce the possible confusion and overlap in terms of the EUCERD/EJA and Europlan websites, as far as possible so as to clearly communicate to the wider community.

It should be mentioned that although it was originally planned to create a common workspace for EUCERD members to elaborate recommendations/reports. However, due to the complexity of the process and the mediation required, it was decided to not implement this functionality and to instead solicit input via email.

3.3. Annual report on the State of the Art of Rare Diseases Activities in Europe

The report is a valuable resource for the rare disease community and has been met with praise at both the EU and MS levels for providing valuable insight into understanding the current resources and activities in the field of rare diseases across Europe that will help determine future strategies to meet the needs of rare disease patients and their families in Europe and further afield. Indeed, the report is a highly accessed document, with around 15'000 downloads of all sections combined recorded annually.

The results of this report have been widely used by EUCERD Members when communicating about National and EU initiatives in the field of rare diseases. In particular, the results were used to create a dynamic presentation during the plenary session of the 2014 European Conference on Rare Diseases and Orphan Products, co-organised by EURORDIS and the DIA in Berlin (<https://prezi.com/5s-clqxzcov4/ecrd-2014-video-rare-diseases-an-ever-evolving-landscape/>). In addition, an open access article based on this work was published at the invitation of the editors entitled: “[Rare disease policies to improve care for patients in Europe](#) », Charlotte Rodwell, Ségolène Aymé, *Biochim Biophys Acta*. 2015 Feb 25. pii: S0925-4439(15)00059-9. A non-exhaustive list of presentations based on this report is provided in the communications list compiled by WP1.

One other particular success was the role played by the report in implicating EUCERD Member State Representatives in the RD landscape in their own countries. The elaboration process evolved over the course of the EUCERD Joint Action to further implicate the involvement of EUCERD/Expert Group Member State representatives by giving them the responsibility of acting as editors and validators of the information in the report concerning their country. They were entrusted with to elaborate this national information in consultation with a wide range of stakeholders identified at national level. More information concerning this process is included in the methodology of the report (see State of the Art Report).

3.4. OrphaNews Newsletter

The OrphaNews letter was already an established and valued communication tool for the rare disease community prior to it being supported by the EUCERD Joint Action. The established readership and subscription list of now around 16'000 subscribers from all stakeholder groups across Europe and the globe has proved very valuable to ensuring that the activities, recommendations and opinion of the EUCERD/Expert Group and the outcomes of the EUCERD Joint Action, have been, and will continue to be widely disseminated (N.B. articles concerning the final outputs of the EJA are foreseen following the final EJA conference in September 2015).

The EUCERD Bureau/ Expert Group stakeholder contact points have played an integral role as members of the Editorial Board and EUCERD/Expert Group members have been given the responsibility to submit national news to the newsletter to further improve the exchange of information and knowledge concerning rare disease initiatives, and to encourage subscription to the newsletter at national level. Orphanet country coordinators are also key national contact points providing national news and promoting readership at national level.

4. Conclusion

The Communications WP has succeeded in elaborating and implementing a communications strategy and delivering the necessary tools to promote the outputs of the EUCERD and the EUCERD Joint Action,

including the delivery of the www.eucerd.eu site (for both the EUCERD and the EJA), the on-target publication of the OrphaNews newsletter, and the delivery of the three annual State of the Art of RD Activities reports. The WP also delivered communications aids to facilitate the dissemination of outputs by EUCERD members and EJA partners and succeeded in making EUCERD Members active partners in disseminating information.

Within the WP, the work on the newsletter contributed greatly to the annual State of the Art Report. Outside of the WP2, the communications teams coordinated with the Management team, and other WP, to ensure the update of the website, the creation of OrphaNews articles on outputs, and the effective dissemination of EJA outputs. WP2 sought with the WP1 Management team and EC solutions to the challenges raised by the change of the EUCERD to the Expert Group on Rare Diseases.

Outside of the Joint Action, contacts were established with other European projects so as to report on their outputs in the annual State of the Art Report (e.g. Support-IRDIRC, Orphanet, E-Rare, etc.). In particular, Orphanet country coordinators (Orphanet Europe Joint Action associated and collaborating partners), acted as national contact points, providing national news for the OrphaNews newsletter, contributing to the State of the Art report, and promoting readership of both OrphaNews and the State of the Art report at national level.

5. References

5.1. State of the art reports

Individual reports on the activities in each of the European countries covered by each year's report are also available via the country pages of the '[National resources](#)' sub-tab on www.eucerd.eu.

2014 Edition

- [2014 Report on the State of the Art of Rare Diseases Activities in Europe – Part I: Overview of Rare Disease Activities in Europe – July 2014](#)
- [2014 Report on the State of the Art of Rare Diseases Activities in Europe -Part II: Key developments in the field of rare diseases in Europe in 2013 – July 2014](#)
- [2014 Report on the State of the Art of Rare Diseases Activities in Europe -Part III: European Commission activities in the field of rare diseases – July 2014](#)
- [2014 Report on the State of the Art of Rare Diseases Activities in Europe -Part IV: European Medicines Agency activities and other European activities in the field of rare diseases – July 2014](#)
- [2014 Report on the State of the Art of Rare Diseases Activities in Europe -Part V: Activities of European Member States and other European countries in the field of rare diseases – July 2014](#)

2013 Edition

- [2013 Report on the State of the Art of Rare Diseases Activities in Europe – Part I: Overview of Rare Disease Activities in Europe – July 2013](#)
- [2013 Report on the State of the Art of Rare Diseases Activities in Europe -Part II: Key developments in the field of rare diseases in Europe in 2012 – July 2013](#)
- [2013 Report on the State of the Art of Rare Diseases Activities in Europe -Part III: European Commission activities in the field of rare diseases – July 2013](#)

- [2013 Report on the State of the Art of Rare Diseases Activities in Europe -Part IV: European Medicines Agency activities and other European activities in the field of rare diseases](#) – July 2013
- [2013 Report on the State of the Art of Rare Diseases Activities in Europe -Part V: Activities of European Member States and other European countries in the field of rare diseases](#) – July 2013

2012 Edition

- [EUCERD Report: 2012 Report on the State of the Art of Rare Diseases Activities in Europe – Part I: Overview of Rare Disease Activities in Europe](#) – July 2012
- [EUCERD Report: 2012 Report on the State of the Art of Rare Diseases Activities in Europe – Part II: Key developments in the field of rare diseases in Europe in 2011](#) – July 2012
- [EUCERD Report: 2012 Report on the State of the Art of Rare Diseases Activities in Europe – Part III: European Commission activities in the field of rare diseases](#) – July 2012
- [EUCERD Report: 2012 Report on the State of the Art of Rare Diseases Activities in Europe – Part IV: European Medicines Agency activities and other European activities in the field of rare diseases](#) – July 2012
- [EUCERD Report: 2012 Report on the State of the Art of Rare Diseases Activities in Europe – Part V: Activities of European Member States and other European countries in the field of rare diseases](#) – July 2012

5.2. Other EUCERD/EJA communications tools

- [Communications strategy](#)
- [EUCERD/ EJA website](#)
- [OrphaNews newsletter and archives](#)
- [Executive summaries](#)
- [EUCERD Recommendations Powerpoint Presentations](#)