RD ACTION
DATA AND POLICIES
FOR RARE DISEASES

Co-funded by
the Health Programme
of the European Union

D2.1. RD-ACTION DISSEMINATION PLAN

[Document status]

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Annexes	Table I: Dissemination rules of Joint Action Table II: Stakeholder Analysis Table III: Dissemination Chart
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CONTENTS

1. INTRODUCTION

RD-ACTION, Promoting the Implementation of Recommendations on Policy, Information and Data for Rare Diseases, is an EU Joint Action (JA) aiming to ensure that there is an integrated, European approach to the challenges faced by the rare disease community.

The Joint Action, co-funded by the Health Programme of the European Union, brings together 34 beneficiaries and 30 collaborating partners in 40 countries. RD-ACTION is articulated in six Work Packages (WPs), three of which are cross-cutting (coordination, dissemination and evaluation) and three specific Work Packages. These are the sustainability of Orphanet, the European database for rare diseases (WP4); steering, maintaining and encouraging the adoption of Orphacodes across EU Member States (WP5) and policy development for rare diseases and integration with other relevant initiatives (WP6). The six Work Packages consist in 30 deliverables.

RD-ACTION started in June 2015 and the “kick-off” meeting took place on 16 September 2015 in Luxemburg. This JA will last for a period of three years, until the end of May 2018.

This document, the RD-ACTION Dissemination Plan, deliverable 2.1 of WP2, will be reviewed and updated by EURORDIS every six to eight months and disseminated to all partners in order to ensure that the information within it is accurate and relevant.

2. OBJECTIVES

2.1. RD-ACTION

RD-ACTION has three general objectives:

- To support the further development and sustainability of the Orphanet database on rare diseases. This database is the biggest repository of information about rare diseases globally, and is run by a large consortium of European partners;
- To contribute to solutions to ensure an appropriate codification of rare diseases in health information systems;
- To continue the implementation of the priorities identified in the 2009 Council Recommendation and the 2008 Commission Communication on Rare Diseases (RD), and to support the work of the Commission Expert Group on Rare Diseases (CEG-RD) by gathering expertise and producing data necessary to its action.

The specific objectives of the JA are:

1. To maintain, expand and update the nomenclature and classification of RD and its alignments with other terminologies (including ICD-10, ICD-11, SNOMED CT and OMIM);
2. To expand and update the encyclopaedia of RD;
3. To produce scientific annotations for RD;
4. To improve database transparency and traceability and manage stakeholders’ contributions and database curation process;
5. To update and expand the directory of expert services in every European Union (EU) Member State (MS), including centres of expertise, clinical laboratories, patient registries, mutation registries, biobanks, patient organisations, European reference networks when set up;
6. To make Orphanet, the European database for RD, sustainable;
7. To define and set the necessary strategy and tools to implement the Orphacodes in the European Countries;
8. To support the work of the CEG-RD;

9. To support the implementation of EUCERD/CEG-RD Guidance and Recommendations in MS, and follow on-going progress and best practices in RD.

2.2. WORK PACKAGE 2: DISSEMINATION

Work Package 2, Dissemination, aims to maximise the impact of the JA and to trigger effects among the targeted stakeholders and communities. Through organised communication and dissemination activities, WP2 intends to disseminate the results of RD-ACTION, which in turn will allow for sustainability beyond the project end.

Within WP2, objectives include:

- To capitalise on all previous work done at the European and national levels in the RD field;
- To achieve a maximum level of inclusiveness of all stakeholders to all dissemination activities performed;
- To ensure back and forth communication between RD-ACTION, CEG-RD and stakeholders;
- To facilitate two-way communication between the national and European levels to:
    - Facilitate integration of EU policies and regulations into national systems;
    - Point out national RD initiatives to EU Policy makers and other stakeholders;
- To produce and deliver up-to-date information;
- To disseminate Best Practices in the field of rare diseases.

The RD-ACTION Dissemination Plan is deliverable 2.1 of WP2. The purpose of the plan is to outline the audience, messages, methods, timing and purpose of dissemination of the actions and results of the JA. It will set out what has already been achieved, and what is planned for dissemination purposes.

3. AUDIENCES

The Dissemination Plan aims to inform all key target groups of the actions undertaken to meet the needs of patients and their relatives, healthcare professionals, researchers, industry and policy makers.

The following target groups have been identified:

- Partners of RD-ACTION and members of the CEG-RD ;
- National and local competent authorities;
- EU decision-makers;
- Patients advocacy and support groups representing the patients and their families;
- Health professionals;
- Industry;
- Academia, learned societies, researchers;
- Regulators;
- HTA bodies/reimbursement authorities;

Stakeholders within RD-ACTION stratify European, national, regional and local levels.

3.1. STAKEHOLDER ANALYSIS

A Stakeholder Analysis (Table I) was carried out in order to better target key stakeholders and recognise the messages that are important for the aforementioned target groups.

This process has been carried out to clearly define stakeholders and their interest in the Joint Action, to prioritise stakeholders and to identify which messages and tools are best to reach them.

The purposes of dissemination have been divided into sections intending to:

- **Raise awareness**: let others know what we are doing;
- **Inform**: educate the community;
- **Engage**: get input/feedback from the community and encourage mobilisation of stakeholders; and/or
- **Promote**: “sell” outputs and results.

In many cases the purpose of dissemination will be multi-faceted; especially considering that one of the overall objectives of the Dissemination Plan is to encourage and facilitate the participation of targeted stakeholders. In this case the primary purpose of dissemination will be prioritised.

4. MESSAGES

RD-ACTION will relay different messages throughout the development of the project to reflect the outcomes of this Joint Action.

Towards the beginning of the project, before there are any concrete outcomes, communications will be focused on raising awareness and providing information about RD-ACTION (e.g. website and leaflet) to reach a wider audience and raise the profile of the project.

RD-ACTION will then adapt to developing specific messages once outcomes of the project begin to emerge. The messages will be disseminated amongst and targeted to different stakeholders depending on their interest in RD-ACTION and the purpose of dissemination, according to the Stakeholders Analysis in Table I.

Nonetheless, certain key, overarching messages will cover the work of RD-ACTION, in line with the objectives and expected outcomes of the JA. Examples include:

- Nomenclature and classification of RD need to be maintained, expanded, updated and aligned with other terminologies, including ICD-10, ICD-11, SNOMED CT and OMIM;
- Appropriate codification of rare diseases in national health systems is fundamental to improve care and research and to foster equal access to diagnostic care and treatment for people living with rare diseases across the EU;
- Recommendations of the CEG-RD - adopted by consensus by EU MS, the EC and other stakeholders - need to be further promoted in order to be better known and used by a wide range of stakeholders with a view to harmonise policy developments on RDs across Europe;
- Multi-stakeholder debates around RD are necessary at national level to support the integration on EU policy developments across EU Member States.

5. DISSEMINATION

RD-ACTION will use a wide variety of dissemination methods and tools to raise-awareness, inform, engage and promote the outcomes of the Joint Action. Dissemination is flexible, and will take advantage of media channels, formal materials, conferences, workshops and face-to-face meetings to share information amongst relevant stakeholders.

Many of the dissemination deliverables are assigned to certain partners. Nonetheless, all partners are expected to engage in the sharing of information within their networks.

The overall strategic approach is flexible and open to adaptation in line with constant evaluation and feedback of the methods.

5.1. MEDIA

Online media will be the most versatile and the most frequently used channel of dissemination.

RD-ACTION WEBSITE

www.rd-action.eu is the main point of communication for this project and other communication tools (social media, newsletters) can be channelled to the website. The website communicates all the project aims and objectives, in addition to providing information on the structural organisation of the project. News and announcements will be available on the website and it will be updated regularly to reflect the deliverables achieved. The website is accessible to all stakeholders and will provide an introduction for those who are not familiar with the project in addition to all the material produced by RD-ACTION.

Key points of interest on the website:

- 'About us' provides a brief introductory summary of the work that RD-ACTION aims to achieve, making it accessible to a wider pool of stakeholders;
- 'Directory' provides the information needed to contact members in charge of each project, which will be updated with any changes that occur;
- 'Work Packages' provides a more in depth view of the project, outlining each Work Package and indicating who is coordinating them;
- 'News' is a continually updated section showing the progress that the Joint Action is making and highlighting any events and advances that are of interest to the project, this section is of particular interest to those stakeholders that are close to the project;
- 'Leaflet and documents' is a dedicated section for publishing the RD-ACTION leaflet intended to the public as well as the relevant documents produced within RD-ACTION.

The Project Coordinator is responsible for the creation, content and maintenance of the RD-ACTION website. Partners send updates, new information and material to the Project Coordinator who will take care of uploading the information on the RD-ACTION website once validated.

www.rd-action.eu went live on 15 December 2015 and is updated regularly.

WEBSITES OF RD-ACTION PARTNERS

All partners of the Joint Action are expected to include at least a link to the RD-ACTION website.

A web section providing an introduction to RD-ACTION, outlining its objectives and outcomes, and including a link to the RD-ACTION website and social media accounts, is especially encouraged. The web section is to be created within the first months of the Joint-Action. This does not need to be updated regularly, although this is encouraged.

ORPHANEWS

OrphaNews reports the latest developments in the field of rare diseases and orphan drugs, and therefore will communicate on the outcomes of RD-ACTION.
The content of the newsletter is comprehensive of all updates in the rare disease community. Each newsletter is organised thematically, which enables more focused communication of the work packages' outcomes. This also makes it easier for stakeholders to access information particularly relevant to their field.

Other OrphaNews sections include:

- Editorial
- Spotlight on…
- National and International Policy Development
- Ethical, Legal and Social Issues
- New Syndromes
- New Genes
- Research in Action
- Patient Management and Therapy
- Orphan Drugs
- Grants
- Courses & Educational Initiatives
- What's on Where?

OrphaNews is freely available and electronic. It is designed to suit all stakeholders in the rare disease and orphan drugs community and to be easily accessible.

OrphaNews is sent to subscribers (around 16000) twice monthly, and all past issues are archived online at www.orpha.net. There are 20 issues annually during the course of the Joint Action.

PARTNERS' NEWSLETTERS

Those partners with newsletters are encouraged to include information on the Joint Action according to the target group of the newsletter in order to inform on the development of the project and outcomes.

Each partner needs to adapt their own newsletter's content according to their audience and according to new information.

When communicating about RD-ACTION in other newsletters, partners must include the link to www.rd-action.eu to channel interested parties back to website.

SOCIAL MEDIA

Twitter account:

The WP6 "Policy Development for Rare Diseases and Integration", led by Prof Kate Bushby and her team at the University of Newcastle (UNEW) has a specific twitter account: @RareDiseaseEU.

@RareDiseaseEU was the Twitter handle used for the previous EU Joint Action on rare diseases (EJA). It has been agreed to keep it after this Joint Action ended and just change the title page and logo to be the Twitter feed for RD-ACTION Policy work.

This twitter account has over 900 followers and is used to create awareness of rare disease policies, inform stakeholders about the project updates and upcoming events within RD-ACTION and promotes outcomes of the work being carried out by the partners.

Using social media creates an engaging presence to enable interested parties to exchange information and further disseminate updates within their own networks. Therefore, when partners of RD-ACTION post updates on their own social media accounts they are encouraged to tag @RareDiseasesEU when relevant to the project, and also retweet messages from the @RareDiseasesEU handle to create a larger reach of the information and show support for the project.

Other social media tools:

For a wider reach a Facebook, LinkedIn or Google+ account could be created if the need arises.

5.2. MATERIALS

RD-ACTION will also create materials that can be used to inform stakeholders of updates. Materials will be available on the RD-ACTION website and will be disseminated via the media channels aforementioned where relevant.

The logos of RD-ACTION and of the European Commission must always be displayed on any communication material related to an action of RD-ACTION. The logos are available on the intranet of RD-ACTION's website (see Table III).

LEAFLET

The Joint-Action leaflet is a short and engaging flyer, providing an overview of the aims and structural organisation of the Joint Action RD-ACTION as well as an exhaustive list of partners. The leaflet is to be disseminated to the public and is intended to create awareness about RD-ACTION. Its content can be easily understood by people who are not familiar with the project and activities carried out in the field of rare diseases.

The leaflet is available online on the RD-ACTION's website since February 2016. All partners are encouraged to widely disseminate it through their media tools and/ or at conferences or events they participate in.

SCIENTIFIC ARTICLES

Partners may contribute to scientific articles about on-going research and activities in the field of rare diseases. Where content is in line with RD-ACTION, scientific articles will serve to inform relevant stakeholders.

Scientific articles will be produced ad hoc. Upon publication, dissemination will be encouraged using media channels aforementioned where appropriate.

ORPHANET REPORTS SERIES

Orphanet reports are a series of texts covering topics relevant to all rare disease stakeholders. Outcomes of the Joint Action may be included in these comprehensive reports.

New reports are regularly put online. There is a direct link from the RD-ACTION website to the reports.

POSTERS AND SPEAKERS' PRESENTATIONS AT CONFERENCES

Results of the project or announcements could be disseminated via posters or during presentations at workshops and conferences. Posters can serve to inform engaged stakeholders about the Joint Action in general, or by specific Work Package or deliverable.

Partners of RD-ACTION are requested to use the graphic chart available on the intranet of the RD-ACTION's website, including the logos of the project and of the European Commission, the templates for poster and power point.

Posters and presentations will be made ad hoc. Partners will be encouraged to share posters and presentations to add them to the Joint Action website.

STATE OF THE ART REPORTS OF RARE DISEASES ACTIVITIES IN EUROPE

Two overviews Reports on the State of the Art of Rare Diseases Activities in Europe constitute a deliverable of WP6 (Policy Development for RD and Integration with other relevant initiatives). The country-specific RD summaries will be published on dedicated webpages and will be updated three times per year, transforming the report into a dynamic, web-based resource, to inform rare disease stakeholders

There will be two Overview reports: the first in Month 18 (November 2016) and the second in Month 30 (October 2017).

INTERIM AND FINAL REPORTS

The main outcomes of the Joint Action are to be outlined in the Interim and Final Reports.

The Interim Reports will be published on Months 12 and 24 and the Final Report will be published at the end of the Joint Action in May 2018.

LAYMAN BROCHURE SUMMARISING THE JA FINAL REPORT

The layman brochure is a shorter, more succinct version of the final report. This will highlight the achievements and results of RD-ACTION in a way that is more accessible to the broader public. It will be disseminated more widely than the Final Report amongst external stakeholders.

The Layman Brochure will be published at the end of RD-ACTION, in May 2018.

PRESS RELEASES

Press releases will be sent to journalists and to a list of correspondents in Brussels as and when there is newsworthy material from the project. They will also be made available on the RD-ACTION website and will be available for translation for partners who wish to send it to national and local press. It is not yet possible to determine what the press releases will be on, although some anticipated topics include:

- ECRD 2016
- State of Art Reports (Annual)

Press releases about or disseminated by RD-ACTION should include:

- The RD-ACTION logo;
- A boiler plate about RD-ACTION;
- A link to the RD-ACTION website;
- Contact information.

5.3 CONFERENCES AND WORKSHOPS

5.3.1. CONFERENCES

ECRD 2016 – EUROPEAN CONFERENCE FOR RARE DISEASES AND ORPHAN PRODUCTS (EDINBURGH, 26-28 MAY 2016)

The European Conference for Rare Diseases and Orphan Products (ECRD) taking place on 26-28 May 2016 in Edinburgh, United Kingdom, is a unique platform to bring together over 800 stakeholders in rare diseases across Europe and beyond. It serves as an opportunity to inform, educate, engage and promote and project the actions in the field of rare diseases, including of RD-ACTION. ECRD 2016 is a deliverable of WP2.

The theme of the conference is “Game Changers”, and the programme is focused around the main measures impacting on the rare diseases field that are taken and implemented at national and European levels. All stakeholder groups are represented in the Programme Committee to ensure a balanced programme.

RD-ACTION is specifically mentioned with their logo on the ECRD website and in the programme. Posters about RD-ACTION will also be exhibited, and partners doing presentations are encouraged to use the logo and template, and to mention the Joint Action in their presentations and at networking events.

There is a link to the ECRD website on the RD-ACTION’s website.

The partners are encouraged to use social media leading up to and during the conference to disseminate outcomes as they happen. A report on the conference findings and outcomes will be produced and disseminated widely following the event.

CONFERENCE ON SUSTAINABLE HEALTH SYSTEMS FOR RARE DISEASES (ROME, 2017)

This conference will be organised by Dr Domenica Taruscio and her team at the Istituto Superiore di Sanità (ISS), Rome, Italy.

The overarching goal of this conference is to support national authorities to quantify the burden of rare diseases and available resources for sustainable and resilient health systems, taking into account principles of equity, quality and efficiency, and involving stakeholders, policy makers, and civil servants in charge of national strategies on rare diseases.

5.3.2. WORKSHOPS

WORKSHOP REPORTS (ORGANISED WITHIN RD-ACTION)

Reports based on the outcomes of workshops organised within RD-ACTION will be published on the Joint Action’s website.

NATIONAL EUROPLAN WORKSHOPS (WP2)

National EUROPLAN Workshops will be organised across all Member States to support the national and European integration of rare disease policies. The workshops will build on the experience of two rounds of EUROPLAN conferences (2010; 2012-2015). The aim is to promote rare disease policies and to engage stakeholders nationally to implement or renew National Plans or National Strategies for rare diseases.

The workshops will be used to disseminate EU policies, including on Centres of Expertise, European Reference Networks, Cross-border health care, registries, e-health and research. They will also offer an opportunity to communicate Recommendations of the CEG-RD. The workshops will be focused on key priorities at national level within each Member State.

National Alliances of Rare Diseases will organise the workshops with the support of national health authorities and EURORDIS. National Alliances will be responsible to disseminate information about the event, and details will be available on the RD-ACTION and EURORDIS websites.

The workshops will be organised between 2016 and March 2018. Reports on the outcomes of the workshops will be disseminated and made available on the RD-ACTION website.

POLICY WORKSHOPS (WP6)

Eight workshops will be organised under WP6 on specific topics. This will be an opportunity to engage stakeholders around policy topics prioritised under this Work Package. The Consultative Group of WP6 will help to define the scope and outputs of each workshop: it is anticipated that Consultative Group members will host some of these workshops.

Information about the policy workshops will be disseminated by the team of Prof Kate Bushby through the internal newsletter and on the website. Orphanet may be able to issue new reports for the Orphanet Report Series based on the conclusions of the workshops. Participants will be encouraged to engage on social media to inform their networks about the workshops and their outcomes.

A first (small) convergence workshop took place in Lisbon the 10-11 December 2015, focused on eHealth, and a meeting on the same topic was held on 18 February 2016. The dates for the 8 main workshops are to be defined for the period between May 2016 and March 2018.

6. COMMUNICATION TOOLS AMONGST PARTNERS

RD-ACTION INTERNAL WEBSITE

A specific restricted area has been created for all partners on the RD-ACTION's website. It is password protected.

The aim is to make available all informative documents to all partners and upload all non-public documents (or draft of non-validated versions).

It houses restricted areas for the different joint actions committees or working groups, e.g. executive committee restricted area, Consultative group restricted area, WP4 area linking to the Orphanetwork internal website and WP5 Steering committee restricted area.

INTERNAL NEWSLETTER

The coordinating team publishes an internal two-monthly newsletter, RD-ACTIONews. The editorial board of the newsletter is composed by Executive committee members. This internal newsletter is sent within the JA consortium.

It features specific updates on the progress of each Work Package and information targeting the partners. It also contains a section called “To Do list”.

7. EVALUATION

The dissemination activities will be evaluated continuously to measure the success of the strategies outlined in the Dissemination Plan.

The evaluation method will involve monitoring the content of the websites, newsletters, and other websites talking about RD-ACTION; using questionnaires following workshops and conferences; discussions about the use of dissemination channels and materials amongst partners; measuring the number of citations of publications, and using in-built measuring systems on websites, newsletters and social media.

Feedback will be taken into consideration and will be implemented where possible to ensure the dissemination process is effective in achieving the objectives of the specific Work Package 2, and the whole Joint Action.

The evaluation process will be continuous, with specific attention every six to eight months when the Dissemination Plan will be reviewed and updated taking feedback into consideration.

8. ANNEXES

RD-ACTION DISSEMINATION PLAN

TABLE I – DISSEMINATION RULES

Co-funded by
the Health Programme
of the European Union

- The Graphic Chart of RD-ACTION can be found on the intranet of RD-ACTION's website

- For each communication related to RD ACTION, always displays:
  - **The logo of RD ACTION**
  - **The logo the EC logo to acknowledge the funding source**

The logos can be found on the intranet of RD-ACTION's website.

Should you need assistance, please do not hesitate to contact the project management team at: project.management@rd-action.eu

- **On each presentation and communication material, always displays the following disclaimer :**

[*This presentation, this leaflet..] is part of the project / joint action '677024 / RD-ACTION' which has received funding from the European Union's Health Programme (2014-2020).*

The content of presentation represents the views of the author only and is his/her sole responsibility; it can not be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.

RD-ACTION DISSEMINATION PLAN

TABLE II - STAKEHOLDER ANALYSIS

Stakeholder Group *(WHO)*	Interest in RD-Action *(WHY)*	Dissemination purpose *(WHY)*	Channels of Dissemination *(HOW)*
Partners of RD-Action & members of the CEG-RD - Orphanet (central & national offices) - Patient Organisations - Academia - Member States	To integrate progress and information into their own work. Seek opportunities to input and influence decision making. Receive support on policy methodology. Production of data to support policy analyses and decisions.	*Inform:* Update on progress of project. *Engage:* back and forth exchange of information. *Promote*: To further disseminate updates within their networks.	EUCERD/ CEG-RD Recommendations & Opinions. Orphanet Report Series. Websites: DG SANTE, RD-ACTION, Orphanet, all partners' website. Newsletters: DG SANTE, OrphaNews, RD-Action internal newsletter; all partners' newsletter. Social media. Leaflet. Posters. Press releases. Attendance at conferences and workshops: - ECRD 2016 - conference on sustainable health systems for RDs in 2017 - WP2 National Workshops - WP6 Policy Workshops Joint Action's meetings & conference calls. RD-ACTION Final Report. Layman version of the final report.
National and local competent authorities - Health ministries - Research ministries	Production of data to support policy analysis and decision. To facilitate integration of EU policy into national and local policies.	*Inform*: Update on new data, guidelines and latest information on RD policy development. Update of RD classification. *Engage:* Share experiences of integrating RD	EUCERD/ CEG-RD Recommendations & Opinions. Orphanet Report Series. Guidelines and review paper on how and

- Social affairs ministries - Regional level health competency authorities and their platforms - Health institutes - Local social service providers	Support from national workshops. Quantify the burden and the resources for sustainable and resilient health systems. Directory of expert services in every MS. Strategy and tools to implement the Orpha codes in European countries.	policy in individual MS. Support the organisation of the national workshops. *Promote*: To take EUCERD/ CEG-RD Recommendations on board and to implement within MS.	why using Orphacode. Websites: DG SANTE, RD-ACTION, Orphanet, other partners' website. Newsletters: DG SANTE, OrphaNews, RD-Action internal newsletter; other partners' newsletter. Social media. Leaflet. Press releases. Attendance at conferences and workshops: - ECRD 2016 - conference on sustainable health systems for RDs in 2017 - WP2 National Workshops - WP6 Policy Workshops Layman version of the final report.
Regulators	Clearer regulatory conditions when RD is better defined. Obtaining information on relevant policy developments.	*Inform:* Latest information on update of RD classification and relevant policy developments.	EUCERD/ CEG-RD Recommendations & Opinions. Websites: DG SANTE, RD-ACTION, Orphanet, other partners' website. Newsletters: DG SANTE, OrphaNews, other partners' newsletter. Attendance at conferences and workshops: - ECRD 2016 - conference on sustainable health systems for RDs in 2017 - WP2 National Workshops - WP6 Policy Workshops Reports of conferences and workshops
HTA bodies/reimbursement authorities	Improved codification means easier to identify and track diseases through the reimbursement process.	*Inform:* Latest information on update of RD classification and relevant policy developments.	Websites: Orphanet Newsletters: OrphaNews. Attendance at conferences and workshops: - ECRD 2016 - conference on sustainable health systems for RDs in 2017

			- WP2 National Workshops - WP6 Policy Workshops Reports of conferences and workshops
EU decision-makers - European Commission: DG SANTE (in particular Public Health and Health Systems and Products), DG CONECT, DG EMPL, DG RTD, CHAFEA - European Parliament: MEPs, ENVI and ITRE committees - Committee of Regions - Economic and Social Council	Information about national RD initiatives. Recommendations to help drive European policy. Production of data to support policy analysis and decision; and to facilitate integration of EU policies. Quantify the burden and the resources for sustainable and resilient health systems. Directory of expert services in every MS. Strategy and tools to implement the Orpha codes in European countries.	*Inform:* Latest information on update of RD classification and relevant policy developments. *Promote*: To take the recommendations on board and to encourage them to advocate for adoption by MS. *Engage*: Use data and recommendations to facilitate integration into European policy development; Encourage an information flow.	EUCERD/ CEG-RD Recommendations & Opinions. Orphanet Report Series. Websites: DG SANTE, RD-ACTION, Orphanet. Newsletters: DG SANTE, OrphaNews. Social media. Press releases. Attendance at ECRD2016. Attendance at WP6 Policy Workshops RD-ACTION Final Report. Layman version of the final report.
Healthcare professionals - RD specific groups - GPs - Specialised MDs - Nurses - Paramedics - Case Managers - Social Workers - Hospital Managers	Improved identification and diagnosis of RD. Improved access to treatment for patients. Better and more constructive networks. Directory of expert services in every MS. Strategy and tools to implement the Orpha codes in European countries.	*Inform*: Latest information on update of RD classification and policy developments in the RD field. *Engage*: Provide input, patient data and participate in the debate. Participate in national workshops.	Websites: RD-ACTION, Orphanet, other partners' website. Newsletters: OrphaNews, other partners' newsletter. Leaflet. Scientific articles. Layman version of the final report. Attendance at ECRD2016. Attendance at WP6 Policy Workshops; WP2 National Workshops.
Industry (Health Related Private Sector) - Pharmaceutical and Biotech companies - Medical devices companies - Trade associations - (Bio) Informatics Companies - Insurance Companies	Better understanding of RD: - Unmet needs of treatment of RD. - Clearer regulatory procedures. Better codification. Information on national plans: public budget and initiatives in MS. Better and more constructive of networks and access to Centres of Expertise.	*Inform:* Latest information on update of RD classification and policy developments in the RD field. *Promote:* Policy developments. *Engage*: Participate in policy and national workshops.	EUCERD/ CEG-RD Recommendations & Opinions. Orphanet Report Series. Websites: RD-ACTION, Orphanet. Newsletters: DG SANTE, OrphaNews. Social media. Leaflet. Press releases.

	Directory of expert services in every MS.		Layman version of the final report. Attendance at ECRD2016. Attendance at WP6 Policy Workshops; WP2 National Workshops.
Academia; researchers	Clearer codification and scientific understanding of RD. Web-based knowledge management services to access and contribute to. Directory of expert services in every MS. Strategy and tools to implement the Orpha codes in European countries.	*Inform:* Latest information on update of RD classification and relevant policy developments. *Engage:* Mobilise to curate on Orphanet database. Participate in policy and national workshops.	Publication of procedures and data sources and updates history. Websites: RD-ACTION, Orphanet, other partners' website. Newsletters: DG SANTE, OrphaNews, other partners' newsletter. Social media. Leaflet. Press releases. Posters. Layman version of the final report. Attendance at ECRD2016. Attendance at WP6 Policy Workshops; WP2 National Workshops.
Patients advocacy and support groups - EURORDIS member organisations - EURORDIS National Alliances - EURORDIS European Federations - RD patient organisations non-member of EURORDIS	Improve the quality of life of People Living with Rare Diseases. Directory of expert services in every MS.	*Inform:* Delivery of information on RD and expert service in Europe through the Orphanet website. *Raise awareness* *Promote:* To take part in advocacy actions, putting pressure on national authorities to continue implementation of RD policy at MS level. *Engage:* Organisation and attendance at national workshops.	Participation in surveys. Websites: Orphanet, EURORDIS, other partners' website. Newsletters: OrphaNews, EURORDIS e-news, other partners' newsletter. Social media. Leaflet. Press releases. Posters. Layman version of the final report. Attendance at ECRD2016. Attendance at WP2 National Workshops.

Patients, families and their representatives	Policy and academic development Directory of expert services in every MS.	*Raise Awareness* *Inform*: Educate patients and families about policy development and their impact on their daily life.	Websites: RD-Action, Orphanet, EURORDIS, other partners' website. Newsletters: OrphaNews, EURORDIS e-news, other partners' newsletter. Social media. Leaflet.
Beyond RD communities - Other Joint Actions and other disease areas e.g. Chronic diseases - Other policy areas e.g. eHealth - Other patient communities	Insight into work and activities carried out within RD-ACTION. Data of interest. Update on cross-cutting issues.	*Raise awareness*: Of RD and the work done in this field. *Promote*: Policy developments and good practices in the RD field. *Engage*: Encourage to share practices and consider integrating RD into their practices.	Websites: DG SANTE, Orphanet, RD-ACTION. Newsletters: DG SANTE Social media. Leaflet. Poster. Layman version of the final report.

RD-ACTION DISSEMINATION PLAN

TABLE III - DISSEMINATION CHART

■	**Active dissemination**
▨	**Specific dates to be defined**
🟦	**Evaluation**

Dissemination Activity	Frequency	Year 1												Year 2												Year 3											
		juin-15	juil-15	août-15	sept-15	oct-15	nov-15	déc-15	janv-16	févr-16	mars-16	avr-16	mai-16	juin-16	juil-16	août-16	sept-16	oct-16	nov-16	déc-16	janv-17	févr-17	mars-17	avr-17	mai-17	juin-17	juil-17	août-17	sept-17	oct-17	nov-17	déc-17	janv-18	févr-18	mars-18	avr-18	mai-18
		M-1	M-2	M-3	M-4	M-5	M-6	M-7	M-8	M-9	M-10	M-11	M-12	M-13	M-14	M-15	M-16	M-17	M-18	M-19	M-20	M-21	M-22	M-23	M-24	M-25	M-26	M-27	M-28	M-29	M-30	M-31	M-32	M-33	M-34	M-35	M-36
Media:																																					
Online																																					
Website and social media	*Continuous update*							■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Newsletters																																					
Orphanews	*20 issues per year (twice a month):* *New codification* *Policy development*	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
DG SANTE	*Particular dissemination topics:* *Recommendations of CEG-RD* *New RD Policy Developments (e.g. ERNs)*	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
EURORDIS e-news	*Sent every two weeks (Wednesday):* *- ECRD 2016* *- Recommendations of CEG-RD*	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■

	- New policy developments	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
EURORDIS Member News	*Once a month:* *- New policy development* *- Opportunities for patient involvement*	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Other partners' newsletters		■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Materials:																																					
CEG-RD Opinions & Recommendations							■					■																									
Leaflet										■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
State of the Art Reports																			■												■						
WP2 Progress dissemination report on health systems equity																									■												
WP2 Final dissemination report on sustainable health systems for RD																																					■
WP5 survey: Deliverable 5.1 – part 1: Review existing technical implementations for RD coding								■																													
WP6 Progress report on policy delivery and implementation																			■																		

WP6 Final report on policy delivery and implementation																																					■
Scientific Articles		▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨
Orphanet Report Series		▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨
Reports of national workshops															▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨
Press Releases	*On notable events*													■	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨
Final Report																																					■
Layman Brochure of final report																																					■
Conferences and Workshops:	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
National EUROPLAN Workshops (WP2)													▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨		
Policy Workshops (WP6)													▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨
European Conference on Rare Diseases and Orphan Products 2016, Edinburgh (WP2)													■	🟦																							
Workshop on "Health Systems Resilience for Rare Diseases", 14 June 2016, Rome (WP2)														■	🟦																						
Conference on Sustainable Health Systems, 2017, Rome																					▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨