RD-ACTION DISSEMINATION PLAN

TABLE I - 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 - Social affairs ministries - Regional level health competency authorities and their platforms - Health institutes - Local social service providers	Production of data to support policy analysis and decision. To facilitate integration of EU policy into national and local policies. 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.	*Inform*: Update on new data, guidelines and latest information on RD policy development. Update of RD classification. *Engage:* Share experiences of integrating RD 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.	EUCERD/ CEG-RD Recommendations & Opinions. Orphanet Report Series. Guidelines and review paper on how and 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, | 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. | *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 | EUCERD/ CEG-RD Recommendations & Opinions.

Orphanet Report Series.

Websites: DG SANTE, RD-ACTION, Orphanet. |

ENVI and ITRE committees - Committee of Regions - Economic and Social Council	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.	facilitate integration into European policy development; Encourage an information flow.	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.	*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.

	Better and more constructive of networks and access to Centres of Expertise. Directory of expert services in every MS.		Leaflet. Press releases. 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	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*	Participation in surveys. Websites: Orphanet, EURORDIS, other partners' website.

- EURORDIS National Alliances - EURORDIS European Federations - RD patient organisations non-member of EURORDIS		*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.	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.