



Deliverable 1.2
Dissemination Plan
March 2022



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Orphanet Data For Rare Diseases

Product	Type	Audience	Objective	Lead contributors	Target date	How
Visual identity	Communication	NA	NA	Coo-Inserm	M3	Displayed on every material and on website
Kick off meeting & report	Dissemination of results and good practice	Project partners and ERNs	Share Project Action plans and expected results and deliveries	All project partners	M3	Online meeting, report made available on project website
Project website	Communication	Project partners and ERNs	Disseminate project results and deliverables	Coo-Inserm	M4	Upon online publication notification on twitter will be made
Twitter	Communication	RD community	Raise awarness about the project			Twitter account info displayed on the project website ad on communication material
Trainings	Dissemination of results and good practice	HCPs / ERNs	Disseminate project results and deliverables in national language	National Hubs	M9	News on trainings will be published on project website. Training

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						material will be shared with participants.
Booths at RD & ERNs events	Dissemination of results and good practice	RD community at large - ERNs	Disseminate project results and deliverables	National Hubs	M12	A Twitter message will be launched when booth opens
Local dissemination events	Dissemination of results and good practice	HCPs	Disseminate project results and deliverables in national language	National Hubs	M12	A twitter message will be launched when booth opens
Orphanews articles	Communication	RD community	Raise awarness about the project	Coo-Inserm	M12	At least 2 articles, one after the KOM and one at M12 to assess the results
Project final leaflet	Communication	Project partners and ERNs	Disseminate project results and deliverables	Coo-Inserm	M12	Displayed on the website and twitter message. Printed version could be distributed at events
Standard Methodology for the revision of the Orphanet	Dissemination of results and good practice	ERNs	Transparency on the methodology in place	Coo-Inserm	M6	Published on orpha.net website, news on project

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Nomenclature with ERNs						website and Twitter
National Hubs Action plan reports	Dissemination of results and good practice	National Hubs Network		National Hubs	M10	Published on orpha.net website, news on project website and Twitter
Report on lessons learned and on improvement of capacity and implementation	Dissemination of results and good practice	National Hubs Network	Serve as guidance for other countries starting to improve implementation	National Hubs	M12	Published on orpha.net website, news on project website and Twitter
Report on ERNs collaborations	Dissemination of results and good practice	ERNs, EC, BoMS	Serve as guidance for new ERN projects	Coo-Inserm	M12	Published on orpha.net website, news on project website and twitter
Evaluation Report	Dissemination of results and good practice	EC	This report will contain the analysis of all relevant, task-related indicators , methods and means, as well as the analysis of the KPI and of the planned intended satisfaction surveys. It will be delivered as a pdf in English.	Coo-Inserm	M12	Published on orpha.net website, news on project website and Twitter

Product	Type	Audience	Objective	Lead contributors	Target date	How
Report on genetic annotations and alignments	Dissemination of results and good practice	ERNs, EC, BoMS	Disseminate WP3 results and make available links for re-use of the data	Coo-Inserm	M12	Published on orpha.net website, news on project website and Twitter
Report on disease coverage by ERNs	Dissemination of results and good practice	ERNs, EC, BoMS	Support evidence based decision making regarding ERNs activities	Coo-Inserm and MUW	M12	Dissemination to interested parties