



**Deliverable 1.2**  
**Dissemination Plan**  
**June 2023**



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**Orphanet Data For Rare Diseases**

Product	Type	Audience	Objective	Lead contributors	Target date	How
<b>Visual identity</b>	Communication	NA	NA	Coo-Inserm	Available (OD4RD)	Displayed on every material and on website
<b>Project website</b>	Communication	Project partners and ERNs	Disseminate project results and deliverables	Coo-Inserm	Available (OD4RD)	Available
<b>Twitter</b>	Communication	RD community	Raise awareness about the project	Coo-Inserm	Available (ORPHAcodes twitter account)	ORPHAcodes Twitter account info displayed on the project website ad on communication material
<b>Kick off meeting &amp; report</b>	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
<b>National Hub leaflet</b>	Communication	Project partners and ERNs	Disseminate knowledge about NH and their activity/composition at national level	Coo-Inserm	M3	Displayed on the website and twitter message. Printed version could be

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						distributed at events
<b>WHY ORPHAcoding vs other terminologies</b>	Leaflet	HCPs	Convince Hospital managers and deciders about the benefits of using ORPHAcodes	Coo-Inserm	M3	Displayed on the website and twitter message. Printed version could be distributed at events
<b>How to implement ORPHAcoding : the IT aspect</b>	Leaflet	HCPs	Derisking IT aspects of ORPHAcodes implementation	Coo-Inserm	M3	Displayed on the website and twitter message. Printed version could be distributed at events
<b>State of Play Survey</b>	Dissemination of results and good practice	ERNs, EC, BoMS	Disseminate information on National ORPHAcodes implementation in HCPs	Bfarm	M5	Published on website, news on twitter
<b>Annual National Hubs Action plan reports</b>	Dissemination of results and good practice	National Hubs Network	Transparency on project activities	National Hubs	M15	Published on website, news and Twitter
<b>Mid-term Report on ERNs collaborations</b>	Dissemination of results and good practice	ERNs, EC, BoMS	Serve as guidance for new ERN projects	Coo-Inserm	M15	Published on website, news on twitter

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<b>Mid-term Internal Workshop report</b>	Dissemination of results and good practice	Project partners	Share Project Action plans and fine tune the final deliveries	All project partners	M15	Online meeting, report made available on project website
<b>Mid-term Evaluation Report</b>	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	M15	Published on website, news on Twitter
<b>Mid-term Report on genetic annotations and alignments</b>	Dissemination of results and good practice	ERNs, EC, BoMS	Disseminate WP3 results and make available links for re-use of the data	Coo-Inserm	M15	Published on website, news on and Twitter
<b>Standard methodology for the revision of the Orphanet Nomenclature with ERNs</b>	Dissemination of results and good practice	ERNs	Transparency on the methodology in place	Coo-Inserm	M18	Published on website, news and Twitter
<b>Mid-term Report on disease coverage by ERNs</b>	Dissemination of results and good practice	ERNs, EC, BoMS	Support evidence based decision making regarding ERNs activities	Coo-Inserm and MUW	M18	Dissemination to interested parties
<b>Annual National Hubs Action plan reports</b>	Dissemination of results and good practice	National Hubs Network	Transparency on project activities	National Hubs	M27	Published on website, news and Twitter

Product	Type	Audience	Objective	Lead contributors	Target date	How
<b>Mid-term Report on lessons learned and on improvement of capacity and implementation</b>	Dissemination of results and good practice	National Hubs Network	Serve as guidance for other countries starting to improve implementation	National Hubs	M27	Published on website, news on Twitter
<b>Evaluation Report</b>	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	M32	Published on website, news on Twitter
<b>Trainings</b>	Dissemination of results and good practice	HCPs / ERNs	Disseminate project results and deliverables in national language	National Hubs	M33	News on trainings will be published on project website. Training material will be shared with participants.
<b>Booths at RD &amp; ERNs events</b>	Dissemination of results and good practice	RD community at large - ERNs	Disseminate project results and deliverables	National Hubs	M33	A Twitter message will be launched when booth opens
<b>Hospital Managers and IT staff workshop</b>	Dissemination of results and good practice	HCPS	Dissemination of results and good practice	Coo-INSERM	M33	

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<b>Local dissemination events</b>	Dissemination of results and good practice	HCPs	Disseminate project results and deliverables in national language	National Hubs	M33	A twitter message will be launched when booth opens
<b>International Congress Poster presentation</b>	Dissemination of results and good practice	RD community	Disseminate project results and deliverables in national language	Coo-inserm	M12-24-33	Poster
<b>Face-to-face and online events organised to exchange with ERN coordinators</b>	Dissemination of results and good practice	ERNs	Disseminate project results and deliverables in national language	Coo-inserm	M33	F2F/ Online Events
<b>Orphanews articles</b>	Communication	RD community	Raise awarness about the project	Coo-Inserm	M33	At least 4 articles, 1 after the KOM and one at M12-24-33 to assess the results
<b>Report on lessons learned and on improvement of capacity and implementation</b>	Dissemination of results and good practice	National Hubs Network	Serve as guidance for other countries starting to improve implementation	National Hubs	M33	Published on website, news on Twitter
<b>Final Report on ERNs collaborations</b>	Dissemination of results and good practice	ERNs, EC, BoMS	Serve as guidance for new ERN projects	Coo-Inserm	M33	Published on website, news on twitter

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<b>Final Report on genetic annotations and alignments</b>	Dissemination of results and good practice	ERNs, EC, BoMS	Disseminate WP3 results and make available links for re-use of the data	Coo-Inserm	M33	Published on website, news on Twitter
<b>Final Report on disease coverage by ERNs</b>	Dissemination of results and good practice	ERNs, EC, BoMS	Support evidence based decision making regarding ERNs activities	Coo-Inserm and MUW	M33	Dissemination to interested parties
<b>Final Meeting Report</b>	Dissemination of results and good practice	Project partners and ERNs	Share Project Action plans and expected results and deliveries	All project partners	M33	F2F meeting, report made available on project website