



RD-CODE Final Evaluation Report

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EXECUTIVE SUMMARY OF PROJECT ACHIEVEMENTS

The RD-CODE project has been able to achieve all the project goals. Detailed information of all the project's KPI per objective is provided in Annex 1.

OBJECTIVE 1. ESTABLISH AN EFFECTIVE AND EFFICIENT GOVERNANCE IN THE PROJECT

The Steering Committee calls were organised on a regular basis; reports have been submitted in due time and project partners have reported a high degree of satisfaction throughout the project with Orphanet's management and support. 17 online Steering Committee meetings were held since the beginning of the project.

OBJECTIVE 2. TO DISSEMINATE PROJECT INFORMATION AND OUTPUTS TO INCREASE AWARENESS AND UNDERSTANDING

Dissemination activities have been regularly reported in the Steering Committee calls. 7 articles on the project have been published in Orphanews, 2 posters were accepted for international conferences (ECRD 2020 and 14th European Public Health Conference) and 4 oral presentations were given at national conferences and 6 oral presentations were given at other project events (see Dissemination report for more information).

In addition, Orphanet produced a [video](#) and a [slide deck](#) targeted to raise awareness among non-experts and the general population. In addition to [the General Public Report and 3 leaflets](#) as planned.

OBJECTIVE 3. MEASURE THE KPI OF THE PROJECT AND INDICATORS PER SPECIFIC OBJECTIVE AND ADMINISTER SATISFACTION SURVEYS

Evaluation aspects were discussed in all Steering Committee calls. Nine surveys have been administered from the beginning of the project until December 2021:

1. Participants' satisfaction survey of Kick-off meeting (EURORDIS)
2. Mid-term partners satisfaction survey (EURORDIS)
3. Survey on toolset (INSERM)
4. Participants Survey First Multistakeholders Workshop 22-23 June 2020 (EURORDIS)
5. Partners satisfaction survey internal meeting June 2021 (EURORDIS)
6. Participants Survey Final Multi-stakeholder Workshop 29-30 Nov 2021 (EURORDIS)
7. Survey exploring the feedback from implementing countries regarding ORPHACodes adoption for rare diseases coding. Nov 2021 (Veneto Region)
8. Final partners satisfaction survey Dec 2021 (EURORDIS)

9. Live survey during the last multistakeholder workshop 29-30 Nov 2021 (EURORDIS)

OBJECTIVE 4. IMPLEMENTATION IN FOUR COUNTRIES

Objectives 4.1-4.4. Implementation in the four countries (Czech Republic, Malta, Romania and Spain)

Czech Republic. To enforce the use of ORPHAcodes according to the “Standard procedure and guide for the coding with ORPHAcodes” and the “Specification and implementation manual of the Master file” in major rare diseases centers reporting to the National Register of Congenital Malformations.

Number of hospitals accepting to participate in the piloting: two hospitals have accepted to participate in the pilot. By the end of 2021, 874 new cases from these hospitals had been coded using ORPHAcodes, approximately 290 per year, well above the target of the project (50). The National Register of Congenital Malformations has managed to implement ORPHAcodes in its data model. By the end of 2021, the two hospitals were reporting their data to the registry using ORPHAcodes.

Three training sessions for 44 clinicians have been delivered throughout the project, and an e-learning module via Moodle platform has been created. A satisfaction survey and knowledge test were administered after the 3 workshops. Only 11 out of the 44 trained clinicians responded to the Satisfaction survey: 73% reported that the information received on the course was beneficial to them.

Compared to the period 2016-2017, the number of cases with a rare disease diagnosis inserted in the national registry has increased more than 16 times (2016-2017: 57 rare disease cases inserted in the registry compared to 965 rare disease cases inserted in the registry in the period 2019-2021).

Malta. To introduce ORPHAcodes according to the “Standard procedure and guide for the coding with ORPHAcodes” and the “Specification and implementation manual of the Master file” in the daily practice of registries including rare diseases.

Malta has introduced automatic ORPHAcoding into the data model of three existing registries: congenital malformations registry, cancer registry and the Treatment abroad data. More than 200 cases were reported using ORPHAcodes between 2019 and 2021.

Also, a remote Workshop was held on the 24 and 27 November 2020: “Introducing ORPHAcodes”. It gathered 5 RD-CODE speakers and 36 participants from Malta: representatives from the 16 Mater Dei Clinical departments were present as well as government representatives, all Directorate for Health Information & Research (DHIR) Registries managers and Hospital Information Systems specialist and several consultants.

A comparison between the period 2016-2017 and the Project implementation period has shown an 1.75 fold increase in the number of RD cases identified and diagnosed (from ca 800 registered cases per year to 1,400 registered cases per year).

Romania. To introduce ORPHAcodes according to the "Standard procedure and guide for the coding with ORPHAcodes" and the "Specification and implementation manual of the Master file" in the daily practice of a major centre dealing with rare diseases diagnosis

Romania has over-achieved the target of coding 30 rare diseases using ORPHAcodes: 1,137 different patients have been registered with 193 different ORPHAcodes. Therefore, the number of cases reported per year using ORPHAcodes is more than 200 (target). A comparison between the period 2016-2017 and the Project implementation period has shown a 5-fold increase in the number of RD cases identified and diagnosed.

As of December 2021 4 centres carried out case registration: Iasi Regional Medical Genetics Centre; C. I. Parhon Hospital Iasi – Nephrology Department, Timis Regional Medical Genetics Centre and Prader Willi Association - NoRo Expert Centre for Rare Diseases

The health authorities have used the information to inform the decision on the allocation of funds for 2 National Health Programmes for the diagnosis and treatment of rare diseases.

The Romanian team has organised four training sessions with the participation of 30 clinicians.

Spain. To pilot the implementation of ORPHAcodes according to the "Standard procedure and guide for the coding with ORPHAcodes" and the "Specification and implementation manual of the Master file" at the rare diseases registries in selected regions in Spain.

Seven Spanish regions have made adaptations in their processes towards the implementation of ORPHAcodes (Comunitat Valenciana, País Vasco, Cataluña, Castilla y León, Madrid, Murcia and Navarra) and six of them have actually implemented the nomenclature in their regional registry (Comunitat Valenciana, País Vasco, Cataluña, Castilla and León, Madrid and Murcia).

In addition, 1 public hospital located in Barcelona (Sant Joan de Deu Hospital) has also implemented ORPHAcodes in the hospital's Electronic Health Record system and 4 hospital services are testing the nomenclature.

The target regarding the percentage of cases coded with an ORPHAcodes (75%) has been reached with 100% of the cases communicated to the national registry with an ORPHAcodes; and 95% of the ORPHAcodes from the Master file with an ICD-10-ES (version 2020) equivalent.

OBJECTIVE 4.5 CENTRALISE AND DEVELOP INFORMATION ON THE ORPHANET NOMENCLATURE FOR CODIFICATION PURPOSES

Orphanet has organised 12 codification project internal meetings. The mid-term partners satisfaction survey revealed that the representatives of two countries participating in the project are satisfied with the tools and documents provided by Orphanet (Malta and Romania representatives did not respond to the survey).

Orphanet has centralised the already available information and has developed new documentation intended to codification purposes, which are available for free in the [RD-CODE website](#) into a dedicated page called « ORPHA coding ». This webpage, a one-stop shop to find information on the Orphanet nomenclature and its related products, and its content were conceived following the guidelines and recommendations published in the frame of the RD-Action Joint Action. Its content is organised into 4 different tabs and for every concept, links to documents and websites of interest are provided to allow more detailed information for the website users (guidelines from WP5, Orphanet server for nomenclature, Orphanet procedures,...). Also from this page one can access the Orphanet tools developed during the project: the Nomenclature Pack, the Orphanet API and the DataViz tool (see below) . Orphanet also releases annually the Nomenclature Pack since July 2019: these files provide the computable information necessary to achieve the implementation of ORPHAcodes in Health Information Systems, and ensure easier and accurate coding. They have been upgraded in July 2021 according to the users' feedback from the Multistakeholder Workshop held in Prague in 2021. In order to help users in the implementation process, a detailed description is produced to provide information on the usage of the nomenclature according to the end-users and implementation settings. This [document](#) describes in details the content of Orphanet nomenclature files dedicated for coding (including classifications files and Orphanet-ICD10 cross-referencing) and the way to explore them. This document is downloadable for free and supplied with the pack of the nomenclature files for coding.

Finally, Web-based applications development by Orphanet was foreseen during this project to facilitate the informatic access to nomenclature data and allow flexible implementation into the various IT systems in use in the different countries and/or settings. An API <https://api.orphacode.org> , was released as a beta version in December 2019 (API for visualisation of Orphanet Nomenclature, Deliverable 4.2) and then the official release and upgrade was made in June 2020 (Facility for ORPHA nomenclature correspondence, Deliverable 4.5). The Orphanet Data visualisation tool <https://dataviz.orphacode.org/> has been delivered in December 2020.

OBJECTIVE 5. PROVIDE BACKGROUND ANALYSIS OF THE “CODING ENVIRONMENT” IN IMPLEMENTING COUNTRIES

A report with the background analysis of the “coding environment” in implementing countries was published in June 2019. The report covers 3 out of 4 implementing countries

answered the questionnaire (Spain, Czech Republic and Malta, Romania did not answer). The background Report accessible in the project's website ([here](#)).

A questionnaire was circulated among implementing countries, and the preliminary results were presented in the final multistakeholder workshop 29-30 November 2021. The available results show that when ORPHAcodes are used at population level (Spain, Veneto Region), the information can be used for epidemiological and public health purposes. Their use at population level also allows to capture patients with ultra-RD, not specifically represented in ICD. The analysis of the responses also confirmed that the successful implementation of ORPHAcodes requires a multidisciplinary approach (medical and IT experts), in the same way that ORPHAcodes data exploitation requires a multidisciplinary approach by medical, IT experts and statisticians.

BEYOND RD-CODE

RD-CODE partners have gained valuable experience throughout the implementation of the project that can be shared with others. The partners have agreed to explore the possibility of creating a virtual **Community of Practice** to enable them to build the capacity of other organisations interested in implementing ORPHAcodes. This Community will also allow the partners to continue sharing coding experiences, mutualise training materials and tools and also review and update the guidance as needed. An expected output of this Community of Practice is to deliver a practical guidance document for hospital managers, and dedicated teams, to implement the ORPHAcodes locally. The platform to host such a Community of Practice with other stakeholders could be the EU Health Policy Platform.

The success of such a Community would be highly dependent on the commitment of RD-CODE partners and others to dedicate time and resources to animate the group, facilitate exchanges and build the Community over time. Therefore, after the end of the RD-CODE project, Orphanet will circulate a survey to assess the willingness of stakeholders to join such a Community of Practice.

An additional follow-up action that was discussed during the final project Conference was the possibility of developing a **pilot jointly with X-eHealth project** to demonstrate the utility of using e-eHealth specifications for rare disease patients and explore how RD-CODE tools could be used together with X-eHealth specifications.

Orphanet, as a participant in the X-eHealth project, will follow-up with X-eHealth partners to refine the scope of such a joint project and identify the relevant use case for rare disease patients – exchange/sharing of patient summaries, emergency department, telemedicine, etc. After the RD-CODE project ends, Orphanet will circulate a survey to explore the willingness of partners and other stakeholders to participate in the pilot project.



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826607 RD-CODE [RD CODE Final Evaluation Report]

ANNEX 1. INDICATORS PER SPECIFIC OBJECTIVE (STATUS DECEMBER 2021)

		Status March 2020	Status Dec 2021
Specific Objective Number	1.1 to 1.4		
Specific Objective	1.1. Establish an effective and efficient governance in the project 1.2. Ensure smooth communication and information exchange amongst project participants & stakeholders 1.3 Provide day to day administrative support to the partners 1.4. Ensure all communication with the CHAFAEA and the DG SANTE: including timely presentation of all deliverables, technical and financial reports. 1.5. Ensure risk management		
Process Indicator(s)	Target		
Steering committee meetings	8	6	17
Output Indicator(s)	Target		
Report availability	8	6	17
		All reports are made available to partners at the latest one week after the conference call	
Outcome/Impact Indicator(s)	Target		
Satisfaction level of partners (coordination activities)	>90%	100% of project partners agree or strongly agree that the Coordination team is effectively supporting the partners to deliver on a timely manner (Ref. Mid-term Partners satisfaction survey).	Overall satisfaction with coordination team: There has been a slight increase in overall satisfaction with coordination from 89% of respondents reporting being satisfied or very satisfied at mid-term to 100% in the final survey. Timely support: No changes. All respondents considered at mid-term and also at the end of the project that the coordination team has effectively supported partners to deliver on a timely manner. Satisfaction with Steering Committee calls - All

		Status March 2020	Status Dec 2021
			<p>respondents at mid-term and also at the end of the project strongly agreed or agreed that the calls were well organised with a clear agenda and schedule ahead of time.</p> <p>Satisfaction with newsletter: There were no changes from mid-term to final survey, with 90% of respondents reporting in both surveys being satisfied or very satisfied with the project newsletter.</p> <p>Overall satisfaction with coordination team: There has been a slight increase in overall satisfaction with coordination from 89% of respondents reporting being satisfied or very satisfied at mid-term to 100% in the final survey.</p>
Specific Objective Number	2		
Specific Objective	To disseminate project information and outputs to increase awareness and understanding		
Process Indicator(s)	Target		
Dissemination item included in the agenda of each steering committee meeting	8	6 A dedicated space for WP2 updates and discussion is included in each Steering Committee agenda	17 A dedicated space for WP2 updates and discussion is included in each Steering Committee agenda
Output Indicator(s)	Target		
Article in Orphanews	4	3	7 Video produced and 2 versions of a general slide deck prepared to raise awareness among the general population (available here and here)
Results presentation in congress	1	Several abstracts have been	2 international congresses and 4 national congresses plus 6 presentations at other project

		Status March 2020	Status Dec 2021
		submitted to the ECRD 2020	events (see dissemination report for more info)
Webpage availability	1	Achieved March 2019 www.rd-code.eu	
Outcome/Impact Indicator(s)	Target		
Downloads of documents increase Y1-Y2-Y3	increase (baseline Y1)	Downloads form Nov 2019 to 16 March 2020 Documents available on Rd-CODE were downloaded approx. 200 times Nomenclature pack available on orphadata was downloaded more than 1500 times in all languages (more than 700 in English only)	Downloads form Nov 2019 to 8 December 2020 Documents available on RD-CODE : downloads have drastically increased since the beginning to achieve more than 130 downloads/month in the last trimester of the project. Nomenclature pack available on orphadata was downloaded more than 4,500 times in all languages (more than 2,413 in English only)
Satisfaction on available documentation Y1-Y3	increase (baseline Y1)	80% (year 1) Result of the Mid-term partners satisfaction survey (Milestone 3.2)	Satisfaction with dissemination materials: There was slight increase from 80% at mid-term to 100% of respondents reporting being satisfied or very satisfied in the final survey.
Specific Objective Number	3.1 and 3.2		
Specific Objective	3.1. Measure the KPI of the project and Indicators per specific objective 3.2. Elaborate Satisfaction surveys for project partners (regarding coordination and dissemination activities),		
Process Indicator(s)	Target		
Evaluation item included in the agenda of each steering committee meeting	8	6 A dedicated space to discuss WP3 is foreseen in every SC meeting	17 A dedicated space to discuss WP3 is foreseen in every SC meeting

		Status March 2020	Status Dec 2021
Output Indicator(s)	Target		
Reports production	2	1	2
Surveys production	4	3	8
		<ol style="list-style-type: none"> 1. Participants satisfaction survey of Kick-off meeting 1 (Milestone 3.1) 2. Mid-term partners satisfaction survey (Milestone 3.2) 3. Survey on toolset (INSERM) 	<ol style="list-style-type: none"> 1. Participants' satisfaction survey of Kick-off meeting (EURORDIS) 2. Mid-term partners satisfaction survey (EURORDIS) 3. Survey on toolset (INSERM) 4. Participants Survey Final Conference 22-23 June 2021 (EURORDIS) 5. Partners satisfaction survey internal meeting June 2021 (EURORDIS) 6. Participants Survey Final Conference 29-30 Nov 2021 (EURORDIS) 7. Survey exploring the feedback from implementing countries regarding ORPHACodes adoption for rare diseases coding. Nov 2021 (Veneto Region) 8. Final partners' satisfaction survey Dec 2021 (EURORDIS) 10. Live survey during the Final Multistakeholder workshop
Outcome/Impact Indicator(s)	Target		
Improvement of KPI from mid-term to final term Satisfaction of end users (regarding the project overall) increased from mid-term to final term			A live survey was carried out during the final workshop to assess end-users satisfaction of the major outputs of the project available beyond the project participants. Overall they were assessed a medium score of 7 on a scale from 0 to 10. With the Orphadata downloadable datasets and cross-references with other terminologies rating at 8.2 and 8.6. Followed by the API

		Status March 2020	Status Dec 2021
			at 7.8 , the guidelines at 7 and the dataviz tool at 6.7. At last the helpdesk (5.9) and ORDO (5.7).
Specific Objective Number	4.1.1 (CZECH REPUBLIC)		
Specific Objective	To enforce the use of ORPHAcodes according to the "Standard procedure and guide for the coding with ORPHAcodes" and the "Specification and implementation manual of the Master file" in major rare diseases centers reporting to the National Register of Congenital Malformations.		
Process Indicator(s)	Target		
Number of hospitals accepting to participate in the piloting	2	2	2
Output Indicator(s)	Target		
Number of newly reported cases from these hospitals coded using ORPHAcodes per year	50	126	874 (approx. 290 per year)
Outcome/Impact Indicator(s)	Target		
National Register of Congenital Malformations manages to implement ORPHAcodes in its recording system	1	1	1
Specific Objective Number	4.1.2 (CZECH REPUBLIC)		
Specific Objective	To train coding clinical experts in the use of ORPHAcodes focused on hospitals participating to ERNs.		
Process Indicator(s)	Target		
Number of training sessions performed	3	1	3
Output Indicator(s)	Target		
Number of clinicians trained	15	19	44
Outcome/Impact Indicator(s)	Target		
Satisfaction and knowledge of trainees	90%		11 out of the 44 trained clinicians responded to the

		Status March 2020	Status Dec 2021
			Satisfaction survey: 73% reported that the information received on the course was beneficial to them.
Specific Objective Number	4.1.3 (CZECH REPUBLIC)		
Specific Objective	To increase the number of hospitals reporting rare diseases cases into the National Register of Congenital Malformations using ORPHAcodes.		
Process Indicator(s)	Target		
Number of hospitals reporting to the register using ORPHAcodes per year	7	2	8
Output Indicator(s)	Target		
Number of cases reported using ORPHAcodes by these hospitals per year	200	126	965 cases in total from 2019 to 2021 (8 hospitals) approximately 321 cases per year
Outcome/Impact Indicator(s)	Target		
A comparison between the period 2016-2017 and the Project implementation period will render significant results as regards overall RD cases identified, accuracy of reporting and variety of diagnoses reported. A report will be issued.	at least a 50% increase in the number of cases identified		Compared to the period 2016-2017, the number of inserted cases increased more than 16 times. 2016-2017: 57 rare disease cases inserted to the registry 2019-2021: 965 rare disease cases inserted to the registry
Specific Objective Number	4.2 (MALTA)		
Specific Objective	To introduce ORPHAcodes according to the "Standard procedure and guide for the coding with ORPHAcodes" and the "Specification and implementation manual of the Master file" in the daily practice of registries including rare diseases.		
Process Indicator(s)	Target		
To introduce automatic ORPHAcoding into the data model of three existing registries: congenital malformations registry, cancer registry and the Treatment abroad data	3	Achieved for the 3 registries	Achieved

		Status March 2020	Status Dec 2021
Output Indicator(s)		Target	
Number of cases reported using ORPHAcodes per year	200	Achieved, more than 200 cases reported	Achieved, 1,400 cases per year cases reported
Outcome/Impact Indicator(s)		Target	
A comparison between the period 2016-2017 and the Project implementation period will render significant results as regards overall RD cases identified, accuracy of reporting and variety of diagnoses reported with accurate prevalence data per RD registered in the general Maltese population reported.	50% increase	Work in progress	Achieved There was a 1.75 fold increase (from 800 cases registered per year to 1,400 cases per year)% increase.
Specific Objective Number	4.3.1 (ROMANIA)		
Specific Objective	To introduce ORPHAcodes according to the "Standard procedure and guide for the coding with ORPHAcodes" and the "Specification and implementation manual of the Master file" in the daily practice of a major centre dealing with rare diseases diagnosis.		
Process Indicator(s)		Target	
Number of rare diseases for which the ORPHAcodes has been implemented by M12	30	Achieved	193
Output Indicator(s)		Target	
Number of cases reported using ORPHAcodes per year	200	Achieved	1,137 in total =379/year
Outcome/Impact Indicator(s)		Target	
Health authorities will have correct numbers that will enable them to allocate adequate funds for National Health Programmes (for diagnosis and therapy of rare diseases)	2 Health Programmes (for rare diseases and for the prevention and diagnosis of congenital defects and genetic disorders)	Achieved	Achieved
Specific Objective Number	4.3.2 (ROMANIA)		

		Status March 2020	Status Dec 2021
Specific Objective	To train coding clinical experts in the use of ORPHAcodes focused on hospitals included in the ERNs.		
Process Indicator(s)	Target		
Number of training sessions	4	1	4
Output Indicator(s)	Target		
Number of clinicians trained	30	12	30
Outcome/Impact Indicator(s)	Target		
Clinicians involved in rare diseases diagnosis will know better how to report their results and will do it in an unitary way. Based on Y1 results other centres will decide to introduce ORPHAcodes.	3 additional centres	100% of the clinicians surveyed agree or strongly agree that the Romanian team is supporting the other rare diseases centres to use ORPHAcodes	4 centres in total, achieved
Specific Objective Number	4.3.3 (ROMANIA)		
Specific Objective	To introduce ORPHAcodes in other centres involved in ERNs. M16-30		
Process Indicator(s)	Target		
Number centres that will join the ORPHAcoding	3	3	3
Output Indicator(s)	Target		
Number of patients with rare diseases reported using ORPHAcodes	100	200	1,137
Outcome/Impact Indicator(s)	Target		
Other National Health Programmes will benefit of the results concerning the frequency of rare diseases. Based on the proofs provided, Health authorities will be able to decide if they want to generalize Orphacoding for Romania	2 other National Health Programmes	2	2
Specific Objective Number	4.4.1 (SPAIN)		

		Status March 2020	Status Dec 2021
Specific Objective	To pilot the implementation of ORPHAcodes according to the "Standard procedure and guide for the coding with ORPHAcodes" and the "Specification and implementation manual of the Master file" at the rare diseases registries in selected regions in Spain.		
Process Indicator(s)	Target		
Number of regions that have made adaptations in their processes towards the implementation of ORPHAcodes at M12	6	6	Achieved 7 regions: Comunitat Valenciana, País Vasco, Cataluña, Castilla y León, Madrid Murcia and Navarra +1 Hospital – Sant Joan de Deu Hospital (Barcelona)
Output Indicator(s)	Target		
Nº of regions having implemented ORPHAcodes by M12	4	5	Achieved 6 regions: Comunitat Valenciana, País Vasco, Cataluña, Castilla y León, Madrid, Murcia +1 Hospital – Sant Joan de Deu Hospital (Barcelona)
Outcome/Impact Indicator(s)	Target		
Percentage of cases coded with an Orphacode at M12	75%	100% of the cases communicated to the national registry with an ORPHAcodes from the Master file with an ICD-10-ES equivalent	Achieved 100% of the cases communicated to the national registry with an ORPHAcodes from the Master file with an ICD-10-ES equivalent
Specific Objective Number	4.4.2 (SPAIN)		
Specific Objective	Following the pilot evaluation phase, to disseminate the results in order to involve other regions in the Project.		
Process Indicator(s)	Target		

		Status March 2020	Status Dec 2021
Nº of new regions working towards the implementation of ORPHAcodes after M15	2		Achieved 5
Output Indicator(s)	Target		
Nº of new regions having implemented ORPHAcodes by M27	2		Achieved 6 regions + 1 hospital
Outcome/Impact Indicator(s)	Target		
Percentage of cases coded with an Orphacode at M27	75%		100%
Specific Objective Number	4.5 (Orphanet)		
Specific Objective	Centralise and develop information on the Orphanet nomenclature for codification purposes		
Process Indicator(s)	Target		
Codification project Orphanet internal meetings	12	12	Achieved
Output Indicator(s)	Target		
Number of new documents available per year	1	1	Achieved FAQ, Xml content description, RD-code website (http://www.rd-code.eu/introduction/)
Outcome/Impact Indicator(s)	Target		
Satisfaction on access to the information and quality per annum. (Survey of the 4 implementing countries satisfaction before/after the release of the webpage and documents)	Increase in the satisfaction level at the end of project (M30) compared to baseline (M3).	The survey has a goal to evaluate the needs of each country member and understand their expectations in terms of providing resources. Partners were satisfied with the documentation available	NTR
Survey of the 4 implementing countries satisfaction before/after the release of the webpage and documents			Satisfaction with website: There is slight decrease in level of satisfaction compared to the mid-term review (1 partner reported being unsatisfied with the project website in the final survey)

		Status March 2020	Status Dec 2021
			whereas at mid-term all respondents were either satisfied or very satisfied).
Specific Objective Number 5.	5.1		
Specific Objective	Provide background analysis of the “coding environment” _____ in implementing countries		
Process Indicator(s)	Target		
Questionnaire definition exploring background analysis of the “coding environment” in implementing countries.	Analysis of information coming from all the implementing countries	Achieved March 2019 3 out of 4 implementing countries answered the questionnaire (Spain, Czech Republic and Malta). Romania did not answer, despite several reminders. 2 additional countries (observers) answered: Austria and Norway.	
Output Indicator(s)	Target		
Document on existing “coding environments” regarding RD coding in implementing countries	1	Achieved June 2019 The document describes the coding environment of the countries which completed the questionnaire before the agreed deadline: Spain, Czech Republic, Malta	
Outcome/Impact Indicator(s)	Target		

		Status March 2020	Status Dec 2021
Results accessible through the project website	Results dissemination at WS: 1 multi-stakeholder workshop 1 international conference 1 national event/implementing country	Background Report accessible in the project website For each country, an overview of the following themes is provided: national RD policy framework, coding framework, RD registration, Centres of Expertise/ERNs, undiagnosed RD patients.	Results presented at the 2 RD-CODE multistakeholder WS and in Malta National Workshop on ORPHAcoding All WP5 documents will be submitted for presentation in upcoming events (i.e. ECRD 2022). All WP5 documents will be available in the project webpage as soon as finalized (end of Dec 2021)
Specific Objective Number	5.2		
Specific Objective	Analysis of the “coding environment” in implementing countries following ORPHAcodes adoption		
Process Indicator(s)	Target		
Definition of a questionnaire exploring changes in the “coding environments” in implementing countries following ORPHAcodes adoption.	Analysis of information coming from all the implementing countries		Achieved The questionnaire has been submitted to implementing countries. So far, Spain (2 implementing regions, Valencia and Murcia), Malta and CZ Republic have answered the Questionnaire.
Output Indicator(s)	Target		
Document on lessons learned from implementing countries following ORPHAcodes adoption.	1		Based on the answers received, the document will be issued by the end of December 2021 as planned.
Outcome/Impact Indicator(s)	Target		
Results accessible through the project website.	Results dissemination at WS: 1 multi-stakeholder workshop;		In progress Results were shared at the final RD Code workshop. All WP5 documents will be submitted for presentation in

		Status March 2020	Status Dec 2021
	<p>1 international conference;</p> <p>1 national event/implementing country</p>		<p>upcoming events (i.e. ECRD 2022).</p> <p>All WP5 documents will be available in the project webpage as soon as finalized (end of Dec 2021)</p>
Specific Objective Number	5.3		
Specific Objective	Refinement of the "Standard procedure and guide for the coding with ORPHAcodes"(17) and the "Specification and implementation manual of the Master		
Process Indicator(s)	Target		
Analysis of need for change of the "Standard procedure and guide for the coding with ORPHAcodes"[17] and the "Specification and implementation manual of the Master file" [19] was performed following Objective 5.1 and 5.2 as well as Workshops in WP 2	Analysis of information specific on the two documents		In progress Workshops' results are under analysis and the final document will be finalised by the end of the project.
Output Indicator(s)	Target		
Document on lessons learned and need for updating	1		In progress WS results are under analysis and the final document will be ready by the end of the project.
Outcome/Impact Indicator(s)	Target		
Results accessible through the project website	Results dissemination at WS: 1 multi-stakeholder workshop;		In progress All WP5 documents will be submitted for presentation in upcoming events (i.e. ECRD 2022).