

## KICK-OFF MEETING 4 FEBRUARY

## KICK OFF MEETING

RD-CODE was launched in Luxembourg, under the auspices of Martin Seychell, Deputy General Director of the Health Division and Food Security and Donata Meroni, Head of Health CHAFEA unit . Discussions focused on the practical guidance on implementation developed in the frame of the [RD-ACTION](#) (2015-2018). This work was recognised as a best practice by the European Commission Steering Group Promotion and Prevention (SPGG). The update of the RD-ACTION ORPHAcodes tool kit as well as the delivery of new Orphanet tools aimed at facilitating the practical implementation of ORPHAcodes are also at the centre of the work to come. The specific activities to be carried out in the five workpackages of the project were also discussed and a roundtable was held in order to make sure that coherence and continuity between the project and the former action is ensured and that all tools, material developed within the new project are not only shared between the four implementing countries but are also of use for any new stakeholder. Furthermore, the roundtable was also the occasion to share experiences with other actors, such as ERNs, EURORDIS, HL7 and inter-regional initiatives like [EMRaDi](#) aiming at building consistency in rare diseases codification across settings.

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*« This project is intended to support the implementation of a codification system specific for rare diseases based on the Orphanet nomenclature of rare diseases in four Member states (Czech Republic, Malta, Romania and Spain) The heterogeneity of contexts and settings within the countries will ease the implementation in other Member States. »*

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# TO DO LIST

✓ Remember to record the time spent on the project by the staff listed in the Grant Agreement. For personnel costs declared as actual costs the beneficiaries must keep time records for the number of hours declared. A time record template is available [here](#). Alternative evidence supporting the number of hours declared can be accepted by CHAFEA if it considers that it offers an adequate level of assurance. Please contact us if you have a doubt concerning your time record system or use the template provided.

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**"Deliverable 1.1  
completed."**

## WORKPACKAGE1

The US14-Inserm is coordinating the project, and the objective of this Workpackage\* is to facilitate and ensure the efficient implementation of actions foreseen, based on effective cross-talk between the 5 work packages within the project.

The KOM report has been delivered. This report is a deliverable (D1.1) that has been uploaded on the ECAS platform together with signing list.

*Milestones update:*

Mls1: organisation of the KOM is completed. **REACHED**  
Mls2: Steering committee meetings **REACHED**

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**"Deliverable 2.4  
and 2.7  
completed."**

## WORKPACKAGE 2

Within this Workpackage (WP leader: Inserm, Participants: CIBERER and IHIS) are the actions undertaken to ensure that the results and deliverables of the project will be made available to the target groups. Engagement of the stakeholders in early consultation exercise to assess their needs will be carried out, in order for the material developed to be effective and useful. Moreover satisfaction on material produced and suggestion for improvements will be sought. Engagement of the stakeholders in early consultation exercise to assess their needs will be carried out, in order for the material developed to be effective and useful. Moreover satisfaction on material produced and suggestion for improvements will be sought. Multi-stakeholder Workshops

will be organised in order to ensure productive cooperation of the different stakeholders . Collaborative methods will be used.

What	When	Where	How
Multistakeholder workshop 1	May 2020	Prague	Project progress reports, roundtables
Multistakeholder workshop 2	March 2021	Valencia	Project progress reports, roundtables

The [www.rd-code.eu](http://www.rd-code.eu) is available online (D2.4).

The Kick off leaflet of the project (D2.7) is available [here](#)

News regarding the Kick off of the project have been published in Orphanews and on [www.rd-code.eu](http://www.rd-code.eu)

*Milestones update:*

*MIs3: Website layout and content validated by the Steering committee **REACHED***

## WORKPACKAGE 3

This Workpackage comprises actions undertaken to verify if the project is being implemented as planned and reaches the objectives . Evaluation will be carried out with quantity (according to the defined indicators and targets) and quality approaches (to assess the needs, and the improvement suggestions) .

A survey was launched after the kick off, the survey was closed on 4 March. 10 answers were collected and a summary report is available. Globally the 10 Respondents were either very satisfied or satisfied of the meeting organisation. They find that the meeting objectives were clearly outlined and that they learned essential information during the meeting discussions. Two out of ten

participants found that time for discussions was a bit short, and therefore we will try to have a longer discussion timeslot at the next meeting.

WP leader: EURORDIS

*Milestones update:*

*MIs5: KOM participant survey **REACHED***

## WORKPACKAGE 4

The objective of the implementing countries (**Czech Republic, Malta, Romania and Spain**) is to implement ORPHAcodes in Health Information Systems . To achieve this, **user-friendly technical resources** will be developed and **coders trainings** will be organised in order to ensure an **easier and more accurate coding**. The heterogeneity of contexts and settings within the countries will **ease the implementation in other Member States**.

**Orphanet Nomenclature material specific for coding purposes** will be made available as well as **new services and tools to help decision making and visualise the nomenclature/classification**.

**New Orphanet nomenclature help desk** will be made available in 2019: a Unique Contact point for Codification issues and for Data, model and technical issues. A **Frequently Asked Questions** will be prepared according to the questions received.

*WP leader: CIBER Participants: IHIS, MFH Malta, DSP IASI, Orphanet*

*Milestones update:*

*MIs10 IT tool development (RO) **ON HOLD***

*MIs 11 Preparation of implementation in Pilot centre **ON HOLD***

## WORKPACKAGE 5

**Exploring the implementing partners' context for ORPHAcodes adoption** and getting feedback from implementing countries regarding ORPHAcodes adoption for RD coding is an asset for developing representative guidelines. **Refinement and update**

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*" Questionnaire to explore the "coding environment" of implementing countries available"*

**of the already existing resources (guidance documents for implementation and exploitation)** based on the feedback from implementing countries will be delivered.

**To tackle the undiagnosed patients' coding issue** a **collection of existing experiences** of coding of undiagnosed or suspected RD patients will be produced, a **Guidelines proposal** will be issued as well as a **Consensus document on codification of suspected/undiagnosed rare diseases** will be produced and disseminated.

A questionnaire to explore the "coding environment" of implementing countries has been prepared , it is organised into 5 sections: one with questions pertaining to national RD policy framework, one to the Coding framework, one to RD registration, one about Centres of Expertise/ERNs, and the last one about Undiagnosed RD patients. This questionnaire will be submitted to WP4 participants in an electronic format and a conference call will be organised with the respondents in order to clarify the questions asked.

*WP Leader: Regione Veneto Participants: APHP; DIMDI*

*Milestones update:*

*MIs22:* questionnaire to explore the "coding environment" of implementing countries **REACHED**

## STEERING COMMITTEE NEWS

In order to guarantee an integrated and coherent approach within the project and promptly address any challenges or emerging risks, a steering group composed of all the WP leaders will meet every two months at distance. WP leaders should liaise with the other participants in their WP in order to collect their feedback (Ideally this should be done through regular distant meetings scheduled before the SC meeting and as often as necessary).

The executive committee bi-monthly conference call was held on the 11/01 and the 28/03. Read the full report [here](#).

## **RD-CODE News**

**IF YOU HAVE ANY  
QUESTIONS:**

**DO NOT HESITATE  
TO CONTACT US**

**pmt.orphanet@inserm.fr**

**www.rd-code.eu**

## **OTHER INFO**

**NTR**

## **WHAT'S NEW ON THE INTERNAL WEBSITE**

N.B. The internal website is not available yet. All material can be found [here](#).

RD-CODE logo

RD-CODE presentation template

RD-CODE KOM report

RD-CODE Grant agreement

RD-CODE consortium agreement

RD-CODE Dashboard and tracking table of indicators

