

## FINAL MULTISTAKEHOLDER WORKSHOP

AND RD-CODE  
PROJECT VIDEO  
AVAILABLE!

## FINAL MULTISTAKEHOLDER WORKSHOP

The second and Final Multistakeholder Workshop was held virtually on the 29 and 30 November 2021, and was organised by CIBER. It gathered 77 participants including all project partners as well as ERNs, European University Hospitals Alliance (EUHA) and European Children's Hospital Organisation (ECHO) representatives. The objectives of this Workshop were multiple: learning about the final outcomes of ORPHAcodes implementation in the 4 Member States participating in RD-CODE as well as discussing on potential improvements on the available coding guidelines, disseminate information about the available coding guidelines including those about coding undiagnosed patients. On the second day representatives from the collaborating project X-eHealth presented their project achievements and in particular how the Patient Summary can serve RDs. It was also the opportunity to discuss with them about setting up a RD Demonstrator. A multistakeholder panel, with representatives from the French National registry, (BNDMR) ERKnet, EUHA and ECHO allowed to discuss with the different stakeholders and to understand their needs. Finally, a closing session on the project legacy allowed to discuss future options to keep the RD-CODE community of practice alive.

Full Agenda, reports and slides will be available [here](#).

## VIDEO AVAILABLE!

A **Video** explaining the benefits of using ORPHAcoding in Health Information Systems AND the RD-CODE project tools and guidelines is available in English and it is being translated in the 7 languages of the consortium and accessible [here](#).

# 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.

## 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 project ends at the end of December 2021 and the reporting period will be open in January for 2 months. All project beneficiaries will receive the relevant information the first week of January!

## 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.

A [Slidedeck](#) is made available to complement the video highlighted above. The slide deck explains further in detail the benefits of using ORPHAcoding in Health information systems was also delivered.

**All project leaflets as well as a General Public report and the project dissemination report** will be made available here: <http://www.rd-code.eu/workpackage-2-dissemination/>

The RD-CODE project website was released online in March 2019 ([www.rd-code.eu](http://www.rd-code.eu)). The website contains all the information regarding partners of the project, the different work packages of the project, and regular news are posted on it regarding project progresses and tools and documentation release.

Since its release online **17,781 pages have been viewed** as of 8 December 2021, **from 142 countries**. The audience has constantly increased since the release of the website! Also **the documents downloads have drastically increased since the beginning to**

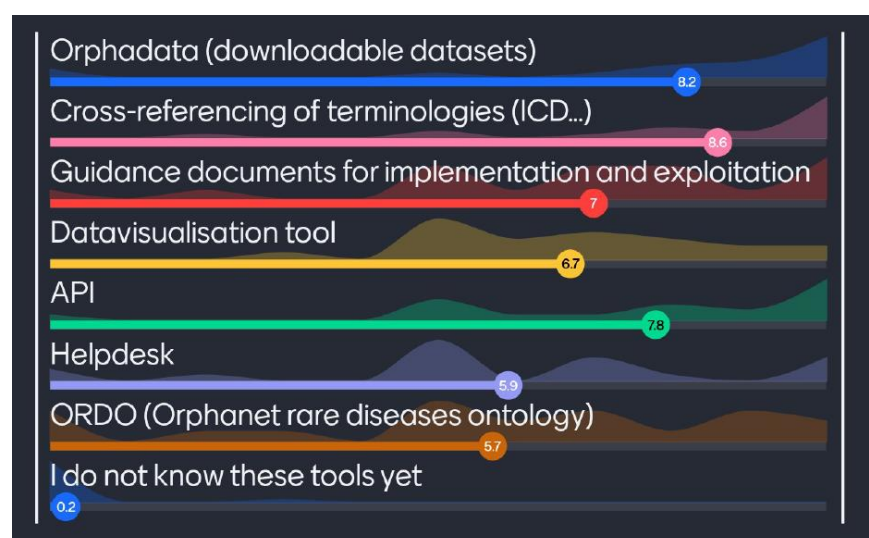
**achieve more than 130 downloads/month in the last trimester of the project.**

A **Dissemination Report** is also available on the RD-CODE website!

## 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) .

During the Final workshop a live survey was launched to assess the utility of the project outputs that can be re-used also after the end of the project. A median score of 7 was observed on a scale form 0 to 10.



**The final evaluation report** will be released before the winter break and it will be available here: <http://www.rd-code.eu/workpackage-3-evaluation/>

WP leader: EURORDIS

## 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** have been developed in Czech Republic, Malta, Romania and Spain and **coders trainings** have been organised in Czech Republic, Malta, Spain and Romania in order to ensure an **easier and more accurate coding**. The heterogeneity of contexts and settings within the countries has contributed to improve the guidelines and recommendations prepared by Workpackage

5 and these diverse experiences feedbacks will ease the implementation in other Member States.

**Outcome reports by Czech Republic, Malta, Spain and Romania will be available here** before the winter break: <http://www.rd-code.eu/workpackage-4-implementation-in-member-states/>

### **Orphanet update:**

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/> was delivered in December 2020. All interrogations exploit the above-mentioned Orphanet API also released within this project, showing at the same time the nice exploitation potential of the Orphanet API. This tool allows to search for the clinical entities (groups of disorders, disorders, sub-types) that are present in the nomenclature pack (here) in all the API languages. Find out more info about the tool [here](#).

Also, the [Frequently Asked Question](#) Page has been updated, do not hesitate to consult it!

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

## **WORKPACKAGE 5**

A smaller dedicated workshop was organised on the 24 September 2021 by APHP to finalise the **Recommendation for coding undiagnosed patients**. It gathered RD-CODE experts from WP4 and WP5, 4 experts from ERNs participating in the SOLVE-RD project (ERKnet, BOND, ITHACA and CRANIO) and 2 representatives from the X-eHealth project. The finalized document is available here: <http://www.rd-code.eu/workpackage-5-enhancements/>

The documents below :

**D5.2. Update to coding resources and guidelines** will both be released before the winter break and will be available here: <http://www.rd-code.eu/workpackage-5-enhancements/>

**D5.3 Implementing countries Report on ORPHAcodes adoption**, this document contains country-specific insights on lessons learned, challenges

## RD-CODE News

**IF YOU HAVE ANY  
QUESTIONS:**

**DO NOT HESITATE  
TO CONTACT US**

[pmt.orphanet@inserm.fr](mailto:pmt.orphanet@inserm.fr)

[www.rd-code.eu](http://www.rd-code.eu)

and potential solutions emerging from different ORPHAcodes' implementation experiences carried out in the framework of the RD-CODE project and will be available here: <http://www.rd-code.eu/workpackage-5-enhancements/>

Finally very interesting transnational study results were presented at the Final workshop and a small working group has been set up to work on a publication.

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

## 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 has met 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 calls were held in 2021 on the 19/01, 16/03, 04/05, 01/06, 23/09, 21/10 and 07/12. Read the full reports [here](#). **In total 17 Steering Committee meetings were held in the course of the project!**

## OTHER INFO

**NTR**

## WHAT'S NEW ON THE INTERNAL WEBSITE

All material can be found [here](#).

[RD-CODE logo](#)

[RD-CODE presentation template](#)

[RD-CODE KOM report](#)

[RD-CODE Dashboard and tracking table of indicators](#)

[RD-CODE steering Committee reports](#)

[RD\\_CODE deliverable template](#)

[Nb. RD-CODE Grant agreement available on ECAS](#)

[RD-CODE consortium agreement: send an email to \[sylvie.maiella@inserm.fr\]\(mailto:sylvie.maiella@inserm.fr\)](#)