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RD-CODE WP 2

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Multistakeholders Workshop Report (M20-M30)

CZ

Deliverable 2.2

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The RD-CODE project was launched in January 2019 for 36 months period, and was extended to the end of December 2021.

More information on the activities of the RD-CODE project can be found at www.rd-code.eu

Content

Introduction and Background

The objective of the RD-CODE project is to support Member States in improving gathering information on rare diseases by implementation of ORPHAcodes (rare diseases specific codification system) and by developing tools and guidelines to facilitate this implementation. The implementation process is guided by the « Standard procedure and guide for the coding with Orphacodes » and the « Specification and implementation manual of the Master file » both developed in the frame of the previous Joint Action on rare Diseases RD-ACTION (2015-2018), these documents will be revised and updated according to real-life implementation in the participating countries and will be delivered by the end of 2021. Implementation of ORPHAcodes into routine coding systems will enable a standardised and consistent level of information on RD to be shared at European level. Monitoring the progresses and difficulties of the countries that had no systematic implementation of the ORPHAcodification at the beginning of the project, will provide a sufficient real-world implementation experience to be captured by other countries in the future.

Rationale for the RD-CODE multistakeholder workshops

In particular, in the frame of the RD-CODE project it was planned to organise 2 Multi-stakeholder workshops in order to disseminate project results and to foster collaboration between stakeholders with common goals regarding rare disease coding and cross-border care and codification exploitation.

Executive Summary

The first RD-CODE multi-stakeholders workshop took place on 22 and 23 June 2020. It gathered 64 participants from 8 countries: all project participants including ERNs ReConnect, ERN-RND, CRANIO and ERNICA as well as SOLVE-RD representatives.

Initially this event was planned as a face to face event, however because of the travel restrictions following the first wave of COVID-19 pandemic in Europe the event was organised as an “hybrid” mode. The Czech applicants were present in person at the Congress Center at Vyšehrad a in Prague and the participants from abroad were connected online via a Webex platform.

The objectives of this workshop were multiple such as learning about the RD-CODE project and Implementing countries specific activities, and to be able to have a forum to discuss country specific experiences and challenges with advice from WP5 team, collaborating partners and external experts. It was also an occasion to disseminate the projects results such as the availability of the Nomenclature Pack and of the Orphanet API to a wider audience and to collect feedback on how to adapt all Orphanet Codification tools to their real-life use. This workshop provided also an important forum to obtain feedback from implementing countries to allow refinement and update of the already existing guidance documents for implementation and exploitation:« Standard procedure and guide for the coding with Orphacodes » and the « Specification and implementation manual of the Master file » both developed in the frame of the previous Joint Action on rare Diseases RD-ACTION (2015-2018)). Finally a final session dedicated to liasing with other relevant projects provided an opportunity to exchange with SOLVE-RD experts on the topic of "undiagnoses patients" as well as with eHealth experts. The Workshop roundtables proved essential in fine tuning the transversal workpackages activities that needed to be planned and launched and also in establishing links with other relevant initiatives/projects working on similar topics. All materials and information are available in the attached presentations, which were taken during the workshop.

Sessions Report

Project members progresses reports (Session 1, 2 and 6)

The current situation in the member countries and the progress in the RD-CODE project were presented by Juan Rico and Clara Cavero-Carbonell (Spain), Cristina Rusu (Romania), Miroslav Zvolský (Czech Republic) and Francis Agius (Malta).

Spain

In Spain, a nationwide population-based RD registry is in place to collect data from the regional registries. The Ministry of Health, with the collaboration of the regional governments, is the responsible of the National Registry of Rare Diseases (ReeR) that produces validation sheets for selected diseases. These documents include several coding systems (ICD-9-CM; ICD-10; ICD-10-ES; ICD-10-BPA; OMIM; ERA-EDTA; SNOMED-CT and ORPHAcode) when the equivalences among them are available. The validation sheets are then circulated and established as references for the codification and communication of the cases diagnosed with such diseases within the national territory. Since 2016, the Spanish version of the 10th International Classification of Diseases (ICD-10-ES) has been used in Spain as the reference classification for clinical coding. Currently, most of the morbidity and mortality data are also collected using this classification and ICD-10.

The RD-CODE goal in Spain is to promote the use of the Orphanet nomenclature for implementation into routine coding systems by establishing equivalences between ICD-10-ES and ORPHAcodes. Six Autonomous Communities (AC), Castile and Leon, Catalonia, Murcia, Navarre, Basque Country and Valencian Region (~19M people). were enrolled from the beginning of the project to participate in a pilot phase consisting in the implementation of ORPHAcodes in their RD registries following the necessary Information Technology (IT) developments and according to the guidelines and Masterfile developed in the frame of the RD-ACTION project. Expected results by M12 of the project included the achievement of significant progress towards the implementation of ORPHAcodes in 6 regional Rregistries and to attain an ORPHAcode correspondence with ICD10-ES for at least 75% of all the RDs listed in the Master file.

Under the RD-code project equivalences to ICD-10-ES for over 90% of the entries registered in the original Master file have been proposed. The number of different ICD-10-ES codes proposed is approximately 1/3 of the total equivalences (2,102/5,933) confirming the lack of enough specific independent codes for RDs in the ICD-10-ES coding system.

FISABIO has centralized the efforts of the different regions involved in the pilot phase for the implementation of ORPHAcodes into their regional RD registries. Most of the equivalence proposal work was conducted at FISABIO in collaboration with the AC involved in the project.

Implementation of ORPHAcodes as the reference system for classification of RDs within regional and national registries has been proven possible in Spain. During the first six months of the project a pilot

phase with a reduced number of ORPHAcodes was set up. (≈85% coverage) with their ORPHAcodes and the equivalences to ICD-10-ES. This document was prepared for the final attempt of implementation of the pilot phase and the regional registries integrated it into their software in order to test the feasibility of its use. Together with this new Master file, the guidelines for their correct interpretation were circulated in order to facilitate their implementation.

However, a number of variables slow down the process:

First of all, each population registry has intrinsic working features that make them different from each others The situations can be roughly divided in two groups:

- The registries that receive the notification of the cases from the clinicians, either with an ORPHAcode or with a descriptor that needs revision to validate and assign an ORPHAcode.
    - The impact of direct translation from ICD-10 to ICD-10-ES to ORPHA, although important, it is indirect.
    - While the Master file allows facilitating the communication with other health services using ICD-10 based systems rather than ORPHAcodes, it doesn't make or makes little impact over the assignment of ORPHAcodes to the registered RD cases.
- The registries that retrieve the cases from information sources with different coding systems and translate them to ORPHAcodes.
    - This type of registries is highly benefited by the establishment of a shared list of ICD-10-ES to ORPHAcode equivalences.
    - This list known as Master file facilitates the assignment of an ORPHAcode (automatically or manually) to the retrieved cases.

The Master file also helps to unify the criteria to choose the same ORPHAcode for the same disease in different registries so they can easily communicate their data in the same format at least in terms of ORPHAcodes.

The other main circumstance that hinders the total homogenization of the registries is the fact that there is a lack of direct and unique equivalences of ORPHAcodes to ICD-10-ES, which is the coding system mainly used by the information sources. This means that:

- Although there are a number of ORPHAcodes that can be directly translated from ICD-10-ES, just 2,102 different ICD-10-ES codes are available to establish 5,933 equivalences to ORPHAcodes.
    - Moreover, 484 of the ORPHAcodes listed in the original Master file lack of associated ICD-10 from Orphanet which difficult ICD-10-ES proposal leaving 404 of those remaining without any equivalence so far.
- Many of these ICD-10-ES codes have been then used more than once for different diseases which have a specific ORPHAcode associated.
- Even in a scenario where we could manage to manually curate the assignment of the right ORPHAcode from the bulk list of them hanging from the same ICD-10-ES code, it would be difficult to keep the homogeneity among services.

The fact that all the AC involved in the project report their RD cases to the National Registry of Rare diseases associated to an ORPHAcode helps filtering discrepancies of criteria. Nonetheless, several improvements including the homogenization of the regional RD registries' procedures and their information sources remain necessary. In addition, new specific codes for RD must be included in the coding system used as reference at national level (currently ICD-10-ES) and future versions of it and

ideally implemented at all information sources. This would actually allow to make a direct translation to ORPHA and to standardize the way RDs are registered at regional and national level.

In summary, adaptation to ORPHAcodes although possible, is limited by the current codification tools. Efforts towards the establishment of equivalences allow us not only to approach the target of systematically report RDs but also help us realize which are the assets of currently employed systems and, moreover, their flaws and lacks.

Romania

In Romania Rare disease cases are reported by ICD-10 coding. Each hospital is using a different database, but all of them report synthetic data to a national database (used by the National Institute of Statistics). One of the goals of the RD-code project in Romania was to be able to report ORPHAcodes in Health Information Systems by developing an IT tool and by training physicians to ORPHAcodes use.

Iasi Regional Medical Genetics Centre covers 20% of the population of the country; with more than 2,400 patients with rare disorders evaluated/year and being part of ERN ITHACA (congenital anomalies & intellectual disability), it is a reliable pilot centre to start to introduce Orphacoding.

The IT tool developed in the frame of the RD-CODE project to allow ORPHAcodes registration was developed in order to fit the databases used by different hospitals and with the national one. After developing the IT tool, young physicians were trained by RD-CODE Romanian team to introduce cases and started uploading cases that have been evaluated in 2019 (precise diagnosis of rare disease –more than 200 cases recorded at the time of the workshop).

IsRMGC used as a pilot centre to introduce ORPHAcoding and other Romanian services - members in different ERNs have been invited to join. However, due to COVID 19 pandemics all the activities were paralysed as the IASI RD centre was closed for 3 months.

All trainings and meetings had to be organised online thus the team worked on developing training materials adapt to this new format). Due to the unexpected events, it was necessary to transfer travel and subsistence budget to purchase and install a teleconference system which is being used for training clinicians to ORPHAcodes and later it will be used for periodic meetings to monitor IT tool application extension).

Due to the crisis the system is busy with specific issues related to: patients try to avoid hospitals for safety reasons; scientific meetings where RD-CODE should have been presented are cancelled; the extension of the IT tool use is difficult. The possible solution will be in online communication in the future.

Czech Republic

In the Czech Republic (population 10.5 million) ascertainment of the prevalence of congenital anomalies is very high, as reporting is mandated by law. Since 1965 all physicians are obliged to report cases of congenital anomalies to the National Register of Congenital Malformations, which since 2016 has also captured data on voluntary reporting of other rare diseases including rare metabolic disorders. The capture rate of the information on newly added group of diseases is low, and has not been well publicised among physicians. ICD-10 international (WHO) version (in the Czech translation) is used for coding diagnoses. The Orphanet Nomenclature is available since 2018 as well as a dedicated IT tool.

One of the goals within the RD-CODE project for Czech Republic was to Train the community of physicians and to develop standardized tools to help physicians accurately code congenital anomalies and rare diseases using ORPHAcodes to ensure the increased accuracy of reporting.

Since the beginning of the project the reporting of rare disease cases with ORPHAcodes started in 2 major Health care providers (hospitals) with at least 50 new cases per year in each, reported to the National Registry of Reproductive Health. Also, the technical readiness of Hospital Information System used was analysed in Motol University Hospital (UNIS) and General University Hospital (Medea).

By June 2020 Motol University Hospital (MUH) and General University Hospital (GUH) has already reported 306 cases with ORPHAcodes (as of 5th June). It was also planned to perform at least 3 training sessions for coders in the field of rare diseases (in Prague and Brno). The first course was held on 19th February 2020 and all the materials are available at http://rd-code.ublg.cz/ . Due to the pandemic situation all other courses will be organised online and preparing of all materials in now in progress.

The next steps to carry out will be to:

- expand to other Health care providers (7 HCP with ERNs);
- push SW developers to improve the primary data collection in HIS interfaces;
- intensify the communication with SW developers;
- Disseminate results at the KlasifiKon conference with stakeholders and SW developers in December 2020;
- perform at least 2 other Training Sessions in hospitals;
- finalise the Czech translation of Orphanet website;
- carry out regular updates of the Czech translation of Orphanet terminology;
- includes ORPHAcodes in Health Insurance Funds reporting.

Malta

Currently all the information about the rare disease cases are coming from:

- The Malta Congenital Anomalies Register (MCAR; 70% of all its cases are rare with around 100-120 cases registered annually);
- The Malta National Cancer National Registry (MNCR; 12% of incident cases matching rare disease diagnoses as registered in Orphanet with 240 new cases of rare cancers annually);
- Treatment Abroad List of Patients (TA; 60% out of all patients sent abroad who have documented rare disease - circa 350 per year).

The main point is now to set a correct data flow by connecting the various organisations and databases to our software, this required the production of APIs (application programming interfaces). POYC (Pharmacy of your choice scheme) entitlement unit is having access to updated schedules of treatment available to patients. Pathology laboratories which supply histology details etc., death register to update automatically on a weekly basis, congenital anomalies register have been concluded. Workflow logic has been collected from these sources and transposed electronically.

Regarding the software so far it was manged to complete the workflow of the rare disease processes from laborious tasks including compilation of excel sheets from various organisations and databases into an automated manner. Thus, the framework of how the rare disease register will function is in place.

The final technical solution will be delivered after the RD-CODE training session that will be organised in Malta soon. The session aims to identify any gaps in the registry coverage and operation. The present digitization has replaced most of the manual work previously inherent in the system, but we see this development as a further opportunity to further expand.

As one of the project activities the training programme was set to happen on 3rd March. Covid19 has disrupted all work as all Public Health Physicians were enrolled in the emergency plan that is still in place. It is planned to have the training programme (virtually) in the coming months.

All information in this part were taken from the following sources: Preliminary results analysis and "Adaptation of procedure for ORPHAcodes use in Spain" (report); RD-CODE Workshop Country Presentation, Romania; RD-CODE Workshop Country Presentation, Czech Republic; RD-CODE Workshop Country Presentation, Malta.

Discussion on implementation barriers and solutions (Session 3)

In this session barriers of ORPHAcodes implementation were discussed.

- Who is coding?

In the Czech Republic it is quite a problem. Clinicians are overwhelmed and the administrative coders are not enough motivated and educated. Reporting ORPHAcodes is still only optional.

In Spain there are differences between regions. Clinicians are in charge of coding, essentially with ICD-10-ES. Only few hospitals are using ORPHAcodes for coding rare diseases.

In Norway the national registry was established, and it is still at the beginning. They have no experiences with ORPHAcodes implementing so far.

From the discussion it appears that the main issue in most of the countries is the motivation for clinicians.

In some country as France, the Expert centres need to report cases using ORPHAcodes otherwise they will not get funded. This could be an effective incentive. Also ERN status should be a sufficient motivation for collecting data about rare diseases.

API, ORPHAcode implementation documents and Orphanet nomenclature (Session 4)

During the session 4 the technical features of the rare disease coding were introduced.

A brief description of what is the Orphanet Nomenclature and how it is produced was provided together with a description of all the tools made available in the frame of the RD-CODE project such as:

- The nomenclature pack release every year in July: In order to allow the implementation of the Orphanet nomenclature in Health Information Systems, Orphanet provides a set of files available on xml format. It includes:

    - the Orphanet nomenclature file,
    - the Orphanet – ICD-10 cross-referencing file,
    - a directory containing the Orphanet classifications files.

- The Orphanet API, based on the nomenclature pack, to facilitate the implementation of the Orphanet nomenclature in Health Information Systems, and enables customised queries for specific use cases.
- The Helpdesk, dedicated to answering questions related to the Orphanet nomenclature content and the implementation of ORPHAcodes in Health Information Systems. For this purpose, an online ticketing system that allows requests to be stored, tracked and made available to others has been set up. This system facilitates an agile and interactive workflow.
- The FAQ pages

The audience was reminded also of the main tools and documents for the ORPHAcodes implementation, that came as a result of RD-Action project, are:

- Standard procedure and guide for coding with ORPHAcodes,
- Master file for statistical reporting with ORPHAcodes (MF),
- Specifications and implementation manual for MF,
- Recommendation for routine maintenance of codification resources for rare diseases.

All these documents will be revised during the RD-CODE project.

The following documents are already available:

- Background Report exploring the “coding environment” of implementing countries (available on WP5 part of RD-Code website),
- Standard procedure and guide for coding with ORPHAcodes;
- RD-Code 1st update, Specifications and implementation manual for MF;
- RD-Code 1st update, Collection of existing experiences about the coding of undiagnosed or suspected rare diseases patients in Electronic Health Records (draft version),

Codification of suspected/undiagnosed rare disease cases (Session 7)

This session, chaired by a SOLVE-RD representative was open with 2 presentations by SOLVE-RD representatives about the project progresses.

Céline Angin gave an overview presentation on the topic of codification of suspected/undiagnosed rare diseases to open the following round-table discussion.

The Milestone 5.3 “Collection of existing experience about the coding of undiagnosed or suspected rare diseases patients in Electronic Health Records is available.

The JRC set of common data elements for RD registration includes element 6.3 Undiagnosed case. This element could contain coding with HPO (for phenotype description) or HGVS (for genotype description).

The Recommendation 1. on identification of undiagnosed patient by the Standard procedure and guide for coding with ORPHAcodes, Guideline 3: Whenever possible capture the information of the diagnostic assertion for all RD cases. Use the Options “Suspected rare disease”, “Confirmed rare disease” and “Undetermined diagnosis”. Additional options might be helpful.

There are several ways to identify undiagnosed patients without adding a new variable into HER:

- using high level of ORPHAcodes (group of disorders)
- creating a new specific ORPHAcode item with general meaning

The Recommendation 2 says that each undiagnosed patient should be described by its phenotype using HPO. When available, the genotype should be associated to help future diagnosis. Additional phenotypic descriptors could be used (Orpha groups of diseases, ICD, SNOMED CT, …) as well as genetic descriptors (HGNC genes, OMIM, …).

The Recommendation 3 says that the level of the Orpha classification (i.e. Group of disorders, disorder, subtype) should be used in the Orphanet data source for all entries in association with the ORPHAcodes.

Fruitful discussions were held during the roundtable with the different RD-CODE, SOLVE-RD, ERN perspectives. As a conclusion, it was decided that a specific workshop on coding undiagnosed RD cases should be organised to understand the current practices, clarify the concepts and decide on the future steps.

Conclusion

The workshop allowed to have fruitful exchanges and to obtain a clear picture of what works and what is difficult in implementation experiences. This allowed to discuss on possible effective operational solutions, such as the integration of MasterFile release in the Nomenclature Pack. It was also the occasion to establish closer interactions between implementers, support providers and recommendations teams in order to make sure that tools and guidelines developed take into account experiences from the field and match users' need, in particular regular inter-workpackage meetings were launched and it was agreed to launch a survey to collect feedback on the available tools.

Advances were also made regarding the undiagnosed RD patients visibility in HIS, thanks also to the presence of SOLVE-RD experts. However it was agreed his particular topic had to be further discussed and a dedicated working group was set up.

List of workshop participants – online via Webex

Organisation
Orphanet France
Department of Health Information and Research Malta
APHP
HSE
Medical University in Gdansk
Norwegian National Advisory Unit on Rare Disorders
ReConnect ERN
FISABIO
University Clinical Center Gdansk
Center for Biomedical Network Research, Rare Diseases Area, SPAIN
Healthcare Pricing Office, Health Service Executive
Ministry of Health of the Basque Government
Veneto Region Coordinating Centre for Rare Diseases
RD-CODE SPAIN (Public Health Office-Castilla and León Goverment_Spain)
ERN -RND
EURORDIS-SOLVE-RD
Orphanet-INSERM US14
EURORDIS
Regional Ministry of Health - Madrid Región. General Sub-Directorate of Epidemiology Health Reports and Research Service
The Children's Memorial Health Institute, Warsaw, Poland
ORPHANET POLAND
University Clinical Center Gdansk Poland
Medical University in Gdansk
Orphanet Ireland/National Rare Diseases Office
Inserm US-14 Orphanet
FISABIO
Children’s Memorial Health Institute in Warsaw
Orphanet-INSERM US14
ERN ReCONNET
National Advisory Unit on Rare Disorders (Norway)
Poland
RD Coordinating Centre - Registry Veneto region Italy
CIBERER
NRDO, Ireland
Healthcare Pricing Office, Health Service Executive, Dublin, Ireland.
Inserm US-14 Orphanet

Sant Joan de Déu Children's Hospital
Orphanet-INSERM US14
FISABIO
Basque Government / Department of Health
University of Medicine and Pharmacy "Grigore T Popa" Iasi
CIBERER
CIBERER
Spanish Ministry of Health
Erasmus MC, Rotterdam, The Netherlands.
National Rare Diseases Office, HSE Ireland
Orphanet CZ
Instituto de Salud Pública y Laboral de Navarra
Bfarm
Medical University in Gdansk
Medical University in Gdansk
FISABIO. Valencia (Spain)

List of workshop participants – in Prague Congress Centre

Organisation
Institute of Health Information and Statistics
General University hospital in Prague
General health insurance company of the Czech Republic
University hospital Motol
Association of Atypical Parkinsonian Syndromes
ČAVO – Czech Association for Rare Diseases

Final agenda of RD-CODE Multistakeholder Workshop
22nd-23rd June 2020, Prague, Czech Republic

Venue (Prague Congress Centre, teleconferencing platform)

Day one

12:00 Preparations (connection of participants)

Session 1 (12:30-14:00) (*chair* Francesc Palau)

Objective: *to learn about the RD-CODE project and Country specific activities*

12:30 – 12:35 Welcome (Miroslav Zvolský)

12:35 – 12:50 Introduction, RD-CODE Project Overview (***INSERM***)

12:50 – 13:30 Presentations from implementing countries on implementation progress and problems and opportunities encountered I

Spain (25 minutes)

13:30 – 13:40 Break

Session 2 (13:40-15:00) (*chair Monica Mazzucato*)

Objective: *to learn about Country specific activities*

to discuss country specific experiences and challenges

13:40 – 14:10 Presentations from implementing countries on implementation progress and problems and opportunities encountered II

Romania (15 minutes)

Czech Republic (15 minutes)

14:10 – 14:30 Discussion, Q&A

14:30 – 15:00 Break

Session 3 (15:00-16:15) (*chair Deborah Lambert*)

Objective: *to discuss country specific experiences and challenges*

questions and answers from experts and WP5 team

15:00 – 16:00 Roundtable discussion of implementation barriers and solutions, commonalities and differences between implementation projects, with advice from WP5 team (common template)

16:00 – 16:15 Break

Session 4 (16:15-17:10) *(chair Sylvie Maiella)*

Objective: to disseminate project results

16:15 – 16:35 Presentation of ORPHAcodes webpage/helpdesk

16:35 – 16:50 Presentation from WP5 team about documentation produced

16:50 – 17:00 Presentation of API

17:00 – 17:10 Closing remarks of Day one

17:20 Prague virtual tour

Day two

10:00 – 12:00 Time reserved for discussion topics that emerged during the first day or small groups chat

12:00 Preparations (connection of participants)

Session 5 (13:00-14:10) *(chair Stefanie Weber)*

Objective: to disseminate project results

13:00 – 14:00 Roundtable on use of documents team's developed resources based on the ongoing implementation

14:00 – 14:10 Break

Session 6 (14:10-15:20) *(chair Miroslav Zvolsky)*

Objective: to learn about available training programs and resources

14:10 – 14:25 Presentations from implementing countries on implementation progress and problems and opportunities encountered II (transferred from Session 2)

Malta (15 minutes)

14:25 – 14:50 ORPHAcodes coding – overview of training programs + discussion

14:50 – 15:20 Break

Session 7 (15:20-16:25) *(chair Gulcin Gumus)*

Objective: to present recent advance and to discuss and finalize the documents

15:20 – 16:20 Roundtable discussion for finalizing documentation on codification of suspected/undiagnosed rare diseases, with SOLVE-RD experts

16:20 – 16:30 Break

Session 8 (16:30-17:30) *(chair Ana Rath)*

Objective: to discuss dissemination plan and other projects in the context of eHealth

16:30 – 16:50 Roundtable discussion for finalizing documentation on codification of suspected/undiagnosed rare diseases, with SOLVE-RD experts (continuing from previous session)

16:50 – 17:00 Dissemination plan update

17:00 – 17:10 Integration with other eHealth activities and projects

17:10 – 17:20 AOB

17:20 – 17:30 Closing remarks