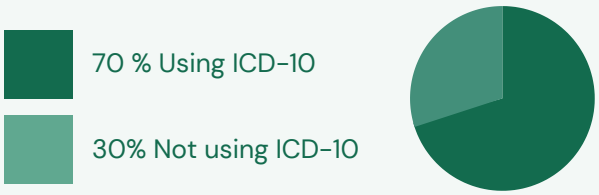
RD-CODE

Codification for Rare Diseases 2019-2021

THE PROBLEM

MAIN CODIFICATION SYSTEM IN HOSPITALS



ONLY 7% OF RARE DISEASES HAVE A SPECIFIC ICD-10 CODE

RARE DISEASES ARE NOT VISIBLE

Rare Diseases are **under reported**, **under recognised** and **under resourced** in health care systems using the main terminologies.

THE PROJECT

The objective of this project, coordinated by INSERM, is to **support** Member States in **implementing ORPHAcodes** into their routine codification systems and to improve gathering information on RD in a standardised and consistent way.

ADDITIONAL COLLABORATIONS

- PATIENT GROUPS
- CLINICAL RESEARCHERS
- HOSPITAL MANAGERS
- CODIFICATION PROFESSIONALS
- POLICY MAKERS
- OTHER RARE DISEASE PROJECTS

These collaborators will require the information and expertise generated by this project, but also by their participation can ensure the correct use of the results gathered on the project.

IMPLEMENTATION IN 4 COUNTRIES

FURTHER DEVELOPMENT AND GUIDELINES WORKING GROUP

orphanet

EURORDIS RARE DISEASES EUROPE

OUR FINDINGS

1. Versatile Coding Tool

Despite the diverse settings in the 4 Implementing countries, ORPHAcodes have demonstrated to be a versatile coding resource, which can be effectively introduced in different settings preserving consistency.

2. Multidisciplinary

Implementation and exploitation of ORPHAcodes require a multidisciplinary approach with multiple stakeholders like clinicians, IT, statisticians, coders/health information management specialist, among others

3. Dissemination

Dissemination to Health Authorities and Hospital managers is a key-intervention pre-requisite to ensure ORPHAcodes appropriate adoption

4. Key Settings for ORPHAcodes Use

Population-based registries and ERN registries (data about RD diagnosis should be issued from health records at the point of care, based on the involvement of hospitals in highly specialized RD patients'care)

5. Coding undiagnosed patients

This visibility can facilitate access to genomics platforms and can accelerate the diagnosis thanks to the shared knowledge of all the relevant experts. A new ORPHAcode (ORPHA:616874 Rare disorder without a determined diagnosis after full investigation) has been created to ensure this visibility without adding any new field in data collection tools.

6. Procedures & Guidelines

Procedures and guidelines developed in RD-CODE are indispensable tools to guarantee the appropriate use of the coding resources allowing comparability across countries and settings

7. Training

Multidisciplinary training (clinicians, IT) is strategic for the successful implementation and maintenance of the coding resources, patients' care.

8. Community

Set up a **community of practice** not to disperse the project legacy, to serve as a collaborative environment to move forward in the process of RD coding to increase patients' visibility, including undiagnosed ones, across diverse health-care settings.

LESSONS LEARNED

CODING ENVIRONMENTS IN THE IMPLEMENTING COUNTRIES

SPAIN

CZECH REPUBLIC

IMPLEMENTING COUNTRIES ORPHACODES ADOPTION REPORT

ROMANIA

MALTA

TOOLKIT & SUPPORT

- API AND DATAVIZ TOOL
- HELPDESK
- NOMEN-CLATURE PACK
- FAQ
- REPORTS
- RECOMMEN DATIONS

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SEE OUR PRESENTATION

WWW.RD-CODE.EU

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