

## RD-CODE Multistakeholder Workshop

22<sup>nd</sup>-23<sup>rd</sup> June 2020, Prague, Czech Republic

Venue (Prague Congress Centre, teleconferencing platform)

### Draft Agenda

#### 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 Zvolosky)

*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

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Czech participants will be present at the Prague Congress Centre, other participants will be connected remotely using teleconferencing platform (to be chosen).