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DEL 14.1
First Report of Orphanet nomenclature
training for trainers and national trainings

EJP RD

European Joint Programme on Rare Diseases

H2020-SC1-2018-Single-Stage-RTD
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Del 14.1

First Report of Orphanet nomenclature training for trainers and national trainings

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Partner 01 – INSERM-Orphanet

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Public

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1. Introduction and Background

The EJP-RD "Orphanet nomenclature and ontology for Rare Disease research" training programme was developed by Orphanet in the framework of the European Joint Programme on Rare Diseases (EJP RD). One of the tasks that Orphanet has been assigned within this project consists of diffusing a training module through the Orphanet Network. It is aimed at improving knowledge and basic skills about Orphanet nomenclature (including the ORPHAcodes) and Orphanet Rare Disease Ontology - ORDO for clinicians, researchers, and for the IT teams involved (EJP RD - WP14 - Task 14.1).

2. Rationale for the training

2.1. Content development

A training need assessment was performed in 2019, then, based on this, the module content was prepared in collaboration with the Orphanet Scientific Team and the EJP-RD Task14-1Scientific Committee (Sci-Comm reports available here).

2.2. Programmed sessions

The "Orphanet nomenclature and ontology for RD research" training programme includes 2 different types of sessions:

1. A TRAINING FOR TRAINERS (TfT) SESSION: reserved to Orphanet Network members in order to empower them to be ambassadors of the Orphanet Nomeclature and ontology in their country and to deliver trainings in their countries in local languages.

2. Around 10 NATIONAL TRAINING SESSIONS that will be open to researchers, clinicians and IT teams in Europe and in non-EU countries present as Orphanet LTPs in the EJP-RD project. The pilot National Trainings are essential as they will be used to improve the module according to feedback from real-life users of the Orphanet nomenclature and ontology for RD research to complement the work initiated in the Training Needs Assessment (TNA) phase.

2.2.1 Initial Plan

A) The TRAINING FOR TRAINERS (TfT) SESSION was initially scheduled in May 2020 as a Face-to-face session in Paris. During this TFT, the External Training module was planned to be presented to the Orphanet Network followed by a session dedicated to improving 'training' skills of the Network.

B) NATIONAL TRAINING SESSIONS: to select the pilot countries where the first training would be launched, acall of interest was adressed to the Orphanet Network at the start of 2020 in order to choose the 3 pilot countries where the National Training would be held. The three pilot volunteers were Norway, Austria and Italy.

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2.2 .2 Changes in the programme due to the COVID-19 Pandemic

A) TRAINING FOR TRAINERS (TfT) SESSION: The TfT which was to be held *face to face*, May 2020, had to be cancelled because of the pandemic. Because of the unforeseen situation and the difficulty in evaluating the possibility to meet face to face before the end of the year, it was decided to switch to an online mode. The TfT was re-scheduled in November 2020 in order to adapt its content to this new dissemination mode and also due to internal staff re-organisation due to COVID-19.

B) Unfortunately, none of the pilot National Teams was able to organise the National training in 2020 because of the second wave of the pandemic and they will re-schedule them in 2021. Currently, only Norway has scheduled its training for 8-9 March 2021.

3. Training for Trainers Objectives

3.1.   General objective

The General Objective of the 3-4 November 2020 Training for Trainers is to enable Orphanet National Teams to improve knowledge on Orphanet nomenclature and Ontologies in order to be able to dispense effective trainings in their country.

At the end of the training participants should be able to:
1- Explain what the Orphanet nomenclature and the Orphanet Rare Disease Ontology (ORDO) are
2- Be able to assist researchers whenever they are experiencing difficulties in their daily use of the Orphanet nomenclature and ontology; to be able to identify potential inconsistencies in the current use and propose solutions and best practices.
3- Access Orphanet data that is relevant to National Training organisation activities.
4- Improve Orphanet National Teams Trainer skills

3.2 Specific Objectives of the 2-day course:

1- EMPOWER the Orphanet National teams so that they can become Ambassadors for the Orphanet Nomenclature in their country.

2- Finalise the beta version of the ORPHANET NOMENCLATURE & ONTOLOGY FOR RARE DISEASE RESEARCH Training according to the Network feedback and first users' needs feedback collected in the countries.

3.3. National Trainings general Objectives

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Please note that Training objectives for the National trainings' participants are slightly different as indicated below. By the end of the EJP RD 14.1 training module, participants will be able to:

1- Explain what the Orphanet nomenclature and the Rare Disease Ontology (ORDO) are

2- Access Orphanet data that is relevant to their rare disease research activities

3- Contribute to Orphanet data by using dedicated forms and helpdesks

4. Training for Trainers Programme

The TfT is organised as follows:

1) Pre-training tasks

2) 2 days of training organised into 4 sessions of 2 hours each:

    Session 1: Beta External training module presentation:

    Session 2: Beta Hands-on basic & workshop

    Session 3: Beta Hands-on advanced

    Session 4: Organisation of National Training and feedback on External module and improvements to be done.

3) Post-training follow-up activities

4) In addition, and in order to improve Orphanet National Teams Trainer skills, access to a dedicated online academy course for Training the trainers will be provided at the start of 2021.

4.1. Pre-Training activities

Pre-training activities consisted in:

- a short questionnaire to revise or learn important notions that are pre-requisites to the EJP RD training module such as Orphanet mission, but also to make sure that participants had already used (at least once) some of the tools demonstrated during the training (instructions and links to useful resources were provided).

- an interview aimed at providing information on the concrete use of the Nomenclature in the daily work of a researcher and the eventual difficulties encountered. This task in the specific case of the TfT could consist instead in interviewing a Researcher within the hosting institution (in the case there was no research work done with the Nomenclature or the ontology within the Orphanet National team). The aim of this exercise was to instruct the group exchanges during the workshop session of the training (for more info see paragraph below).

4.2 Sessions description

4.2.1 Session 1 Beta External Training module presentation

During this session the External Beta Training module on Orphanet Nomenclature and Ontology for RD research was presented to the Orphanet Network.

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The first webinar was organised into three different chapters (nomenclature, classifications and ORPHAcodes) to facilitate participants' learning because the content on the Nomenclature is particularly rich. To make sure participants were engaged, a live quiz was carried out: one question was launched live at the end of each chapter and results were showed live before launching the following chapter presentation. For the second webinar presented during this session "ORPHANET DATA AND HOW TO ACCESS IT" its content was also organised into three chapters (Orphanet Data available, Orphanet RD ontologies and examples of Orphanet data exploitation).

2 Q&A sessions following the 2 webinars presentations were included to address any questions and doubts and enhance the knowledge of Orphanet teams' on the Nomenclature, the ontology and available tools.

Short demonstrations on tools were also provided in addition to the planned webinars.

4.2.2. Session 2 Beta Hands-on basic & workshop
1. General objective

This session had a double purpose: to present the hands-on and workshop module but also to actively involve the participants in the exercises, for them to "experiment" the practical use of the data by researchers. Ultimately, this will enable the future trainers to assist the researchers whenever these are experiencing difficulties in their daily use of the Orphanet annotated data and to identify potential inconsistencies in the current use and eventually propose solutions and best practices. This would enable them to hold National trainings autonomously.

In the hands-on part of the session, participants were asked to execute 3 exercises using an Excel file, the Orphanet website and the EBI Ontologies look-up service (OLS). Most of the exercises "mimic" actions that are automatised in electronic health records or registries exploitation tools and are not done manually. However, for the purpose of the training, trainees manually "play" with some of the data.
The specific objectives of the hands-on session were to:
1. Understand that an ORPHAcode is an unambiguous way to exchange data between systems/people/countries about rare diseases
2. Understand the wider potential for analysis that ORPHAcode annotation provides

The document used is a fictive and simplified Excel file, as one would potentially obtain from a rare disease registry or from a health electronic record.
Each exercise was presented, then step by step instructions were indicated and each participant had time to answer the exercise by him/herself. Finally, one participant was invited to share the answer and the trainer could provide complementary information if necessary.

Workshop part of the session: the goal of this part of the external module is to involve each participant into trying actively to identify good practices and potential

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challenges for users when using the Orphanet nomenclature/ontology for rare disease research.

4.2.3. Session 3 Beta Hands-on advanced

This module presented more advanced exercises; the purpose of this session was the same as 5.2.2 but for more expert users. An additional skill and tool to be used for this practical session was manipulation of xml files downloaded from the Orphadata platform. We allowed more time to carry out the 3 advanced exercises to ensure that this advanced session was fully understood and could be effectively managed when dispensing National trainings.

4.2.4 Session 4 Organisation of National Training and feedback on External module and improvements to be done.

The last session was dedicated to discussing around the organisational aspects of the national trainings (Final Programme, Trainers' toolkit, detailed timeline for organisation, logistics, calendar, call for interest for National Training set up) and to collect feedback on the improvements that could be done to the external module content before submitting it to Graphic designer work to improve the "cosmetics" of the webinars. For this, a live survey was carried out to collect immediate feedback on the module (available in the annexes) and to identify missing content. Results were presented live and allowed to launch the group discussion on suggestions for improvements (see session 8).

4.3 Post-Training activities

These activities consisted in a participant satisfaction survey and in an understanding questionnaire to evaluate the knowledge gained following the training (one immediately after the training, and then 6 and 12 months following the training). More information is available in section 5.

5. Participants evaluation and feedback

Two different types of evalutions were carried out: 1) to assess the knowledge gain of the participants and 2) to allow the participants to evaluate the training per se.

5.1 Evaluation on participants' gained knowledge

This assessment was carried out during the training (live quiz, template available in the annex 9.3) and immediately after the training (understanding questionnaire template available in the annex 9.4). Results showed that knowledge on the topic was already high in the beginning as quiz results indicated that 80% of respondents provided correct answers. The final test shows that 100% of the respondents provided the correct answers (N.B. only 15 respondents answered the survey, 52% response rate).
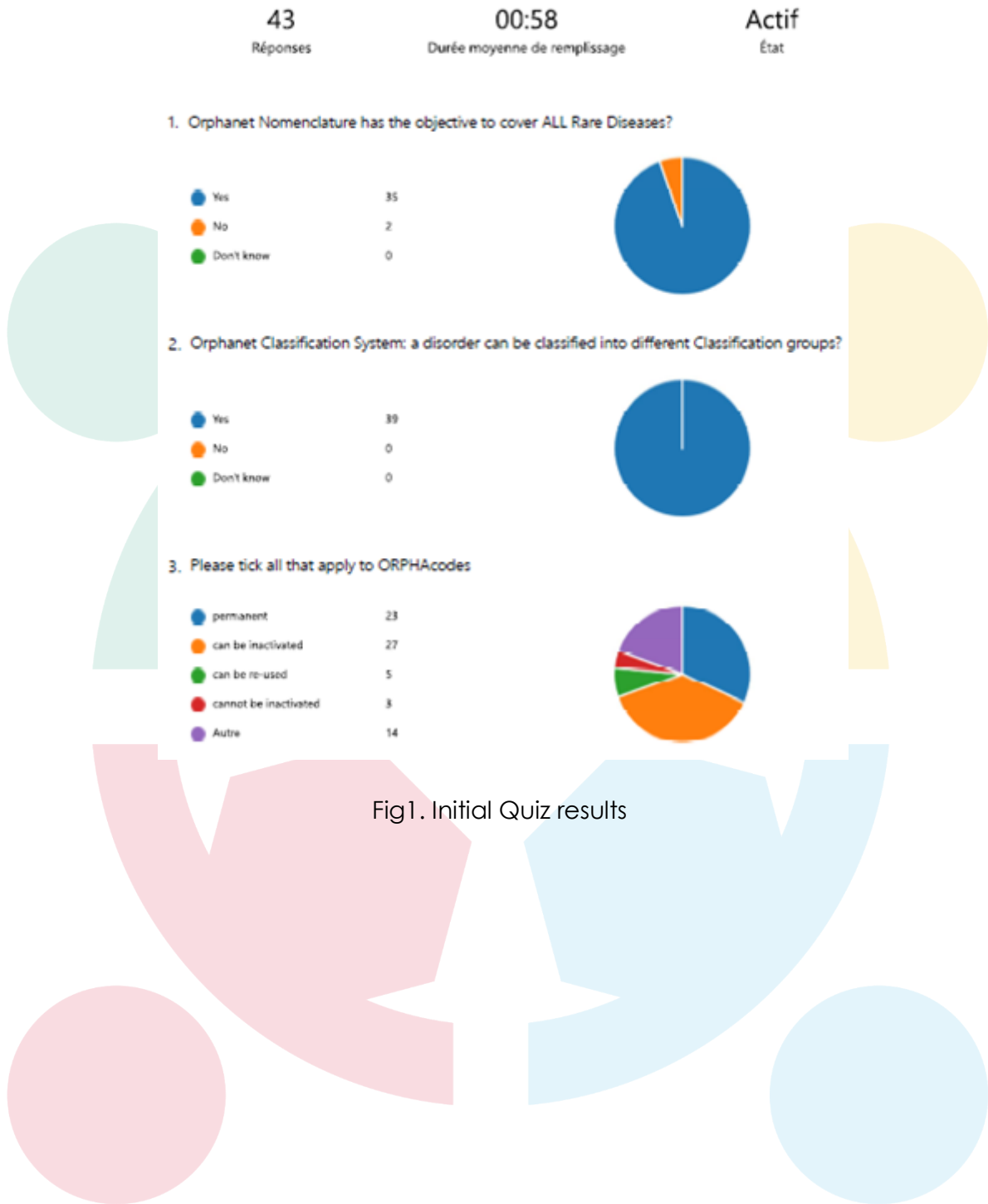
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43	00:58	Actif
Réponses	Durée moyenne de remplissage	État

1. Orphanet Nomenclature has the objective to cover ALL Rare Diseases?

● Yes	35	
● No	2	
● Don't know	0	

2. Orphanet Classification System: a disorder can be classified into different Classification groups?

● Yes	39	
● No	0	
● Don't know	0	

3. Please tick all that apply to ORPHAcodes

● permanent	23	
● can be inactivated	27	
● can be re-used	5	
● cannot be inactivated	3	
● Autre	14	

Fig1. Initial Quiz results

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Final Survey - Orphanet Nomenclature and Ontology for RD research

15	105:49	Actif
Réponses	Durée moyenne de remplissage	État

1. What is the Orphanet nomenclature?

- The only medical terminology ... 15
- The only medical terminology ... 0
- The only scientific reference sy... 0

2. What is a "rare" disease in Orphanet?

- A disease that occurs less ofte... 15
- A disease that occurs less ofte... 0
- A disease that occurs less ofte... 0
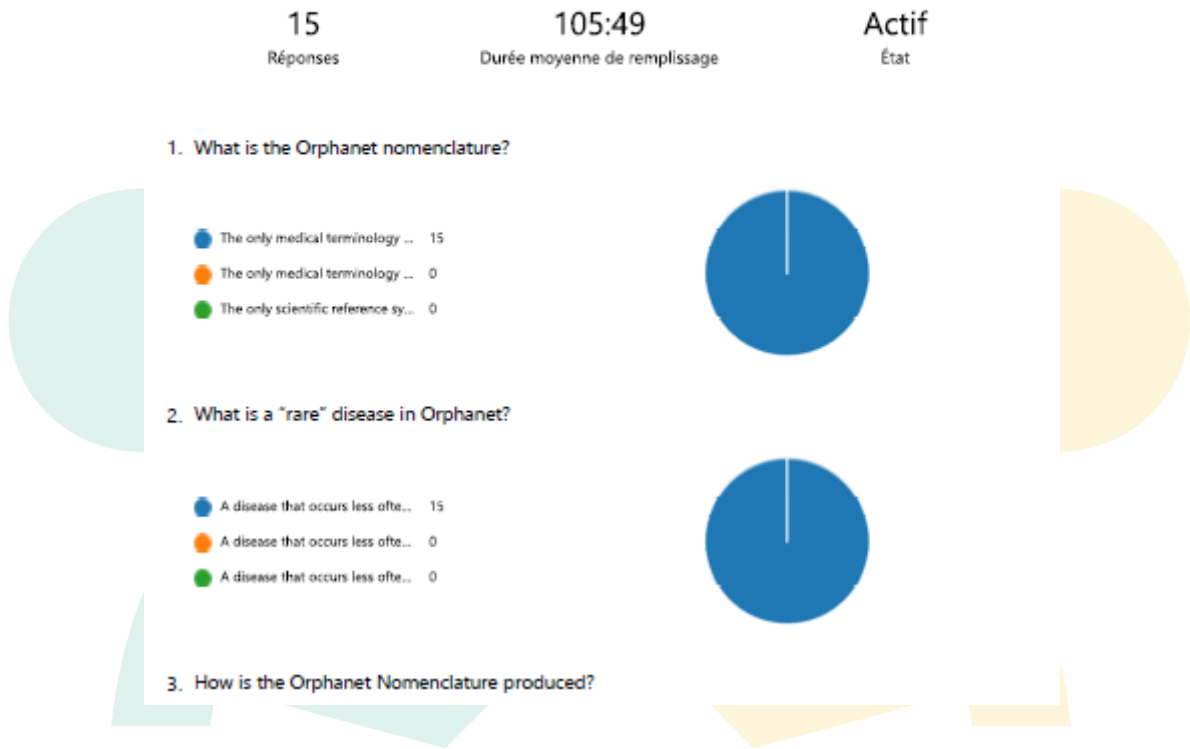
3. How is the Orphanet Nomenclature produced?

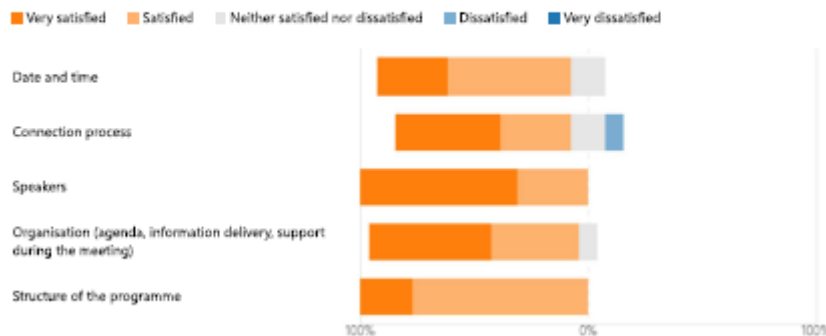Fig.2. Final understanding questionnaire results (Q1 and Q2)

5.2 Feedback

Participants were able to evaluate the training by completing a feedback questionnaire (annex 9/6). As of today, only 15 participants provided answers (52% response rate).

Overall participants:

1) were satisfied with logistic aspects of the training

1. Please rate your satisfaction level for the following aspects of our meeting:

Legend: Very satisfied | Satisfied | Neither satisfied nor dissatisfied | Dissatisfied | Very dissatisfied

- Date and time
- Connection process
- Speakers
- Organisation (agenda, information delivery, support during the meeting)
- Structure of the programme

100%   0%   100%

2) asked to have more time

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2. Was the module too short, too long or about right?
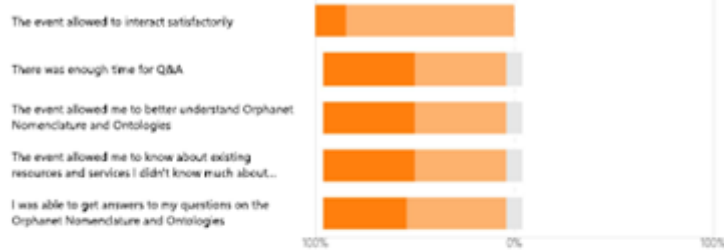
- Much too short   0
- Too short   5
- About right   8
- Too long   0
- Much too long   0

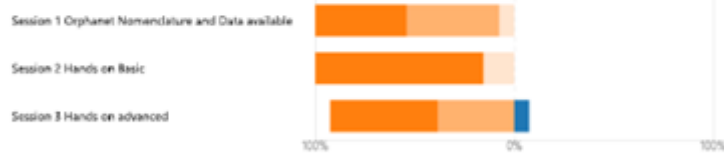3) were overall satisfied with the module content:

3. How much do you agree with the following?

■ Totally agree   ■ Agree   ☐ Neither agree nor disagree   ■ Disagree   ■ Totally disagree

- The event allowed to interact satisfactorily
- There was enough time for Q&A
- The event allowed me to better understand Orphanet Nomenclature and Ontologies
- The event allowed me to know about existing resources and services I didn't know much about...
- I was able to get answers to my questions on the Orphanet Nomenclature and Ontologies

4. How likely the following sessions allowed for better understanding of the Orphanet Nomenclature or ORDO?

■ Very likely   ■ Likely   ☐ Neither likely nor unlikely   ☐ Unlikely   ■ Very unlikely   ■ I did not participate in this session

- Session 1 Orphanet Nomenclature and Data available
- Session 2 Hands on Basic
- Session 3 Hands on advanced

5. Overall, how satisfied were you with the meeting?

- Very satisfied   6
- Satisfied   7
- Neither satisfied nor dissatisfied   0
- Dissatisfied   0
- Very dissatisfied   0

6. Barriers encountered

Training was conducted smoothly despite a few technical problems.
There were a few barriers that needed to be addressed in order to make a following TFT and National trainings more effective:

- A workshop modality to involve ALL participants was not fully applied because of the online mode.
- A 15 min delay was observed for all session in order to allow all the questions to be addressed
- In order to make sure that ALL participants answer the 2 final surveys, a dedicated slot before closing the training needs to be included.

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Overall, learnings were taken from the barriers encountered which enabled to enrich the trainer's handbook with additional tips should the National Training be organised online and to increase the amount of time dedicated to each session.

7. Learning and future recommendations

During the final session, it was decided to re-organise the sessions in order to allow more time. In particular, it was suggested to add more exercises to the hands-on that could be selected for the National training also according to participants' level.

Some additional resources to be made available for the Pre-training activities were identified: short videos on Orphanet missions, a short video explaining the use and characteristics of Ontologies in general and finally a general public video on WHY ORPHAcodes are needed. These resources are not yet available.

It was also agreed that the aesthetic of the slide show should be improved to increase the impact of the presentation.

Content wise: some minor improvements regarding ORDO content were discussed (and implemented in the final version). Inclusion of additional short demos on the tools use during the course (ORDO/OLS, API, Classifications…) was also agreed.

Finally, it was suggested that some more advanced module on ORDO for example and End users-oriented modules could be developed after proper users' feedback is obtained.

8. Annexes

8.1 Participants
During the TfT we had 29 participants from 19 countries (15 EU MS (of which 5 EU13); 1 associated EU country and 3 non-EU countries) as indicated below.
Numbers of persons per team are indicated next to the team name.
Orphanet Austria 1
Orphanet Croatia 1
Orphanet Georgia 1
Orphanet Turkey 2
Orphanet Luxembourg 2
Orphanet Czech Republic 1
Orphanet Italy 1
Orphanet Bulgaria 1
Orphanet Belgium 2
Orphanet Spain 2
Orphanet Poland 3
Orphanet Slovenia 1

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Orphanet Norway 2
Orphanet Ireland 2
Orphanet Switzerland 1
Orphanet Germany 1
Orphanet NL 1
Orphanet UK 3
Orphanet Lithuania 1
Orphanet Scientific Team 4
Presenter 1

8.2 Timetable

3 November 2020	
Time	**Title**
11:00 – 11:10	Welcome & introduction
11:10 – 11:20	Icebreaker / pairing (organising teams)
11:20 – 11:35	Presentation: ORPHANET NOMENCLATURE Chapter 1
11:35– 11:45	Presentation: ORPHANET NOMENCLATURE Chapter 2
11:45 – 11:55	Presentation: ORPHANET NOMENCLATURE Chapter 3
11:55 – 12:00	Key Messages
12:00-12:20	Break
12:20-12:35	Questions / answers
12:35-12:50	Presentation 2: ORPHANET DATA AND HOW TO ACCESS IT
12:50-13:00	Questions / answers
13:00-14:00	Lunch Break
14:00 – 14:05	Warm up / reminders
14:05 – 14:45	Practice time "buddies": HANDS-ON BASIC
14:45– 15:00	*Break*
15:00-15:10	Questions / answers
15:10- 15:55	Online group workshop: exchange around results of interviews (from pre-training) and feedback on local user difficulties collected in each country/region
15:55-16:00	Tomorrow's agenda

4 November 2020	
Time	**Title**
11:00-11:10	Warm up / reminders
11:10-12:00	Practice time "buddies": HANDS-ON Advanced
12:00-12:20	*Break*
12:20-12:50	Questions / answers

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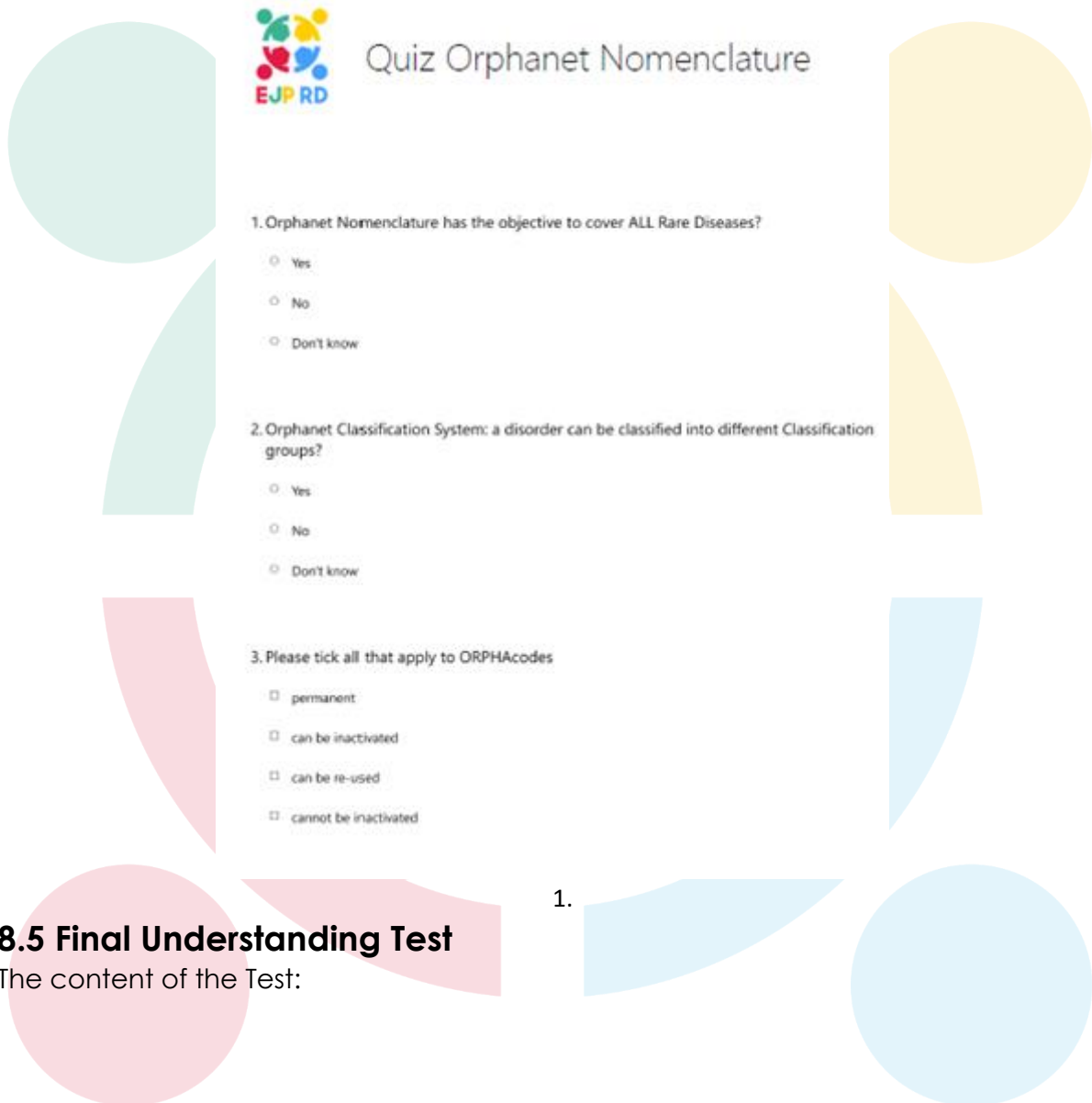| 12:50-13:00	Final Test
13:00-14:00	Lunch Break
14:00 – 14:15	Presentation: How the module for National training will be organised (Agenda, Trainers'toolbox, Timeline logistics , Calendar, Call of interest…)
14:15 – 14:25	Questions / answers
14:25 – 14:45	Training for trainers online course
15:00-16:00	ONLINE WORKSHOP FUTURE TRAINERS FEEDBACK
15:00 – 15:50	- exchange around the module content (live survey: is the module too basic/too advanced; is it too dense; missing infos...) - suggestions for improvements - next steps module preparation - brainstorming on advanced module for Registries support
15:50-16:00	Wrap up and link to feedback survey

8.3 Material Distributed: Trainers toolkit

EJP-RD Task 14-1: Trainers Toolkit CLICK	
Trainers handbook	Document providing a detailed timeline for National Trainings organisation, Additional info on pre-training workfor the trainers, A detailed step by step "National Training Programme" with tips and advices for the trainers and list of additional useful resources of Trainers toolkit
Webinars in English	Nomenclature & Orphanet Data and how to access it in
Hands-on working file	Excel Hands on working file (advanced and basic)
Excel files compiled interviews-TFT	Excel file anonymised interviews
Wrap-ups&FAQ TfT	Short document presenting the main conclusions of the workshop, the suggestions for improvement of the module and on the course in general, as well as next steps and FAQ.
Email templates in English	Template Email for REGISTRATION
	Template email for PARTICIPATION CONFIRMATION

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	Template email for PRE-TRAINING ACTIVITIES & FINAL PROGRAMME	
Surveys templates in English	Template Live survey	
	Template Understanding survey	
	Template Satisfaction survey	
Template Pre-training document in English	Pre-training document including instructions for Pre-requisite Questionnaire and Concrete use of data interview	
Template National Training Final Programme in English	Final Programme	
Template Slide shows in English	ALL Slide shows (Nomenclature + Orphanet Data+ Hands-on) with scripts and additional useful info in comment section	
Videos	EJP-RD Video on Challenges in RD resources	
EJP-RD MS teams		
EJP-RD Online event organisations guidelines	here	
EJP-RD examples of training tools useful resources	here	
Procedures		
www.orpha.net	Orphanet nomenclature and classification of rare diseases ICD-10 coding rules for rare diseases Naming rules for the rare disease nomenclature in English This document has been translated into Polish (2017) and Spanish (2018) and German (2019) and Japanese (2019) Nomenclature production in national language Linearization rules for Orphanet classifications	
ORPHANET NOMENCLATURE INTERNAL TRAININGS SLIDESHOWS	Nomenclature and classification general aspects	
	Nomenclature and classifications technical aspects	
	Nomenclature workflow	
RD-CODE website		
www.rd-code.eu	ORPHAcoding	
	Tools	
	Helpdesk	
	FAQ	
	API	
ORPHADATA PLATFORM		
www.orphadata.org	Nomenclature Pack	
	List of free datasets and Description	
	List of on request datasets and Description & samples	
	ORDO and Userguide	
	HOOM and Userguide	

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Additional resources	
	How to record a ppt with Audio

8.4 Live Quizz

Quiz Orphanet Nomenclature

1. Orphanet Nomenclature has the objective to cover ALL Rare Diseases?
   - ○ Yes
   - ○ No
   - ○ Don't know

2. Orphanet Classification System: a disorder can be classified into different Classification groups?
   - ○ Yes
   - ○ No
   - ○ Don't know

3. Please tick all that apply to ORPHAcodes
   - ☐ permanent
   - ☐ can be inactivated
   - ☐ can be re-used
   - ☐ cannot be inactivated

1.

8.5 Final Understanding Test
The content of the Test:

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1. What is the Orphanet nomenclature?

○ The only medical terminology that is specific to rare disease

○ The only medical terminology registering only genetic diseases

○ The only scientific reference system registering clinical signs and genes for all known diseases

2. What is a "rare" disease in Orphanet?

○ A disease that occurs less often than in 5 cases out of 10'000 people in Europe (or 1 in 2'000)

○ A disease that occurs less often than 5 cases out of 100'000 people in Europe (or 1 in 20'000)

○ A disease that occurs less often than 5 cases out of 1'000'000 people in Europe (or 1 in 200'000)

3. How is the Orphanet Nomenclature produced?

Entrez votre réponse

4. How is the Orphanet nomenclature updated

Entrez votre réponse

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5. Why did Orphanet develop the rare disease ontology ORDO?

Entrez votre réponse

6. Where can you find technical help to use the nomenclature , or implementing the data into your organisation information system, etc.?

Entrez votre réponse

7. How can you contribute to the Orphanet nomenclature (ex. suggest to add, modify or remove the name of a disease, a definition, a synonym, etc.)?

Entrez votre réponse

8. Where can you download the nomenclature pack? Where can you find help if needed?

Entrez votre réponse

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9. Where can you download ORDO or HOOM files? How can you read the OWL file? Where can you find help if needed?

> Entrez votre réponse

10. Your action plan: by the end of this year I want to.... in order to.... (report main action here)

> Entrez votre réponse

11. In your own words, how would you explain to a new colleague what the Orphanet nomenclature is and why it is useful to know?

> Entrez votre réponse

12. In your own words, how would you explain to a new colleague what the Orphanet rare disease ontology ORDO is and why it is useful to know?

> Entrez votre réponse

8.6 End of course evaluation questionnaire/satisfaction survey

The content of the survey/questionnaire :

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1. Please rate your satisfaction level for the following aspects of our meeting:

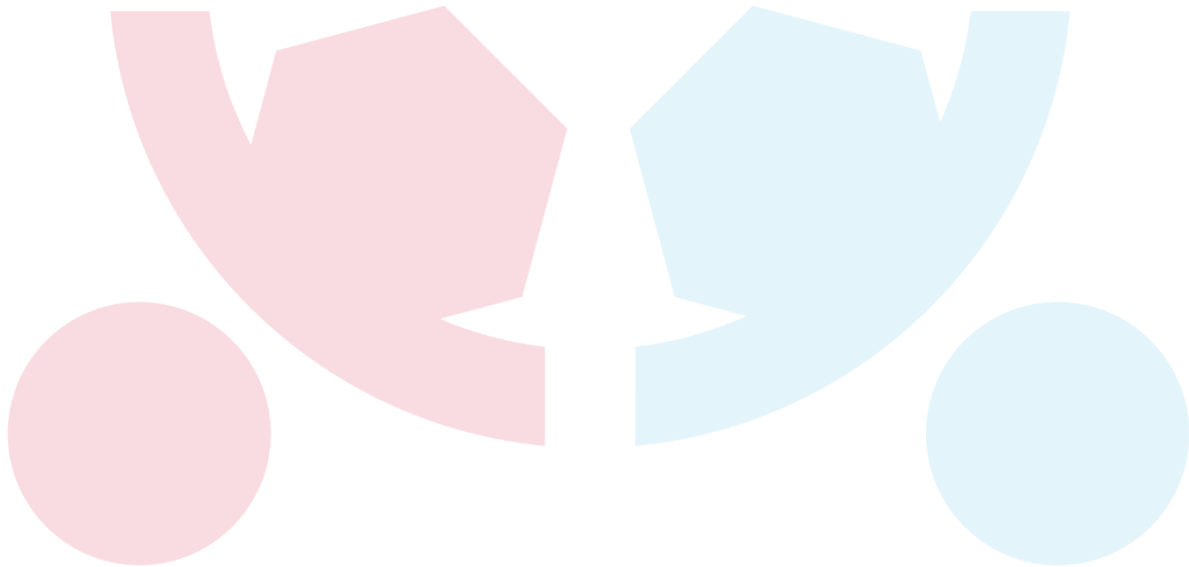|	Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied
Date and time	O	O	O	O	O
Connection process	O	O	O	O	O
Speakers	O	O	O	O	O
Organisation (agenda, information delivery, support during the meeting)	O	O	O	O	O
Structure of the programme	O	O	O	O	O

2. Was the module too short, too long or about right?

- O Much too short
- O Too short
- O About right
- O Too long
- O Much too long

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3. How much do you agree with the following?

	Totally agree	Agree	Neither agree nor disagree	Disagree	Totally disagree
The event allowed to interact satisfactorily	○	○	○	○	○
There was enough time for Q&A	○	○	○	○	○
The event allowed me to better understand Orphanet Nomenclature and Ontologies	○	○	○	○	○
The event allowed me to know about existing resources and services I didn't know much about before	○	○	○	○	○
I was able to get answers to my questions on the Orphanet Nomenclature and Ontologies	○	○	○	○	○

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4. How likely the following sessions allowed for better understanding of the Orphanet Nomenclature or ORDO?

	Very likely	Likely	Neither likely nor unlikely	Unlikely	Very unlikely	I did not participate in this session
Session 1 Orphanet Nomenclature and Data available	○	○	○	○	○	○
Session 2 Hands on Basic	○	○	○	○	○	○
Session 3 Hands on advanced	○	○	○	○	○	○

5. Overall, how satisfied were you with the meeting?

○ Very satisfied

○ Satisfied

○ Neither satisfied nor dissatisfied

○ Dissatisfied

○ Very dissatisfied

6. What did you like about the meeting?

Entrez votre réponse

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7. What did you dislike about the meeting?

> Entrez votre réponse

8. How likely are you to recommend this meeting to a colleague?

0	1	2	3	4	5	6	7	8	9	10

Not at all likely   Extremely likely

9. What format would you prefer for the next Orphanet Network Training for Trainers

○ Face to Face meeting

○ Full Online meeting

○ Combination of Face to Face & Online meeting

10. Do you have any suggestions for us to improve future meetings?

> Entrez votre réponse

8.7 Live feedback on External module content

The content of the survey is :

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1. Is the Agenda for the External module too short, too long or about right?

- ○ Much too short
- ○ Too short
- ○ About right
- ○ Too long
- ○ Much too long

2. Is the module:

- ○ Much too basic
- ○ Too basic
- ○ about right
- ○ Too advanced
- ○ Much too advanced
- ○ Autre

3. In your opinion, the webinars content (Chapter 1-2-3 Nomenclature and Data availbale) should:

- ○ be recorded
- ○ be presented live
- ○ Autre

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4. Is the External module

○ is too dense

○ is missing info

○ [Autre]

5. In your opinion, and from a content point of view something important was missing?

[Entrez votre réponse]

6. Regarding the Hands on BASIC session

○ much too basic

○ Too basic

○ Basic enough

○ Not basic enough

7. Regarding the Hands on Advanced session

○ much too basic

○ Too basic

○ About right

○ too advanced

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8. What did you like about the module?

> Entrez votre réponse

9. What did you dislike about the module?

> Entrez votre réponse

10. What format would you prefer for the National trainings

○ Face to Face meeting

○ Full Online meeting

○ Combination of Face to Face & Online meeting