



***CHILDREN WITH RARE DISEASES AND THEIR
INCLUSION IN BASIC LEARNING
ENVIRONMENTS***

CREDIBLE

MEETING MINUTES

Meeting Date: [23-24/03/2023](#)

Meeting Location: [FEDER headquarters](#)
Madrid

Approval: [Draft](#)

Recorded By: [Carlos Casero / Oscar Lozano](#)

1 ATTENDANCE

Name	Title	Organization	Country
Rosa Fonfría	Ms	Universitat de Valencia	Spain
Óscar Lozano	Mr	Universitat de Valencia	Spain
Óscar López Jiménez	Mr	Conselleria Educació	Spain
Eva Camarero	Ms	Conselleria Educació	Spain
Adoración Alfaro	Ms	CEIP Féliz Rodríguez de la F.	Spain
Carlos Casero	Mr	CEIP Féliz Rodríguez de la F.	Spain
Larisa Damsa	Ms	Alianta Nationala Pentru Boli R.	Romania
Ramona Mocutiu	Ms	Alianta Nationala Pentru Boli R.	Romania
Irini Tzovla	Ms	4 th Primary school of Pefki	Greece
Eleni Kioroglou	Ms	4 th Primary school of Pefki	Greece
Guillem Barnolas	Mr	Desarrollo de Plataformas Digitales	Spain
Eva Belmonte	Ms	Desarrollo de Plataformas Digitales	Spain
Egija Laganovska	Ms	Latvijas Universitāte	Latvia
Evija Latkovska	Ms	Latvijas Universitāte	Latvia
Andrea McDonald	Ms	Ashton Secondary Schoo	UK
Catherine Brown	Ms	Ashton Secondary Schoo	UK
Julie Hand	Ms	Glasgow City Council	UK
Barry Syme	Mr	Glasgow City Council	UK
Alba Ancochea Díaz	Ms	FEDER	Spain
Celia Morala	Ms	FEDER	Spain
M ^a Carmen Murillo	Ms	FEDER	Spain

2 MEETING LOCATION

FEDER Headquarters

(C/ Doctor Castelo, 49 Pl 1^a, 28009, Madrid, Spain)

3 MEETING START

Meeting Schedule Start: 9:30 (23-24/03/22)

Meeting Actual Start: 10:00 (23/03/22); 9:30 (24/03/22)

Meeting Scribe: Carlos Casero / Oscar Lozano

4 AGENDA

Welcoming

CURRENT SITUATION (MEETINGS AND INTELLECTUAL OUTPUTS)

- The coordinator explains all the actions that are already finished and the ones that will be held (transnational meetings, multiple events and intellectual products).
- Multiplier event III and V-TM (Glasgow)

The dates for the Multiplier Event and V Transnational Meeting is finally maintained. No changes necessary despite the first rejection from Ashton Secondary School. It is agreed that these dates are suitable for all partners, so they will be on 27th and 28th of June.

- I.O.1: Some small improvements have been made to the platform, in terms of translations and the possibility of removing cases made for testing. We need to report and add cases. All partners are encouraged to spread the platform to reach as many teachers as possible. It is necessary to have a critical number of cases uploaded to turn the platform into something useful. Otherwise, it will have no interest at all and will become useless.

I was also pointed out that the platform must have a legal text where users are informed about the legal aspects of data protection, norms of use, etc. Currently there is a checkbox where users must click and accept the terms and conditions. These conditions will be reviewed by the FEDER lawyers so that they are drafted in accordance with all EU legislation.

- I.O. 2: The training activity was canceled due to the COVID situation in January 2022 and was postponed to May 9-13 in Valencia. In this training activity, the contents made for the Teachers Course (MOOC-deliverable) will be presented and used in the face to face activity. In order to have the best Intellectual Output possible, all partners work in groups to find out what contents would be desirable to include in it. The best structure for this course is also discussed. All proposals are collected by the coordinator and the leader of the IO-2 (CEFIRE). All of them will be taken into account in the final output performance.

In the face-to-face training activity there will be two days where different approaches will be presented in various conferences. These first two days will be broadcast openly (streaming) to reach as many teachers as possible (and get them involved in project collaboration)

- I.O. 3: The guide it's almost finished in the draft version. It will contain 30 different diseases (the most prevalent) and the structure of the descriptive cards is shown. Every disease includes: Name; Orphanet code; description of the disease; main bodies or systems affected; other frequently affected organs or systems; potential problems in the classroom and recommended strategies; pedagogical adaptation; space adaptation – ergonomic; environmental adaptation; accessibility; inclusion strategies; Therapeutic support in the absence of a school nurse; potential emergencies and action; and a general table with all features summarized.

DISSEMINATION:

All partners are again encouraged to carry out as much as possible the dissemination actions planned. RONARD offers to perform a series of radio podcast with interviews to all partners. It is also reminded that it is mandatory to include some comment to the project in the front page of partners websites, making it quite visible.

DOCUMENTS EXPLANATION AND ECONOMICAL CONTROL

- All documentary control is again explained. Coordinator will remind all partners their obligations on this sense, including a table where all the documents still not delivered will be clearly written down.

5 MEETING END

Meeting Actual End: 13:30 (23/03/22) – After this, visit to Royal Palace

Meeting Actual End: 12:00 (24/03/22)

6 POST MEETING ACTION ITEMS

Action	Assigned To	Deadline
Boost dissemination activity	All partners	N.A.
Fill and deliver project documents	All partners	N.A.
Prepare Course taking into account the working groups proposals	Conselleria Educacio	May 2022
Gather cases (teachers) as much as possible to feed the platform and make it useful	All partners	N.A.
Perform radio podcast with partners interviews	RONARD	N.A.
Review legal aspects of platform	FEDER	N.A.

7 NEXT MEETING

Learning Activity, 9-13/05/22 - Valencia