



**Intelligent ecosystem to improve
the governance, the sharing, and the re-use
of health data for rare cancers**

Agenda

Plenary Meeting and scenario validation workshop Madrid, 22-23 November 2023

16 November 2023





This project has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement no. 101057048

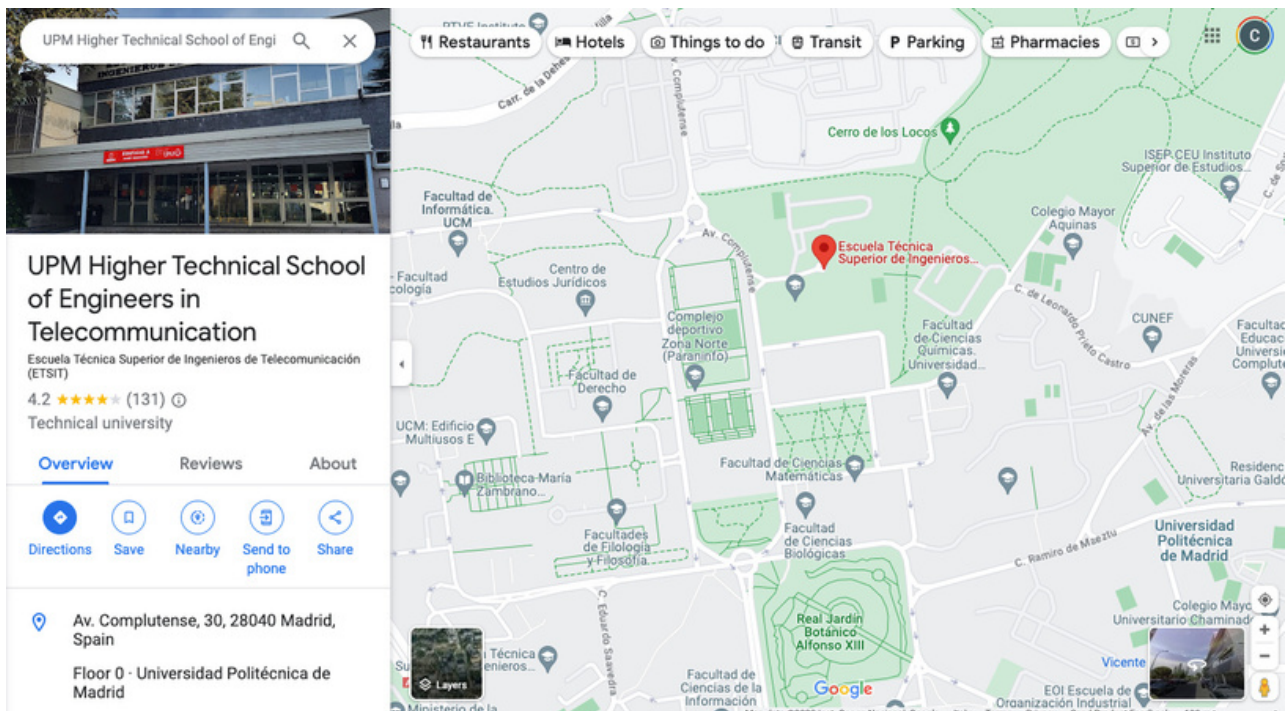


Venue

Venue: Universidad Politecnica de Madrid – Avenida Complutense nº 30, Building A - Escuela Técnica Superior de Ingenieros de Telecomunicación (ETSIT)

Date: 22 November 2023 from 9:15 to 17:00
23 November 2023 from 9:00 to 13:00

Plenary session
Parallel sessions (users/technical)



Accommodation

There is a wide offer of hotels in Madrid. UPM does not have any agreement for special rates but, if you want to stay close to our premises, we can recommend you the following hotels:

- AC Hotel Los Vascos <http://www.marriott.co.uk/hotels/travel/madv-ac-hotel-los-vascos/>
- Jardín Metropolitano <http://www.metropolitano-hotel.com/en/>
- Hotel Exe Moncloa <https://www.eurostarhotels.co.uk/exe-moncloa.html>

From the airport

From the airport, you can reach the ETSIT by taxi (30 minutes and 30€) or by metro (about 1 hour, around 5€ if you also buy a 10-way ticket for 12€). You can take the metro line 8 (pink) up to “Nuevos Ministerios”, then take line 6 (grey) up to “Ciudad Universitaria”. From there you can walk (1 km approximately) or you can take a bus (G, U or 82) for 4 stops.



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The Plenary meeting consists in two sessions.

22 November full day (plenary session) from 9:15 to 17:00.

23 November morning: separate thematic sessions from 8:30 to 10:30 and wrap-up until 11:00, and a 3-hour session for scenarios validation from 11.30 a.m. until 1.30 p.m.

All partners are requested to attend both events.

PLENARY SESSION - 22 NOVEMBER

Time	Topic	Chair
9:15-9:45	Venue of participants & welcome coffee	
9:45-10:30	LifeSpace visit	UPM - E. Gaeta
10:30-11:00	IDEA4RC objectives and progresses: what is expected by end of 2024	INT - A. Trama
11:00-11:30	Introduction to legal aspects - Data access/data sharing agreements explanation - current status of discussions - next steps Discussion and assignment of works and responsibilities	ECCP- V. Tsiompanidou
11:30-12:00	WP3, WP4, WP5 - Data capsules: what they are, what pilot sites are expected to do - Data flow Discussion and assignment of works and responsibilities	UPM - E. Gaeta
12:00-12:30	Data preparation - Management of unstructured data - Management of structured data - Data annotation (HNC and sarcomas) Discussion and assignment of works and responsibilities	UDEU - A. Almeida



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PLENARY SESSION - 22 NOVEMBER

Time	Topic	Chair
12:30-13:15	WP9 Implementation at pilot sites - Current status and major open issues and roadblocks - Proposal and agreement on the plan to address major open issues and roadblocks (assignment of work and responsibilities; deadlines; Pilot sites involvement; technical support)	MME – F. Mercalli
13:15-14:00	Lunch break (talks among partners)	
14:00-14:30	Data search (Navigator) - Data navigator concept - Data navigator implementation Q&A: discussion and assignment of works and responsibilities	UPM- L. Lopez
14:30-14:45	The Federated data analysis concept: discussion and assignment of works	IKNL – G. Geleijnse
14:45-15:15	The IDEA4RC data governance	INT - A. Trama
15:15-15:30	WP7 The IDEA4RC data governance layer: EHDS data permit	CERTH
15:30-15:45	Stakeholder engagement: activities foreseen for the next months	ACC/DIGICORE – D. De Persis
15:45-16:00	Short break	
16:00-16:30	Coordination aspects - Due deliverables and results - modification of PM distribution and WP7 description - planning review (preparation actions) - Issue from Norwegian partner for data access (new partner to be added?) - any other issues	INT - E. Martinelli
16:30-17:00	Summary of day and plans for thematic sessions tomorrow. Date for next meeting	INT - A. Trama



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PARALLEL SESSIONS - 23 NOVEMBER

Time	Topic	Chair
8:30-9:00	Gathering of participants and split of groups: - Group 1: Virtual navigator (clinicians, UPM, UDEU, MME?) - Group 2: Technical group (all tech partners) - Group 3: Legal group (ECCP, INT, legal from clinical partners, NIO)	

CLINICAL

9:00-10:30	Data navigator, data access etc. Data annotation and data preparation Assignment of responsibilities and deadlines	UPM- L. Lopez
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TECHNICAL

9:00-10:30	Capsule next steps: FHIR, OMOP and Vantage6 integration - UPM How to: populate the Capsules - ENG/INT Data model and NLP algorithms - UDEU/FBK	UPM- E. Gaeta ENG/INT - V. Falanga/P. Baili UDEU/FBK -
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LEGAL

9:00-10:30	Data processing and data sharing agreements	ECCP- V. Tsiompanidou
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PLENARY SESSION - 23 NOVEMBER

Time	Topic	Chair
10:30-11:00	Summary of the group discussions and end of the plenary meeting	INT- A. Trama UPM - E. Gaeta
11:00-11:30	Coffee break	
11:30-13:30	Scenarios validation workshop (agenda in the following page)	UU- C. Egger S. van Hees
13:30 -	Lunch break	



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Scenario validation workshop

The aim of the workshop is to validate the three scenarios that have been developed about the future development and implementation of IDEA4RC based on your earlier input (D 2.1). During the workshop we will work together to (i) determine which of these scenarios you deem most desirable and what main societal values shape each of them; (ii) to further develop and nuance these scenarios and reflect on the values that (should) underlie them.

SECOND CO-CREATION WORKSHOP - 23 NOVEMBER

Time	Topic
11:30-11:40	<p>Brief introduction about the goals of the workshop</p> <ul style="list-style-type: none"> - Rules of engagement: plenary format; active participation; constructive and open dialogue - The use of audio-recording devices during the workshop & informed consent forms - Overview of the main goals of the workshop
11:40-12:10	<p>Quick recap of Scenario 1</p> <p>Discussion of Scenario 1: IDEA4RC as a Platform Stimulating and Facilitating Research Into Rare Cancers</p>
12:10-12:40	<p>Quick recap of Scenario 2</p> <p>Discussion of Scenario 2: IDEA4RC as a Platform Stimulating and Facilitating Research Into Rare Cancers and also Supporting Clinical Decision-Making</p>
12:40-13:10	<p>Quick recap of Scenario 3</p> <p>Discussion of Scenario 3: IDEA4RC as a Platform Stimulating and Facilitating Research Into Rare Cancers, Supporting Clinical Decision-Making, and Enabling Patients to Use and Re-use Their Data</p>
13:10-13:15	Short break
13:10-13:15	Open discussion of overarching issues and concerns emerged during the scenario validation