IDEA4RC

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

Agenda

Plenary Meeting
and WP2 Co-Creation Workshop
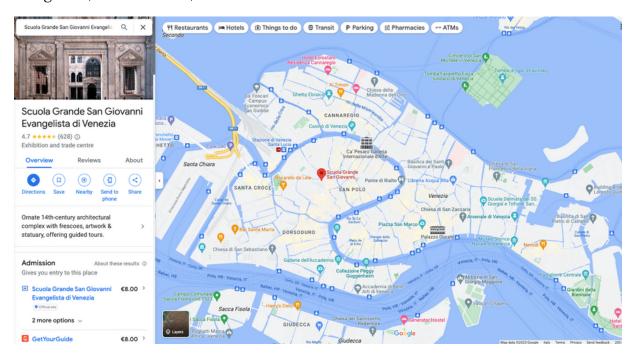
Venice, 19-20 April 2023

18 April 2023

Venue

Venue: Scuola Grande San Giovanni Evangelista, San Polo 2454, 30125 Venice
Date: 19 April 2023 from 13.30 to 18.00   Plenary session (Guarana room)
20 April 2023 from 9.00 to 17.30   Parallel sessions (clinical/technical)
(Guarana and Stendardo room)
Both Guarana and Stendardo rooms are located at the Scuola Grande San Giovanni Evangelista, San Polo 2454, 30125 Venice

Accomodation

Venice has plenty of accommodation facilities.
The following are recommended by the Privacy Symposium organizers and are at walking distance from the meeting location:

- Hotel Saturnia & International - Stars: 4. https://www.hotelsaturnia.it/
- Ca' Pisani Boutique Design Hotel - Stars: 4. https://www.capisanihotel.it/
- Hotel Papadopoli Venezia – Mgallery – Stars: 4.
  https://all.accor.com/hotel/1313/index.en.shtml

Travel information

Venice is best served by plane (Venezia airport) and by train. No cars are allowed in the city.
Venue information can be found here: https://privacysymposium.org/venue-information/

Agenda

The Plenary meeting consists in two half-day sessions: 19 April afternoon and 20 April morning.

The meeting is followed by the WP2 co-creation workshop on 20 April afternoon.

All partners are requested to attend both events.

PLENARY SESSION - 19 APRIL		
Time	**Topic**	**Chair**
13:45-14:15	IDEA4RC objectives and progresses	INT- A. Trama
14:15-15:00	User stories presentation and discussion: • Data manager/processor expectations • Data user expectations	MME - F. Mercalli
15:00-15:30	IDEA4RC architecture, next steps and discussion	UPM- E. Gaeta ENG - P. Zampognaro
15:30-16:00	IDEA4RC data-flows, next steps and discussion	UPM- E. Gaeta
16:00-16:30	Coffee break	
16:30-16:50	T2.2 Ethical data ecosystem governance Status of work, open questions to be answered. Actions, contributions needed, deadlines.	ECCP- S. Ziegler
16:50-17:15	Discussion	
17:15-17:45	Data models to be used in the project	UDEUSTO, HL7
17:45-18:00	Status of co-creation, preparation of the workshop	UU- C. Egher S. van Hees

PARALLEL SESSIONS - 20 APRIL		
Time	**Topic**	**Chair**
CLINICAL		
9:00-12:00	Objectives Core data set Integration of unstructured data Expected query/ analytics Discussion and agreements Introduction to Clininote	INT- A. Trama
TECHNICAL		
9:00-12:00	Technical platform, technological overview Review of user stories and implementation approach FHIR and OMOP harmonization solutions Data ingestion architecture into Capsules Data quality checks on OHDSI or custom implementations	UPM- E. Gaeta

PLENARY SESSION - 20 APRIL		
Time	**Topic**	**Chair**
12:15-12:45	Summary of the group discussions	INT- A. Trama UPM - E. Gaeta
12:45-13:00	Outline of open tasks for the next 6 months Planned activities (summary) and timing/deadlines Recap of responsibilities and expected results	INT- E. Martinelli
13:00-14:00	Lunch break	
14:00-17:30	Co-creation workshop	

The co-creation workshop will elicit the main values and concerns the different IDEA4RC consortium partners experience in regard to the sharing, use, and re-use of data about and in the context of establishing a data eco-system for rare cancers. The co-creation work entailed feeds into the different WP2 layers, as represented by the different tasks. It is an essential part of the research conducted within this WP for the benefit of the early stage, pro-active signaling of issues that may potentially impede the successful and widespread implementation of this data ecosystem. Such early stage anticipation work and inclusion of a variety of perspectives is vital, as it allows for the issues identified to be addressed when they are still manageable and when changes to the development and governance of the ecosystem can still be made.