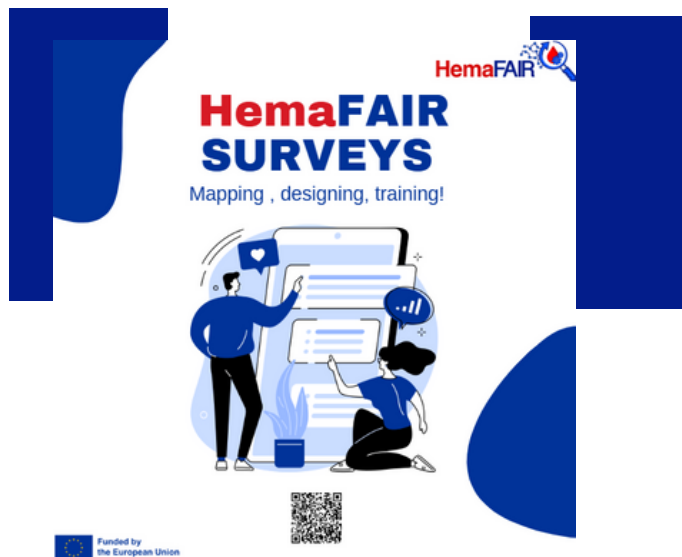


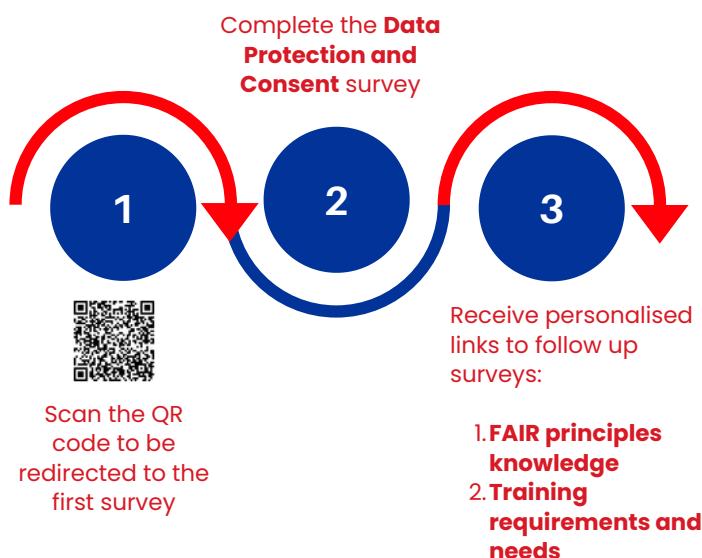
## MAPPING THE NEEDS OF CYPRUS IN RESEARCH INFRASTRUCTURE AND FAIR DATA KNOWLEDGE!



To design an effective training program, we first set out to understand the knowledge and needs of Cypriot researchers regarding FAIR principles. Using surveys and questionnaires, we mapped existing expertise, identified knowledge gaps, and gathered input on the challenges researchers face in making data FAIR.

These insights are now shaping a tailored training program, ensuring that the skills and support provided align with real-world needs. By listening to the research community, we are building a stronger foundation for FAIR data practices in Cyprus!

## HAVE YOUR SAY! VISIT OUR WEBSITE TO PARTICIPATE



Our surveys and questionnaires will remain open throughout the project, ensuring we continue to gather valuable insights from the research community. Your input helps us refine and adapt our training program to better meet real-world needs.

[www.hemafairproject.eu](http://www.hemafairproject.eu)

## HEMAFAIR LECTURE SERIES



18 - 18  
NOV

### Lecture series #1: Introduction to HemaFAIR

🕒 2024-11-18 02:00 PM - 2024-11-18 03:00 PM

📍 The Cyprus Institute of Neurology and Genetics



27 - 27  
NOV

### Lecture series, #2: Introduction to FAIR principles

🕒 2024-11-27 03:00 PM - 2024-11-27 04:00 PM

📍 Online Event



14 - 14  
JAN

### Lecture series #3: Biomedical Ontologies

🕒 2025-01-14 02:00 PM - 2025-01-14 03:00 PM

📍 Online Event



27 - 27  
JAN

### Lecture series #4: Conceptual Models

🕒 2025-01-27 02:00 PM - 2025-01-27 03:00 PM

📍 Online Event



11 - 11  
FEB

### Lecture Series #5: The OMOP Common Data Model

🕒 2025-02-11 02:00 PM - 2025-02-11 03:00 PM

📍 Online Event



27 - 27  
FEB

### Lecture series #6: Introduction to European Rare Disease Registry Infrastructure (ERDRI)

🕒 2025-02-27 03:00 PM - 2025-02-27 04:00 PM

📍 Online Event

## FROM LEARNING TO DOING: ADVANCING FAIR PRINCIPLES

Since the start of our project, we have hosted a series of insightful lectures on FAIR principles, providing a strong foundation for understanding their impact on research. These sessions have been invaluable in introducing key concepts, fostering discussions, and setting the stage for more in-depth learning.

## FAIR PRINCIPLES TRAINING SCHOOL



Now, we're taking it a step further! Our upcoming Training School will transform theory into practice, offering hands-on experience in applying FAIR principles to real-world research scenarios.

This immersive approach will ensure that participants gain not only knowledge but also the skills needed to implement FAIR data practices effectively.

## WE PRACTICE WHAT WE PREACH! OPEN ACCESS TO FAIR TRAINING RESOURCES



### Lectures Slides

Lecture 5: HemaFAIR "The OMOP Common Data Model" slide deck

[READ MORE »](#)

February 12, 2025

Lecture 4: HemaFAIR Introduction to Conceptual Models slide deck

[READ MORE »](#)

February 5, 2025

Lecture 3: HemaFAIR Biomedical Ontologies slide deck

[READ MORE »](#)

January 15, 2025

Lecture 2: HemaFAIR Introduction to FAIR principles slide deck

[READ MORE »](#)

December 4, 2024

Lecture 1: HemaFAIR Introduction lecture slide deck

[READ MORE »](#)

December 4, 2024

### Lectures Recordings

Lecture 5: The OMOP Common Data Model lecture recording

[READ MORE »](#)

February 12, 2025

Lecture 4: Conceptual Models lecture recording

[READ MORE »](#)

January 27, 2025

Lecture 3: Biomedical Ontologies lecture recording

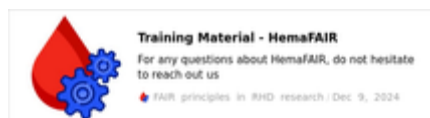
[READ MORE »](#)

January 15, 2025

Lecture 2: Introduction to FAIR principles lecture recording

[READ MORE »](#)

December 4, 2024



## OUR LATEST DISSEMINATION EFFORTS: WHAT WE'VE BEEN UP TO



We presented a poster at the International Multithematic Scientific Bio-Medical Congress 2024 at European University Cyprus to disseminate news about the project locally in Cyprus!

### HemaFAIR: Fostering F.A.I.R data and standards in rare hematological diseases

**ABSTRACT**  
Research on rare diseases (RDs) is scarce and fragmented in the EU, leading to delayed diagnosis, limited availability of medicinal products and challenging access to care.  
Like in most RDs, data-driven research on rare hematological diseases (RHDs) is affected by the lack of data standardisation and the fragmentation of available data in close repositories. Adhering to the principle of making data findable, accessible, interoperable and reusable (FAIR) is pivotal in fostering collaborative research and maximising the potential of available data.  
By bringing together key experts in RHDs, biomedical informatics, ethics and regulations, and research management fields, HemaFAIR will strengthen the scientific profile and competitiveness of Cyprus in RHDs, research management and administration.

#### OBJECTIVES

HemaFAIR aims to promote multi-centre, data-driven, patient-centred research in RHDs by demonstrating the application of FAIR principles to RHD research at national and international levels

- ♦ To implement ontology-based conceptual models, biomedical domain ontologies, genetic data standards, ontologies for reuse of human data, and other specifications for creating FAIR and AI-ready data in RHD research
- ♦ To strengthen the administrative skills and develop sustainable research management and support infrastructures
- ♦ To raise the research profile of researchers in Cyprus through a detailed training programme with a focus on Early Career Researchers, project managers and administrative staff

#### FAIR principles

**F:** Other humans and computers can find the data due to presence of strong metadata and persistent identifiers that are registered in a searchable resource repository  
**A:** The data/metadata are available and downloadable from a repository by both human and computers  
**I:** The data from different sources can work together, datasets can be combined with the help of standardized protocols and naming conventions  
**R:** The data should be ready for future research and processing for the community to build on new research questions while considering data sharing restrictions and intellectual property rights

#### OVERVIEW OF THE USE CASE

	Cyprus Hemoglobinopathy Patient Registry	INTERHEM
Data types	Demographics, consent, diagnosis, clinical, laboratory, treatment, genetic, patient reported outcomes (PROs)	Demographics, consent, data use, clinical, laboratory, treatment, genetic
Contributing centres	All haematology clinics in Cyprus	10 internationally
FAIRification status	Use of the following vocabularies: ORDO, LOINC, HPO	

#### WAYS TO BE INVOLVED

HemaFAIR will implement comprehensive training and capacity building activities

- Summer Schools
- Expert visits
- Lecture series
- Webinars
- Workshops
- Mentoring programmes

#### MEMBERS & EXPERTISE

Scan the QR code to follow HemaFAIR on social media

Partners and expertise include: NHUs and biomedical informatics, FAIR data standards, Research management RHDs, Research management, ethical, legal, social issues.

Funded by the European Union

This project has received funding from the European Union Horizon Europe Technology Sub-programme under Grant Agreement No. 101019080

www.hemafairproject.eu  
info@hemafairproject.eu



HemaFAIR: an EU-funded medical informatics project  
29 views • 4 months ago

VJHemOnc – Video Journal of Hematology & HemOnc

In this video, Petros Kountouris, PhD, The Cyprus Institute of Neurology & Genetics, Lefkosia, Cyprus, int

Our Project Coordinator Dr Petros Kountouris introduced HemaFAIR in the *Video Journal of Hematology & HemOnc*, highlighting the project's mission and impact on advancing FAIR principles in rare hematological disease research.



## PROJECT MANAGEMENT AND ADMINISTRATION WORK PACKAGE

Our awesome partners at Vall d'Hebron Institut de Recerca (VHIR), who are steering the ship for project management and admin work packages, have kicked off interviews with project management teams in Cyprus and across our EU partner institutions.

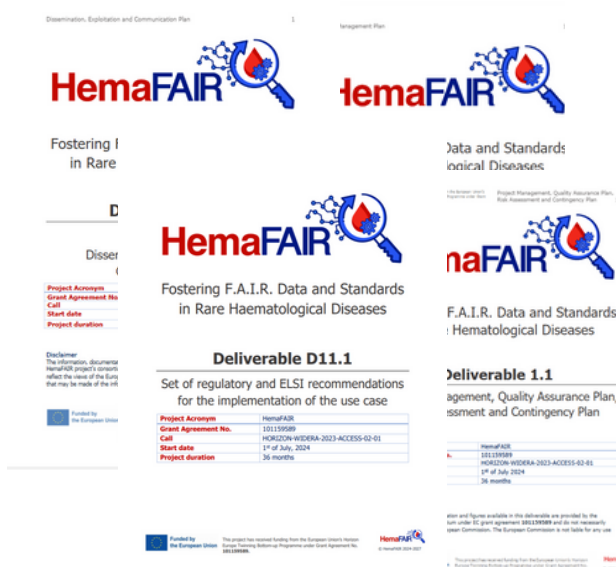
The insights from this work will help us bridge the gap between Cyprus and EU standards in project management, using benchmarking and gap analysis with the help of top EU experts.



## DELIVERABLES AND MILESTONES HEMAFAIR ON ZENODO

We're on the move and making great strides toward hitting our milestones for the second quarter of the project

You can check out all our deliverable documents on **Zenodo** — most of them are open access. Dive in and explore!

The screenshot shows the HemaFAIR project page on Zenodo. It includes the project title "Fostering F.A.I.R. Data and Standards in Rare Hematological Diseases", the project acronym "HemaFAIR", and the project duration "36 months". It also lists the project manager "Vall d'Hebron Institut de Recerca (VHIR)" and the project coordinator "Dr. Maria Vitoria Gomes". The page highlights two deliverables: "Deliverable D11.1" (Set of regulatory and ELSI recommendations for the implementation of the use case) and "Deliverable 1.1" (Project Management, Quality Assurance Plan, Risk Assessment and Contingency Plan).

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## WHAT'S NEXT FOR HEMAFAIR?

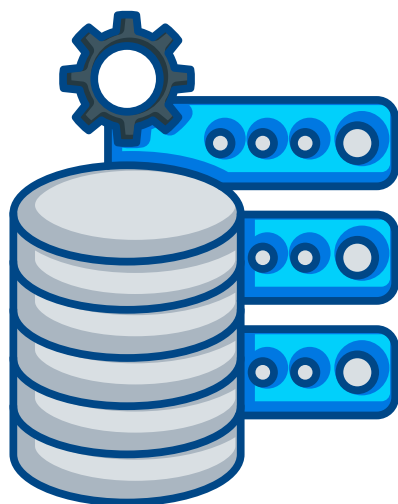
### ON THE HORIZON

Plenty of exciting things are on the horizon! We're diving deeper into collaboration, expanding our knowledge-sharing activities, and gearing up for new capacity-building actions and expert knowledge exchanges with short-term staff exchanges, a mentoring programme, and many more activities

### TECHNICAL UPDATES

#### Patient reported outcomes

Our team is diving into the world of PROMs (Patient-Reported Outcome Measures)! We're carefully selecting the best tools to include in our platforms and to design our use case — because patient voices bring meaning to the data!



#### FAIRification of Patient Registries

Our team at CING is working closely with FAIR experts across the consortium to define the requirements for our research use case. This involves FAIRifying one local platform — the Cyprus Haemoglobinopathy Patient Registry — and one international platform — INHERENT.

This collaboration will help ensure both platforms meet FAIR standards and support broader data sharing and reuse.

