HemaFAIR

FOSTERING F.A.I.R DATA AND STANDARDS IN RARE HEMATOLOGICAL DISEASES

NEWSLETTER

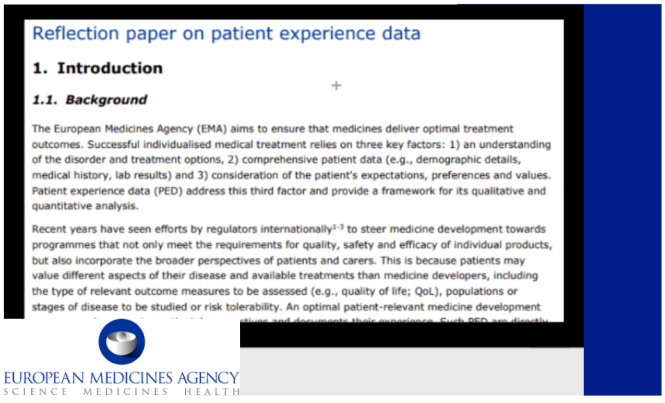
ADVANCING FAIR RESEARCH: HEMAFAIR'S FIRST PUBLICATIONS WITH INHERENT AND HELIOS NETWORKS

HemaFAIR is pleased to highlight its first scientific publications developed in collaboration with the INHERENT and HELIOS networks. These studies represent important milestones in advancing FAIR data practices, strengthening international research collaboration, and supporting the development of interoperable data infrastructures for hemoglobinopathy research.

Together, these publications contribute to the growing evidence base needed to improve data sharing, harmonisation, and collaborative research across the global hemoglobinopathy community.

HEMAFAIR CONTRIBUTION TO THE EMA REFLECTION PAPER ON PATIENT EXPERIENCE DATA

HemaFAIR partners contributed to the European Medicines Agency (EMA) Reflection Paper on the use of Patient Experience Data (PED) in medicines development and regulatory decision-making. This contribution supports ongoing efforts to strengthen the integration of patient perspectives into healthcare research and innovation, aligning with HemaFAIR's work on patient-reported outcomes, data interoperability, and FAIR health data practices.



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FEDERATED LEARNING HACKATHON

CO-ORGANISED BY HEMAFAIR AND HELIOS ACTION

HemaFAIR and HELIOS successfully delivered the Federated Data Analysis Training School and Hackathon in Ayia Napa, Cyprus, bringing together participants from multiple countries for hands-on training in FAIR data principles, semantic interoperability, OMOP, and federated data analysis. The event strengthened participants' skills in FAIR data implementation while fostering collaboration and knowledge exchange across the rare disease and hemoglobinopathy research communities.

Stay tuned for event recordings, participant testimonials, and additional highlights showcasing the impact and outcomes of this successful training initiative.

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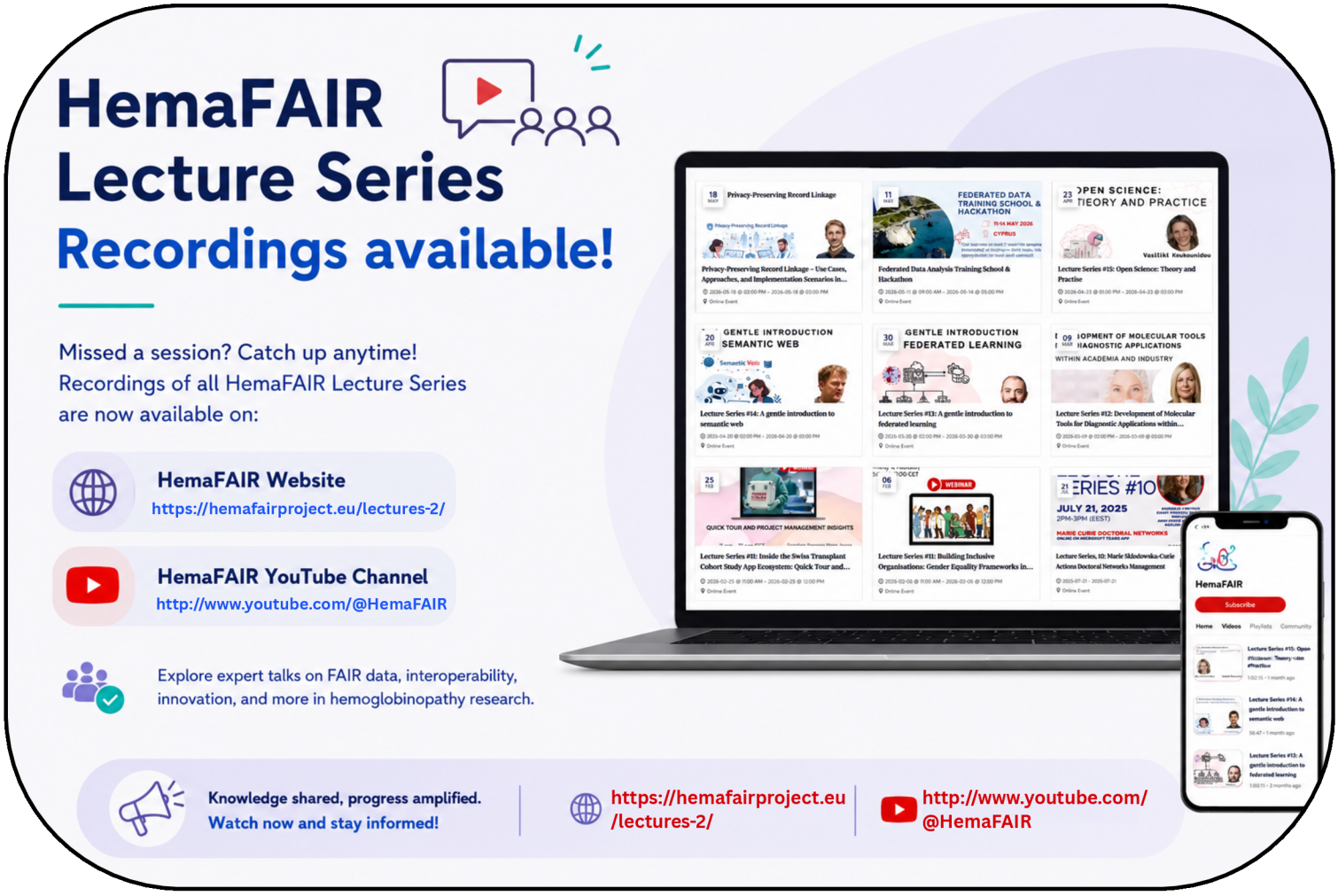
HEMAFAIR LECTURE SERIES CONTINUES TO GROW!

The HemaFAIR Lecture Series continues to bring together leading experts to share knowledge and foster collaboration in the fields of rare diseases, FAIR data, biomedical informatics, and hemoglobinopathy research.

Recent lectures have covered a wide range of topics, providing participants with valuable insights into emerging research, innovative methodologies, and best practices. Through these events, HemaFAIR continues to strengthen capacity building, knowledge exchange, and collaboration across the scientific community.



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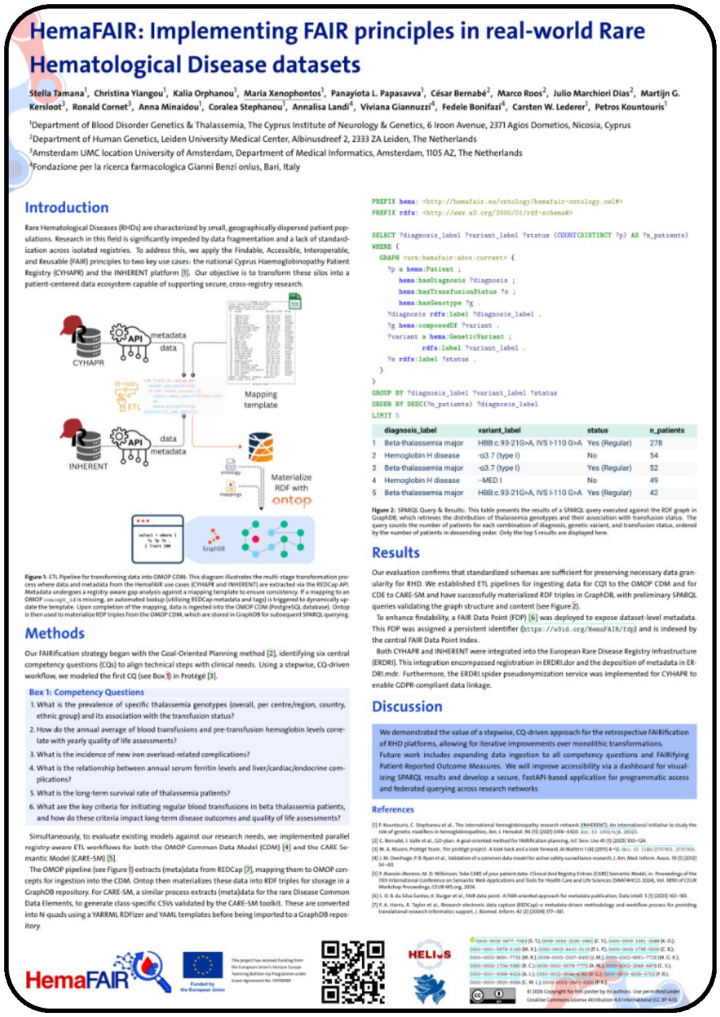
EXCHANGE VISITS BETWEEN HEMAFAIR PARTNERS!

A recent exchange visit from CING to Amsterdam UMC (AUMC) provided a valuable opportunity for collaborative work on the FAIRification of rare hematological disease registries. Through close interaction and knowledge exchange, the teams advanced activities related to data findability, interoperability, and reusability, further strengthening the partnership and supporting HemaFAIR's mission to develop FAIR and interoperable health data infrastructures.

HEMAFAIR PRESENTED AT SWAT4HCLS 2026!

HemaFAIR was presented at SWAT4HCLS 2026 in Amsterdam through the poster "HemaFAIR: Implementing FAIR Principles in Real-World Rare Hematological Disease Datasets." The conference provided a valuable platform to showcase the project's progress in FAIRifying rare hematological disease data and to connect with researchers working on semantic web technologies, interoperability, and FAIR data solutions in health research.



HemaFAIR: Implementing FAIR principles in real-world Rare Hematological Disease datasets

Stella Tamana[1], Christina Yiangou[1], Kalia Orphanou[1], Maria Xenophontos[1], Panayiota L. Papasavva[1], César Bernabé[2], Marco Roos[2], Julio Marchiori Dias[2], Martijn G. Kersloot[3], Ronald Cornet[3], Anna Minaidou[1], Coralea Stephanou[1], Annalisa Landi[4], Viviana Giannuzzi[4], Fedele Bonifazi[4], Carsten W. Lederer[1], Petros Kountouris[1]

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Introduction

Methods

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Discussion

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WHAT'S NEXT FOR HEMAFAIR?

ON THE HORIZON

CONTINUED STAFF EXCHANGES
Strengthening collaboration and knowledge exchange across partners.

CAPACITY BUILDING
Sharing knowledge and building essential skills together.

FAIR DATA EXCELLENCE
Advancing findability, interoperability and reusability of health data.

Together, we continue to build a FAIR and interoperable future for rare hematological disease research.

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