SYNTHEMA Newsletter!

May 29, 2023

Here is SYNTHEMA in a nutshell.

SYNTHEMA is a Horizon Europe research and innovation action that aims to establish a cross-border health data hub for rare haematological diseases (RHDs).

Haematological diseases are highly diversified, with oncological and non-oncological subcategories. The scarcity and fragmentation of patient data across scattered transnational repositories hinder effective health planning and make difficult to engage in basic and clinical research. SYNTHEMA aims to tackle this challenge by establishing a research platform connecting clinical centres of excellence in the research and care of RHDs, technical research centres, industries and SMEs, to advance translational and clinical research by generating and validating anonymised and synthetic data in RHDs.

To ensure data security and patients' privacy, the project will make use of a federated learning (FL) infrastructure, privacy preserving by design, that will allow to iteratively train, refine and validate AI algorithms at hospital premises, without sharing of data outside local repositories. Also, it will equip it with secure multi-party computation (SMPC) protocols and differential privacy (DP), allowing distributed computation of mathematical functions between centres without revealing the underlying data.

SYNTHEMA will focus on two representative RHD use cases: sickle-cell disease (SCD), for non-oncological haematologic diseases, and acute myeloid leukaemia (AML) for haematologic cancers.

To make the project vision a reality, the research is articulated into five strategic objectives, as below:

1. Provide novel methods and capabilities to generate synthetic multimodal clinical, omics, and imaging data for RHDs with a validated clinical result.
2. Develop de-identification and anonymisation pipelines at the service of clinical research and care.

3. Consolidate and scale-up the use of FL applications, SMPC and DP solutions for privacy-preserving local algorithm training and global model aggregation.
4. Ensure ethical and GDPR compliance in anonymised and synthetic data-driven research in RHDs
5. Ensure wide uptake and scalability of the developed methodologies and tools through effective stakeholder engagement, dissemination and open science practices.

SYNTHEMA will contribute to existing data registries such as the European Rare Blood Disorders Platform (ENROL), the European Platform on Rare Disease Registration (EU RD Platform), and the European Rare Disease Registry Infrastructure (ERDRI) with data standards, pipelines, and shareable data assets, and support their long-term sustainability.

Consortium highlights.

SYNTHEMA consortium in Lisbon

SYNTHEMA consortium at the Hospital da Luz Learning Health Center

During the review meeting, the team had the opportunity to visit the state-of-the-art simulation center at Hospital da Luz. This visit proved to be enlightening, highlighting the importance of being aware of and actively engaging with other initiatives aimed at addressing complex challenges in the healthcare sector. By embracing collaboration and staying informed about emerging trends and solutions, SYNTHEMA demonstrates its commitment to remaining at the forefront of healthcare innovation.

Hospital da Luz Learning Health stands at the forefront of excellence in medicine, embodying a steadfast commitment to the continual advancement of health care delivery and management. It achieves this through three primary avenues: professional training, translational research, and innovation. As a pioneering institution, its vision is to be recognized globally for its role in the development of health professionals. It also actively fosters the generation and distribution of knowledge, technologies, and practices pertinent to health care.

The cornerstone of its mission lies in enhancing patient safety and quality of care, aligning with the broader goals of the Luz Saúde group in providing exceptional patient care and fostering professional development. Through its activities, Hospital da Luz Learning Health is transforming the vision of the future hospital into a tangible reality today.

Operating across the key domains of training, research, and innovation, the institution utilizes its state-of-the-art medical simulation center at Hospital da Luz Lisboa as the foundation for these activities. In the realm of training, it designs, implements, and assesses training and simulation programs tailored to the needs of health care professionals, both within and outside the Luz Saúde Group. These programs span a variety of experiences, from scientific events to training courses, each catering to the specific competencies required by the participants and aligning with the organization's value system.

In the field of research, Hospital da Luz Learning Health not only develops, promotes, and supports research within the Luz Saúde group but also encourages the creation of innovative methodologies that enhance the value of patient care. The research activities focus on several areas, including preventative medicine, early diagnostic methods and biomarkers, personalized medicine, and outcomes research. Each of these areas leverages advanced analytical methods and human factor engineering to optimize patient value.

The institution's commitment to innovation is underpinned by a robust support system for open innovation, providing the resources necessary for the development of new products and services from conception to market placement. It also actively engages in acceleration programs such as Protechting, offering invaluable support to health startups and serving as a conduit for innovation within the Luz Saúde group.

In creating the Hospital da Luz Learning Health, the Luz Saúde group reaffirms its unwavering commitment to excellence and innovation in medicine. By ensuring value for patients and fostering the development of outstanding health care professionals, it is not only shaping the future of health care but also turning it into a reality today.

Visit the Hospital da Luz Learning Health Center website here.

SYNTHEMA consortium partners at the Learning Center

Project's next steps.

At present, the SYNTHEMA consortium is engaged in the definition of its user and system requirements. On one side, it is collecting the needs of AI developers and clinical researchers that will use the platform for generating and validating anonymised and sythetic data based on clinical research-driven goals, while analysing their values and concerns to ensure a value-sensitive design. On the other, it is defining technical specification for its privacy preserving data platform, including details of the FL infrastructure, SMPC protocols and DP and how to combine those into a unified workflow.

The consortium is also assessing its available clinical records from its 7 participating clinical centres for SCD and AML use cases, including characterisation of all data sources, variables and formats. Meanwhile, it is collecting documentation to obtain ethical clearance for the project by the relevant Ethics Research Commitees.

In the next months, the consortium will be engaged in the definition of a common data model to harmonise all data into a unique format, and make it compatible with other haematological disease registries. It will also define its data management plan, describing the flows of data within the project, how to process and store data preserving patients' privacy, and start defining privacy risks and assessment procedures. Also, it will start identifying methologies for the generation of synthetic data and their subsequent validation.

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