

A PRivacy-prOTecting Environment for Child Transplants health-related and genomic data integration in the European Reference Network – PROTECT-CHILD

Project funded by the European Commission - Horizon Europe - Work Program 2023-2024 - Health - HORIZON-HLTH-2023-TOOL-05-04: Better integration and use of health-related real-world and research data, including genomics, for improved clinical outcome.

Partnership

Coordinator: Universidad Politécnica de Madrid

Partners: IRCCS Istituto Mediterraneo per i Trapianti e Terapie ad Alta Specializzazione (ISMETT), Universidad Politécnica de Madrid, Servicio Madrileño de Salud, Multimed Engineers Srl, Ethniko Kentro Erevnas Kai Technologikis Anaptyxis, Inetum España, Universiteit Twente, Universidad de Granada, Biomeris Srl, Stichting Integraal Kankercentrum Nederland, Preduzece Za Informacione Tehnologije I Elektronsko Trgovanje Belit Doo, Universidad de la Iglesia de Deusto Entidad Religiosa, Universitaetsklinikum Hamburg-Eppendorf, Università degli Studi di Padova, HI7 International Foundation, Georgia Tech Research Corporation, Università degli studi di Roma La Sapienza, Udg Alliance.

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Children undergoing a liver transplant experience numerous complications mainly due to variable responses to treatment and the transplanted organ. This variability is linked to genetically-determined factors that complicate the understanding of the impact of relevant genomic factors. Additionally, the small number of pediatric transplants has made the collection of genomic and epigenetic data a complex process.

The aim of this project is to integrate genomic data from four hospitals of the ERN Transplant Child network, linking these clinical data to outcomes, natural history, and

pharmacogenomic parameters. The study focuses on two groups of rare pediatric diseases that require liver and kidney transplantation. The task of this project is to conduct a preliminary verification of the validity of pilot models, based on the validated infrastructure in the preclinical sector, within the real-world care environment. Clinical and family history data will be integrated with genomic data to assess the contribution of genomics and develop the best model for predicting liver and kidney transplant outcomes in patients enrolled in the pilot study cohort. The project network consists of a committee of clinicians and engineers who evaluate the required genetic and genomic measurements, and will analyze and interpret the data, including comparisons of follow-up, patient history, and genomic data.

PROTECT-CHILD is a project that aims to improve the outcomes of rare pediatric transplant patients by integrating multiple sources of high-throughput data from registries, hospital-based and public repositories, complying with ongoing initiatives such as the European Open Science Cloud (EOSC) and the European Health Data Space (EHDS). The project focuses on the co-design of a secure and privacy-preserving infrastructure, harmonization of data standards, and creation of a public/private infrastructure for assembling large datasets to improve clinical outcomes. The project involves top-level expertise from a consortium of technology specialists, data standardization experts, and High-Performance Computing (HPC) centers, as well as clinical experts, legal experts, patients' representatives, and policy makers. The project is aligned with EHDS and General Data Protection Regulation (GDPR) principles and aims to empower secure and compliant processing, analysis, and sharing of sensitive personal data, including genomics, while preserving data privacy and security.

Website: <https://protect-child.eu/>

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