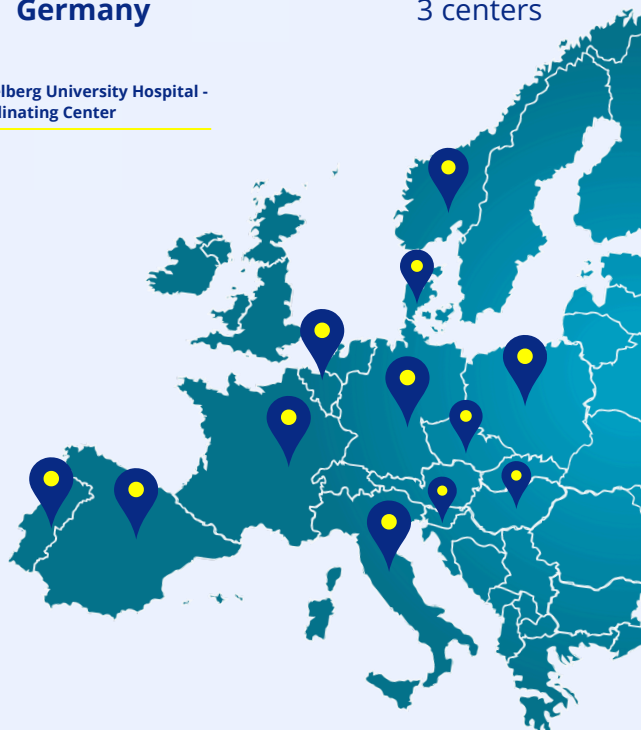


U-IMD Partners

Belgium	6 centers
Czech Republic	1 center
Denmark	1 center
France	1 center
Hungary	1 center
Italy	7 centers
Norway	1 center
Poland	1 center
Portugal	3 centers
Slovenia	1 center
Spain	5 centers
Germany	3 centers



Heidelberg University Hospital -
Coordinating Center

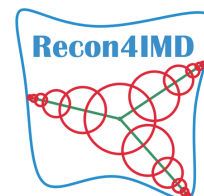


Collaborating Stakeholders



European Reference Network

MetabERN
European Reference Network
for Hereditary Metabolic Disorders



Unified European Registry for Inherited Metabolic Disorders

Official patient Registry of MetabERN

Unique data source collecting longitudinal data on all IMDs

Integration with the European Rare Disease Registry Infrastructure (ERDRI)

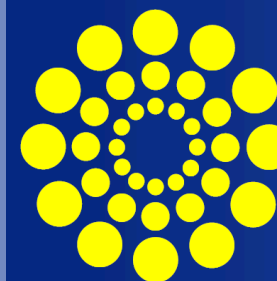
Do you need more information?

Please, contact us by via the contact form on the project website www.u-imd.org



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UIMD

Unified Registry for Inherited Metabolic Disorders

About U-IMD

U-IMD is the first registry covering all 1500+ inherited metabolic disorders, collecting longitudinal observational data from routine patient care. U-IMD is structured as a scientific consortium, using its data source to facilitate original research and collaborative research with different stakeholders.

Data Model & Access

M1 Common Data Elements (CDE)

U-IMD implements the CDE developed by the EU Joint Research Centre.

M2 Clinical and Cognitive Phenotype

U-IMD uses the terms of the Human Phenotype Ontology and results from IQ tests.

M3 Patient perspective

U-IMD uses the PedsQL and the WHOQOL questionnaire.

M4 Treatment

U-IMD records dietary treatment, drug treatment and transplantations.

M5 Biochemical markers

U-IMD uses disease specific selections of biochemical markers.

M6 ERKNet collaboration

U-IMD collaborates with the European Reference Network for Rare Kidney Diseases.

M7 Newborn Screening (NBS)

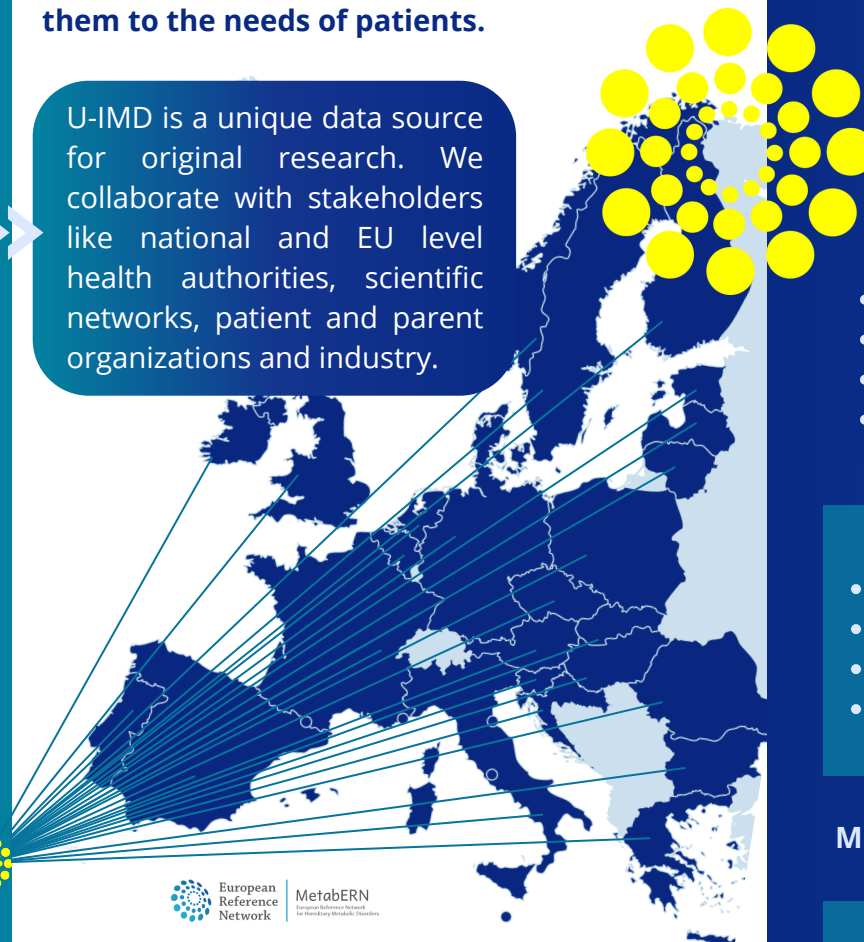
Module for NBS-related parameters.

The U-IMD registry is accessible for all members of MetabERN and for voluntarily collaborating European and international health care providers.

MetabERN

MetabERN is a European non-profit network established by the EU to facilitate access to the best available care and to address the cross-border needs of all patients affected by a rare inherited metabolic disease (IMD) and their families. MetabERN aims to bring together the most specialised centres in the field of rare IMDs to speed up diagnosis and improve standards of care for patients living with IMDs across Europe. By combining patient experience and expert knowledge from across the EU, it captures the most innovative medical advances and tailors them to the needs of patients.

U-IMD is a unique data source for original research. We collaborate with stakeholders like national and EU level health authorities, scientific networks, patient and parent organizations and industry.



How to participate

- Apply for membership via our website
- Go through local ethics (HCP/IRB) with the U-IMD Study Protocol and Informed Consent Forms (ICFs)
- Sign the U-IMD Consortium Agreement
- Start enrolling patients

The U-IMD Consortium Agreement provides the framework for the secure and transparent collection and sharing of data across all U-IMD partners, using the expertise developed by the European Rare Disease Research Coordination and Support Action (ERICA).

