

# IHI Call Days | Call 9

## ERDE

### European Rare Disease Empowerment



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Link to the IHI brokerage platform:

- [Proposal sharing tool](#)
- [Participant profile](#)



# Challenges and objectives

- Challenges in Rare Diseases:
  - Limited patient and data availability and integration
  - Limited patient support and empowerment
  - Limited evidence for clinical trials and therapy decisions
- IHI objectives:
  - SO2: bringing together industry, carers and patients to improve diagnosis, treatment and management of rare diseases
  - SO3: demonstrate the value and drive of empowering patients
- Unmet public health need for rare diseases:
  - Faster and more cost effective support, diagnosis and therapy
  - Faster and more efficient advancements in treatment development



# European Rare Disease Empowerment

- Create an empowerment portal for rare diseases
- For patients:
  - Collect and manage their disease journey and QoL data over time
  - AI information and support for diagnoses, procedures, therapies
  - Connect with similar patients and study protocols
- For health-care professionals:
  - Easy access to patient data as needed
  - Compare symptoms, find similar patient and treatment suggestions
- For research bodies:
  - Data mining and retrospective analysis for hypothesis testing
  - Prospective study management and participant recruiting
  - Real world data integration, both medical and personal



# ERDE is suitable for IHI



- A public-private collaboration on European level is mandatory to bring rare disease management forward:  
IHI funding enables a primary focus on patients' needs to ensure inflow of data to the portal, while the collaboration with companies ensures suitability for research purposes.
- The contribution of health industry sectors such as pharma, medical devices or diagnostics ensures that the portal will enable their research needs, and thus the patient data is put to best use to advance diagnosis, therapy and management of rare diseases.



# Outcomes and Impact

- Expected outcome:  
A living portal to support patients with rare diseases and their healthcare providers by managing their data over time, understanding their disease and finding additional support.
- Translation from Research to practice:  
The ERDE can be used by research bodies to perform data mining on retrospective rare disease data and plan and manage prospective studies. First proof points are expected by the end of the project.
- Strengthening competitiveness:  
Improve cost effectiveness and success of health care for rare diseases.  
Bring European data integration and utilization to a next level for translation to other fields.
- Benefits for patients:  
The portal will benefit patients immediately to manage their rare disease: improved patient information, earlier diagnosis, better and earlier treatment, connection to similar patients and relevant studies.



# Expertise and resources

- We have expertise with
  - Large databases and platform design
  - Data analytics
  - AI and LLM, specifically for medical image data
  - Patient support structures
  - Research and data networks
- We are looking for:
  - Patient organizations
  - Health insurance organizations to drive efficiency and cost effectiveness
  - Pharmaceutical companies
  - Companies from the diagnostic sector, such as biotech and medical device manufacturers
  - Clinical research organizations dealing with rare diseases
  - Rare disease platforms and data capture organizations



**As a non-profit research organization, we can not bring in-kind contributions.**

# Additional information

ERDE



European  
Rare Disease  
Empowerment

The brochure cover features the Fraunhofer MEVIS logo at the top. Below the logo, it reads 'FRAUNHOFER INSTITUTE FOR DIGITAL MEDICINE MEVIS'. The central part of the cover is a horizontal strip of three images: a CT scan of lungs with a color-coded overlay, a 3D anatomical model of a liver with a surgical tool, and a 3D model of a brain with white matter fibers. Below the images, there is a section titled 'SOFTWARE ASSISTANCE FOR PERSONALIZED DIAGNOSIS AND THERAPY'. To the left of this section, there is a text block with contact information for Fraunhofer MEVIS. At the bottom left, there is a DEKRA logo. At the bottom right, there is a section titled 'What Distinguishes Us?' with a list of bullet points.

**Fraunhofer**  
MEVIS

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*Left: Quantitative and visual assessment of perfusion defects in the lungs. Center: Patient-individual planning of RF tumor ablation in the liver. Right: White matter fibers for neurosurgical planning.*

### SOFTWARE ASSISTANCE FOR PERSONALIZED DIAGNOSIS AND THERAPY

**About Us**

Fraunhofer MEVIS develops interactive assistance systems for clinical applications. This development focuses on medical image data used in early detection, diagnosis, therapy planning, therapy support, or follow-up.

This contributes to earlier, more accurate disease detection and therapy decisions that are tailored to each patient and evaluated in terms of patient risk. Not least, the success of each therapy becomes more understandable and measurable.

In close cooperation with clinical experts the entire process is considered: from image generation and analysis to interpretation and therapeutic decision making.

Our portfolio ranges from contract research to consultancy and from software design to prototype development, quality-assured software components, and standalone applications.

**What Distinguishes Us?**

- Clinical Network: over 150 partners worldwide
- Transdisciplinary: bridging medicine, science, and industry
- Complete Innovation Process: from basic research to product
- Certified Software Development: EN ISO 13485 (Medical Devices) since 2005
- Scientific Excellence: established in the medical and technical community
- Fraunhofer-Gesellschaft: largest organization for applied research in Europe
- MeVisLab: rapid prototyping platform [www.mevislab.de](http://www.mevislab.de)

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