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Integrating Health Data across Europe to aid Clinical Decision-making for Lung Cancer Patients

The newly formed [IDERHA](#) consortium, consisting of academia, industry, health authorities, clinicians, and patient representatives, addresses the obstacles in accessing, integrating and analysing health data to maximize their value for patient care and research. Focusing on lung cancer, IDERHA wants to use complex digital health data to improve patient health outcomes by enabling more personalized care.

14 June 2023 – Today a consortium of public and private entities announced the official launch of [IDERHA](#) (Integration of heterogenous **D**ata and **E**vidence towards **R**egulatory & **H**TA **A**ceptance). The consortium aims to propel health care innovation in Europe by addressing the key obstacles to achieve appropriate access, sharing, use and reuse of digital healthcare data. IDERHA will, therefore, develop the first pan-European health data space, and through policy recommendations drive health data access and the acceptability of heterogeneous health research results for regulatory and Health Technology Assessment decision-making. The initiative will focus on lung cancer, which is responsible for [20% of cancer-related deaths in Europe](#) and one of the key priorities of the [Europe Beating Cancer](#) program.

IDERHA is one of the first research projects funded through the [Innovative Health Initiative \(IHI\)](#), a public-private partnership (PPP) between the European Union and the European life science industries that supports transformative research and innovation.

Exponential growth of health data

In recent years, there has been an exponential growth in the generation of data that could be harnessed for use in healthcare delivery and research. These data include readouts generated by digital technologies, patient reported outcome and experience measures, and results from clinical trials and routine clinical care. However, accessing, integrating and analysing these data to maximize their value for patient care and research is extremely challenging.

IDERHA aims to create a scalable platform for the seamless integration or linkage of diverse data at scale to support healthcare professionals, patients, and researchers with new capabilities to improve patient outcomes by better treating and manage disease, enable personalized care, bolster research and innovation, based on the development of common standards and practices – reducing current disconnected information silos. This enables more personalized health care along the patient's journey via data-driven tools and solutions.

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Improving the lives of patients

IDERHA's pilot program will focus on key priorities of the Europe Beating Cancer plan, which include the improvement of early cancer detection and the quality of life of individuals with cancer. It will link and analyse diverse data stemming along the continuum of a lung cancer patient's journey: from early screening of citizens at risk to develop lung cancer to remote monitoring of late-stage patients to enable better care in an at home setting. Ultimately, the platform and policy recommendations will be disease independent.

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New recommendations to inform policy making

To enable patients and health care providers to benefit from novel health solutions, IDERHA also seeks to accelerate policy development. Informed by patient needs, we will develop consensus recommendations for fully compliant health data access and sharing as well as for the acceptability of heterogeneous health research results for regulatory and HTA decision-making. This may lead to a framework for data governance that can be used as a model globally.

"IDERHA is an exciting project that really exemplifies what the Innovative Health Initiative is about," said Dr. Hugh Lavery, IHI Executive Director ad interim. "A true cross-sectoral, public-private partnership, it brings together experts from diverse fields like health data, imaging and oncology to improve the lives of people with lung cancer."

Consortium of 32 partners

The initiative will be led by the [Fraunhofer Institute for Translational Medicine and Pharmacology ITMP](#) and [Johnson & Johnson Medical GmbH](#), part of Johnson & Johnson MedTech, in a consortium of 32 academic, clinical, medtech, pharmaceutical, IT and patient advocacy organizations as well as public authorities.

"IDERHA is a pioneering project focussed on creating health care solutions that integrate diverse health data, to bring improved care and treatments for patients. I am thrilled that such a talented group of researchers, united under the frame of IDERHA, will develop a platform to revolutionize the use and interpretation of clinical data, from which lung cancer patients will directly benefit," said Dr. Philip Gribbon, Coordinator of IDERHA at Fraunhofer ITMP. "We are honoured to be selected as one of the first consortia supported by IHI, with this challenging yet rewarding project."

About Fraunhofer-Gesellschaft

The Fraunhofer-Gesellschaft based in Germany is the world's leading applied research organization. Prioritizing key future-relevant technologies and commercializing its findings in business and industry, it plays a major role in the innovation process. Founded in

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1949, the Fraunhofer-Gesellschaft currently operates 76 institutes and research units throughout Germany.

The three Fraunhofer institutes participating in IDERHA, Fraunhofer Institute for Translational Medicine and Pharmacology ITMP, Fraunhofer Institute for Software and Systems Engineering ISST and Fraunhofer Institute for Algorithms and Scientific Computing SCAI, combine expertise in project coordination and the setup of federated analysis methods for healthcare. In addition to its coordinating role, Fraunhofer will lead work on developing novel AI/ML tools to analyse health data from clinical partners. Fraunhofer will support the whole EU-wide consortium with its expertise in the conceptual design of complex infrastructures and data ecosystems, algorithm development, FAIR data management and infrastructure sustainability.

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About IDERHA

IDERHA is committed to improve clinical decision-making and enhance patient access to health innovations. For this, the consortium will develop an EU-wide health data space to enable connectivity to and access of digital health data, while simultaneously driving policy recommendations for data access and acceptance of real-world data for regulatory and health technology assessment decision-making.

About IHI

The Innovative Health Initiative (IHI) aims to translate health research and innovation into real benefits for patients and society, and ensure that Europe remains at the cutting edge of interdisciplinary, sustainable, patient-centric health research. Health research and care increasingly involve diverse sectors. By supporting projects that bring these sectors together, IHI will pave the way for a more integrated approach to health care, covering prevention, diagnosis, treatment, and disease management.

IHI is a partnership between the European Union and European industry associations representing the pharmaceutical, medical technology, biotechnology, digital health and vaccine industries, namely COCIR, EFPIA, EuropaBio, MedTech Europe and Vaccines Europe. IHI's total budget is EUR 2.4 billion. Half of this comes from Horizon Europe, the EU's research and innovation programme. The IHI industry partners have committed EUR 1 billion to IHI, and a further EUR 200 million can be committed by other organisations that decide to become Contributing Partners.

IHI builds on the successes of the Innovative Medicines Initiative (IMI), and the IHI Programme Office continues to manage the IMI project portfolio.

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