

Press Release

Paris, 03/07/22

EHDS2 Pilot - A European Consortium Pilot project, candidate for the future European Health Data Space

A large European consortium bringing together 8 national health data infrastructures, 2 EU agencies, 1 ERIC, 4 research infrastructures, and one association is applying for a European Commission's call for projects to set up a test version of European Health Data Space (EHDS), leading to major breakthroughs on European policies on the secondary use of health data for research, innovation and healthcare system improvement purpose.

The *EHDS2 Pilot consortium* aims to be selected to build and test a first version of the European Health Data Space for the secondary use of health data

Sharing data at European scale is fundamental to develop research and improve citizens' health. It allows, for example, to build more efficient artificial intelligence algorithms for research, to improve the large-scale management of pandemics such as COVID-19, or to study rare diseases thanks to health data sharing.

This is why the ***EHDS2 Pilot consortium*** brought together **16 partners from all over Europe (national platforms, ERICs, research infrastructures, EU agencies and associations in the area of health)** to answer the European Commission's call for projects to set up a test version of the future European Health Data Space (EHDS) for the secondary use of health data.

On January 25th, the *EHDS2 Pilot consortium* submitted its application to **build this prefigurative EHDS by interconnecting data provider platforms, either national infrastructures, EU agencies or research infrastructures, in a network of nodes**. If the consortium is selected, the EHDS2 Pilot project would aim to **implement and test a first user journey for creating, deploying and running health data research projects at EU level**: the main objective of the network is to investigate the technical tools and set up the standards which can allow project researchers to query the metadata catalogs of all the nodes, to request selected data via a single common form and to analyze data across national nodes. In order to build this network, the EHDS2 Pilot will propose legal and technical frameworks based on concrete research use cases.

In the application, the consortium has proposed preselected use cases for the Commission to choose from, to illustrate the potential of transnational health data reuse. They will address topics from population health to healthcare pathways, cancer, rare diseases and genomics. If selected, the EHDS2 Pilot is aiming to fully operate the chosen use cases in order to demonstrate the potential powerful impact of exploiting health data from several countries for public health, research, innovation and policy and healthcare system improvement.

The results of the call for projects are expected before the summer of 2022 and the winning candidate will start its work in September 2022 with a budget of 8 million euros financed up to 60% by the European Commission.

Sharing health data on a European scale is a real game changer for research, innovation and healthcare improvement, and a high priority for the European Commission

EU countries face similar challenges from the increasing incidence of diseases related to lifestyle and changing demography, to rising unsustainable healthcare costs, and most recently the COVID-19 public health crisis, emphasizing the importance of health policies as a cross border issue.

Since 2019, **the European Commission has identified the creation of a European Health Data Space as one of the priorities for European health policy**. As a matter of fact, many European countries possess substantial health data sets and data collections, however health data is very fragmented in Europe with varieties of data sources of diverging quality and different governance models and access policies for reuse and sharing. The aim of the EHDS is to facilitate discoverability and access to different types of data available in European countries to develop innovative tools in the service of citizens' health.

Several prefiguration instruments have already been set up by the European Commission. This is the case of [TEHDaS](#) Joint Action (Towards a European Health Data Space), a reflection program bringing together more than 26 EU Member States and several *EHDS2 Pilot consortium* partners. It provides options and recommendations for the EHDS based on research, such as surveys, forums, country visits and literature reviews.

To support Member States in building stronger, more resilient and accessible health systems the EU4Health Programme was set up to enable instruments and solutions in March 2021. In order to support the development of a common European Health Data Space, the EU4Health Programme has launched the *"EU4H-2021-PJ-06 - Action grants for developing an EHDS2 Pilot for an EU infrastructure ecosystem for the secondary use of health data for research, innovation, policy making and regulatory purposes"*.

In this context, the EHDS2 Pilot consortium, coordinated by the French Health Data Hub, has applied to the action grant to demonstrate the feasibility and relevance of such a space to improve research and health systems.

All consortium partners are very happy to collaborate together in this ambitious project and hope to be selected in order to provide a variety of expertises and build an effective and operational first version of the EHDS.

ABOUT THE HEALTH DATA HUB

Health data are essential for research and innovation in health, yet these data are often under-used because they remain too scattered. The HDH was hence conceived as the unique gateway to health data in France. Implemented in November 2019, it interacts with a variety of actors within the health ecosystem. The Health Data Hub has set up a highly efficient technological platform enabling public interest project leaders to mobilise very large data sources, to cross-reference them, and to use enough computing power to run complex search algorithms. In a word, the HDH supports ambitious project leaders who contribute to finding tomorrow's solutions to improve all citizens' health.

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ABOUT Sciensano

Sciensano is a federal research institute that operates under the authority of the federal minister of Public Health and the federal minister of Agriculture of Belgium and the scientific reference in the field of public health in Belgium. Its EU health information systems unit has taken the lead in many European projects: BRIDGE Health project, the Joint Action in Health Information InfAct, BAHCI, Bringing a Health Claim to Information) and PHIRI (the Population Health Information research infrastructure for COVID-19) in health information since its establishment in 2014. Furthermore, the EU HIS unit is involved in other European project focussed on facilitating the (re)use of health data for research, such as HealthyCloud, the Joint Action TEHDAS (Towards the European Health Data Space) and BeYond COVID (BY-COVID). Sciensano's EU HIS unit is in an ideal position to contribute to the consortium, being well-connected in the European health data landscape.

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ABOUT THE DANISH HEALTH DATA AUTHORITY

The Danish Health Data Authority (DHDA) is a part of The Ministry of Health, established in 2015 with 300 employees. Main task is to develop and run the national health registers to ensure comprehensive and valid health data for patient treatment, development, planning and research. Affiliated partners: 1) Central Denmark Region (CDR) with 5 hospitals, a mature business intelligence platform, and a mature electronic health record, also performs research with more than 2,600 peer-reviewed publications per year from the

University Hospital of Aarhus 2) Central Denmark EU Office (CDEU) investigate policy impacts and supports EU funded projects 3) Danish Life Science Cluster (DLSC) facilitates translation of knowledge to technological solutions for the benefit of patients.

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ABOUT FINDATA



Social and Health Data Permit Authority

The Finnish Social and Health Data Permit Authority Findata is a one-stop shop for the secondary use of social and health care register data in Finland. Findata was established in 2019, started operations in 2020 and has currently 22 employees. The main objectives of Findata are to improve data security and streamline the utilisation of social and health care data resources. Findata grants permits for the secondary use of data when it is needed from several public data controllers, the private sector or Kanta services. After granting the permit it compiles, combines and pre-process the data and offers Kapseli – a secure remote access system with tools for analysing. Findata works in conjunction with Finnish Institute for Health and Welfare, under the performance guidance of the Ministry of Social Affairs and Health.

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ABOUT THE HEALTH DATA LAB



HDL

The Health Data Lab (HDL) is a unit of the Federal Institute for Drugs and Medical Devices (BfArM), Germany. It is currently under construction, but once operational, it will contain health claims data of all people in Germany with statutory health insurance (> 70 million people). In the future, it will also maintain voluntarily shared data from electronic patient records. The purpose of the HDL is to review data applications, minimise the re-identification risk and provide secure data access to legally determined beneficiaries such as researchers or public institutions aiming to improve the healthcare system. The HDL has extensive experience in national and international consortia (TEHDAS, CIOMS, NFDI4health, EMA Big Data Steering Group and DARWIN EU ® Advisory Board) which could strengthen the interconnection of the various European initiatives.

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ABOUT THE NORWEGIAN DIRECTORATE OF eHEALTH



The Norwegian Directorate of eHealth is a sub-ordinate institution of the Norwegian Ministry of Health and Care Services. The Directorate is responsible for steering and coordination of eHealth through close cooperation with regional health authorities, local authorities, technical organisations, and other interested parties. Main responsibilities include developing and implementing the national policy on eHealth, establishing the requisite standards, and administrating the use of eHealth methodology nation-wide.

As the national competent authority of eHealth in Norway, our responsibilities include: Implementation the country's policy on eHealth ; Ensuring efficient national administration of eHealth ; Serving as the secretariat of national fora on eHealth ; Providing technical advice and interpretation of the relevant laws ; Problem description and analysis in eHealth ; Formulating and following-up the national eHealth strategy ; Determining the codes, terminology and ICT standards, and their administration ; Ensuring intersectorial and international cooperation in ICT in health and care services.

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ABOUT NATIONAL DIRECTORATE GENERAL FOR HOSPITALS



ORSZÁGOS KÓRHÁZI FŐIGAZGATÓSÁG - OKFŐ (official English version: National Directorate General for Hospitals). A public body responsible for coordination, development and quality assurance of healthcare provision and services, also functions as the maintainer of almost 100 hospitals all over Hungary. OKFŐ as a public authority monitors the operation of the healthcare system, facilitates strategic government decisions concerning the revision of the healthcare provision, and contributes to the development of a new, integrated and transparent national health care system. OKFŐ manages a great number of EU-funded international and domestic projects for health development, thus having an extended international partner network. In Interreg funded projects OKFŐ represents the health sector from Hungary and provides assistance to articulate user needs in service and product development and testing, as well as implementing Policy Pilots to design e-Services, focusing on home care, day/outpatient surgery, and other different care types by health care providers. It is the designated National Contact Point for eHealth in Hungary and the central data provider managing the National eHealth Digital Service Infrastructure (EESZT). Today, more than 26 thousand health care professionals and 13 thousand pharmacy staff use the EESZT data infrastructure in more than 22,000 institutions, including private service providers.

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ABOUT THE CROATIAN INSTITUTE OF PUBLIC HEALTH



The Croatian Institute of Public Health is a central public health institute in the Republic of Croatia. CIPH carries out epidemiological surveillance and proposes, organizes and undertakes preventive and

counter-epidemic measures. ICIPH collects all relevant health statistics data for the Republic of Croatia. The Institute functions as a statistical authority which maintains national public health registries, supervises data storage and coordinates the work of other health registers.

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ABOUT ARAGON HEALTH SCIENCES INSTITUTE



IACS is a Regional Health Research Institute that supports stable research groups in the areas of clinical and translational medical research, biomedicine, public health, health systems and policy research. In addition, IACS hosts and manages technological core platforms supporting biomedical research in the region, linking to the national and European networks. IACS Biocomputing Unit combines two major activities and services: medical informatics and bioinformatics.

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ABOUT EUROPEAN CENTRE FOR DISEASE PREVENTION AND CONTROL



ECDC is an EU agency aimed at strengthening Europe's defences against infectious diseases. The core functions cover a wide spectrum of activities: surveillance, epidemic intelligence, response, scientific advice, microbiology, preparedness, public health training, international relations, health communication, and the scientific journal Eurosurveillance. ECDC disease programmes cover: Antimicrobial resistance and healthcare-associated infections; Emerging and vector-borne diseases, Food- and waterborne diseases and zoonoses; HIV, sexually transmitted infections and viral hepatitis; Influenza and other respiratory viruses; Tuberculosis; Vaccine-preventable diseases.

ECDC contributes to EU and global health security, giving particular attention to the areas like antimicrobial resistance, the effectiveness of vaccination programmes, preparedness for cross-border health threats, monitoring of COVID-19 and supporting the response by Member States to the pandemic.

The Centre is tasked with development of digital platforms and applications, supporting epidemiological surveillance at Union level and enabling the use of new digital technologies in the compilation and analysis of data. ECDC already started to work on projects and initiatives aiming to build integrated epidemiological surveillance systems (i.e. for severe acute respiratory infections, and information systems such as EpiPulse, IDSS). The next generation of digital platforms and applications for surveillance will be developed with the intention to ensure that the data from European Health Data Space will be used for infectious disease surveillance.

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ABOUT EUROPEAN MEDICINES AGENCY

The mission of the European Medicines Agency (EMA) is to foster scientific excellence in the evaluation and supervision of medicines, for the benefit of public and animal health in the EU. EMA's scientific committees provide independent recommendations on medicines for human and veterinary use, based on a comprehensive scientific evaluation of data. EMA is involved in and supports a number of research projects with academia, learned societies and research groups. EMA also plays a key role in forming and managing networks, including the European Network of Centres for Pharmacoepidemiology and Pharmacovigilance (ENCePP).

EMA is establishing the Data Analysis and Real World Interrogation Network (DARWIN EU ®), a network of European real-world healthcare databases and related analytical services. DARWIN EU ® contributes to the delivery of the European Medicines Agencies Network Strategy to 2025. DARWIN EU ® will act as a pathfinder for the European Health Data Space (EHDS) and will ultimately connect to the EHDS services, enabling the use of the EHDS in the context of medicines regulation in Europe.

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ABOUT BBMRI

The Biobanking and BioMolecular resources Research Infrastructure - European Research Infrastructure Consortium (BBMRI-ERIC) facilitates access to samples and data as well as biomolecular resources to advance and implement precision medicine. BBMRI-ERIC is constituted by 23 Member States and one International Organization (AT, BE, BG, CH, CY, CZ, DE, EE, ES, FI, GR, HU, IT, MT, LT, LV, NL NO, PL, SI, SE, TR, UK and IARC/WHO), making it one of the largest research infrastructures for health research in Europe. Together with its National Nodes, about 700 affiliated biobanks, stakeholders and partners as well as its Expert Centres, BBMRI-ERIC provides services and advancements in the areas of Ethical, Legal and Societal Issues (ELSI), Quality Management (QM), Information Technology (IT), Biobanking Development (BBD), Public Affairs (PA), and Outreach, Education & Communications (OEC).

In the EHDS2 Pilot, BBMRI-ERIC will particularly contribute with its expertise on regulatory and legal compliance including ethics data access procedures, security requirements and GDPR compliance to build a unique data access application for the EHDS and allow cross-border use of data. BBMRI-ERIC will further provide expertise on data interoperability, quality and protection including solutions for query and semantic interoperability with the goal of enabling precision medicine and provide guidance to personalized health care.

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ABOUT eBRAINS**EBRAINS**

EBRAINS is an AISBL registered in Belgium. EBRAINS is a new digital research infrastructure, created by the EU-funded Human Brain Project, to foster brain-related research and to help translate the latest scientific discoveries into innovation in medicine and industry, for the benefit of patients and society.

It draws on cutting-edge neuroscience and offers an extensive range of brain data sets, a multilevel brain atlas, modelling and simulation tools, easy access to high-performance computing resources and to robotics and neuromorphic platforms.

All academic researchers have open access to EBRAINS' state-of-the art services. Industry researchers are also very welcome to use the platform under specific agreements.

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ABOUT Elixir

ELIXIR is an intergovernmental treaty based consortium, which builds on existing life sciences data resources and services within Europe to orchestrate the collection, archiving, access, and processing of large amounts of data. ELIXIR is constructing and operating a sustainable federated ecosystem of interoperable services to enable access to population scale genomic and biomolecular data across borders. ELIXIR coordinates the B1MG project that supports the 1+MG Initiative delivering the blueprint for the Genomic Data infrastructure that will have to interoperate with the EHDS.

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ABOUT ORPHANET-INSERM US-14

Orphanet is an international network, coordinated by Inserm US-14, which provides manually-curated, expert-reviewed information and data on rare diseases (RD). This includes the Orphanet knowledge base, the Orphadata.org portal, and the Orphanet Ontology for Rare Diseases (ORDO). Orphanet produces the standard nomenclature for rare diseases (ORPHAcodes) used in health information systems and RD registries. It additionally provides expertise on metadata models and access to an international network of experts in RDs in 42 countries.

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ABOUT THE EUROPEAN PUBLIC HEALTH ASSOCIATION



The European Public Health Association, or EUPHA in short, is an umbrella organisation for public health associations in Europe. Our network of national associations of public health represents around 20'000 public health professionals. The thematic network 'EUPHA Public health monitoring and reporting section' with almost 3000 members, represents an important stakeholder group for the EHDS Pilot project that brings together researchers, policymakers and practitioners working in the same field for knowledge sharing and capacity building.

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