



Alliance for IoT  
and Edge Computing  
Innovation

Webinar • 19 June 2024

# Presentation of AIOTI White Paper on Health Data Spaces

# Opening and Welcome

Pietro Dionisio, AIOTI WG Health Chair (Medea)

# Agenda

# Agenda

- 14.00**      **Opening and Welcome (10 min)**  
Pietro Dionisio, AIOTI WG Health Chair, Medea
  
- 14.10**      **Presentation of the paper (15 min)**  
Pietro Dionisio, AIOTI WG Health Chair, Medea
  
- 14.25**      **Presentation of the paper uses cases & recommendations (20 min)**  
Pietro Dionisio, AIOTI WG Health Chair, Medea  
Joro Penchev, Astea Solutions
  
- 14.45**      **Questions from the audience (15 min)**  
Moderator: Pietro Dionisio, AIOTI WG Health Chair, Medea
  
- 15.00**      **Wrap up and end of Webinar**  
Pietro Dionisio, AIOTI WG Health Chair, Medea

# About AIOTI WG Health

Pietro Dionisio, AIOTI WG Health Chair (Medea)

# AIOTI Working Group Health

## Leadership:

### Chair

Pietro Dionisio, Medea



### Co-Chair

Roumen Nikolov, Virtech



**Vision:** To build a dynamic pole for knowledge sharing in the domain while acting as a bridge between initiatives that bring added value to healthy living

**Scope:** To improve the members' visibility, to support members in assessing and forming consortia for HE and DE calls and in defining, implementing and assessing expected value in terms of networking, know-how sharing and creating market opportunities

## Highlights:

**54** member organisations

**78** participants

## Main achievements:

1. AI for better health white paper
2. White Paper on Health Data Spaces
3. HE calls matchmaking and proposal building
4. Collaboration on paper IoT Improving Healthy Urban Living
5. Participating in EU funded projects
6. Participating in AIOTI organised events

# Presentation of the Paper

Pietro Dionisio, AIOTI WG Health Chair (Medea)

# White paper: IoT/Edge Computing and HealthData and Data Spaces (EHDS)

The White Paper can be found on the AIOTI website:

<https://aioti.eu/wp-content/uploads/2024/03/AIOTI-White-Paper-IoT-Edge-Computing-and-Health-Data-and-Data-Space-Final.pdf>



**White Paper  
IoT/Edge Computing and Health  
Data and Data Spaces**

**Release 1.0**

**AIOTI WG Health**

**March 2024**



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# White paper: IoT/Edge Computing and HealthData and Data Spaces (EHDS)

## EU momentum for an EU Health Union; why?

After Covid-19 pandemic...

- **Better preparation** for future health crises
- Improve the benefits of **information sharing**
- Improve **best practices of cooperation** for developing digital tools



**The EHDS** as one of the concrete answers from the EC as part of the **Health Union Package** (Nov. 2020)

# White paper: IoT/Edge Computing and Health Data and Data Spaces (EHDS)

## **EHDS's objectives:**

- (1) improve and support healthcare delivery within Europe by allowing public health data to be accessible throughout Europe
- (2) promote better access and exchange of different types of health data for research and policy purposes.

## **Specific objectives:**

- Empower individuals through better digital access to their personal health data; support free movement by ensuring that health data follow people;
- Unleash the data economy by fostering a genuine single market for digital health services and products; and
- Set up strict rules for the use of individual's non-identifiable health data for research, innovation, policy-making and regulatory activities.

# White paper: IoT/Edge Computing and Health Data and Data Spaces (EHDS)

## ▪ White paper's goals:

- 1) shedding the light on some key elements of the EHDS Regulation,
- 2) its relationship and comparison with international big players such as the USA and China as well as on the vision,
- 3) expectations and use cases and best practices provided by the AIOTI WG Health's members

# White paper: IoT/Edge Computing and Health Data and Data Spaces (EHDS)

## ■ A comparison between EU, US and China

“The debate on the role of data usage and data transfers is unquestionably urgent, contemporary and relevant as “rule-making on data flows is hard to separate from geopolitical rivalry” (WEF, 2023)”

## ■ A comparative analysis to....

- I. clarify the regulatory fragmentation that has emerged in relation to cross-border data flows,
- II. assess what is at stake for each of the three polities, and
- III. identify convergences as well as divergences

# Use cases Overview

Pietro Dionisio, AIOTI WG Health Chair (Medea)

Joro Penchev, Astea Solutions

# Examples and Use cases in the paper

1. Azienda ospedaliero-universitaria Senese
2. HealthData@EU pilot - European Health Data Space (EHDS2) EU project
3. BEIA
4. CCG
5. IDERHA project
6. Astea

# Examples and Use cases in the paper

## Azienda ospedaliero-universitaria Senese

- Stating the concept of a Europe without borders, where all citizens can freely move for work or tourism, it is crucial that clinical data can also follow patients. As a consequence, clinicians will have access to patient's relevant data in order to provide clinical decisions that are consistent with the patient's medical history. The availability of shared data would allow the doctor, who knows the patient, and the specialist, to get to shared decisions (second-opinion) wherever they are. As an example, the following use case is briefly introduced.
- A patient from Germany who is visiting Italy requires medical attention. With the cross-border health data exchange system, the Italian hospital can access the patient's medical history and treatment records from their home hospital in Germany. It will allow Italian healthcare physicians to provide informed and coordinated care, knowing about the patient's allergies, previous treatments, and medical conditions.
- Using the same approach in the field of applied research would allow us to use the health data not only for clinical purposes, but also in sharing datasets for research purposes. A realistic use case is presented in the following paragraph.
- Researchers, from different hospitals in Europe, collaborate on a study to understand the effectiveness of a new cancer treatment. They access anonymized and aggregated patient data from multiple hospitals, pooling their resources and expertise. This collaborative approach accelerates research progress and leads to potential breakthroughs in cancer treatment.

# Examples and Use cases in the paper

## HealthData@EU pilot - European Health Data Space (EHDS2) EU project

- French [Health Data Hub](#) coordinates and sets up a pilot project called [EHDS2](#) (2022 -> 2024) with sixteen partners from ten European countries for the European Health Data Space to feed the legislative discussions about the draft regulation proposed by the European Commission on May 3rd on the EHDS. The project addresses the challenges of accessing health data throughout the EU. Five use cases have been selected: 1) infectious disease surveillance, Antimicrobial Resistance (AMR), 2) Thrombosis in COVID-19 patients, 3) COVID-19 testing, vaccination and hospitalization, 4) cardiometabolic diseases, and 5) colorectal cancer. Health Data Hub also highlights the need to compare health standards, nomenclatures, data formats, etc. such as SNOMED, HL7 FHIR, OMOP, DICOM. The ambition is to implement a first end-to-end European user pathway including data discovery (European metadata catalogue) and data access requests (development of a single data access application form).



# Examples and Use cases in the paper

## BEIA

- SHIFT-HUB proposes a technical platform pilot including a Health Data Hub, a Smart Health Apps Repository and an on-line Marketplace to support the experimental development based on a secure and interoperable access to data and showcase a portfolio of solutions developed by the community members. SHIFT-HUB aims to establish a pan-European Smart Health Innovation Hub bringing together a rich network of multidisciplinary stakeholders across the dimensions of the quadruple helix, with the mission to facilitate the development, ensure the promotion and foster the uptake of Smart Health technologies and services. SHIFT-HUB will develop and test with the community a complete service offer, integrating networking and matchmaking, identification of partners and support for procurement, guidance for access to funding, research infrastructures and scientific expertise.

# Examples and Use cases in the paper

## CCG

- Health data may come from many sources. Often sources are the annotations resulting from medical appointments, periodic records created by health professionals that track long-term patients, different health exams prescribed by doctors, and, more recently, data automatically generated by new technological devices like smartwatches.
- A significant effort is being made to create standards and implement interoperable systems, seeking an ideal scenario with a unique record for each person, regardless of the data source. This praiseworthy effort would create a data lake. It would benefit patients, who would have permanent access to their unified data, and practitioners, who would have more information that eventually helps make medical decisions.
- Falls are the worldwide leading cause of injury-related deaths and non-fatal injuries in people 65 years and older. Falls represent the second leading cause of unintentional injury death. When falls are not fatal, they leave serious injuries and levels of morbidity with a major risk of long-care needs.
- Alertfalls research project aimed to identify the prevalence and risk factors of falling in older people living alone. The research team made an analytic cohort study, including 186 participants aged 65+ living alone or in community-dwelling.
- The questionnaires included sociodemographic information, social and health resources, physical conditions, functionality, technical devices used, difficulties related to daily life, medication, risk behaviours and physical environmental conditions related to the house. It included data that can't be found in any regular health database.
- Although some constraints may arise from the small sample of participants, the project data allowed us to achieve some valid results:
  - It enabled the identification of various fall risk profiles. This awareness should be considered by those who get in touch with older persons living alone in a community context.
  - A predictive model was developed, revealing a satisfactory discriminatory performance of the model to identify the risk of falling among older people living alone in a community context.
  - Some falling factors currently are subject to no records on health databases. Expanding information about older people would enable calculating a falling risk and, consequently, working to mitigate it.
- Based on the Alertfall findings, it is possible to facilitate more proactive interventions across multiple stakeholders in the social and health sectors.

# Examples and Use cases in the paper

## IDERHA project

- The aim of [IDERHA project](#) is to facilitate access and reuse of heterogenous health data and it will be demonstrated in use cases selected throughout the lung-cancer patient journey. The IDERHA network infrastructure will connect (WP1) existing data resources at data providers' sites and allow users to access the data, share them and perform their integrative analysis (WP2) through the application of common data standards (WP4) and in conformance with GDPR and regulatory requirements (WP5). Existing (retrospective) datasets will be used by the project partners for the development of analysis algorithms (WP2), as well as to evaluate and demonstrate the value and utility of the IDERHA platform to patients, researchers, regulators, and other stakeholders (WP3). In addition, remote patient monitoring and data access consent management will be enabled with dedicated mobile applications (WP1).
- The expected types of research data that will be addressed within IDERHA include several categories of low and high dimensional data: clinical and molecular data (such as genomics, transcriptomics, proteomics, metabolomics), image data and patient generated data types, including wearables measurements, PROMs and PREMs, and questionnaires. In addition to interconnecting data providers, IDERHA aims to also offer solutions for individual data providers to enable them to share their own resources, so-called citizen-controlled data, with other users for specific purposes. With the citizen-controlled data sharing application, citizen users (whether patients or not) can decide what personal health data (PHD) pertaining to themselves is shared with other parties, and for what purposes.

# Examples and Use cases in the paper

## Astea

- Several ongoing projects with strategic partners focused on similar workflows: train state-of-the-art prediction and diagnostic models on high-volume anonymized medical data; assist physician needs in areas and domains with high ratio of patients to physicians; connect to existing patient data systems in hospitals and elsewhere, including cross-border. The projects further involve reusable medical workflows components, addressing the needs of physicians for AI-assisted tele-based quick diagnostics and patient journey discovery.
- Domains include ophtalmology, neurological conditions, e.g. stroke detection, pregnancy related conditions, with methods such as imaging data, bloodwork, behavioral data and others. Data is supplied by medical and research partners.
- High volumes of data that require all dataspace prerequisites, as provided by the reference model: automated conversion workflows, anonymisation, data rooming, among others. Medical facilities participate on a single time basis, i.e. it is difficult to provide enough trust in the flow to incentivize more providers of medical imaging data.
- Interoperability with national and European standards and government systems and this is where a common European dataspace for medical data is a crucial asset for the success and scaling up of the innovative component of the projects.

# Questions from the Audience

Moderated by:  
Pietro Dionisio, AIOTI WG Health Chair (Medea)

# Wrap up and end of the Workshop

Pietro Dionisio, AIOTI WG Health Chair (Medea)



# Thank you for listening

Any questions?

You can find us at [@AIOTI\\_EU](https://twitter.com/AIOTI_EU) or email [sg@aioti.eu](mailto:sg@aioti.eu)