# INTERNATIONAL DATA SPACES ASSOCIATION









# We are happy to collaborate!

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# VELES Regional Smart Health Data Space

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# **Project Overview**

#### DOI

10.3030/101087483

#### Start date

1 June 2023

#### End date

31 May 2027

#### Funded under

Widening participation and spreading excellence

#### Total cost

€ 4 750 000,00

**EU contribution** € 4 750 000,00



#### Coordinated by

SOFIA UNIVERSITY ST KLIMENT OHRIDSKI

HORIZON-WIDERA-2022-ACCESS-04 - 101087483

• Start Date: 1st June 2023

Duration: 4 years – 48 Months

• Funding: 4 750 000.00

• Consortium: 15 Partners from 7 from EU countries

IoTBig DataSmart HealthData SpacesPersonalized medicineHealth care ServicesExcellence HubInnovation Eco System

VELES Excellence Hub - Strengthening the South-East Europe Smart Health Regional

Excellence and Boosting the Innovation Potential | VELES | Project | Fact sheet | HORIZON |

CORDIS | European Commission (europa.eu)

# **VELES OVERVIEW**

**HORIZON-WIDERA-2022-ACCESS-04** 

**Call: Excellence Hubs** 

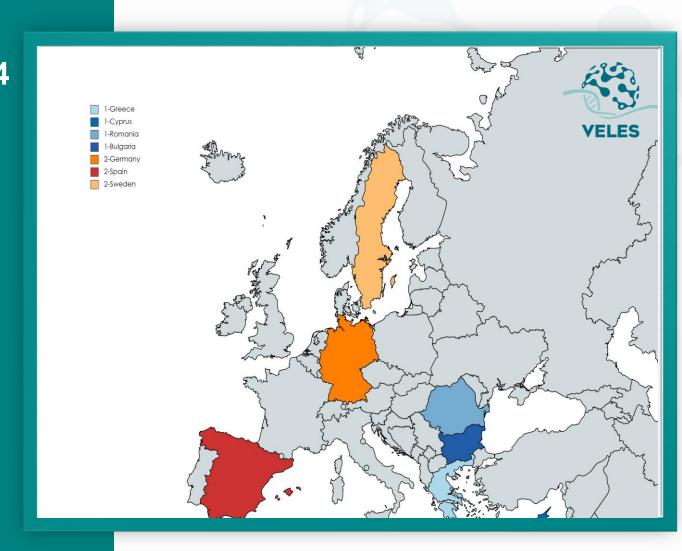
Start Date: 1st June 2023

**Duration: 4 years** 

**Consortium: 15 Partners** 

from 7 from EU countries

**Coordinator: GATE** 



# **VELES CONSORTIUM**

15 partners from 7 Member States forming the Quadruple-Helix







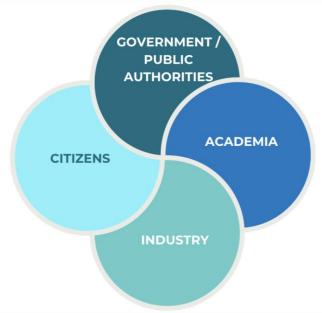






**Academia** 































# **Pilots**





The Regional Smart Health Data Space is demonstrated through 4 interrelated pilots



**Bulgaria** (BIOBG/ GATE Inst.)
Alzheimer



**Cyprus (CYENS)**Dementia



**Greece (HDHC)**Cancer treatment



Romania (IMAGO-MOL)
Cerebral tumors (in the North-East Region of Romania)

# Pilots' objectives



- To specify the pilot projects architecture and technologies following the Data Space framework.
- To define legal, ethical, security and business requirements of the pilot projects related to data sharing.
- To plan the development and implementation of demonstrator R&I projects.
- To assess the feasibility of multi-ecosystem demonstrations of the pilots.
- To provide interoperability for all stakeholders involved in the ecosystem.

# Pilots' goals



To provide interoperability for all stakeholders involved in the ecosystem



Demonstration planning – combination of various data:

- Smart objectives
- Market placed data from various stakeholders
- Cloud platforms
- Individuals
- Open data sources public authorities & policy makers

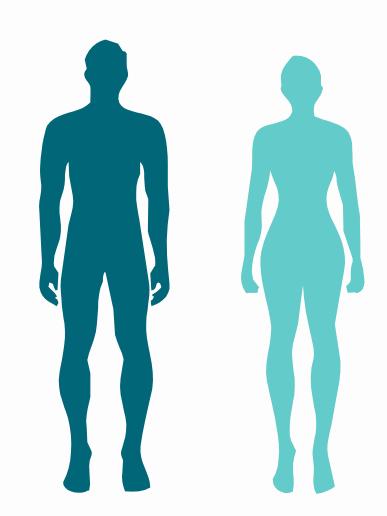


# Who are stakeholders?

**Patients** 

**Public hospitals** 

**Private clinics** 



Policymakers at national level

**Private sector** 

Professional/Branch organisations and associations

**Academia** 

**Researchers / Scientific community** 

Media (including local press)

# **CHALLENGES**

# Bulgaria, Cyprus, Greece and Romania are lagging behind in healthcare digitalization and innovation



Current regulations provide for setting up centralized healthcare databases, but offer **no specific guidance on interoperability** 



Growing innovation potential in the healthcare domain, but **not adequate policies and instruments for supporting it** 



Many innovative start ups and companies **needing guidance** in their path to data driven healthcare innovation.



Available funding mechanisms do not encompass the whole field of Digital Health and Innovation

# **OPPORTUNITIES**



**Smart Health - defined as one of the Strategic Value Chains** by EC- to enable the "future ready EU industry" and having significant importance for growth, jobs and competitiveness;



OECD Recommendation on Health Data Governance -encourages greater availability of timely health data within countries and across borders;



**EC sets the creation of a European Health Data Space as one of its main priorities till 2025**, to promote better exchange and access to different types of health data;



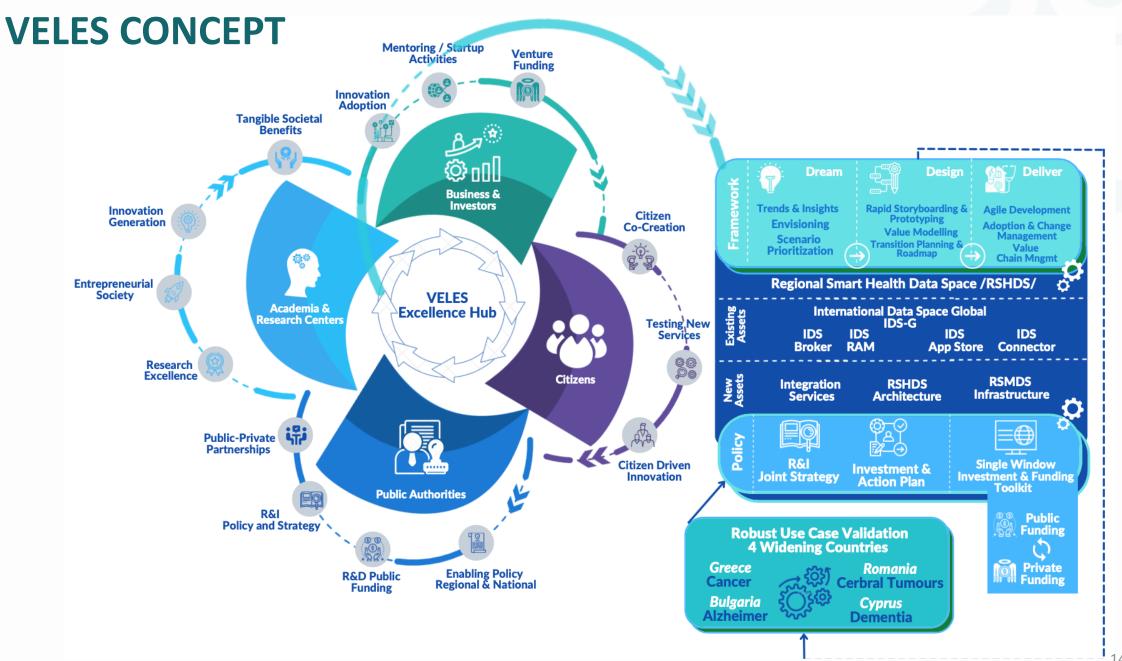
On a regional level, the new RIS3 strategies emphasize the need for advancement and digitalization of the healthcare sector and **improvement of the essential services provided by public and private stakeholders**.

## **VELES HUB VISION**



VELES accelerates the smart health innovation excellence in Bulgaria, Greece, Romania and Cyprus.

VELES creates a sustainable placebased innovation ecosystem, enabled by Regional Smart Health Data Space, including a novel transformational framework, R&I and investment strategy and action plan for development and adoption of innovative and secure digital solutions to underpin the delivery of sustainable healthcare services.



## PATHWAYS TOWARDS HEALTH DATA SPACES

<u>Technical Infrastructure</u>: Develop robust and interoperable technical infrastructure capable of securely storing, managing, and exchanging health data.

<u>Data Readiness:</u> Ensure that health data is **high-quality, comprehensive** and accessible for analysis and innovation.

<u>Governance</u>: Establish clear governance structures and policies to guide the use and sharing of health data.

<u>Human Resources</u>: Build a **skilled workforce** capable of leveraging health data for innovation and research.

<u>Skills and Training</u>: Enhance the <u>skills of healthcare professionals and researchers</u> to effectively utilise health data.

<u>Legal and Regulatory</u>: Navigate complex legal and regulatory landscapes to **ensure compliance and foster trust** in the health data ecosystem.



# **BUT ULTIMATELY...**



Successful national, regional and EU Health Data Spaces are possible only through active stakeholders engagement and intensive collaboration

# **OUTCOMES**



Regional Smart Health Data Space Ecosystem (Deliverable 3.1)



State of Play and Strategy for Innovation Ecosystem Transition Path (Deliverable 2.1)





# Revolutionizing Healthcare with Compliant Al Pipelines

101189771 — DataPACT — HORIZON-CL4-2024-DATA-01

# Introduction to DataPACT

Norway

Austria

Belgium
Bulgaria

Denmark Germany

Greece

Malta Netherlands

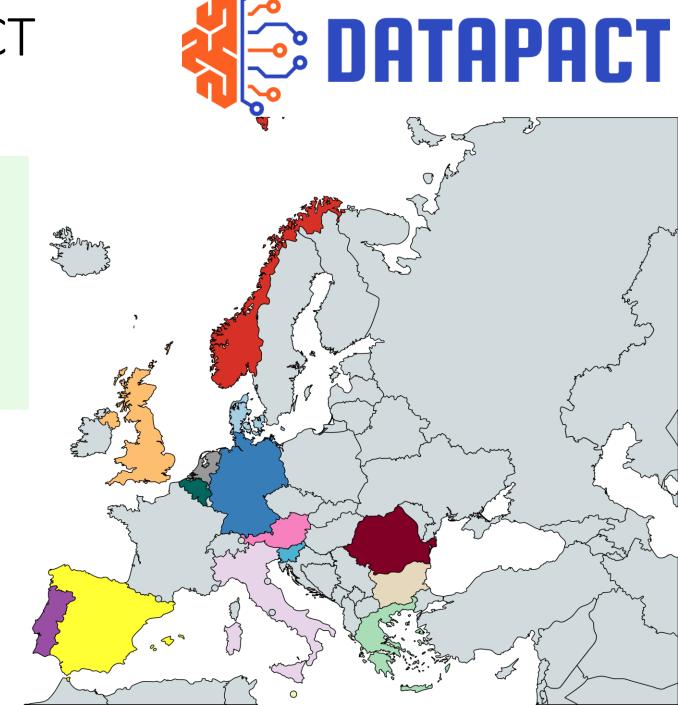
Portugal
Romania
Slovenia

Spain

United Kinadom

A diverse consortium of **19 partners** from **15 countries**, including: Research institutions, public organizations, SMEs, and large companies.

Covers a wide range of commercial and public sectors: Healthcare, Media and entertainment, Customer Relationship, Manufacturing, Smart Cities, Law Enforcement and Security, Public Data ensuring solutions are broadly applicable and impactful.



# Introduction to DataPACT



## Mission

Embedding compliance, ethics, and sustainability into data/Al pipelines.

## **Tools**

#### **DataPACT Compliance Toolbox**

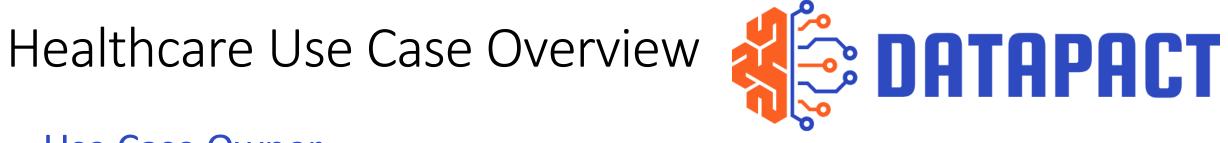
Offers innovative technical solutions for assessing and ensuring compliance with regulations, privacy, and ethical guidelines.

#### **DataPACT Compliance Framework**

A methodology supported by tools to integrate compliance into data/AI pipelines from the design phase.

# Compliance-aware Data/Al Pipeline Toolbox

Enables design, deployment, and execution of compliant, privacy-preserving, and sustainable data/Al pipelines.



### **Use Case Owner**

Healthcare - CAREPATH

## Goal

Enable secure and compliant health data processing while improving patient outcomes.

# **Objectives**

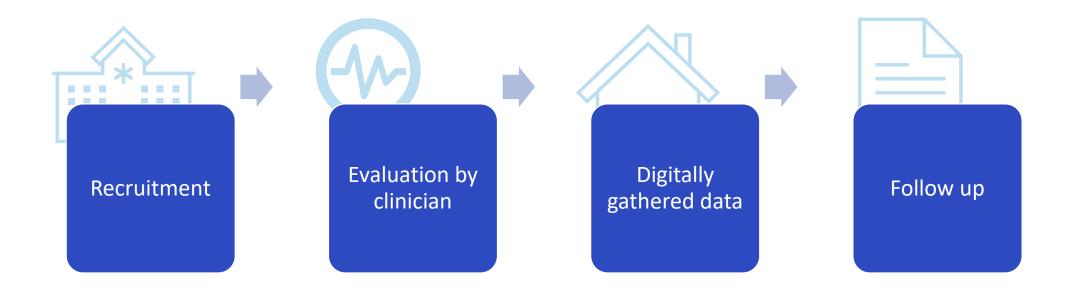
To predict high-risk negative health outcomes of patients after hospitalization and the optimal day of discharge, providing healthcare providers essential information on patients' functional status when transitioning from hospital to home care.

Compliance with health data regulations (e.g., GDPR).

Ethical use of AI to ensure fairness and mitigate bias.

Sustainable data processing practices.







## Infrastructure

Living Lab in Ippokrateion General Hospital, Thessaloniki









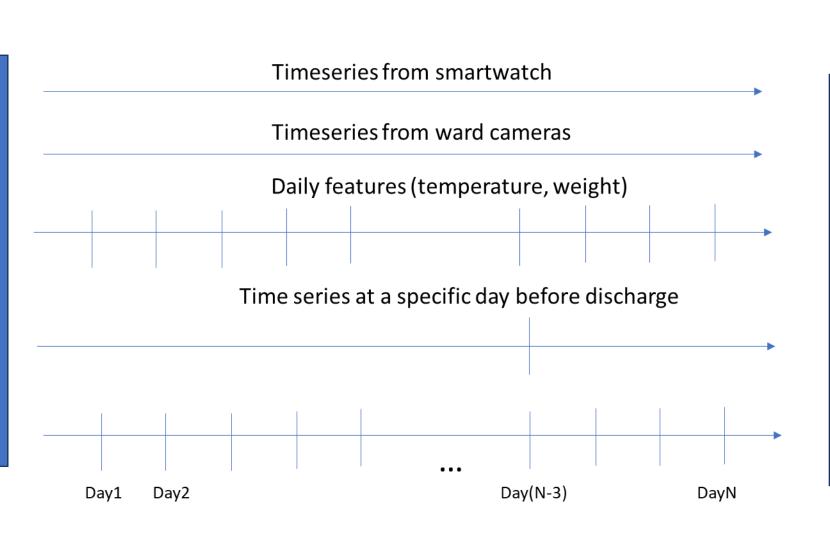
# Dataset Description



Collected in admission

PROMs / PREMs for state before Noncontinuous
data/ Single
value
features

Data from EHR Demographi cs



Collected in discharge

Noncontinuous
data/Single
value
features

Status in discharge

# Healthcare Challenges Addressed



- 1 Regulatory Compliance:
  - GDPR: personal data of patients and sensitive data.
  - Data Governance Act: public sector protected data.
  - Al Act: high-risk as the Al-decision will influence the care plan.
  - Medical device regulation: software that provides information for diagnostic or therapeutic purposes.
  - Data Act: IoT devices portability across providers.
  - **Data security** in sensitive medical contexts.
- 2 Ethics in Al:
  - Reducing biases in diagnosis/treatment algorithms.
  - Transparent decision-making processes.
- **Sustainability:** 
  - Optimizing resource-intensive health data processing systems.

# Solutions and Benefits



#### **DataPACT Healthcare Solutions:**

Compliance-aware Al pipeline tools: **PipelinR, AssessR, TrustR, PolicyR**.

Real-time data auditing frameworks.

#### **Benefits:**

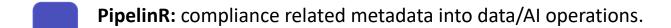
- Faster compliance with evolving regulations.
- Enhanced trust in Al-driven healthcare solutions.

Environmentally sustainable operations.

# Solutions and Benefits



#### **DataPACT pipeline tools:**



**TrustR**: explainability of data/AI operations.

**AssessR**: ethical and responsibility assessment of data, social impact assessment of data/AI.

PolicyR: Consent management tool.

# Stakeholder Impact



#### **Hospitals & Clinics:**

- Improved data security and compliance.
- Cost-effective implementation of Al solutions.
- 25%-time reduction in identifying legal compliance issues and management of consent, compared to the current practices
- 3 major clinics or hospitals adopting CAREPATH.

#### **Patients:**

- Fair and unbiased access to care.
- Greater data privacy and transparency.
- 5 additional risk factors were identified (and mitigated through DataPACT) for transitional care decision-making support compared to the currently used ones.

#### **Researchers:**

- Accelerated development of ethical Al models.
- 85% agreement of our algorithm with the actual discharge day (as decided by the healthcare professional).

# **Future Directions**



1

2

Extending beyond compliance: Driving innovation in ethical AI applications in healthcare.

Collaboration opportunities within the DataPACT consortium.

# Closing and Acknowledgements



Key Message: DataPACT transforms healthcare by embedding compliance, ethics, and sustainability.

Acknowledgements: DataPACT consortium members and the European Commission.

## How dataPACT HealthCare Use Case relates to the VELES?

- 1. The DataPACT project is pioneering a transformative framework that integrates compliance, ethics, and environmental sustainability into AI-powered health data pipelines. By embedding these principles at the core of data and AI operations, DataPACT ensures that health data management aligns with legal, ethical standards. This approach not only fosters trust and transparency but also promotes responsible innovation in healthcare.
- 2. A practical application of DataPACT's framework is exemplified in the CAREPATH project, which focuses on doping AI-driven solutions for **personalized healthcare**. By adhering to DataPACT's compliance-aware methodologies, CAREPATH ensures that **patient data is handled ethically and sustainably throughout the AI pipeline, from data collection to analysis and application**.
- 3. This approach is particularly relevant to initiatives like the VELES Excellence Hub, which aims to establish the first Regional Smart Health Data Space across Bulgaria, Greece, Romania, and Cyprus. VELES focuses on enhancing health data sharing strategies to improve clinical practices, safeguard patient privacy, and empower citizens with access to innovative, secure, and data-driven digital health services.
- 4. By incorporating DataPACT's framework, VELES can ensure that its health data space operates within a governance structure that prioritizes compliance, ethical considerations, and sustainability. This alignment is crucial for navigating the complex regulatory landscapes of the involved countries and for building a robust infrastructure that supports data readiness and interoperability.

# What is a role of IDSA in DataPACT and VELES projects?

The International Data Spaces Association (IDSA) plays a pivotal role in both the DataPACT and VELES projects by contributing its expertise in secure and sovereign data sharing.

#### In the DataPACT Project:

- As a consortium partner, IDSA guides the development of federated data spaces that prioritize data sovereignty and ethical
  considerations.
- Their involvement ensures that the data sharing frameworks within DataPACT adhere to high standards of security and trust, facilitating compliance-aware data and AI pipelines.

#### In the VELES Project:

- IDSA contributes to the development of sustainable Smart Health innovation ecosystems in Southeast Europe. By accelerating knowledge exchange and promoting best practices for healthcare data sharing, IDSA supports the establishment of a Regional Smart Health Data Space.
- This initiative aims to enhance clinical practices and empower citizens with secure, data-driven digital health services.

In both projects, IDSA's contributions are instrumental in ensuring that data sharing is conducted in a secure, ethical, and sovereign manner, aligning with European standards and promoting innovation across sectors.