

"My Data Our Health - Advancing the European Health Data Space in Greece"  
1<sup>st</sup> Workshop and Launch: Shaping the Future of Innovation in Cancer Care in Greece  
July 2025, Athens

## PROCEEDINGS

*Please note: This document is a summary of the workshop and not a verbatim transcript. While presentations, discussions and questions are captured in summary form, further details can be found in the accompanying slides of the moderators.*

**Venue:** ELLOK Forum, Wyndham Grand Hotel, Athens. **Event date:** Wednesday, 2 July 2025

Participants: Invited participants included representatives from the following fields

1. Academia / Research – Doctors, nurses, health care professionals, academia, research institutes that provide scientific evidence, knowledge and technological expertise.
2. Pharmaceutical industry / Business – Companies that develop products, technologies, services and bring solutions to the market.
3. Government / Public Sector – Ministries, regulators and public authorities that provide policy guidance, funding and regulatory frameworks.
4. Civil Society / Community – Patient groups, advocacy organisations and citizens who represent societal needs and values.
5. Media – Journalists were invited to ensure societal engagement and awareness.

Why the broad spectrum of stakeholder is important for this initiative

- It moves beyond traditional top-down approaches by ensuring all stakeholders contribute equally to the discussion and understand the importance of the European Health Data Space.
- It encourages co-creation of solutions that are technically feasible, socially acceptable and policy-aligned.
- It ensures that patients' voices, research evidence, industry innovation, government policy, and public communication all shape the system.

### 1. Opening & Welcome

#### George Kapetanakis

- Welcomed participants, including Dr. Aris Angelis (Secretary General, Ministry of Health), Dr. Stelios Kypouropoulos, former MEP and Hugo Soares, Science Manager at AICIB (The Portuguese Agency for Clinical Research and Biomedical Innovation & Co-coordinator, ECHoS Project).
- Outlined the Workshop aims to provide information and understanding of all the EHDS will encompass and what work is necessary, update stakeholders initially with reference to cancer specifically but with a wider perspective on upcoming data initiatives.

- Emphasised collaborative approach to implement the European Health Data Space (EHDS) regulation in Greece.
- Highlighted the importance of multi-stakeholder dialogue (patients, pharmaceutical industry, academia, research, government, public sector, civil society and media).
- Noted potential outcome: a White Paper to guide national EHDS implementation.

### **Ioannis Kotsiopoulos (Chairman, PIF)**

- Also warmly welcomed participants, including Dr. Aris Angelis (Secretary General, Ministry of Health), Dr. Stelios Kypmpouropoulos, former MEP and Hugo Soares, Science Manager at AICIB (The Portuguese Agency for Clinical Research and Biomedical Innovation & Co-coordinator, ECHoS Project).
- Underlined the importance of discussing health data at a training workshop level, with as much interaction as possible with attendees.
- Emphasised the role of this workshop in developing common positions across patient organisations and industry.
- Encouraged broad participation to constructively shape EHDS legislation in Greece.

### **Addresses**

#### **Aris Angelis (Secretary General, Ministry of Health)**

- Highlighted the connection between the workshop and Greece's national digital health strategy.
- Emphasised EHDS as a framework for safe cross-border health data exchange.
- Outlined Ministry initiatives: mapping national health datasets, developing regulatory frameworks for electronic health records, building digital infrastructure for secondary data use and active participation in European EHDS committees.
- Goal: create a modern, human-centric health system leveraging EHDS to improve care, research, innovation and policy.

#### **Hugo Soares (ECHoS Coordinator)**

- Emphasised multi-stakeholder engagement as essential for meaningful cancer care improvements.
- Noted ELLOK's role in convening stakeholders domestically and ECHoS' support in providing international expertise.

### **Session One: Understanding the European Health Data Space**

Moderators: Dipak Karla, Zoi Kolitsi, Bart Vannieuwenhuysse

\* The moderators' slides are attached for complementary context.

Commentator: Charalambos Vasileiou, apology Mina Boumpaki

#### **Zoi Kolitsi (i~HD)**

- Explained EHDS is more than a regulation; it is a systemic redesign affecting data holders, users, patients, and the public.
- Workshop designed to align stakeholders, identify barriers and discuss future-proof solutions.
- Introduced slides on EU Digital Governance Act, EHDS building blocks, and the novel regulatory and operational structures (HDABs, certified environments, primary/secondary data use).

## Dipak Kalra (i~HD)

- Summarised EHDS provisions: primary use (healthcare delivery) and secondary use (research, innovation, policy).
- Emphasised patient empowerment, cross-border interoperability and member state responsibilities (education, access, digital upskilling).
- Noted the opportunity to co-create EHDS implementation from a bottom-up perspective.

## Charalambos Vasileiou (EHDS Expert | Digital Strategy and Business Development Advisor)

- Highlighted the long-term work on EHDS in Greece.
- Emphasised the win-win benefits for all stakeholders (patients, professionals, researchers, regulators, industry).

## Bart Vannieuwenhuysse (i~HD)

- Focused on practical FAQs, Belgian experience and implementation challenges.
- Discussed pre-existing arrangements, federated analytics, data anonymisation and regulatory compliance for secondary use.

## Takeaways:

- **Collaborative foundation:** Multi-stakeholder engagement (patients, policymakers, researchers, industry, civil society) is essential to co-create Greece's national EHDS framework.
- **Aligning vision with practice:** EHDS is a systemic redesign; Greece is working to strengthen data infrastructure, literacy and governance to improve care, research and innovation.

## Q&A:

Question from the audience: What is the timeline for the creation of the data access body? A brief discussion followed between the moderators and commentator outlining the status quo.

## Session Two: How could the EHDS change patient care?

Moderator: Dipak Karla

Commentators: Dimosthenis Sarigiannis, Elvina Sakellariou, Dimitris Gerogiannis

\* The moderator's slides are attached for complementary context.

## Moderator Opening: Patient Benefits from the EHDS

- Priority EHR Data Categories for Primary Use
- Example Health and Care Benefits (Primary Use)
- Patient-Driven Healthcare
- Medicines - Information for Patients
- Patient Pre-Screening for Clinical Trials
- Secondary Data Use Benefits

## Elvina Sakellariou (Duchenne Foundation)

- Emphasised proactive patient engagement and alignment with EHDS principles.
- Advocated for pilot integration of patient data into EHDS infrastructure with sustained collaboration including pharma.

## Dimosthenis Sarigiannis (National Research Foundation of Greece)

- Focused on primary use benefits: better access, improved care coordination.

- Highlighted secondary use: enabling EU-wide research, data-driven policy, AI and federated learning integration.
- Stressed patient empowerment, education and semantic interoperability.

### **Dimitris Gerogiannis (AI Catalyst)**

- Raised ethical considerations for AI and large-scale data use.
- Discussed balancing public good with data privacy.

### **Takeaways:**

- Patient empowerment and improved care: EHDS enables better access to health data, supports care coordination, patient-driven healthcare and access to clinical trials, while emphasizing patient engagement, education and ethical use of AI.
- Secondary use for research and innovation: Leveraging EHDS data for secondary purposes (e.g. research, policy, AI and federated learning etc.) can drive evidence-based decision-making and support cross-border healthcare improvements.

### **Q&A:**

- How does the empowered patient impact on the clinician and the workload and the anxieties of clinicians? (question P. Michalopoulou). Dr. Kalra agreed this was an important question and could be discussed in greater depth during upcoming workshops, i.e. how do we really give people some control over their data in an impossible-to-control environment?
- Observation: Further to the discussion of real-world applications, M. Tzima underlined the importance of patients having access to clinical trials.

### **Session Three: Industry Innovation Panel: How can we enable responsible and timely access to cancer data?**

Moderator: Bart Vannieuwenhuysse

Commentators: Ioannis Kotsiopoulos, Panos Bassios

\* The moderator's slides are attached for complementary context.

### **Moderator Opening:**

- Real-world data (RWD) potential: research, market access, patient outcomes.
- Challenges: privacy, ethics, ownership, trust, data quality, interoperability.
- EHDS expected to facilitate RWD use while safeguarding rights.

**Panel Members:** Ioannis Kotsiopoulos, Panos Bassios were invited to address the following questions

1. How would you evaluate the level of maturing of RWD in Greece?
2. What is the most important application domain for RWD in industry?
3. Given the maturing of the data ecosystem what are some of the biggest challenges to reuse data?
4. What should the EHDS deliver to reduce some of these challenges?

### **Discussion Highlights:**

- Trust-building is critical; transparency and stakeholder consultation essential.
- AI factories and national infrastructure (Ministry of Health and Ministry of Digital Governance) will support implementation.
- Need for alignment between policy makers, industry, patients and researchers.

## **Takeaways:**

- Responsible access to real-world data (RWD): EHDS can unlock the potential of RWD for research, market access, and patient outcomes, but success depends on addressing challenges.
- Collaboration and infrastructure are key: Building national infrastructure and aligning policymakers, industry, patients and researchers are essential to ensure timely, transparent, and effective use of cancer data.

## **Session Four - What Would Meaningful, Societally Valuable Use of Cancer Data Look Like in Greece?**

Moderator: Zoi Kolitsi

Commentators: George Dafoulas, Nikos Vasilakis, Elpida Fotiadou

\* The moderator's slides are attached for complementary context.

### **Moderator Opening:**

- Focus: Cancer data use is taking too long to be implemented in Greece.
- Goals: Improve common understanding, facilitate early adoption, and encourage participation.
- Three framing questions for discussion:
  - What is currently happening in your organisations that advances the EHDS data space?
  - How are these initiatives articulated and coordinated?
  - How do we engage multiple stakeholders effectively?

### **George Dafoulas (Ministry of Digital Governance - MODG):**

- Highlighted close cooperation between Ministry of Health (MOH) and MODG.
- DGA legislation passed; a special Secretary General for AI and data spaces will be appointed for high-level coordination.
- Efforts aim to align all data spaces and ensure timely implementation.

### **Nikos Vasilakis (Digital Innovation and Transformation at GRNET):**

- Observed fragmentation and silos in current initiatives but acknowledged promising projects.
- Cancer registry is a good starting point but does not fully meet patient, research, or industry needs.
- EHDS presents both opportunity and imperative for change.
- AI Factory (operational early 2026) aims to boost AI innovation, support SMEs, and leverage hyper-computing infrastructure (Daedalus).
- Challenges: Fragmentation, data quality, access and duplication of efforts between ministries and at EU commission level.
- Opportunities: Strong political mandate, public data streams and combining data from multiple registries and research centres.

**Elpida Fotiadou (Head of eHealth Horizontal Actions Directorate, IDIKA SA, e-Government Centre for Social Security Services):**

- Greece holds extensive electronic health data: prescriptions, patient records, national cancer registry and other registries.
- EHDS enables cross-border use, critical for rare diseases.
- AI integrated into electronic patient files to inform health policy; primary and secondary data use being developed.
- Cross-border initiatives underway (e.g., patient summary sharing, XTHR, etc).
- Emphasis on stakeholder consultation: patients, industry, logistics and other stakeholders need coordination for effective outcomes.
- Optimistic view: rapid development, secondary implementation post-pandemic and potential for prevention data to “feed” policy.

**Takeaways:**

- Greece has dual responsibility between MOH and MODG; alignment is crucial.
- AI Factories and EHDS present strategic opportunities but require coordination, stakeholder engagement and quality data.
- Multi-stakeholder consultation is essential for actionable policy and rapid implementation.
- Focus should be on practical, implementable steps rather than solely on legislation.

**Stelios Kypouropoulos (former Member of the European Parliament):**

Stelios Kypouropoulos, former Member of the European Parliament, highlighted the importance of multi-stakeholder consultations to align actors and stressed that concrete recommendations are needed to guide policymakers. He emphasised that fostering a common understanding among organisations will accelerate implementation and underlined that repetition is necessary to achieve change in Greece. Zoi thanked Dr. Kypouropoulos for his input, suggesting the continuation of deep-dive sessions to cross-fertilise knowledge and facilitate implementable policies

**Session five - What happens next?**

George Kapetanakis and Ioannis Kotsiopoulos emphasised that EHDS implementation in Greece requires multi-stakeholder collaboration, with workshops playing a key role in aligning patient, industry, and government perspectives. They highlighted that the primary use of EHDS data is to improve care and patient outcomes, while secondary use supports research, innovation, and public health policy.

They pointed out that trust, transparency, and education are critical for successful adoption, while a White Paper underlining insights from the workshops could guide EHDS implementation in Greece. The next steps include analysing positions and feedback from the workshop, planning deeper-dive sessions on technical, legal, and operational aspects, preparing participants for subsequent, more detailed workshops with pre-reading materials, developing a White Paper and an implementation skeleton, and sharing workshop outcomes with broader society, patient communities, and the media. They drew the launch to a close and warmly thanked the moderators, commentators and all the participants for their attendance.