

LAUREL WEBINAR #3 · EHDS & PATIENT NEEDS IN INTEGRATED LONG-TERM CARE

# "The Patient Perspective: EUPATI and Meaningful Engagement in I-LTC"

*A patient perspective on the European Health Data Space*

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# Why this matters to me — and to patients

*I don't read EHDS as legislation first. I read it as what happens at the kitchen table — when someone with a complex, lifelong condition, and the people caring for them, try to make the system work.*



**A decade with patients** Working across pharma, hospitals and patient organisations to embed the patient voice.



**The carer is in the room** Most long-term care runs on informal carers who are too often locked out of the data.



**Engineer + human lens** Scientific rigour, but the test is always: does this actually help a real person?

“

*Rights on paper change nothing until they change a Tuesday afternoon for a patient and their carer.*

— the lens for today

# What it feels like from the patient's side



## “Telling my story again”

Every new clinician, every new setting — start from scratch, repeat everything.



## Fragmented across systems

Hospital, GP, home care, social care and informal carers all hold separate pieces.



## Carers locked out

The people doing the daily caring often can't see or contribute to the record.



## Crossing a border = zero

Travel or move country and your health history effectively disappears.



## Data you can't see or move

Records exist about you — but out of your reach and hard to pass on.



## Slow, repeated, risky

Lost time, duplicated tests, avoidable errors, and a heavy coordination burden.

# New rights over your own health data



## Access

Fast, free access to your own electronic health records.



## Share

Share data with any clinician — including across borders.



## Control

Restrict access, see who viewed your data, request corrections.



## Portability

View records in a standard European format.

## FROM POLICY TO PRACTICE

**In force since 26 March 2025.** Patient-facing rights (patient summaries, ePrescriptions) roll out across Member States from **2029**; images, lab results and discharge reports from **2031**. The rights are real — the everyday experience is still being built.

# What EHDS could actually solve



## Fragmentation → continuity

One connected record that follows the patient across hospital, home and social care.



## Borders → care that travels

Your history moves with you across the EU, in a standard format clinicians can read.



## Secondary use → faster research

Easier clinical-trial matching and real-world evidence — research that reaches patients sooner.



## Standardised data → better decisions

Interoperable data strengthens HTA, value assessment and public-health policy.

**Will this have an impact on “health-economic” data?** EHDS doesn't “harmonise” it directly. What it does is make data interoperable and open it for secondary use (research, HTA, real-world evidence) — which is what powers better health-economic and policy decisions.

## THE GAP

# But rights on paper are not yet reality



**Legislation alone won't integrate care** Data stays fragmented across systems, organisations and settings unless we act.



**Tools must fit real needs** Digital care planning and data sharing only help if designed around patients and carers.



**Implementation is regional** How it lands depends on local rollout, accessibility and digital literacy.

*So the real question is: do today's policies and tools actually answer what patients and carers need — and can citizen-mediated sharing truly be guaranteed?*

# From benefits for patients to building with patients

## PATIENTS AS RECIPIENTS

- Rights handed down
- Tools built for patients
- Consulted late, if at all
- Trust assumed



## PATIENTS AS CO-CREATORS

- ✓ Rights co-designed into real tools
- ✓ Built with patients and carers
- ✓ Involved from the first decision
- ✓ Trust earned via transparency & control

*Citizen-mediated data sharing has to be built with the people it serves — that is how rights become trustworthy in practice.*

# Patient experts across the data journey



## Design

Define what data matters, and make consent and interfaces usable for real people.



## Implementation

Pressure-test regional rollout for accessibility and low digital literacy.



## Governance

Bring legitimacy to secondary-use, consent and ethics decisions.



## Education

Help peers understand — and actually exercise — their new rights.



# Introducing **EUPATI**: Empowering patient involvement through education



THE EUROPEAN PATIENTS' ACADEMY ON THERAPEUTIC INNOVATION Stichting EUPATI Foundation,

Daltonlaan 600, 3584BK Utrecht, The Netherlands VAT: NL861533197B01 - Registration: KVK 80029019 [www.eupati.eu](http://www.eupati.eu) - [info@eupati.eu](mailto:info@eupati.eu)

# Who we are



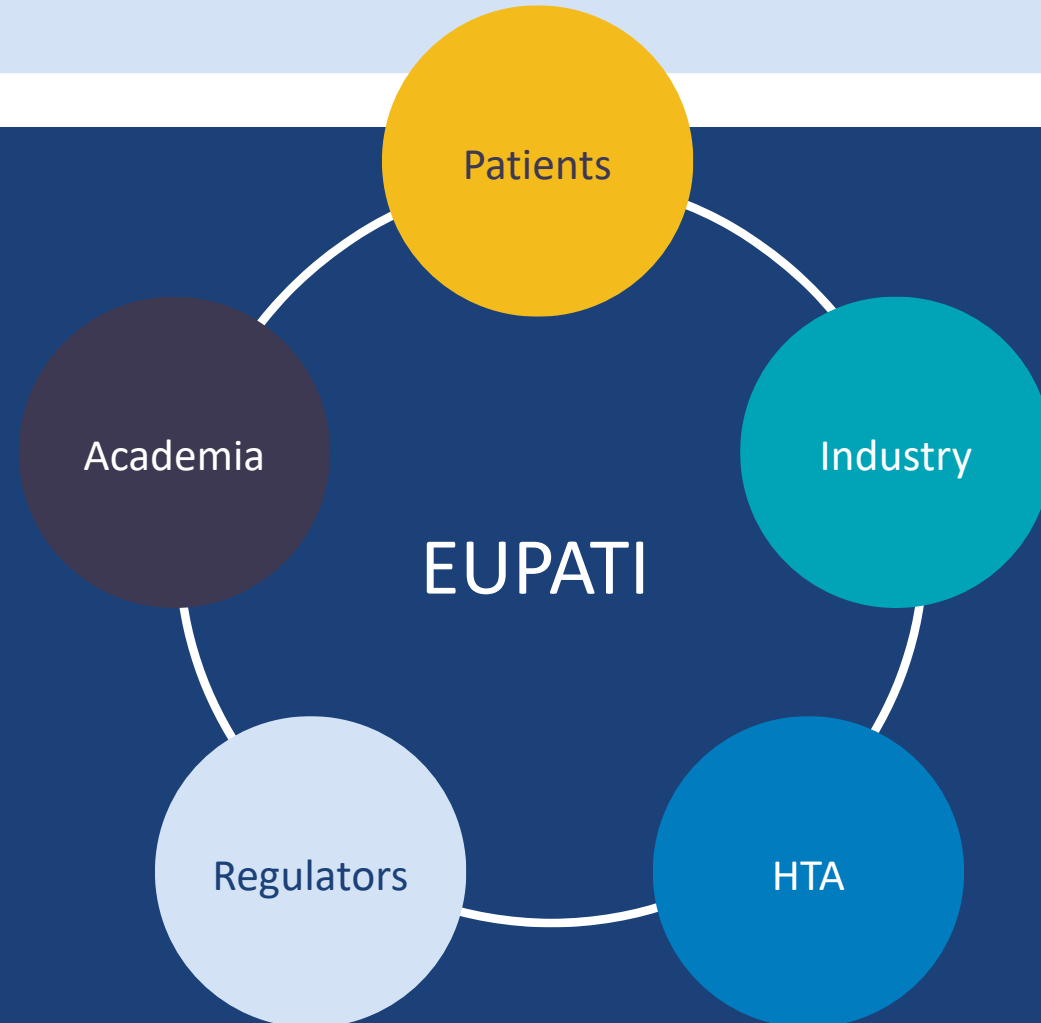
## Vision

To drive positive change in global health innovation by empowering effective patient-researcher partnerships.



## Mission

To provide education and resources that enable patients and researchers to collaborate, co-create and innovate, inspiring collective global change across the health innovation ecosystem.



## Say again?

Patients working together with researchers for positive change

## In other words...

Education that powers multistakeholder collaboration

# More specifically specifically...



## Free information

[EUPATI Toolbox - Online library on Medicines R&D](#)

Medicines R&D    Patient Involvement

Keywords:

Basics of Medicines R&D    Personalised Medicine    Regulatory Affairs    HTA

Clinical Development/Trials    Drug Discovery    Pharmacoeconomics    Safety of Medicines



8 M+  
Users



14  
Languages



150  
Articles



500+  
Glossary Terms



30+  
Case Studies



## Enhanced collaboration

[EUPATIconnect](#): Matchmaking platform bringing together EUPATI Patient Experts & Researchers



[24 EUPATI National Platforms](#): Independent multi-stakeholder structures with the aim to promote patient education & involvement at national level

Austria	Belgium	Cyprus	Czech Republic
Denmark	Finland	France	Germany
Greece	Ireland	Italy	Japan
Luxembourg	Malta	Netherlands	Norway
Poland	Portugal	Scotland	Slovakia
Spain	Sweden	Switzerland	Turkey

[EUPATI Projects](#) - Leading or involved in EU projects to develop new material and ensure a patient-centred approach



## Accessible education

[EUPATI Education for Patients](#)

EUPATI Open Classroom



[EUPATI Patient Expert Training Programme](#)  
6 MODULES AND 2 TRAINING EVENTS

[EUPATI Education for Stakeholders](#)

EUPATI Learning Lab



Training portfolio for **academia and industry members** to upskill their knowledge in patient involvement.

# EUPATI Fellows

Cohorts 1 to 8 (2015- 2025)

## GEOGRAPHIC REPRESENTATION

# 513+ EUPATI Fellows

REPRESENTING MORE THAN  
**+25 DISEASE AREAS**

## STAKEHOLDER REPRESENTATION



COMING FROM  
**60 COUNTRIES**



90%

Patients



5%

Industry



2%

Academic/Res  
earcher



2%

Healthcare



1%

Other

# EUPATI — building patient experts across Europe

The European Patients' Academy on Therapeutic Innovation educates and connects patients to collaborate as equal partners with researchers, regulators and industry — exactly the capacity EHDS now demands.

**513+**

EUPATI Fellows trained

**23**

National Platforms

**8M+**

Toolbox users

**220+**

National patient experts

**258**

Experts on EUPATIconnect

**45+**

Connect research projects

# Learn the language of the system

EUPATI's Open Classroom is free, self-paced, multilingual and non-disease-specific. A few modules speak directly to today's themes:



## Digital Health

The module most aligned with EHDS, data sharing and digital tools.



## Clinical Development

How trials work — the backbone of secondary use and trial matching.



## Health Technology Assessment

How value and access decisions are made from health data.



## Regulatory Affairs

The rules that govern medicines, devices and data.



## Intro to Medicines R&D

The shared foundation for engaging confidently with the system.



## Patient Expert Training Programme

The flagship blended programme — 6 modules + 2 events — that makes Fellows.

## TAKE-AWAYS

# From rights to reality



### **Patients need continuity, control and trust**

Access alone isn't the goal — joined-up care that the patient and carer can actually steer is.



### **Citizen-mediated sharing must be co-designed**

It only works, and only earns trust, when built with patients and carers — not just for them.



### **Test policy and tools against real needs**

The open question is whether today's tools truly answer what people need. We have to keep asking.



### **Educated patient experts are the bridge**

They turn rights into practice — and EUPATI is how Europe builds them.

## Thank you

**Mitchell Silva**

EUPATI Fellow

Learn / get involved:

[eupati.eu](https://eupati.eu)

[learning.eupati.eu](https://learning.eupati.eu)

[connect.eupati.eu](https://connect.eupati.eu)