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THE **EPF** European Patients Forum
PATIENT PERSPECTIVE
FEBRUARY 2025

European Health Data Space (EHDS) Regulation

What are the implications for patients?

Empowering Patients and Advancing Healthcare: The Promise of the European Health Data Space (EHDS)

EHDS aims to revolutionise how health data is accessed and managed across the EU. Set to come into force in the upcoming weeks, this ambitious regulation aims to break down barriers to health information accessibility while simultaneously harnessing the vast potential of health data for research and policymaking.

One of the EHDS's primary objectives is to grant patients electronic access to their health data, free of charge, regardless of their location within the EU through interoperable Electronic Health Records (EHRs). This would allow healthcare professionals to retrieve critical patient information, such as medical history, prescriptions, allergies, and diagnostic results.

Furthermore, the EHDS enhances patient autonomy by allowing individuals to manage their health data actively. Patients will be able to add personal notes, request corrections, monitor who has accessed their records, and restrict access to specific data.

Beyond direct patient care, the EHDS introduces a framework for the secondary use of health data in research, policy development, and innovation. Through the decentralised HealthData@EU infrastructure, anonymised and pseudonymised health data will be made available to researchers, public institutions, and industry stakeholders.

Importantly, the EHDS ensures stringent security measures to protect personal data. Data users will only have access to data under strict conditions, and processing will occur within secure environments that adhere to the highest standards of privacy and cybersecurity. Additionally, data use for commercial exploitation or decisions detrimental to individuals will be strictly prohibited.

Despite its transformative potential, the success of the EHDS will depend on addressing

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more connected, efficient, and patient-centered healthcare system.

Read more about EHDS in our [legislative analysis](#).

SECRETARIAT NEWS



BAROMETER ON THE INVOLVEMENT OF PATIENTS' ORGANISATIONS IN EU MEMBER STATES

The European Patients' Forum is working on a Barometer about the involvement of patient organisations in health policy at national level. The Barometer aims to address the lack of information regarding whether and how patient organisations are involved in health policy at national level as well as a lack of evaluation on whether their involvement has positively influenced policy outcomes. Objective metrics are needed to provide consistent and actionable insights.

The Barometer will:

- Assess and map the level of patient involvement in health policies across Europe;
- Identify good practices in patient involvement;
- Examine barriers to patient involvement across countries;
- Highlight the benefits of patient involvement and how it affects policies;
- Benchmark European countries as questions will be weighed and points allocated based on the quality and level of patient involvement.

Your participation will be invaluable in deepening our collective understanding of the involvement of patient organisations in health policy in Europe. We look forward to closely working with you on the development of this tool and ensuring that it supports your advocacy at national level.

You can access the Barometer [here](#).



INFORMING AND EMPOWERING PATIENTS THROUGH ACCESSIBLE AND CLEAR INFORMATION ON MEDICINES

EPF highlights key recommendations to enhance patient information leaflets (PILs), successfully integrate electronic product information (ePI), and advance health literacy across the EU. [Read the full paper here](#).

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UNDER THE NEXT MULTIANNUAL FINANCIAL FRAMEWORK

As a member of the EU4Health Civil Society Alliance, EPF invites stakeholders to join us at "Unlocking Europe's Future: Prioritising Health under the Next Multiannual Financial Framework".

📅 Wednesday, 26th March 2025 (15:00-17:00 CET) | 📍 European Parliament, Brussels

[Find out more and register here.](#)



STYPA 2025
IS OPEN FOR APPLICATIONS

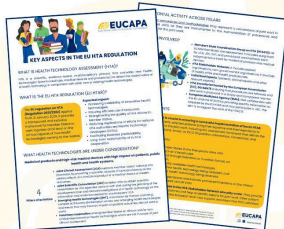
The Skills Training for Young Patient Advocates (STYPA) is back for 2025! This year's topic will be dedicated to digital health and Artificial Intelligence in healthcare. If you are a patient between 18 and 30, [find out more and apply here.](#)

PROJECTS PORTAL



NEW LEAFLET

Check it out now!



With the EU HTA Regulation in effect as of 12th January 2025, check out the newly updated **EUCAPA** leaflet to stay informed and prepared!

[Download it now!](#)

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On 6th March 2025, **H2O**, in collaboration with **Data Saves Lives**, is hosting its third and final patient engagement event in Barcelona, Spain. This event will bring together patients, patient organisations, healthcare professionals, and partners for discussions, knowledge sharing, and co-creation.



YOUTH GROUP UPDATES

EPF Youth Member Participates in Inaugural EU Youth Policy Dialogue on Crisis Preparedness

On 26th February 2025, Erato Markantoni, a member of the EPF Youth Group, participated in the first Youth Policy Dialogue on Preparedness with EU Commissioner for Preparedness and Crisis Management, Hadja Lahbib.

This event, supported by the Directorate-General for European Civil Protection and Humanitarian Aid Operations (DG ECHO) and the Health Emergency Preparedness and Response Authority (HERA), provided a platform for young people to actively contribute to the EU's policymaking processes.

Drawing on lessons from the past and working to improve our preparedness for health crises, EPF urges public health authorities to collaborate closely with patient organisations, helping them relay vital info to their communities. It is also essential to minimise disruptions to care, provide the necessary resources to keep healthcare systems running, and effectively manage future health crises or pandemics.

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MEMBER FOCUS



Rare Disease Day 2025: Global Solidarity for 300 Million People Living with Rare Diseases

EURORDIS-Rare Diseases Europe coordinates the 18th edition of Rare Disease Day, bringing together over 70 national partners across 100 countries. This global movement aims to raise awareness and drive policy change for the estimated 300 million people living with a rare disease worldwide.



Shaping the future of COPD care in Europe: EFA calls for urgent action at the European Parliament

The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) presented **key policy recommendations for raising COPD standards of care** in the European Parliament, with the strong support of MEPs Romana Jerković, Tilly Metz and András Kulja from the MEP Lung Health Group. The event emphasised the need for early detection programmes, stronger tobacco control and improved air quality policies. With input from the patient community, **EFA's newly-launched**



Results of EFNA's survey on the invisible issues of neurological conditions published

In 2024, the European Federation of Neurological Associations (EFNA) conducted a survey to investigate the invisible issues that affect people with neurological conditions. With 4,687 responses, this survey provides critical insights into the societal, financial, physical and mental challenges associated with having a neurological condition. These challenges extend far beyond health; affecting access to education, employment, and insurance, while perpetuating stigma, discrimination, and isolation. [Read the report here.](#)



Fertility Awareness Matters: Tackling the Knowledge Gap for European Youth

Join Fertility Europe on 26th March 2025 at the European Parliament in Brussels for the Facts! game project report, featuring insights from scientists, patients, and teens on fertility awareness. [Register by 5th March 2025](#) to secure your entry and participate in this engaging discussion.



America First, Global Health Last! What does Trump's agenda mean for global health and the HIV/AIDS response?

In support of communities, civil society organisations, international and regional organisations and individuals living with and affected by HIV/AIDS globally, the European AIDS Treatment Group (EATG) and its members echo that the US administration should in all cases uphold the rights, dignity and freedom of vulnerable populations including migrants, transgender people, people living with HIV and those belonging to key populations.

HIV Voices for Transformation | HIV in prison –Webinar

EATG aims to create a space where all voices are welcome to tell their HIV story. The first webinar took place on 5th February 2025, focusing on the experience of living

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