



The Patient Perspective

September 2021



Reflections

Welcome to Autumn!

Our Policy team has been extremely busy with the EU4Health Programme, the newly launched HERA and still trying to #SaveEUHealthNGOs. Now that the DHE Summit and Health Forum Gastein are over, all attention towards the EPF Congress.

Our Projects team is proud to announce the launch of the first EHDEN Academy Patient/Patient Group Course, where we co-designed all modules with the EHDEN colleagues. More on that below. Our Youth Group is on the lookout for new members, so if you know any 18-29 year olds looking to improve the lives of young European patients, find out below.

We're now one month away from the #EPFCongress2021 and registration is still open. With 300+ guests already registered, it's going to be a packed house as we explore the digital transformation of healthcare. For more information regarding registration, programme and exhibitor booths, please visit epfcongress.eu.

Don't forget to check our Calendar of Events at the bottom to see the special days and events from us and our member organisations.

Stay safe and get ready for Congress!



News From the Secretariat

updates from the inside

EPF Congress 2021 - ONE MONTH AWAY

We are officially one month away! With 300+ guests already registered, you can now view the preliminary programme with updated speaker lists for EPF Congress 2021. Registration is open until 22 October.

Visit epfcongress.eu for all registration and programme details

Digital transformation of healthcare

Virtual event
OCT 26-29, 2021

The EU Patients' Podcast - New Episodes Available!

In September, we put out a few new podcast episodes. Have a listen:

- **#18 - World Duchenne Awareness Day with Elizabeth Vroom**
- **#19 - World Patient Safety Day with Quentin Schoonaere**
- **#20 - FH Awareness Day with Magdalena Daccord**
- **PERISCOPE Monthly Talks #6 - Health Governance with Timothy Yeung**



New episodes available on:



or wherever you get your podcasts!

Welcome to our new Director of Operations Eric Moris

A warm welcome to Eric Moris, who joined EPF in September as Director of Operations.

He leads the organisation's overall planning, Financial Management, Human Resources and Operational Resources development and management. As DOO, he acts as legal representative of the organisation towards Belgian authorities, providers and external stakeholders in liaison with the Board.

He has an expertise and multiple skills within a wide range of knowledge areas and an extensive experience in working at European level in the private and public sectors. Before joining EPF, Eric was leading major operations in the private sector and involved in different CSR projects for corporate companies worldwide.



Farewell to our dear Desislava

We want to wish Desislava Ekzarova, our departing Membership and Governance Officer, the best of luck on her future endeavours.



Welcome Aboard to Martina Continisio

Taking over from Desislava, we'd like to welcome our new Membership and Governance Officer, Martina Continisio.

Martina will be the primary point of contact for current and potential new EPF members. She also provides active support to the Board of Directors and the Ethics Committee. Before joining EPF, she worked in project management and advocacy for the European coordination office of an NGO, in the event organization sector in Italy, and in public affairs for a governmental organization.



Policy and Advocacy Corner

*discussing the most relevant patient-centered
policy and advocacy issues*

Our Policy Activities in September

Over the past month, EPF continued to work in collaboration with several other EPF members and public health civil society organisations, to further campaign on the topic of operating grants within the **EU4Health Programme**. Following our meeting with Health Commissioner Stella Kyriakides, we attended a workshop organised by the European Commission on 10 September. Commission officials present at the meeting confirmed the reception of input provided by civil society organisations in a preceding targeted consultation, including the reception of numerous concerns on the re-establishment of operating grants.

We continue following the developments around the new **European Health Emergency Preparedness and Response Authority** (HERA). The HERA will be a new EU agency for strengthening the **European Health Union** with the aim of better preparedness and response to serious cross-border health threats by enabling rapid availability, access and distribution of needed countermeasures. Together with the **European Public Health Alliance** (EPHA), we published a **joint statement** asking the European Commission to ensure that the new HERA will serve patients' needs.

On cross-border healthcare, we spoke in a virtual workshop organised by the European Commission in which a new series of Guiding Principles for the prior authorisation of cross-border healthcare was discussed. This workshop took place in the context of the ongoing European Commission study to enhance the implementation of the Cross-Border Healthcare **Directive 2011/24/EU** to ensure patient rights in the EU. During our intervention, we presented the patients' perspectives on cross-border healthcare. I.e., patients' rationale for seeking care abroad is based on "need" as much as "choice". In addition, we commented on the provided draft Guiding Principles, explaining how we think National Contact Points' websites can and should be improved, providing better and more tailored information to patients.

The European Commission invited us to attend a call together with the **European Consumer Organisation** (BEUC) to discuss the ongoing situation about the replacing of Directive **98/79/EC** on In Vitro Diagnostic medical devices (IVDs) with a new Regulation (**2017/746**). The application date for this file is 26 May 2022, but there are concerns about the feasibility of the timetable. During the meeting, EPF intervened to say that said that the best solution is the one that addresses patients' needs, minimising the risk of having shortages of IVD devices in the market or making it more difficult for patients to access them. EPF would not be against delaying the implementation of the Regulation if that is necessary to avoid access problems.

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of European Foundations on Artificial Intelligence in Healthcare. The secretariat is regularly updating the [EPF AI Knowledge Hub](#). Furthermore, the AI [Webinar series](#), following its kick-off on 8th July, continued last 29 September with a webinar on AI in Healthcare: Ethics and Implications (more info [here](#)).

Finally, The VAC-PACT tender has now entered its final stage, with the final deliverables (the Advanced Toolkit and a Final Report with policy recommendations) having been submitted on 31 August. We will now wait for the Commission's approval or further comments on the submission. The Toolkit will be available in 24 EU languages.



Projects Portal

briefings on EPF's ongoing projects

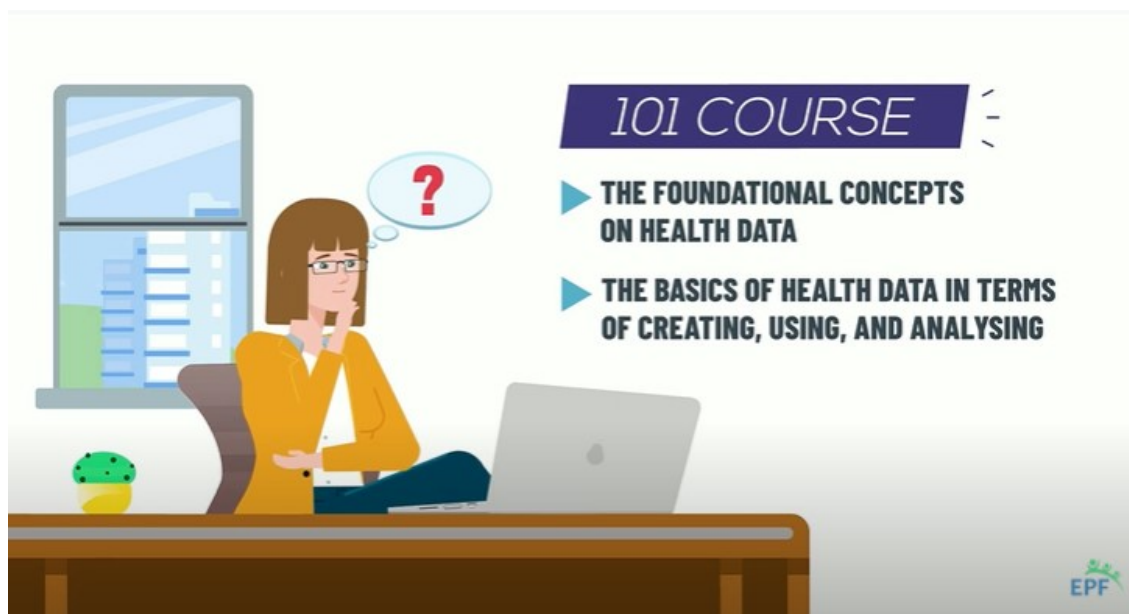
Special announcement 🗨️ launch of the first EH DEN Academy Patient/Patient Group Course

On 28 September 2021, the [EH DEN \(European Health Data & Evidence Network\)](#) launched its first course for non-experts as part of its EH DEN Academy course offering. This series of three introductory modules was designed by the European Patients Forum and EH DEN colleagues.

This free introductory course is designed to familiarise non-experts with the **basics of health data** in terms of how it's created, shared and analysed. It uses a real-life example to illustrate how EH DEN is collaborating with research partners to **maximise the value of health data** to ultimately **improve patient treatment and outcomes**.

This first course will cover key foundational concepts such as: real world data, real world evidence, real world use cases.

>>> Access the course, and other free training materials
>>> Or, watch Course 1 on the EPF YouTube



Registrations are still open: October #PEOF 2021

We are excited to announce that **the Patient Engagement Open Forum 2021** is going virtual again as sessions on **October 6 and 7** are still open for registrations.

Through a series of virtual events planned around the year, we will work in a multi-

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forward to your participation and active contribution to advancing the patient engagement impact.

>>> [Register to participate here](#)



Patient Engagement
open forum

Towards Stronger
Patient Engagement

Are you ready to co-create in a multi-stakeholder context?

Register now to #PEOF 2021 going virtual with a series of virtual events

Powered by



Save the Date - H2O Public Event on 5 October, 12:00 CET

Interested in patient reported outcomes and the European healthcare data landscape?

The **Health Outcomes Observatory** (H2O) project will be hosting a public event, as part of its annual general assembly meeting, featuring experts in panel discussions sharing insights from the clinical, research, European regulatory, and patient perspectives.

October 5th: 12 - 15.30 CET

Register here >>> <https://lnkd.in/ezsW43nX>



SAVE THE DATE FOR THE FIRST
H2O VIRTUAL PUBLIC EVENT

Driving a brighter future in healthcare through patient-reported outcomes (PROs): The H2O approach

5th October 2021
12:00 - 15:30 CET



Youth Group
initiatives, stories and events from our most budding members

EPF Youth Group is Looking for New Members

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EPF Youth Group

We're looking for
New Members!

Together we can change the lives
of **young patients in Europe**


 europeanpatients'forum
Youth Group



Member Focus

highlights from our member organisations

EHCUCATE

Education on the move and at your fingertips

Education on the move and at your fingertips!

Discover **EHCucate** – the European Haemophilia Consortium's new educational app on rare bleeding disorders and novel therapies! EHCucate is an easy and entertaining way to learn all about the **key role of genes, genetic disorders, blood clotting, clotting factor deficiencies, clinical studies** and much more! You can design your personalized library of content, explore the numerous resources freely, test your knowledge, earn badges and track your progress! The app is now available for free and for all.



World Duchenne Day Highlights

The 8th World Duchenne Awareness Day was a reminder of the importance of creating opportunities to improve the lives of adults living with Duchenne muscular dystrophy (DMD). The World Duchenne Organization would like to thank everyone who created and participated in activities that were organized throughout the world.

**More on World
Duchenne Day>>>**



The EUPATI Fundamentals training is now open for registration! The next training is taking place on the **19 and 20 October** and there are only 9 seats left! EUPATI Fundamentals' mix of practical and classroom learning will guide you through the processes of engaging patients throughout medicines development providing a strong foundation for a successful partnership with patients and patient organisations.

Register Now>>>



Inside the Bubble

updates, stories and events around EU healthcare

EU extends vaccine export controls

The European Commission extended the EU's vaccine export authorization program, which permits it to monitor and control shipments of coronavirus vaccines outside the bloc. The EU set up its authorization mechanism in January after AstraZeneca underdelivered on its contract with the bloc. The Commission already extended the mechanism for an extra three months until September, and is now extending it for another three months until the end of the year.

Commission starts funding cancer research 'mission'

The European Commission kicked off a major research effort to tackle cancer, promising €378 million until 2023 for its cancer mission. The mission sets out to "improve" the lives of more than 3 billion people by 2030 "through better prevention, cure and quality of life."

Commission opens public consultation into pharma legislation overhaul

The EU Commission wants to hear from citizens and interested parties regarding gaps in the bloc's medicines regulation. The EU plans to overhaul pharmaceutical legislation to tackle some of the most pressing issues in pharmaceuticals — many of which have been laid bare by the coronavirus pandemic. These include drug-supply issues, the need for medical treatments where none exist, and the dwindling efficacy of antibiotics. Feedback on plans to update the EU's pharmaceutical legislation, which has not been changed in 20 years, begins with a questionnaire seeking views from across the sector.

EU countries have donated 10 percent of coronavirus vaccine doses pledged by year-end

EU countries have so far donated roughly 28 million COVID-19 vaccine doses to low- and middle-income countries. The donations make up 10 percent of the more than 266 million doses EU countries pledged by the end of 2021. Of those pledged, more than two-thirds will go to COVAX. Another 10 percent will go directly to countries, 6 percent is via the EU's Civil Protection Mechanism, and another 5 percent is still to be determined.

Keep your vitality. A life without health is like a river without water
Maxime Lagacé



Calendar of Events

2 October

EATG Workshop on Healthy Living
with HIV

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11 - 17 October

Carers Week

18 October

**Webinar on the Rare2030
survey findings**

19-20 October

EUPATI Fundamentals Training

26 - 29 October

EPF Congress 2021

31 October

Halloween

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