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The Patient Perspective

July 2021



Reflections

As July comes to a close, we take a look back at some of the exciting initiatives we engaged with during the past month.

Our **Policy** team has been extremely busy, particularly with engagement on the EU4Health Programme and several activities concerning digital health. Today, EPF, along with other civil society organisations, will meet with EU Health Commissioner Stella Kyriakides to discuss the reinstatement of Operating Grants. More on that to follow.

Our **Projects** team experienced a particularly busy month in the lead up to summer break. There were two project general assemblies, three patient advisory group kick-off meetings, one publication and many other events. Full details and links to the materials are available below.

Our **Capacity Building** team continues with STYP2021 and was happy to launch the first edition of our brand new **Understanding AI webinar series** on 8 July. The Members only webinars will recommence in September following the summer break.

Registration is OPEN for our virtual **#EPFCongress2021**. The online event is free for EPF Members while patient advocates and health NGOs are eligible for free registration before 1st September. For more information regarding registration, programme and exhibitor booths, please visit epfcongress.eu.

Stay safe and get ready for August!



News From the Secretariat

updates from the inside

EPF Congress 2021 - Preliminary Programme now available!

Our preliminary programme for EPF Congress 2021 is now available. You can check out the titles and themes of all of our sessions as well as the timetable for each day from the 26 to the 29 of October.

Exhibition Booths & Poster Sessions: Due to the brief virtual nature of the Congress, poster sessions will only be available to partners, sponsors and exhibitors.

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booth comes the option to participate in the poster sessions. For more information or to reserve a booth for your organisation, please contact congress@eu-patient.eu.

N.B. Registration is FREE for EPF Members and we're granting complimentary registration to patient advocates and health NGOs before 1st September 2021.

Visit epfcongress.eu for all registration and programme details

Digital transformation of healthcare

Virtual event
OCT 26-29, 2021

CALL FOR TENDER

EPF is currently looking for a **Consultant to write Research Reports** on Artificial Intelligence in Healthcare from the patient perspective.

Deadline for Submission: 5 August 2021 (23:59 CET) [Full Details>>>](#)

A graphic with an orange background. On the left, there is a top-down view of a desk with a blue keyboard, a small potted plant, a white coffee cup on an orange saucer, a blue notebook, and a smartphone. On the right, the EPF logo (European Patients Forum) is at the top. Below it, the text 'CALL FOR TENDER' is written in large, white, bold, sans-serif capital letters. Underneath this, a horizontal line is followed by the text 'head to our website for all the details!' in a smaller, white, lowercase sans-serif font.

EPF European Patients Forum

CALL FOR TENDER

head to our website
for all the details!

New Episodes of the European Patients Podcast

In July, the European Patients Podcast published several new episodes. Listen below

#16 - World Brain Day with EMSP's Emma Rogan

#17 - EPF Congress 2021 and Patient Co-Production with EIT Health CEO Jan-Philipp Beck

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New episodes available on:



or wherever you get your podcasts!



Policy and Advocacy Corner

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

In July 2021, the EPF Policy team was very active on several topics, in particular on the EU4Health Programme and on digital health.

On the EU4Health Programme, EPF has continued its strong collaboration with several public health and patient organisations to call for **an EU4Health programme closer to civil society (CSOs) needs**. Following the publication of the Work Programme 2021, which confirmed the absence of Operating Grants for CSOs, we have continued our engagement with the European Commission and launched a **dedicated campaign on social media**. Today, on 30 July, representatives of EPF, EPHA, Alzheimer Europe and EURORDIS will meet with the European Commissioner for Health and Food Safety Stella Kyriakides to further discuss our concerns.

Over the past few weeks, we've also been engaged in the discussion on digital health, in particular working with our members to put together a response to the European Commission's open consultation on the European Health Data Space (EHDS).

As per our response and accompanying paper, the EHDS can be considered as a welcome exercise to better harmonise and clarify the health data panorama in Europe, while also having a potential positive impact on digital health in more general terms. If shaped and implemented correctly, the EHDS can become a crucial pillar of the 'European Health Union', and ultimately improve the lives of citizens and patients.

To know more about EPF response, have a look at our full **consultation questionnaire submission** and **accompanying paper**. In the coming weeks we will also publish a summary of our response. Stay tuned!



Projects Portal

briefings on EPF's ongoing projects

H2O Project Launches Three Patient Advisory Boards' Activities

Throughout July, the **Health Outcomes Observatory** (H2O) project held three kick-off

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to get to know each other and share their experiences and expectations, and hear from project leaders about the role of the PABs, patient reported outcomes in their disease area and the condition-specific workstream leader.

The PABs will play an integral role in shaping the work of H2O – they will not only ensure that a strong patient perspective is present throughout all workstreams, but that patients are real partners in the project. The PABs will provide guidance to the condition-specific workstreams, and will help to produce tools to ensure outreach at both the national and condition-specific levels.

H2O, a project of the **Innovative Medicines Initiative**, aims to equip patients with the tools to measure their outcomes in a standardised way, while giving them full control of their data. This is the first-ever attempt at scale to collect and incorporate patient outcomes into healthcare decision making at an individual and population level. **Head to the dedicated project page to learn more about the project, EPF's role, and the value for patients >>>**



H2O Patient Advisory Board Induction Meeting

July 2021
11:00 – 13:00 CET
Virtual Meeting

This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement N° 945345-2.
This Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA and Trial Nation and JDRF.
DISCLAIMER: This bulletin reflects only the author's view and the JU is not responsible for any use that may be made of the information it contains.

PEOF session on Diversity, Inclusion & Equity in Patient Engagement

On 24 June, the European Patients' Forum, together with the Savvy Cooperative, hosted a session on Diversity, Inclusion and Equity in Patient Engagement as part of the 2021 **Patient Engagement Open Forum (PEOF)**.

The session addressed the gap in patient engagement frameworks around the inclusion of diverse groups. Hosts and participant explored ways to meaningfully include the perspectives of wider populations, accounting for gender, age, geographic and socio-economic diversities, with the ultimate goal of guaranteeing access to appropriate, high-quality care to all people.

Across three breakout groups representing different aspects of diversity in patient engagement, and lead by patient advocates sharing their personal stories, participants reflected on the challenges. This was followed by a brainstorming on possible approaches and solutions.

PEOF is organised as an online series of quarterly events, and has been held since 2019 with the aim of making patient engagement the norm in the healthcare ecosystem. **Save the date for the next sessions to be held on 6 & 7 October 2021 >>>.**

Access the Diversity, Inclusion and Equity session materials here >>>

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NEW on ResearchGate : EATRIS-Plus Summer School Patient Engagement slides

Did you miss the Patient Engagement session of the [EATRIS-Plus Summer School](#) or would like to recap the results of the interactive session?

On 20 July 2021, the slides for the session were [published on Research Gate](#). The session, which was prepared by the European Patient's Forum together with the European AIDS Treatment Group ([EATG](#)), centred on providing participants with an introduction on how to begin engaging patients in their work.

The publication of these slides can be an important resource for researchers searching for patient engagement materials. The workshop introduced participants to two patient journeys, followed by an interactive session to identify what different researchers wanted to know about patient engagement and how to approach it.

The presentation provides an introduction to good practices of patient engagement, which can be carried over into diverse fields, as well as other tools like reporting and dissemination guidance. [Access the slides here >>>](#)



PharmaLedger General Assembly

PERMIT Project General Assembly

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since the start of the project. The assembly, marking the half-way point of **PharmaLedger**, was an opportunity for partners from 29 different private and public organisations to review the accomplishments so far, and review the goals for the months ahead. Since its start, PharmaLedger partners have:

- > Attended **44 events**
- > Forged **4 partnerships**
- > Held **3 webinars** with over **949 registrants**
- > Drafted **38 blog posts**
- > Been featured in **18 articles**
- ... and much more.

PharmaLedger, a project of the **Innovative Medicines Initiative**, aims to drive the early adoption of blockchain-based technology in the healthcare sector. Read more about EPF's role and the benefits for patients on the **dedicated project page** >>>



was an opportunity for partners to reflect on the achievements in the last 6 months and look ahead as the project shifts towards drafting the recommendations on personalised medicine research. In the last 6 months, project partners:

- > Held **9 working sessions, focus groups & stakeholder consultations**
- > Reviewed the **gaps identified** during the project scoping review

Additionally, partners voted to extend the project by an additional 6 months due to the ongoing impact of the pandemic.

PERMIT, a **Horizon 2020** initiative, aims to develop recommendations to ensure scientific excellence in personalised medicine (PM). The potential of PM is important for patients, as it can potentially reduce trial and error treatments, help make better choices to decide which medicines would be most effective and help to manage healthcare costs. To learn more about the project, EPF's role and the benefit for patients, **head to our dedicated page**>>>



Member Focus

highlights from our member organisations



EURORDIS 30 Million Reasons Join EURORDIS-Rare Diseases Europe's new campaign #30millionreasons for Europe's Action Plan for

EUROPA UOMO

The Voice of Men with Prostate Cancer in Europe

EUROPA UOMO has published a booklet which provides an accessible summary of the findings from EUPROMS (Europa Uomo Patient Reported Outcome Study). Europa Uomo has been using the EUPROMS findings to encourage politicians to



The **European Haemophilia Consortium (EHC)** is looking for an experienced, analytical and passionate European public policy and

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for change, now:

[join the campaign>>>](#)

awareness of approaches such as active surveillance which have less effect on quality of life.

team of staff and volunteers.

[apply now>>>](#)[read the booklet>>>](#)

Youth Group

initiatives, stories and events from our most budding members



Moderating the PEOF 2021 Webinar: Taking Action to Engage Paediatric and Young Patients in Medicines R&D

EPF Youth Group Vice President Anastasia Semaan discusses her role as moderator at the latest Patient Engagement Open Forum and what it meant for young patients.

[Read Full Article>>>](#)



Inside the Bubble

updates, stories and events around EU healthcare

EU countries double vaccine-sharing promise to 200M doses

EU countries have committed to sharing 200 million doses of coronavirus vaccines to low- and middle-income countries by the end of 2021, doubling a previous commitment. The pledge comes following an announcement in May that EU countries would share 100 million doses, mainly through COVAX, the mechanism for equitable vaccine distribution.

EMA adds neurological disorder as 'very rare' side effect of J&J vaccine

The European Medicines Agency listed Guillain-Barré syndrome (GBS) as a "very rare" side effect of Johnson & Johnson's coronavirus vaccine. GBS is a rare neurological disorder in which the body's immune system attacks nerve cells, causing weakness, pain and, in the

worldwide by the end of June.

Commission to make HERA proposal September 14

The European Commission will present its European Health Emergency Preparedness and Response Authority (HERA) package on September 14. HERA, a new agency, is one of the key European Health Union plans to improve the EU's response and coordination in a health emergency. Last year, the Commission proposed changing the mandates for both the EU's infectious disease agency and medicines agency, and made a proposal for a regulation on serious cross-border health threats.

Big brands embrace EU's green food code

The European Commission rolled out a voluntary new code of conduct last week for food businesses to commit to a range of nutrition and sustainability goals, part of its wider Farm to Fork strategy to make the bloc's food chain more environmentally friendly and improve diets across the Continent. The EU executive plans to trot out the code on the world stage as a "model for global transformation" at the U.N. Food Systems Summit (UNFSS) in New York this fall, with an impressive list of participants attached: PepsiCo, Nestlé and Unilever, for example, as well as umbrella lobby groups like UNESDA Soft Drinks Europe, Copa & Cogeca and EuroCommerce.

"The human body has been designed to resist an infinite number of changes and attacks brought about by its environment. The secret of good health lies in successful adjustment to changing stresses on the body."

Harry J. Johnson



Calendar of Events

12 August

International Youth Day

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