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# The Patient Perspective

June 2021



## Reflections

Summer is officially upon us!

Our **Impact Report 2021** was officially launched this past month, shining a strong light on the importance of patient organisations and our services over the past year. More on that below. We're also happy to announce the launch of our **AI Knowledge Hub**, created to boost understanding of AI within the patient community..

Our **Projects** team has been busy launching its first edition of its DSL Coffee Morning Chat while also taking part in the first edition of the EATRIS-Plus Summer School in Personalised Medicine. More on that below.

Our Capacity Building team continues with STYPA2021 and looks forward to launching the first edition of our brand new **Understanding AI webinar series** on 8 July. The webinars are strictly for EPF Members only.

Please visit our **Calendar of Events section** at the end of the newsletter to see some crucial events taking place in July in the patient community.

Registration is NOW OPEN for our virtual **#EPFCongress2021** so please visit [epfcongress.eu](https://epfcongress.eu) for more details. The online event is free for EPF Members while patient advocates and health NGOs get free registration before 1st September.

Stay safe and enjoy the weekend!



## News From the Secretariat

*updates from the inside*

### EPF Congress 2021 - Registration Now Open!

Developed by and for patients, the #EPFCongress2021 will focus on the digital transformation of healthcare. Join us from 26-29 October to explore the added value of patient partnerships in the field of digital health.

Registration is free for EPF Members. We're granting free registration to patient advocates and Health NGOs before 1st September. **[Register today>>>](#)**

# Digital transformation of healthcare

Virtual event  
OCT 26-29, 2021

## Release of the EPF Impact Report 2021

Our Impact Report 2021 is now available! It shines a strong light on the importance of patient organisations and the services we provide with and on behalf of the patient community. [Read our Impact Report>>>](#)



## CALL FOR TENDER

EPF is looking to expand its coverage of the Western Balkan region. We're looking for a consultant to map the patient organisation community in that region.

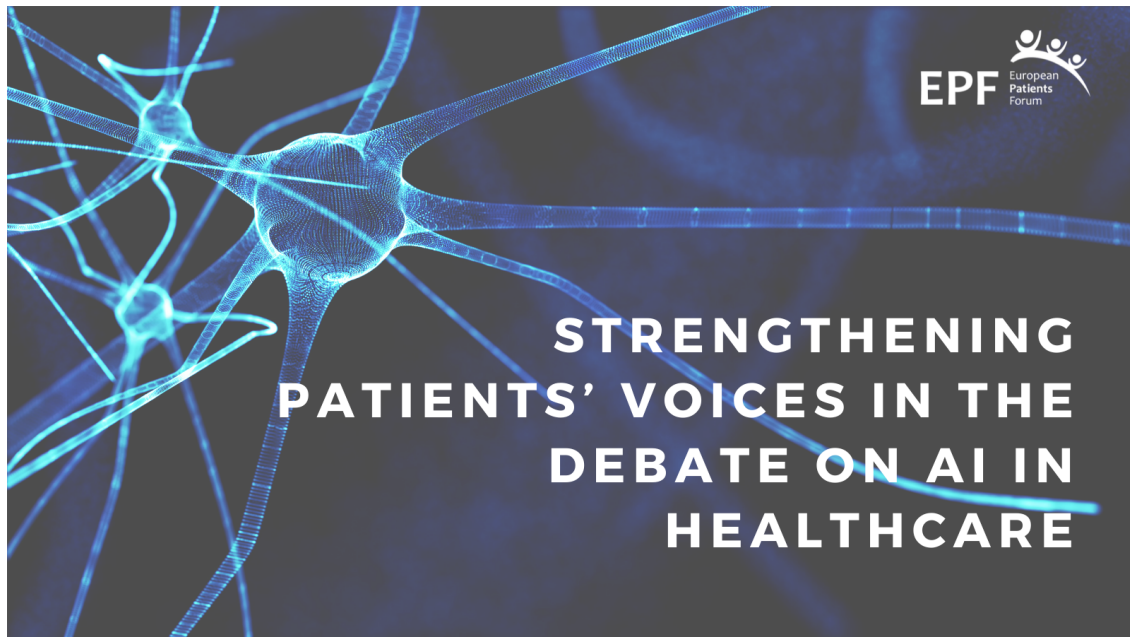
**Deadline for Submission: 15 July 2021 (23:59 CET)** [Full Details>>>](#)



## KBF: Strengthening Patients' Voices in the Debate on AI in Healthcare

[Subscribe](#)[Past Issues](#)[Translate ▼](#)[towards digitalisation.](#)

In the King Baudoin Foundation's latest newsletter, they highlight how we will work to shape A.I. frameworks through the patient perspective using our latest grant from the EU AI fund. [Read the article>>>](#)



### New Episodes of the European Patients Podcast

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

**#13 - Impact of COVID-19 on Liver Patients with Dr Gautam Mehta**

**#14 - Medication Related Patient Safety with Tjasa Zajc**

**#15 - World Continence Week with WFIPP's Mary-Lynne Poelgeest**



New episodes available on:



or wherever you get your podcasts!



### Policy and Advocacy Corner

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

Over the next five years, the European Commission has ambitions to forge a plan for Europe's digital transformation, including AI. But without a strong civil society taking part in the debate, Europe risk missing opportunities to better society and instead, might choose a path paved with societal harm.

To help with this work, EPF has been awarded a €90,000 grant from the European AI Fund, set up by a consortium. Set up to help strengthen civil society's voice in debates on Europe's digital future, one of the Fund's aims is to bring newer voices to the fore.

The AI Knowledge Hub was created to boost understanding on AI and close advocacy and capacity-building gaps within the EPF and its membership to build a more AI-savvy and engaged patient community, which can contribute meaningfully to EU and national policy debates on the topic.

Visit EPF's [AI Knowledge Hub](#)



## Projects Portal

briefings on EPF's ongoing projects

### The First Data Saves Lives Coffee Morning chat is out now

The [Data Saves Lives initiative](#) has recorded its first video in its 'coffee mornings' series with expert panellists. In the new series, Data Saves Lives will explore the latest hot topics in the health data space, over a hot drink! For this coffee talk, Data Saves Lives spoke to expert representatives of three important projects coordinated by the multistakeholder [Innovative Medicines Initiative \(IMI\)](#), that share common goals to standardise and make health data more accessible, the [EHDEN](#) project (Nigel Hughes), [H2O](#) (Meni Styliadou and Tanya Stamm) and [PIONEER](#) (Sarah Collen).

[Watch the video here >>>](#), and share your comments with any feedback or questions, including any future topics you'd like to see explored in the next coffee talks.



### Patient Engagement session at the EATRIS-Plus Summer School in Personalised Medicine

On 17 June 2021, the European Patients Forum (EPF), together with EPF member the



The **Summer School** is an initiative of the **EATRIS-Plus Project**, which aims to deliver scientific tools to support the long-term sustainability of EATRIS and build its capabilities as a key European research infrastructure in personalised medicine. The overall goal is to address the range of topics central to personalised medicine – from the pillars of personalised medicine, to clinical trials and regulatory aspects, through to health economics, and patient engagement, among others.

Following an intriguing introduction to patient engagement and why it is important, this patient engagement (PE) satellite session was developed to provide participants with an introduction on how to start integrating patients in their work. As such, the session focused on working together with participants, as well as members of the projects' Patient Advisory Committee to understand what PE looks like from a patients' perspective, address any participant questions on PE in their field, and discuss the challenges and possible solutions to successful PE implementation in different settings.

Learn more about the **EATRIS-Plus Summer School in Personalised Medicine** [here >>>](#)



### 3rd EU-PEARL Project General Assembly

On 8-10 June 2021, the **EU-PEARL project** held its third General Assembly (GAM) under the banner Inspire, Engage, Enable and Transform. EU-PEARL, a project of the **Innovative Medicines Initiative**, aims to develop Integrated Research Platforms to make clinical trials more efficient and patient friendly. The meeting was joined by over 200 project participants, and aimed to review the progress made so far, and outline the next steps in the project.

Valentina Strammiello and Hannes Jarke of the European Patients' Forum led a session on Enabling a Patient Centric Approach, focusing on the project's aims for early patient involvement, and detailing the role of the EU-PEARL Patient Advisory Group (PAG). The next step for the patient centric work stream was also introduced: A patient engagement platform to provide guidance and resources on patient involvement in platform trials, which will be the focus until the end of the project. The session was ended with keynote addresses from members of the PAG, Claas Röhl (**NF Patients United**) and Fanni-Laura Mäntylä (**GAMIAN Europe**), who shared their personal journeys and the importance of early patient involvement and co-creation.

Other sessions featured interventions from project partners and experts on the renewed focus on the Master Protocol concept following the COVID-19 pandemic, establishing opportunities and challenges to optimise trial design and implementation, and using federated networks to optimise trials. To learn more about EU-PEARL, go to the

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## New EPF blog post for COMPAR-EU: Patient Panel activity mid-year review

On 31 May, the COMPAR-EU self-management blog series published its new blog post, featuring an update from the European Patients' Forum.

In the blog, Lyudmil Ninov, EPF Senior Programme Officer, highlights the achievements of the COMPAR-EU Patient Panel (PP) so far this year – including regular webinars, and the PP participation in the project online platform task force – and shares the plans for the second half of 2021. [Read the full blog here >>>](#)



31. May 2021 | by Lyudmil Ninov | European Patients' Forum (EPF)

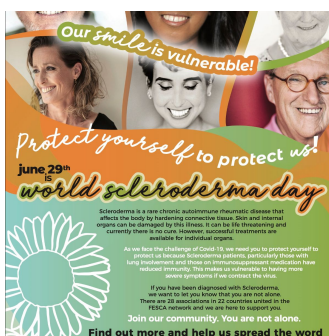
### COMPAR-EU Patient Panel Activities – 2021 Mid-Term Review

European Patients' Forum (EPF) is a COMPAR-EU project partner, tasked with ensuring that patient centricity remains at the heart of the project's activities, objectives, and future endeavours. In this edition, EPF shares what has been achieved so far in 2021 and highlights immediate next steps, mainly in connection to the work carried out by members of the Patient Panel.



## Member Focus

highlights from our member organisations



**World Scleroderma Day** June 29 is a day to



EUPATI FUNDAMENTALS  
6 and 7 July 2021  
10:00 - 16:00 CET

TRAINING ON PATIENT  
ENGAGEMENT ONLINE

TAILORED FOR ACADEMIA &  
PHARMIA PROFESSIONALS

**EUPATI Fundamentals  
6-7 July)**  
EUPATI Fundamentals'  
mix of practical and  
classroom learning will  
guide you through the

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scleroderma, and to demand equal treatment and equal care for people with scleroderma across Europe.

[join the campaign>>>](#)



EATG has launched a **survey report on HIV & Mental Health** as well as shorter versions in several languages. The reports were launched and key findings were presented during the first part of the multi-stakeholder meeting on HIV and mental health which was held online on 27 May.

[read the survey report>>>](#)

medicines development providing a strong foundation for a successful partnership with patients and patient organisations.

[learn more>>>](#)



**EPDA's Parkinson's Carers Survey Report** A large proportion of carers are under so much strain from caring for loved ones with Parkinson's that their own health – both physical and mental – is at risk. This leads to a greater reliance on prescription medicines and consultations with healthcare professionals, thereby indirectly increasing the global health cost of managing Parkinson's.

[read the survey report>>>](#)



## Youth Group

*initiatives, stories and events from our most budding members*

### Advocacy and Fundraising during a Pandemic

EPF Youth Group Member **Cornelia Pauna** details her advocacy and fundraising efforts with certain patient organisations during the pandemic. [Read full article>>>](#)



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Distance

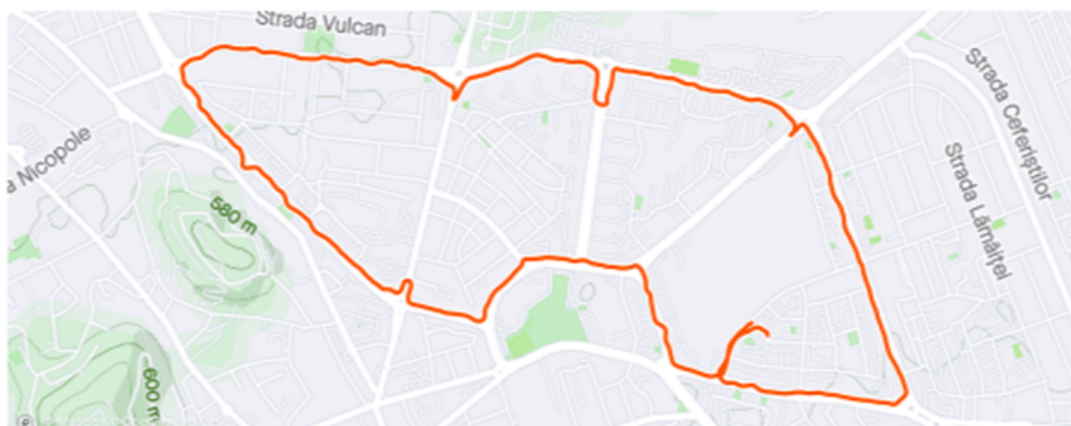
7.57 km

Pace

5:33 /km

Time

42m 2s



## Inside the Bubble

updates, stories and events around EU healthcare

### EU signs off decision to ease travel from US

The Council of the EU confirmed that countries should ease travel for all U.S. citizens effective immediately, under an update to the EU's approved travel list. EU ambassadors agreed to add the U.S. as well as Albania, Lebanon, North Macedonia, Serbia and Taiwan to the list. Ultimately it is up to EU member countries to decide whether to act on today's recommendation. Some European countries, including Greece and France, have already lifted restrictions on U.S. travelers.

### Belgian court gives AstraZeneca partial win in vaccines dispute with Commission

The drugmaker AstraZeneca must deliver 80 million coronavirus vaccine doses to the EU by September 27 or else pay a fine. The court ruled the drugmaker has to deliver 15 million doses by July 26; 20 million doses by August 23; and a final 15 million doses by September 27, according to the court. This total of 50 million doses comes on top of the 30 million doses that AstraZeneca delivered at the end of the first quarter of 2021. The company will incur a €10 fine per dose not delivered, according to this schedule.

### Negotiators reach informal HTA deal

Negotiators for the European Parliament and Council reached an informal agreement on the health technology assessment (HTA) regulation early this morning. The regulation will boost cooperation between EU countries when assessing medicines and medical devices with the hope of improving medicine access and simplifying the application process for drug companies.

### ECDC: 90 percent of coronavirus cases will be Delta by end of August

Countries must keep up public health measures and ramp up vaccinations against coronavirus as modeling shows the Delta variant, first identified in India, is likely to represent 90 percent of all cases in Europe by the end of August, the European Centre for Disease Prevention and Control said. Studies show that one vaccine dose is not enough to protect against the Delta variant. The ECDC urged countries to prioritize second doses in the shortest time possible for vulnerable people.

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**“The cheerful mind perseveres, and the strong mind hews its way through a thousand difficulties.”**





## Calendar of Events

### 29 June

World Scleroderma Day 2021

[visit our website](#)

**Premiere of "OVER(DOSE): A documentary about Patient Safety & Medications"**

[contact us](#)

### 30 June (11:00 CET)

**WEBINAR: "A Look Beyond Europe's Beating Cancer Plan. How we PERSIST with cancer patient-centered care plans across Europe"**

### 7-8 July

**EUPATI Fundamentals Training**

### 8 July

Understanding AI Webinar Series  
#1 - AI in Healthcare: From Science Fiction to Reality

The Economist's **From donor to patient: solutions for a sustainable plasma market**

### 22 July

World Brain Day

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