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# The Patient Perspective

May 2021



## Reflections

We'll begin first with some big news. Registration is NOW OPEN for our **#EPFCongress2021** so please visit [epfcongress.eu](https://epfcongress.eu) to sign up for our 4-day virtual event. The online event is free for EPF Members.

May was quite a busy month as with the release Survey Report on the **Impact of the COVID-19 Pandemic on Patients and Patient Organisations**. It has been well-received thus far and its key findings and learnings will inform our policy work in the coming months.

Our **Projects** team worked diligently across its portfolio contributing several key articles and participating in numerous webinars and events. The Data Saves Lives team is now looking for patient stories, more on that below.

In our **Member Focus** section, We sit down with each of our newest members - FH Europe, EUROPA UOMO, GlobalSkin and Global Heart Hub - to discuss their vision and hopes for the future.

There are several special theme days and virtual events such as **Shot Callers Part 2** and **EMSP's Virtual Conference** happening in June so please visit our **Calendar of Events section** at the end of the newsletter to register.

Don't forget to check our **COVID-19 Resource Point** on a weekly basis or listen to the latest episodes of the **EU Patients' Podcast**.

Stay safe and enjoy the weekend!



## News From the Secretariat

*updates from the inside*

**SHOT CALLERS PART 2**  
**16 June 2021 (15:00-16:15 CET)**

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members of World Health Organisation, European Medicines Agency and EMA.

[Register Now>>>](#)

# SHOT CALLERS: PART 2

A VIRTUAL DISCUSSION  
ON COVID-19 VACCINES,  
VARIANTS AND VERACITY

16 JUNE 2021 | 15:00-16:15 CET

**Speakers include:**

**Marco Greco**  
European Patients' Forum

**Prof. Jean-Michel Dogne**  
WHO Global Advisory Committee on Vaccine Safety

**Prof. Guido Rasi**  
former Executive Director of European Medicines Agency

**Moderated by: Nicola Bedlington**  
European Patients' Forum




**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. [Register today>>>](#)

## Digital transformation of healthcare

Virtual event

OCT 26-29, 2021

**Survey Report on Impact of the COVID-19 Pandemic on Patients & Patient Organisations**

We're happy to publish our Survey Report on the impact of the #COVID19 pandemic on patients and patient organisations. The results will support us in providing the patient perspective to several European initiatives relating to COVID-19.

[Infographics & Key Stats>>>](#)[Full Survey Report>>>](#)

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**EPF** European Patients Forum

## Survey Report

The Impact of the COVID-19 Pandemic on Patients and Patient Organisations

Available now on [www.eu-patient.eu](http://www.eu-patient.eu)

## New Episodes of the EU Patients Podcast

In May, the EU Patients Podcast published several new episodes. Listen below:

**#10 - European Mental Health Week with MEP Aliviina Alametsa**

**#11 - World IBD Day with EFCCA's Isabella Haaf**

**#12 - International Day of Action for Women's Health with EUROPA DONNA**



New episodes available on:



or wherever you get your podcasts!



## Policy and Advocacy Corner

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

## May in Review

EPF was invited by the **Portuguese Presidency of the Council of the European Union** to attend and moderate a session in the "3As Conference - Availability, Accessibility, Affordability - of Medicines & Medical Devices". This event took place virtually on 29 and 30 April 2021, including a variety of high-level speakers from the EU Health Policy sector. **Elisabeth Kasilingam**, EPF's Interim Executive Director, moderated a session on patients' unmet medical needs.

the first blocks of a European Health Union. They are working towards a healthier Europe, in which no patients are left behind. For that, they aim at tackling medicines and medical devices shortages – both of which of utmost importance for patients – at the European level. The European Commission is also working towards improving the affordability, availability and accessibility of medicines and medical devices in Europe.

Her intervention was followed by Dolors Monserrat (Member of the European Parliament, Christian Democrat, Spanish, and member of the Committee on the Environment, Public Health and Food Safety). She also considers medical devices and medicines shortages to be a problem for patients, which should not occur anymore in Europe – the reason for which measures to mitigate them are included in the new EU Pharmaceutical Strategy.

Elisabeth Kasilingam explained in the session she moderated how and why patients' unmet medical needs is an important topic for EPF and introduced participants to the [Pricing of Innovative Medicines position paper](#) that EPF has published. She also explained that a multi-stakeholder forum for better access to health innovation could help to develop concrete solutions for the introduction of new technologies into healthcare systems. For understanding patients' unmet needs concretely, we first need to define what these are, together with patients' key priorities. She concluded by emphasising the importance of meaningful patients' engagement in the definition of priorities and the shaping of policy solutions as a key for successful health policies.

Other speakers of the Conference (among others) were Emer Cooke (Executive Director, European Medicines Agency), Monique Goyens (Director General, BEUC) and Rui Santos Ivo (Portuguese National Authority of Medicines and Healthcare Products).



## Projects Portal

briefings on EPF's ongoing projects

### DSL Call for Patient Stories

The Data Saves Lives initiative aims to raise wider patient and public awareness about the importance of health data, improve understanding of how it is used and establish a trusted environment for multi-stakeholder dialogue about responsible use and good practices across Europe.

To help us achieve this aim **we're looking to share individual patient stories to highlight personal experiences** of being involved in health data research projects or initiatives. We would like to share these personal experiences on a new 'Patient Stories' section of the [Data Saves Lives website](#).

Would you or your members be interested in taking part?

[Learn more about Patient Stories >>>](#)

# #DataSavesLives

### EU-PEARL at International Clinical Trials Day 2021

This 20 May 2021 marked International Clinical Trials Day (ICTD). The focus of this year's event was [platform trials](#) – a type of clinical trial that aims to test and compare several treatments at once, aiming for higher efficiency. Platform trials also allow for a **bigger role of patients** in trial design and the choice of outcome measures.

As part of its role in the [EU-PEARL project](#), the **EPF participated in a roundtable discussion** hosted by the European Clinical Research Infrastructure Network (ECRIN) to discuss the challenges related to platform trials, their design, implementation & the role of

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EU-PEARL is a project of the [Innovative Medicines Initiative 2 programme](#) (Grant Agreement no. 853966-2). You can learn more about EU-PEARL on the project [website](#). To explore EPF's role and the impact on the patient community, you may find the [dedicated project page](#) on the EPF website.

[Learn more about EU-PEARL's involvement in CTD 2021 >>>](#)

May 20th

# International Clinical Trials Day 2021

## EPF guest blog for EHDEN: RWE/RWD & the patient community

On 18 May 2021, the European Patients' Forum published a featured guest blog for the European Health Data & Evidence Network ([EHDEN](#)) project. The article centres around the role of the Patient Community, engaging this group and harnessing their insights for Real World Data/ Real World Evidence (RWD/RWE).

Patients and patient communities are an integral part of the RWD/RWE dynamic – however, engaging meaningfully in this topic requires technical expertise that can be challenging for many patient groups to develop. [Read the blog post here >>>](#)



## COMPAR-EU blog: Patient Decision Aids For Self-Management Interventions

On 21 April the COMPAR-EU blog series published its new monthly update.

In the blog post, Dr. Ana I. Gonzalez, of the Fundacion Avedis Donabedian (FAD), reviews some of the key drivers and barriers for the adoption of Patient Decision Aids (PDAs). PDAs are integral to shared decision-making and patient-centred care; they complement counselling from a clinician, and are designed to support people's participation in regarding care options for their health conditions. However, important barriers remain to the full implementation of PDAs in real practice. Read the full blog to learn more!

[Read the full blog here >>>](#)

## SELF-MANAGEMENT BLOG

### PharmaLedger at the Block Chain Convention

On 12-16 April 2021 the 5<sup>th</sup> edition of the European Blockchain Convention (EBC) took place. The event featured keynotes and panel discussions with over 100 world-class speakers on the subject of blockchain technology. [PharmaLedger](#) partners, including the European Patients' Forum (EPF) participated in panel discussions.

**EPF's Valentina Strammello spoke at the EBC panel on using blockchain technology to prevent the problem of counterfeit medications.** In her intervention, Valentina highlighted the role of patients at the forefront of this issue – patients are not only more likely to spot fake medications but are also more likely to suffer their harmful

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### PERISCOPE Monthly Talks #3 - Modelling Vaccination Roll-Outs with Raffaele Bruno

With vaccines and variants acting as potential game-changers, new models to forecast epidemic scenarios have become essential. We discuss the effectiveness of modelling vaccination roll-outs on our latest episode. [listen now>>>](#)

periscope  
MONTHLY TALK

EPF

E P I S O D E > 3

25 MAY 2021

about

Modelling  
Vaccination  
Roll-Outs

RAFFAELE  
BRUNO

The EU  
Patients'  
Podcast



### Member Focus

highlights from our member organisations

[Subscribe](#)[Past Issues](#)[Translate](#) ▼**Q&A with FH Europe**

FH Europe became a member of EPF in April 2021. We sat down with them to discuss their mission and vision and what they will bring to the EPF community!

[read the q&a>>>](#)



The European Multiple Sclerosis Platform (EMSP) will gather the European Multiple Sclerosis community virtually between 9-11 June at the **#EMSP2021 Conference** addressing the topic of "MS Care in a Changing World". Registration is FREE for patients, nurses, carers, MS societies and patient advocates.

[register now>>>](#)

**Q&A with EUROPA UOMO**

EUROPA UOMO became a member of EPF in April 2021. We sat down with them to discuss their mission and vision and what they will bring to the EPF community!

[read the q&a>>>](#)

**European Health Management Association (EHMA)**

has recently launched a Call for Abstracts for the EHMA 2021 Annual Conference, to be held digitally from 15-17 September 2021 under the theme of "Health management: Managing the present and shaping the future". EHMA is welcoming abstracts for oral presentations or poster presentations. The deadline for submissions is 3 May 2021 at 9 AM CEST.

[learn more>>>](#)

**HEART Hub**

The Alliance of Heart Patient Organisations

**Q&A with Global Heart Hub**

Global Heart Hub became a member of EPF in April 2021. We sat down with them to discuss their mission and vision and what they will bring to the EPF community!

[read the q&a>>>](#)



International Alliance of Dermatology Patient Organizations

**Q&A with GlobalSkin**

GlobalSkin became a member of EPF in April 2021. We sat down with them to discuss their mission and vision and what they will bring to the EPF community!

[read the q&a>>>](#)

**Youth Group**

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

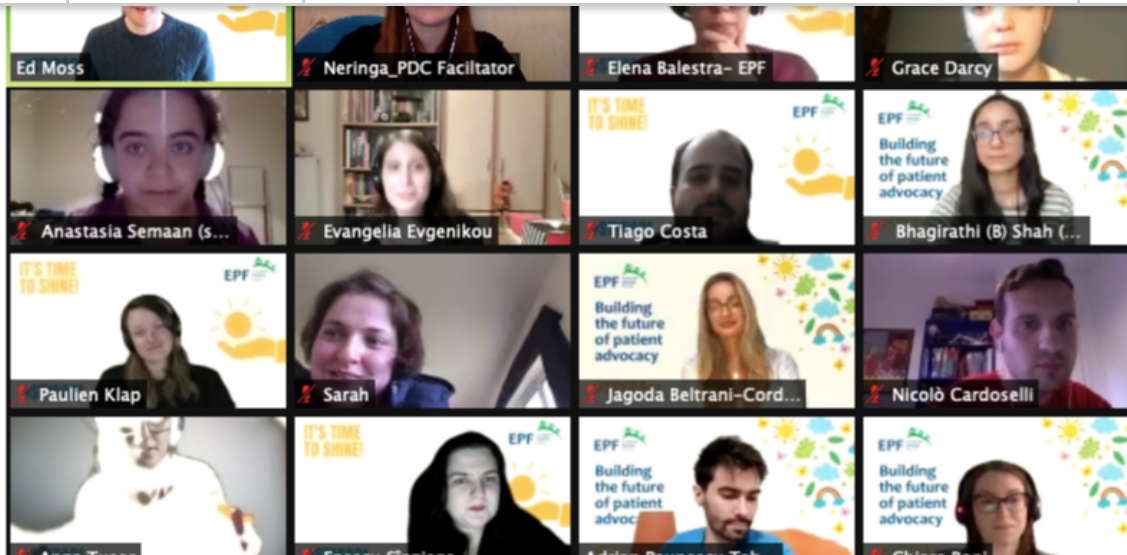
**STYPA2021 Kick-Off**

STYPA 2021 has begun, and the participants have started to get to know one another and what the journey will look like in a nutshell. This year we have 36 participants from across Europe representing 20 different chronic conditions. [Read more>>>](#)

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## Inside the Bubble

updates, stories and events around EU healthcare

### Parliament committee endorses COVID certificates deal

Lawmakers in the European Parliament's civil liberties committee endorsed a compromise deal to set up EU-wide COVID certificates. The EU wants to ease travel this summer by using the passes, which will certify whether travelers got vaccinated, tested, or have immunity from a previous infection. The committee's endorsement clears the way for a vote in the European Parliament's plenary meeting starting June 7.

### Belgium restricts use of J&J coronavirus vaccine to over-41s

Belgium today said it would no longer give people aged 41 and younger Johnson & Johnson's COVID-19 vaccine after the death of a woman. The health ministry said the woman died on May 21 after being admitted to hospital with severe thrombosis and platelet deficiency — rare side effects the European Medicines Agency has previously said could be linked to the vaccine following analysis of cases in the U.S.

### EU leaders agree to donate 100M vaccine doses

EU leaders agreed it will donate "at least" 100 million coronavirus vaccine doses abroad by the end of 2021. At the end of last week, three countries promised doses totalling 75 million, with Italy pledging 15 million, and France and Germany each kicking in 30 million.

### WHO wants 10 percent vaccinated in every country by September

The World Health Organization has set a target of at least 10 percent of the population in every country being vaccinated by September, a goal that would need to see 250 million people vaccinated in four months. To reach the 10 percent milestone, followed by a second goal of 30 percent of populations vaccinated by the end of the year, WHO pointed to a role for both member countries and manufacturers.

"If you know the art of deep breathing, you have the strength, wisdom and courage of ten tigers."

– Chinese adage



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## Calendar of Events

**3 June**[GlobalSkin Conference Thrive 2021](#)[visit our website](#)**5 June**

World Environment Day

[contact us](#)**9-11 June**[Virtual EMSP Conference](#)**14 June**

World Blood Donor Day

**16 June**[Shot Callers Part 2:](#)[Virtual Discussion on COVID-19](#)[Vaccines, Variants & Veracity](#)**29 June**[World Scleroderma Day 2021](#)[Premiere of "Overdose: A documentary about Patient Safety & Medications"](#)[view this email in your browser](#)

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