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The Patient Perspective

January 2022



Reflections

Welcome to our first Patient Perspective newsletter of 2022!

Here's a recap of what we have been up to in the first month of the new year:

Our **Policy** team has kicked off with the first webinar of 2022, dedicated to Patient involvement in nutritional care, and it's now concentrating its efforts on the consultation process on the new EU initiative on non-communicable diseases.

Our **Projects** team has a few announcements on Data Saves Lives and PharmaLedger projects, and they also have some news about the launch event for the Innovative Health Initiative that you will find below.

Our **Youth Group** has been quite busy during 2021, and they are already preparing for lots of interesting activities in 2022.

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 taking place in February.

We look forward to spend the next eleven months with you!



News From the Secretariat

updates from the inside

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WE ARE HIRING!

Send your cover letter, CV and references to
recruitment@eu-patient.eu

We are hiring!

EPF is looking to recruit two new positions:

- **A Senior Communications Manager** (Deadline: **4 February**)
- **A Senior Policy Adviser** (Deadline: **10 February**)

If you know someone who is passionate about patients' rights in Europe, let them know about this unmissable opportunities!

[Here you can find the full job descriptions.](#)



Policy and Advocacy Corner

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

Consultation process on the new EU initiative on non-communicable diseases

In January, the European Commission continued work on its **new initiative on non-communicable diseases** (NDCs). Launched in December 2021, this initiative aims at helping the EU Member States to reduce the burden of NDCs in five areas: cardiovascular diseases, diabetes, chronic respiratory diseases, mental health and neurological disorders and health determinants. In each of these strands, the initiative will promote the reduction of health inequalities. Health-stakeholders' (including patient organisations) wishing to contribute to the initiatives' objectives could be eligible for support.

The initiative's development stage, currently taking place in collaboration with the EU Member States and other health stakeholders, will last **until 22 June 2022**.

Patient organisations and other health organisations wishing to contribute to the initiative's shaping can participate in stakeholders' discussions and provide input only via the Non-Communicable Diseases Thematic Network of the **EU Health Policy Platform**. For that purpose, the European Commission has already made available via the Platform a template for input collection.

In addition, the European Commission will organise a webinar on the topic **on 3 February, from 14h00 to 16h00**. You can already register [here](#). Participation in this webinar is free of charge. The (provisional) dates for the next stakeholder webinars are 17 March, 27 April, and 3 June, with a launch event on 22 June.

On 13 January 2022, EPF and ONCA hosted a webinar on patient involvement in nutritional care policy & practice. This webinar kicks off a series of activities to establish a structural collaboration between the patient advocate, nutritional care expert and policymaker.

You can read EPF's position on food and nutrition [here](#).

About ONCA

Launched in 2014, the Optimal Nutritional Care for All (ONCA) campaign is a multi-stakeholder initiative to facilitate greater screening for risk of disease-related malnutrition/undernutrition and nutritional care implementation across Europe.

The campaign supports national professional societies, associations and patient groups in public health and health care to implement nutritional risk screening and optimal nutritional care in their country. The campaign is now implemented in 19 European countries.

State of play of Artificial Intelligence in Healthcare in EU member states

On 11 November 2021, the European Commission published its **"Artificial Intelligence (AI) in Healthcare" report**, accompanied by [country factsheets](#) on the situation in each EU member state. The reports provide an overview of the development, adoption and use of AI technologies and applications in the healthcare sector across all Member States. The reports aim to identify and address issues that could hamper the adoption of AI technologies in the healthcare sector and will help the Commission to advance the effective adoption and implementation of AI in healthcare.

The reports highlight that most EU member states have developed AI strategies that identify healthcare as a priority sector, but they have not designed specific policies, within these strategies, targeting healthcare. Likewise, healthcare organisations in the EU are open to adopting AI applications, but adoption remains limited. The main challenges identified by relevant stakeholders include the lack of confidence in AI-based decision support and issues relating to the integration of new technologies into current practices. However, the reports note that EU Member States have made progress in proposing regulatory frameworks around health data management, which is fundamental to the roll-out of AI technologies in the healthcare sector.

As the study and country factsheets point out, AI is already being used in the healthcare sector and has potential for further development. EPF has been engaging in extensive work, both through policy inputs and capacity building, to bring the patient perspective to the development and use of artificial intelligence in healthcare.

For further information on Artificial Intelligence in Healthcare from a patient perspective, please check EPF [AI Knowledge Hub](#).



Projects Portal

briefings on EPF's ongoing projects

Launch of the Innovative Health Initiative

On 26 January 2022, the **Innovative Health Initiative** (IHI) held a **kick-off event** to mark the launch of the world's largest public-private research collaboration in the life sciences, supported by €2.4 billion in financing.

IHI Executive Director Pierre Meulien presented the initiative at the launch event, and highlighted its core goals – to translate its work into 'tangible benefits for patients and society,' and ensuring Europe remains at the cutting-edge of research. He also underlined the key ways in which the IHI would differ from the previous Innovative Medicines Initiative (IMI) programmes.

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Executive Director on patient engagement and education, highlighting **EPFAT2**, an IHI project and now independent foundation, as a key success of the former IMI programme, and an example of the type of work IHI hopes to reinforce.

The IHI has published its **Strategic Research and Innovation Agenda**, highlighting its priority areas for the programme and thematic aim which will focus on the healthcare pathway: from early-stage research and prevention, to diagnostics, to disease management. The IHI will also publish a patient engagement strategy.

The IHI has launched a call for expression of interest for participants in a **Science and Innovation Panel**, which will include different stakeholder groups, including patients. The call is open until **21 February**.

The first call for proposals is estimated to go online by April 2022.

[Learn more about the new IHI here >>>](#)



HAVE YOUR SAY! 🗣️ Priority topics & tools for Data Saves Lives in 2022

Data Saves Lives has launched a survey on the priority topics for the initiative.

The survey will help DSL to identify the most pertinent health data topics for events and education for its community, and will **shape the programme** for DSL in the coming year.

[Fill in the short 2 min. survey here >>>](#)

#DataSavesLives

Recordings now available for *Making ePI a Reality: The User Journey*

On 23 November 2021 and 11 January 2022, the **PharmaLedger project** held its 3rd open webinar and live Q&A on the user journey in making electronic product information (ePI) a reality.

The webinar, which featured EPF Project Coordinator, Hannes Jarke, covered PharmaLedger's blockchain-enabled ePI use case, its evolution over time, and the

JUST PUBLISHED! PharmaLedger In-depth Ethical and Legal Study

On 25 January 2022, the **PharmaLedger** project published an in-depth ethical and legal study to assist the developers of the project to ensure the platform and its solutions meet all data protection, ethical, and legal requirements. This **study was co-authored by the European Patients' Forum**.

One of the aims of PharmaLedger is to

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Missed the live event? You can hit the link below for the recording, and watch to learn how PharmaLedger is reimagining the way product information is delivered to improve patient outcomes.

To learn more about the project, the role of EPF and the benefits for patients, head to our [dedicated project page](#).

[Watch the webinar here >>>](#)

and confidential health data. Maintaining **data privacy safeguards is of the utmost importance in the considerations of patients** when applying blockchain to healthcare.

However, implementing blockchain technologies into highly regulated industries, like healthcare, can move slowly largely due to legal and regulatory questions regarding compliance with existing legislation.

[Read the study to learn more about these important considerations >>>](#)



PharmaLedger
BLOCKCHAIN ENABLED HEALTHCARE



Youth Group

initiatives, stories and events from our most budding members

What the EPF Youth Group has Accomplished in 2021....

By Ivett Jakab and Anastasia Semaan

As the EPF Youth Group (YG) we are very proud of our accomplishments in 2021 and very much looking forward to working towards our goals for 2022. Throughout 2021 we have achieved our ultimate goal of representing the young patient perspectives on different platforms, and we are very proud of the growth of our youth group and the progress that we have made within our own projects.

We proudly present to you the year of 2021 for the EPF Youth Group in numbers:

- 20+ virtual YG meetings, including Monthly calls, our Spring and Fall Meetings 2021, virtual team building games nights, a multi-session training on project management and a communications training with the EPF Comms Team. We hope to finally meet in person in 2022!
- 4 new members joined our Youth Group family and we have bonded well together over the year. We are entering 2022 with the hopes of recruiting new members and working together on upcoming projects.
- 1 YG member represented us with full voting rights in the EPF Board throughout the year.
- 3 of our YG members were team leaders within the Summer Training for Young Patient Advocates (STYPA) and had a great role in educating and inspiring the future leaders of patient advocacy.
- 3 EU projects where our members contributed to the Patient Panel or the dissemination of the results in collaboration with EPF.
- 2 YG sessions organized during the EPF Congress and our President co-hosted the event.

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(PEOFs), EPF member organizations' events and more.

- 2 YG-lead projects kicked-off in 2021, one on the 'Sexual health and wellbeing of young patients' and one on 'Young Patient Engagement in Patient Organizations'. 2 surveys were conducted and numerous deliverables produced, including social media posts on our [Facebook](#), [Instagram](#) and [Twitter](#) accounts, an [article](#) and a [podcast episode](#). Keep your eyes on our channels for the next steps in 2022!

To find out more about what we are achieving in 2022 continue to follow us on our social media channels. If you have any question, reach out to us through the following email address: youthgroup@eu-patient.e



Member Focus

highlights from our member organisations



European
AIDS Treatment
Group

RBDCOV: EATG represents community in a new project aiming to study COVID-19 vaccine

EATG is participating in **RBDCOV**, a project aiming to study a COVID-19 vaccine in children, adolescents and immunocompromised patients. Drawing from its experience in patients' advocacy and representation, EATG will contribute to the studies through community insights and outreach.

[Find more information about RBDCOV in this press release>>>>](#)

[Learn more on EATG's website>>>](#)



Registration is now open for the first event in the **European Life After**



Meeting of Minds 4: "How can new technologies better support patients?"

On February 23-24, the "Cancer Survivorship – AI for Well-being" (CS_AIW) Cluster will hold its 4th Meeting of Minds, the first to be open to the public, as patients and survivors will be part of the audience. In fact, the event will revolve around the question "How can new technologies better support patients?"

[Learn more about the event >>>](#)



Improving lung health through the future European Health Data Space

Organised by the MEP Lung Health Group, and



Survey: Are mental health needs being met by patients?

Gamian's survey, developed in collaboration with the European Psychiatric Association, seeks to explore the impact of COVID-19 on mental health care and services, from the patient and the clinician's points of view.

The survey report will serve to advocate for national-level change, as well as raise awareness of the importance of EU-level action on mental health.

The survey is now available in **11 European languages!**

Deadline: **March 1st.**

[Take the survey >>>](#)

Patient-clinician experience in

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With two plenary sessions, the event will cover the important topics of self-management and communications after stroke. There will be a mix of presentations from stroke survivors and other eminent speakers from across Europe.

[Learn More and register>>>](#)



Everybody was looking forward to the **Annual Pulmonary Hypertension European Conference** (APHEC) and General Assembly (GAM), however the sudden surge of the new mutation of COVID (which resulted in various measures and restrictions) washed away the in-person meeting plans.

As the mandate of the previous board has ended, new elections were made as part of the virtual GAM in the middle of January.

PHA is delighted to welcome our new president **Eva Otter** from Austria.

[You can get to know PHA's new board here>>>](#) and the [auditors here>>>](#)



Share Your Colours on Rare Disease Day 2022

For Rare Disease Day 2022, everyone is invited to [Share Your Story](#) and [#LightUpForRare](#) at

Margarita (S&D Portugal) and Sara Cerdas (S&D – Portugal) - the event will bring together digital health experts, policy makers, healthcare professionals, and patient representatives to discuss how the expectations from the respiratory community could be reflected in the future European Health Data Space (EHDS) legislation, and its huge potential to improve prevention, diagnosis, management and quality of life of people living with lung diseases.

It will crucially mark the launch of the European Lung Health Group (**ELHG**) policy brief on the future European Health Data Space (EHDS), a document to expand the group's BREATHE Vision on the topic of digital health. Breathe Vision is an informal group of European level non-profit organisations with currently 179 member associations across 34 European countries, including 9 from non-EU states. Its mission centres around bringing together know-how to support our organisations in empowering patients with lung diseases, improving quality of life, optimising multidisciplinary care, and early diagnosis, and research.

The event will take place online **February 8 from 14:00 to 15:00 CET**.

[More details and registration here>>>](#)



A trustworthy relationship with a clinician is key for improving treatment outcomes in individuals with schizophrenia. But, at present, we lack knowledge of the key ingredients and challenges of an effective therapeutic relationship. To address this gap, GAMIAN-Europe has teamed up with the **EPA**, to undertake an in-depth qualitative analysis of this topic.

Research is currently ongoing – with interviews being carried out in mental health centres in Germany, Poland, Italy, and Hungary.

Suicide Prevention in Young Men

Suicide is commonly described as a 'male phenomenon', as men are 4 to 5 times more likely to die by suicide compared to women, in the European Union.

This project aims to explore and raise awareness of the mental health challenges faced by young males during the pandemic and the factors behind a potential increase in suicide ideation amongst this population group. >>

[Stay tuned for more information!](#)

Are you someone with lived experience who would like to share their views and experience on this topic? (Financial compensation provided). >> Get in touch!

[Learn more on GAMIAN's website>>>](#)

Voting for the EURORDIS Social Media Award is open now.

The brand new Award

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your solidarity and help to raise awareness for people living with a rare disease!

Ministerial Conference on Research and Care Pathways: For a European policy on rare diseases

Be sure to join EURORDIS-Rare Diseases Europe at this high-level conference, organised in accord with the Presidency Trio on the occasion of Rare Disease Day, to define the EU roadmap for rare diseases and discuss the implementation of a European plan for rare diseases. [Learn more](#)

Have you registered to attend the **Black Pearl Awards 2022** yet? Don't miss this opportunity to celebrate those who make a difference for the rare disease community! Join us for FREE remotely on Tuesday 8 February 18:00-19:30 CET.

VOTE: You can learn more about EURORDIS' three finalists and VOTE for your favourite one [here](#). The winner will be announced at the live EURORDIS Black Pearl Awards Ceremony celebrating the amazing achievements of people living with a rare disease on 8th February (from 18:00 CET).



Inside the Bubble

updates, stories and events around EU healthcare

EU regulator backs Pfizer's antiviral pills to treat COVID-19

The European Medicines Agency recommended the use of Pfizer's antiviral therapy Paxlovid to treat people diagnosed with COVID-19.

The oral tablets should be given to people most at risk of developing severe disease from the infection. The therapy, a combination of two pills, is intended for people who do not require supplemental oxygen.

ECDC eyes transition to 'post-acute' phase of coronavirus pandemic

The EU's disease control agency has issued a mixed verdict on the state of the pandemic in its latest risk assessment: infections have hit new records but there are signs that the pandemic will transition to a more manageable phase following this latest wave.

Cases in the EU/EEA are four times higher than the previous peak, with a 14-day notification rate of 2,621 cases per 100,000, the European Centre for Disease Prevention and Control said. The more infectious Omicron variant is driving this increase as it spreads eastward across the continent.

Denmark becomes first EU country to scrap all COVID-19 restrictions

Denmark is to lift all remaining COVID-19 restrictions, with Omicron hospital admissions and deaths remaining stable and high rates of vaccination. "Tonight we can shrug our shoulders and find the smile again. We have incredibly good news, we can now remove the last coronavirus restrictions in Denmark," Prime Minister Mette Frederiksen said at a press conference, following recommendations from the Epidemic Commission and with all the main political parties' support. The last restrictions will be dropped on February 1.

Life's most persistent and urgent question is, 'What are you doing

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Martin Luther King Jr.



Calendar of Events

4 February
World Cancer Day

[visit our website](#)

22 February
World Encephalitis Day

[contact us](#)

27 February
World NGO Day

28 February
Rare Disease Day

[view this email in your browser](#)

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