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The Patient Perspective

October 2022



Reflections

Welcome to our October Patient Perspective newsletter!

October just flew by! It was an active and busy month for us at EPF, but for our members too!

Here's a brief overview of the topics we cover in this month's issue:

- Our policy team is bringing us up to date with the most discussed dossiers in the EU Bubble.
- We are ready to share the first insights from the third webinar from the "Understanding AI" series. More will come soon!
- We joined a group of 29 stakeholders in formulating recommendations to consider in the implementation of the European Health Data Space.
- Our STYPA22 participants delivered their final project and proposed the Communication Principles on Young Patients and Sex.

Our Youth Group is sharing their personal experience and insights gained from attending several European conferences on patient involvement.

It has been an intense month for the Projects Team, with milestone events taking place all over Europe: the inaugural DSL Training Bootcamp in Prague, The H2O General Assembly in Basel, and the kick-off meeting for a new project: PROPHET.

Moreover, we are less than three weeks away from the COMPAR-EU Advocacy Event, that will mark the end of the project. Our preliminary agenda is ready with contributions from a wide range of stakeholders. Interested in finding out more about self-management? We have great news for you: there are still some free spots left!

Stay connected to the relevant discussions in healthcare by having a look at what our members are doing: Europa Donna, World Duchenne Organization, Alzheimer Europe, EATG, and Gamian-Europe have shared with us some updates from this month. Keep an eye out for the newest EPF updates on our social media channels!

The EPF Team



Policy and Advocacy Corner

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

Policy Corner: October in review

September to December is always a busy time for the European Patients' Forum (EPF), and October was no exception!

This month has been full of events where the policy team has brought a patient perspective on a wide range of issues. From the Biosimilars 2022 **Conference** organised by Medicines for Europe to the EULAR Annual Conference of PARE (People with Arthritis and Rheumatism in Europe) to the event on Bertelsmann Stiftung's **new report** on tech giants in healthcare, we discussed, among other things, the pharmaceutical strategy for Europe, access to medicines or digital health literacy.

The policy team also continued its ongoing collaboration with **the Organisation for Economic Co-operation and Development** (OECD) to bring a patient perspective on the OECD's work and encourage more patient involvement. We have been particularly involved in the Working Party on Health Care Quality and Outcomes and the Patient-Reported Indicator Surveys (PaRIS) Patient Advisory Panel.

The policy team further continued its work on two major digital health dossiers: **the European Health Data Space** (EHDS) and **artificial intelligence** (AI) in healthcare. After **responding** to the European Commission's call for feedback on the EHDS last July, we conducted two internal consultations to refine our position in view of the discussion by the two EU co-legislators. In parallel, EPF joined a group of 29 stakeholders and co-signed a consensus stakeholder **response** to the proposed EHDS regulation, calling for, among other things, the involvement of a wide range of stakeholders from the outset or a harmonised interpretation and implementation of the regulation across the EU.

As part of our AI webinar series, EPF hosted a webinar on EU AI legislation and the healthcare sector, where, for the occasion, our two latest reports on AI and our member survey were presented. These shed light on how patients perceive AI in healthcare, with a particular focus on expectations, challenges and understanding the impact on patient care.

In addition, the policy team responded to the Commission's public consultation on the **EU framework for cross-border recognition of associations**, highlighting the need for such a legal framework to alleviate the administrative burden and obstacles faced by associations in their cross-border activities.

The European Commission's 2023 work programme is out

On Tuesday 18 October, the Commission presented its **2023 work programme**, which sets out its plans for the coming year.

In the field of health, the focus is on the **medicines ecosystem**, which aligns with EPF's core priority to improve access to high-quality, safe, effective and affordable medicines and innovative therapies that meet patients' needs. The Commission will indeed publish a

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direct intellectual property rights around medicines and vaccines and ultimately patient access.

In addition, the Commission will revise the **variation framework for medicines** in the fourth quarter of 2023. Announced in the Pharmaceutical Strategy, this initiative aims to revise the rules setting out the procedures for post-authorisation changes to a marketing authorisation for medicines for human use.

Although the revision of the pharmaceutical legislation is not mentioned in the 2023 work programme, it will undoubtedly be a huge piece of legislation in which EPF will be heavily involved to ensure that the patient voice is heard.

The coming year will further focus on the **European Health Data Space** (EHDS). Listed as a priority pending proposal by the Commission, it is also high on the agenda of EPF, which will continue to engage with policymakers to ensure that the EHDS is developed with patients' interests at the centre.

Mental health is also gaining ground at EU level. The Commission will publish a **comprehensive approach to mental health** in the second quarter of 2023. As part of a holistic view of health, we are continuously supporting actions in favour of mental health and will amplify the voice of our members working on mental health.

Outside the health field, EPF will also focus on the legislative initiative on **cross-border activities of associations**, which the Commission plans to publish in the second quarter of 2023. This initiative will have an impact on EPF and our members, as associations operating across the EU, and follows the public consultation on this issue to which we responded.

All in all, it is a busy year ahead, during which EPF will continue to engage with policymakers, monitor legislative developments and inform our members, in order to amplify the voice of patients in the EU!



News From the Secretariat

updates from the inside

EPF presents
Understanding AI | Webinar series

**WEBINAR 3:
EU Legislation on AI**

28 OCTOBER 2022 at 14:30. WITH:

 HANNAH VAN KOLFSCHOOTEN
PhD researcher, ICHL

 MAHSA SHABANI
Assistant professor, UGent

Understanding AI Series: Webinar #3

the end of the year and registration is public and free:

Our speakers today, Mahsa Shabani and Hannah van Kolschooten, delivered insightful information that allows us to upkeep the conversation on Artificial Intelligence, specifically on the use of AI in healthcare and how this reflects on patients' rights. – your insights and input were enlightening and so important in the upkeep of the conversation on #AI, #healthcare, and #patientsrights.

What's next? We will of course keep you informed about the follow-up results and reflections. More to come very soon.

We look forward to receiving you at our next webinars!



EPF joined the stakeholders' consensus response to the proposed European Health Data Space (EHDS)

On 20 October, EPF joined a group of 29 stakeholders in welcoming the European Commission's proposal on the European Health Data Space (EHDS). The stakeholders, including medical professional and research organisations, patient representatives, industry associations, and data collaborations, strongly support the aims of the EHDS as proposed by the European Commission.

The consensus response statement formulates recommendations to consider when developing the more specific implementation plans to put the regulation into practice across the member states:

1. A broad range of stakeholders must be strongly involved from the outset of the process to guarantee the success of the EHDS.
2. The EHDS must align with all relevant horizontal and sectoral European laws.
3. There must be harmonised interpretation and implementation of the regulation across the EU.
4. Approvals for secondary use of health data must be consistent and harmonised across Europe.
5. The scope of EHR systems must be defined clearly within the regulation.

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build on existing expertise.

The full statement is available [here](#).

The first step in successful communication about sex is to think about your own feelings, your sexual needs, and what you want out of sex and relationships.

YOUNG PATIENTS & SEX COMMUNICATION PRINCIPLES



Final project - Communication Principles on Young Patients & Sex

We are pleased to announce that the final project of [#STYPA22](#) is here! This year's participants worked very hard on developing a wonderful set of principles to use in your communication around sex as a young patient.

Did you get curious to learn more about the communication principles? Find them [here](#)!



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Represented

Anastasia Semaan

Over the past month, as a Youth Group we have had multiple opportunities to represent not only our individual perspectives as young patients but as a group too. Many of our members have attended conferences and workshops around new topics that surround us today as young patients but also some that are very near and dear to us. We hope to continue this participation in order to develop our advocacy skills and awareness as patient advocates, but also to continue to ensure that the patient voice is represented.

Thank you to Cornelia Pauna and Konstantina Boumaki for representing our Youth Group and I too have loved the opportunity.

Let's hear from our amazing participants and youth group members what they have been participating in and their personal key takeaways:

According to our amazing Vice President Cornelia:

"In October I participated in PEOF in Barcelona where I presented the perspective of young patients in the involvement of young patients in innovative clinical trials. I took part in very insightful presentations and discussions which not only opened my mind in new ways, but also made me even more hungry to understand and argue the status quo for patients in general, but particularly for young patients.

As part of the session I took part in, we needed to work on a case study about a hypothetically clinical trial that has as target group adolescents with acne. It was very interesting to observe how most of the participants were adults trying to imagine how it is like to be in adolescent shoes. The truth is that this is also the reality, which brings me to my conclusion: We need more representation of young adults in designing and taking part in the clinical trials, which will not only benefit the young patient population since their needs are directly represented, but also

member and Social Media Officer Konstantina:

"I had the opportunity to participate in the Data Saves Lives training bootcamp, which was an amazing experience! The speakers had a great way of explaining all the information we needed, so we can form groups, discuss possible difficulties we might have experienced already or we think we may have when we start collecting data and present solutions in these. We had the opportunity to be acquainted with Data Saves Lives toolkit and talk about it thoroughly.

My key takeaways from this training were:

- The importance of data gathering
- There might be a lot of difficulties in this effort, but there are a lot of ways to solve them or find another way to succeed in your goal.
- Together we are stronger! By sharing possible difficulties and trying to figure a way out to solve them all together is way easier than facing them alone!
- Last but not least, there is never enough data for anything!

It was an amazing experience and I am very happy that I had the privilege attending this training, as part of the Youth Group, and I am so thankful that EPF is giving us these opportunities!"

Finally, I had the opportunity to join in the 30th United European Gastroenterology Week, in Vienna, where I got to participate in the Patient Organisation Workshop on Transitional Care, all hosted by ESPGHAN. It was such an amazing opportunity and I was able to represent the young patient perspective and the EPF YG to highlight our voice and the importance of the patient voice in the transitioning stages as a patient.

Transitional care was an area of knowledge that I initially did not feel very connected to, but as I reflected on my journey as a patient, I recognized the importance of the transition process and

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to be a young patient in the current society.

Another take away was about involving the patient more in post-launch activities of a drug as well as in its design. There were several questions that came up from this discussion, such as: is the feedback of the patient for the specific drug used and how can a patient know that? What role does the "Quality of Life" play in these feedback forms? Is it even considered?

One last idea that I wanted to highlight here is about the labels used for patients and their impact. Right now we use several layers, like: expert, patient expert and young patient expert. Each of these terms mean or represent something and their importance is not equal and thus, not treated as such.

One important key takeaway for me from these meetings is that we should redefine the meaning of these terms and their meaning. Our role as patient advocates is to help in bridging these gaps in the terminology, which will help us not only in receiving more accurate attention from the doctors, industry but ultimately to receive better treatments tailored for our needs.

If I were to sum up my takeaways, they would look like this:

- Young patients need more representation in clinical trials, both in designing it and actually testing it.
- Patients in general need to be more visible in the design of a new drug as well as their feedback which should be considered also in regards to the Quality of life.
- Bridge the gaps in labels."

workshop I gained an understanding of the importance of the relationship between the patient and the doctors and the strong role that they both play in collaboration for a "successful transition process".

Being able to learn more about the transition process of young patients and the different stakeholders that are involved and should be considered was very empowering. Furthermore, being able to work together with other members within the field and with those who have different expertise was very insightful. It was promising to experience the feeling that my voice was valued and I see the view of patient to be placed more at the forefront in the future.

I have gained the following takeaways:

- Transitional care happens from birth, from the moment that patients are born, the first stage of transitional care is the baby going home. This for many is not granted, or can happen later than expected.
- The patient voice within their own transitioning phase and period is of utmost importance because many are being silenced and it is important that we represent who who cannot.
- The Empowerment of the Patient should be the call of action and ultimate goal/commitment within any additional future steps within transitional care.

I look forward to continuing to work with this amazing team and ultimately share the future of the patient's role and voice in their transitional care.

We have loved as a Youth Group to take part in such events and we hope that these opportunities for us to take part continue.

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Calling all future EUPATI Fellows – register now to graduate in 2023

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development (R&D) from design and execution of clinical trials to regulatory processes and Health Technology Assessment (HTA). In addition to detailed information on each step of the process, the training also describes how patients can be involved at each step of the way. Are you interested in diving deeper into the medicines R&D process and taking an active role in collaboration with other involved stakeholders? Would you like to join a network of soon to be 200+ trained patient experts? [More information here.](#)

Still space available for the next **EUPATI Fundamentals Training!** Register today for the upcoming Fundamentals training taking place **online 14 and 15 November from 10.00 – 16.00 CET**. Throughout this 2-day training, participants will learn about **patient engagement and get hands-on lessons** and experiences on how to engage with patients in a meaningful and sustainable way. EUPATI Fundamentals focuses on patient engagement for professionals in academia and the pharmaceutical industry. The **mix of practical and classroom learning guides professionals** through the processes of engaging patients through medicines development **providing a strong foundation for a successful partnership with patients and patient organisations.** [Register now.](#)



Projects Portal

briefings on EPF's ongoing projects

NEW ! Preliminary Agenda available for the COMPAR-EU Final Conference Advocacy Event


The European Patients' Forum is pleased to announce that it will host the **COMPAR-EU Final Conference Advocacy Event**, to mark the end of the project.

This advocacy conference marks the culmination of **5 years of interdisciplinary work** to identify, compare, and rank the most effective and cost-effective self-management interventions for adults in Europe living with high-priority chronic conditions.


The aim is to gather ~70 stakeholders to exchange experiences and expertise on self-management (SM) best practices, share the lessons learned from the implementation of SM policies, and discuss how to best integrate and incorporate the project's findings across various settings. Other topics, like the **Self-Management Europe Initiative**, project lay-language materials, and self-management policy implementation practices will also feature in the programme.

The conference will take place in Brussels, and will feature patient representatives from across Europe, EU policy makers, other EU health stakeholder organisations, COMPAR-EU project partners, and national public health representatives.

Key information:

 15 & 16 November, 2022

 Brussels, Belgium

 Interested in attending? Get in touch with Lyudmil Ninov at lyudmil.ninov@eu-patient.eu

[>> Access the preliminary and other information here.](#)



Data Saves Lives Training Bootcamp

On 10 & 11 October, **Data Saves Lives** held its inaugural Training Bootcamp in Prague. The aim of the bootcamp was to equip ambassadors with an understanding of key terminology used in health data conversations, provide an overview of European legislation (like GDPR and the European Health Data Space), and build confidence to handle challenging questions around health data.

17 Ambassadors from across 14+ countries, representing many different conditions, joined for two days of all things health data – from covering key issues, to workshopping their own ideas on the promotion and education about the responsible use of health data. Participants came away with a clear plan of action to implement once the bootcamp ended.

We ended the bootcamp with a 1 hour tweet chat with trainers Lars Munter (Danish Committee for Health Education), and Angela Bradshaw (Alzheimer Europe) around the topic of making health data more inclusive.

Learn more [about Data Saves Lives](#), or read the [play-by-play of the Tweet chat](#).



Health Outcomes Observatory (H2O) General Assembly in Basel

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assembly for H2O, which began in October 2020.

Our EPF colleagues **Lyudmil, Valentina**, and **Estefania** attended the meeting to represent our work on bringing patient engagement to the core of the project.

The event was kicked-off with an insightful keynote address from Seonaid McNabb, a member of the project Patient Advisory Boards. Valentina Strammiello and Estefania Cordero, with support from **JDRF** consortium partner Carmen Hurtado, led a session on patient empowerment; and our colleague Lyudmil Ninov, together with Carmen Hurtado, led a session on patient value propositions. Keep reading here for her **full** update.

H2O aims to set up patient-centric, pan-European, and national observatories to amplify the patient voice in their own healthcare and in healthcare systems more broadly. It is a project funded by the Innovative Medicines Initiative (**Innovative Health Initiative**).

Learn more about H2O, EPF's involvement, and how the project is bringing value to patients.



EPF attends kick-off meeting for PROPHET project

On 21-23 September, the PROPHET project held its inaugural meeting in Rome at the **Università Cattolica del Sacro Cuore**, the project coordinator.

PROPHET is a **Horizon Europe** project, composed of 18 European partner organisations. The project aims to create a personalised prevention roadmap for the future of healthcare in Europe. The roadmap will be co-created together with a large panel of stakeholders gathered in the PROPHET Stakeholder Forum, and aims to support the definition and implementation of innovative, sustainable and high-quality personalised strategies that are effective in preventing chronic diseases.

EPF's participation in the project will centre around mapping current practices and gaps in patient engagement in personalised prevention; capacity building activities for member organisations; and supporting the project's impact and visibility with communications activities. **Lyudmil Ninov**, Sr. Programme Officer will coordinate EPF's contributions.

>> **To learn more about PROPHET, the project's aims, EPF's role and the value for patients, click here.**

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Member Focus

highlights from our member organisations



EUROPEAN BREAST CANCER CONFERENCE

Europa Donna invites us in Barcelona for the EBCC-13 European Breast Cancer Conference and to be part of a unique gathering of physicians, scientists and patients to continue advancing the rapid translation of clinical research into practice. ED is the only patient advocacy organisation that is a co-organiser of a major European Breast Cancer Conference.

DEADLINE for Registration is 7 November 2022

[To register, click here >>>](#)

You can also join virtually if you cannot travel to Barcelona!

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**11
22**

TIME
13:00
17:00
CET

ONLINE

**INTERNATIONAL
FAIR MEETING ON DATA VISITING**

*For Duchenne, Becker and other
Rare Diseases*

**WORLD
DUCHENNE
ORGANIZATION
WDO**

The **World Duchenne Organization** is pleased to announce that the 3rd International FAIR data 'visiting' for Duchenne & Other Rare Diseases is taking place on 22nd November 2022. Registrations are now open. This meeting is of interest to representatives of patient organizations, clinicians, researchers, companies, academia, FAIR experts, funders, and health policymakers.

Objectives of this meeting are to:

- Understand the value of FAIR by Patient Organizations and patients themselves
- Increase awareness amongst Patient Organizations on the FAIR solutions available to them
- Be familiar with the latest infrastructure and ecosystem for data visiting in Europe
- Show tangible examples of successful FAIR practices
- Agree on next milestones on data visiting for Duchenne and other Rare Diseases

The agenda and the registration link are [available here >>>](#)

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17-19 October: Alzheimer Europe held its 32nd Annual Conference #32AEC in Bucharest and online

The 32nd Alzheimer Europe Conference (#32AEC) "Building bridges" was held from 17 to 19 October 2022, at the JW Marriot Hotel conference centre in Bucharest, Romania. It was held as a hybrid event for the first time ever, with delegates and presenters able to join either on site or online, thus making it as accessible, inclusive and interactive as possible. 544 participants from 42 countries attended the conference, and the agenda included over 250 presenters (187 oral presentations, 38 quick oral presentations and 63 poster presentations), who shared their research, knowledge and experience in an atmosphere of true collaboration and solidarity.

Iva Holmerová, outgoing Chairperson of Alzheimer Europe (pictured, centre), opened the conference, extending a special welcome to the 22 people with dementia among the delegates, as well as to their supporters. Echoing the theme of the conference, she said, "we hope to 'build bridges' across European borders, to ensure that good practices in dementia care and innovations in diagnosis and treatment are made equally available across the whole European continent." As our countries are slowly emerging and recovering from the impact of the COVID-19 pandemic, our continent has unfortunately seen the return of war. However disheartening, she stressed that she was encouraged by neighbouring countries welcoming Ukrainians fleeing the conflict and by organisations doing their best to support refugees with dementia and their carers. She highlighted the vital work of the European Working Group of People with Dementia (EWGPWD), noting the 10th anniversary of the group this year, singled out the fantastic collaboration that Alzheimer Europe has developed with the INTERDEM network, and expressed the organisation's gratitude to its corporate conference sponsors, Biogen, Lilly, PAVE and Roche. In closing, she informed delegates of her decision to step down from the position of Chairperson of Alzheimer Europe. "The organisation has grown a lot in my time here and I am very proud of our achievements, not least of which is our success in truly giving a voice to and integrating people with dementia in all our work", she stated. She also warmly congratulated her successor, Rosário Zincke dos Reis from Portugal, who was elected as her successor, during Alzheimer Europe's Annual Meeting, just prior to the conference.

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vugt, Chairperson, INTERDEM (Early detection and timely INTERvention in DEMentia) and Cătălina Tudose, Chairperson of Societatea Română Alzheimer. The opening ceremony was followed by a keynote presentation delivered by Alexander Kurz, Klinikum rechts der Isar, Technical University of Munich, Germany, called " Building bridges - Promoting good dementia care through pan-European collaboration".

You can read [Alzheimer Europe's full conference report, here](#).



Updates from EATG

The Glasgow Manifesto, issued by iCOPE HIV, was launched on the 26th of October, at the HIV Glasgow conference. The manifesto, endorsed by more than 110 organisations, calls to action all stakeholders to work in partnership to empower and to improve the care and quality of life of people living and ageing with HIV. iCOPE HIV is an initiative of EATG and Realize.

EATG published a **new position paper** on *Why people living with HIV must be included in non-HIV clinical trials*.

Have a look at this update from EATG's **General Assembly**

'HIV, TB, viral hepatitis and STIs' Thematic Network led by the EU CSF is selected by the Commission. EATG is **part of the coordination team** of the EU Civil Society Forum on HIV, TB and Viral Hepatitis and is supporting its secretariat functions together with AIDS Action Europe.

They also coordinated an **Open statement** on access to long-acting injectable Cabotegravir for HIV prevention in Europe. The statement remains open for more endorsements. In case you missed it, EATG has also **published an interesting blog** from one of our members who was invited by the WHO Regional Committee for Europe.



Updates from GAMIAN-Europe

Gamian-Europe welcomes its new President: On the 29th of September, Péter Kéri from Awakenings Foundation, a mental health patients' organisation in Hungary, was elected by the GAMIAN-Europe's Board of Members. More information [here](#).

On World Mental Health Day, held on the 10th of October, GAMIAN-Europe together with stakeholders from different organisations including EPF, called on the European Commission for more actions on mental health. Watch the video [here](#).

There isn't one set route out of depression. Don't miss the campaign "Breaking Depression" launched in October with the collaboration of GAMIAN-Europe and EUFAMI. Visit www.breakingdepression.eu to learn more.

On the 25th of October, GAMIAN-Europe and the MEP Alliance for Mental Health co-hosted a meeting in the European Parliament to capitalise on the current EU-level momentum with respect to mental health. Read more [here](#).

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