



The Patient Perspective

December 2020



Reflections

2020 has been an extraordinary year.

It has shown ordinary citizens how fragile our societies are and how fast everything can be turned upside down by something so small that it is invisible to the naked eye. It has taught ordinary citizens that health is a precondition for our societies and economies to function and prosper. These are already concepts that we, as patients and patient organisations, are inordinately familiar with. In 2020, everyone finally recognized the patient perspective.

More than anything, these extraordinary circumstances have reminded us of the value of solidarity, cooperation and being united in diversity to overcome the biggest health crisis in modern times.

In this newsletter, we take a look back at the issues, initiatives and events that stood out for the EPF team in 2020 and what will shape us for the upcoming year.

As 2021 approaches, we look forward to your continued collaboration on our mission to advance the interests of patients and patient communities by strengthening their collective impact across Europe through effective advocacy, education, empowerment, and partnership. We wish you good health and a strengthened resolve in 2021.

Happy Holidays!

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Policy and Advocacy Corner

discussing the most relevant patient-centered policy and advocacy issues

2020 was an extremely busy time for the Policy team as the pandemic caused a paradigm shift in terms of EU actions in healthcare. Our typical workflow was upended and shifted to the virtual realm leading to increased participation in conferences, webinars and meetings. While we pursued several issues over the year across different policy areas, four topics stand out the most, which we have shared below.

Digital Health

A busy year for digital health at EPF, started with the publication of the Summary of our survey on the European Health Records and the Policy Briefing Paper on Big Data and AI. These two documents supported the preparation and submission of EPF's responses to two major EU Consultations on the most recent European Commission's plan on digital: the [EU Data Strategy and the White Paper on Artificial Intelligence](#). The two consultation responses were published together with more comprehensive position statements on these topics that will serve as a basis for our 2021 activities. Furthermore, on AI and to better understand EPF's community views on it, we have launched a dedicated survey in October. The results of the survey will be available in early 2021.

EU4HEALTH and the future of health in the EU

The pandemic led to a broad rethinking of EU actions on healthcare. Following the proposal for a new and reinforced standalone health programme called 'EU4Health' EPF has engaged with European institutions to shape a proposal that would take into account the needs and asks of patients and patients organisations through an inclusive and adequately funded Programme. The final agreement, reached in December, includes a welcome budget of 5.1 billion euros and many elements at the centre of our advocacy efforts on the Programme. However, patient organisations will still need to engage in the EU4Health design and governance to ensure the adoption of work programmes taking into consideration the real unmet needs. EPF's own initiatives on the health programme

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with civil society organisation through the [EU4Health Civil Society Alliance](#), co-led by EPF and EPHA.

Furthermore, EPF has started to engage in the discussion around the European Health Union with a vision statement and participation in several events, including a webinar organised by the European Parliament's group of the Socialists and Democrats in December.

Medicines and Vaccines

In July 2020, EPF launched its paper '[The Value and Pricing of Innovative Medicines](#)' with a successful event co-hosted by MEPs Kateřina Konečná, Tomislav Sokol and Tiemo Wölken and featuring a keynote speech from EU Commissioner for Health and Food Safety, Stella Kyriakides. The release of the Paper, however, is just one element of EPF's work on medicines, which also included engagement on one of the key European Commission's initiatives on this topic: the new Pharmaceutical Strategy.

Furthermore, 2020 saw the launch of our tender project VAC-PACT, which is aimed at producing important resources, including dedicated toolkit and an informative website, on vaccination for chronic disease patients.

COVID-19

Our Survey on COVID-19, which collected more than 120 responses, and the constant engagement with EU institutions and agencies to discuss the impact of the pandemic on European patients and to call for safety and transparency on the [COVID-19](#) vaccines.



Projects Portal

briefings on EPF's ongoing projects

2020 has passed in a flurry for the EPF Projects Team. Consortium meetings, project kick-offs and closing conferences which normally take place as in-person events to mark the years invested into projects were all moved to digital realms. Like everyone, we got acquainted with Zoom, Teams, GoToMeeting, WebEx ... the list goes on. Although we had several highlights over the year and a number of successes across our project portfolio, four stand out the most, which we have shared below. In the meantime, we are eager for a few days of rest over the winter holidays, and are looking forward to begin the new year on a high note.

DigitalHealthEurope workshop and roadmap:

One of our main highlights this year was the 5 & 6 October two-day multi-stakeholder workshop under the framework of the [DigitalHealthEurope](#) project.

The Workshop was a great success, and brought together key stakeholders with an interest in digital tools to empower



CHRODIS-PLUS Joint Action closing:

On 27 October 2020, the CHRODIS-PLUS JA held its closing conference on Chronic Diseases, bringing the project to a close. The

aim of CHRODIS-PLUS was to support countries to overcome the burden of

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the opportunity to validate its patient empowerment roadmap, and gather view points from the participants. Ultimately, the insights generated at the Workshop will inform the work of EPF to deliver and White Paper to empower patients through their active cooperation with health and care professionals in large-scale health ecosystems.



PARADIGM project closing: On 30 November 2020, the Patients Active in Research and Dialogues for an Improved Generation of Medicines

([PARADIGM](#)) project came to a close. PARADIGM, which was [co-led by EPF](#), aimed to make patient engagement in medicines development easier for all. To close the project, there was a final session of the Patient Engagement Open Forum, co-organised with [PFMD](#) and [EUPATI](#). Two outputs of the project were presented: the Patient Engagement Toolbox, which centralises the project recommendations, and the Monitoring and Evaluation Framework with metrics, which connects the dots between metrics to understand how patient engagement translates into impact and why initiatives fail or succeed. We take this opportunity to thank all the partners involved inside or outside the consortium that helped the project to deliver on its promises. For more explanation on how PARADIGM can be factored in the bigger picture, please read [this letter](#) from Magda Chlebus at EFPIA, and EPF's Nicola Belington and Mathieu Boudes.

the project. A main objective of the Final Conference was focused on tailoring good practices implemented by the project to various settings across Europe. EPF participated in the implementation phase of the project methodology and assessed patient involvement throughout this process. EPF worked together with partners to develop and pilot the CHRODIS-PLUS Workbox on Employment and Chronic Conditions, which supports EU member states and their workplaces in creating working conditions that foster wellbeing, health, and work ability; prevent the development of chronic diseases; and help individuals with chronic health problems to continue working.



Data Saves Lives campaign launch: This year, the [Data Saves Lives initiative](#) was formally launched. Led by the European Patients' Forum (EPF) and the

European Institute for Innovation through Health Data ([i~HD](#)) Data Saves Lives aims to raise wider patient and public awareness about the importance of health data, improving understanding of how it is used and establishing a trusted environment for dialogue about responsible use and good practices across Europe. In a timely debut, DSL has a crucial role to play in stimulating structured and meaningful discourse with the health data community on societal questions about the uses of health data, with a view to enhance trust and cooperation. The initiative launched its new website and social channels on [Twitter](#) and [Instagram](#), and held two webinars, two [tweet chats](#), and published [blog-posts](#) from guest writers on the most topical health data questions. This year was culminated in a two-hour [workshop](#), hearing from key stakeholders – like patient experts, patient organisations, association and industry partners – on what most resonated, and how to make a bigger impact in 2021.



Capacity Building Centre

a rundown on EPF's seminars and learning tools

In 2020 EPF had to move our highest Governance event online. Usually, representatives

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50 attendees, the most we have ever had, in our first ever virtual AGM. In the span of a few hours, we were successful in covering all agenda items which would have usually taken two days.

During the 2020 AGM, our members voted on, and elected the first ever [EPF Ethics Committee](#). It is a key part of the organisation's mission. The roles of the Ethics Committee members include issuing opinions or advice upon written request from the Board; recommending appropriate handling of conflict of interests and providing general advice on wider ethical issues that EPF needs to address, in the context of legislation or practice.

Subsequently, we held an extraordinary member-wide GM event in October. This meeting gave our members the opportunity to vote on the [EPF Strategic Plan for 2021-2026](#). This document was developed with the support of the whole EPF Board, Secretariat and Membership. It is the basis for a renewed approach towards advocacy, research participation, fundraising, a more vibrant communication plan and an enhanced project engagement strategy. It reflects the latest changes in the European health and social policy environment and the new challenges and opportunities for EPF as an umbrella of patient organisations active across Europe. It was approved unanimously by the voting participants of the EGM and it is already guiding our workplan towards 2021.

EPF in 2020 moved to a fully online platform to offer the first ever fully online Summer Training Course for Young Patient Advocates (STYPA). Thanks to the online nature of the training we could open to more participants involving around 50 young patients. EPF also launched the 3rd edition of the capacity building module on Empowering Leadership and Positive Governance, which saw 24 patient leaders from 18 different countries working on their leadership skills for nine months via collaborative online working groups, one to one coaching and peer learning. Last but not least, EPF, in collaboration with PFMD and GCO Global, launched a webinar series on how to organise high impact virtual event. The first episode is available [here](#), but the other two will be broadcasted live on the 15 January and 5 February 2021.



Youth Group

initiatives, stories and events from our most budding members

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challenging circumstances in the world and especially in the patients' community, the EPF Youth Group remains active and continues to communicate the needs of young patients.

History was made during the EPF Annual General Meeting (AGM) in April 2020 as a Youth Group representative was elected to the EPF Board with full voting rights for the first time. Having a Youth Group representative in the Board is proof of EPF's continued nurturing of the next generation of patient advocates.

COVID-19 transformed how events took place in 2020 but members of the EPF Youth Group played an active role in different online conferences and international congresses. We had representatives and speakers in international forums like European Conference on Rare Diseases and Orphan Products, Young Coalition for Prevention and Vaccination, European Health Parliament, Mental Health Ireland, Digital Health Europe, XLH Alliance Meeting, Coeliac Youth of Europe and European Health Forum Gastein. The active participation in these events demonstrated the strength of the young patient community.

We also launched our Work and Youth Strategy (WAYS) project and findings, which began in 2018 and ended this year. During the webinar launch, we facilitated a great discussion regarding employment tips and tricks for young people with chronic conditions. You can find the report and webinar video [here](#).

Finally, this year within the EPF YG we welcomed new members from different countries and representing even more disease areas. During the course of the year, we held our Fall and Spring meeting with all of our YG members, and due to the Covid-19 Global Pandemic they were both held virtually. Despite it being the first time that these meetings were held virtually it was still very successful and we were able to get to know each other as members and work together to devise our focus and plans for the upcoming year and for future projects.



Inside the Bubble

updates, stories and events around EU healthcare

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against the coronavirus, opening the way for vaccinations to start in the bloc from December 27. The EMA recommended that the European Commission now grant a conditional marketing authorization, which will give the green light to EU capitals to begin administering the jab.

Commission approves BioNTech/Pfizer vaccine

The European Commission approved the BioNTech/Pfizer coronavirus vaccine just hours after a positive recommendation from the European Medicines Agency. The Commission said deliveries would begin on December 26, so countries can begin vaccinating on December 27.



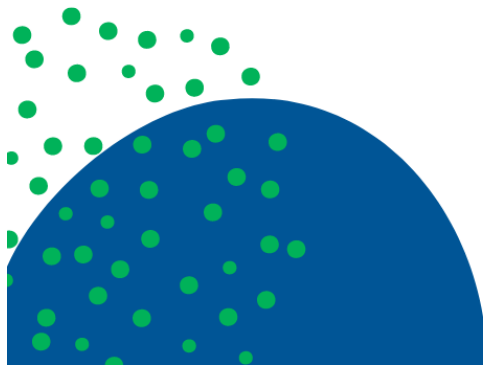
News From the Secretariat

updates from the inside

▶ EPISODE 2

Prof. Vincenzo Salvatore

ON COVID-19
VACCINE APPROVAL
IN EUROPE



The EU
Patients'
Podcast

Episode 2 - On COVID-19 Vaccine Approval in Europe with Prof. Vincenzo Salvatore

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WE'RE HIRING!

BE OUR NEW PROJECT COORDINATOR.

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

We're hiring a new Project Coordinator!

The Project Coordinator will support EPF's participation in different European projects, including those requiring patient engagement, education and involvement.

Job Posting: <https://lnkd.in/d-dUncN>
Deadline to apply is January 6, 2021

"Good health is not something we can buy. However, it can be an extremely valuable savings account."

– Anne Wilson Schaeff



Calendar of Events

1 January 2021
New Year's Day

[visit our website](#)

8 January 2021
[EMA second public stakeholder meeting on the approval and roll-out](#)

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15 January 2021

[HIVE-33 webinar series: Episode 2](#)

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