

Looking ahead

What's to come in the next 12 months at the European Patients' Forum?

Over the next 12 months, the European Patients' Forum (EPF) will continue to provide the overarching patient voice in Europe, building capacity and capability and providing a cross-disease perspective to help shape the policy-making process on issues that are important to Europe's patients.

The next two quarters of 2019 will keep the Secretariat on its toes, monitoring the outcomes of the [European Parliament Elections](#) and tracking the developments of Brexit, ensuring that health is a priority, cooperating closely with fellow health stakeholders to mitigate the risks for European patients, alongside our day-to-day activities. We will also be working hard to deliver several key events such as the third edition of our Summer Training course for Young Patient Advocates, the PARADIGM second Open Forum on Patient Engagement, and of course, our first ever EPF Congress; a culmination of much work and thinking to date on a structured approach to meaningful patient involvement in health systems' and services' design and strengthening.

In 2020, EPF will continue its valuable work as the voice of patients across Europe and will look to expanding the membership via a revised Constitution, which extends EPF's geographic remit to the wider Europe, and also formalise an ethics committee and youth section. The new Strategic Plan for 2021-2027 will also be formulated.

Overall, our work will focus on two areas; **Patient Perspective** and **Patient Voice**. *Patient Perspective* comprises our policy work on patient **rights** and **access**, and *Patient Voice* embraces **knowledge** obtained from our participation in EU projects, reinforcing **patient education**, via our Capacity Building Programme, EUPATI programme and PARADIGM project. Furthermore, projects where the patient perspective is required, offer a unique and safe environment for exchange with other stakeholders represented in the consortium.

Milestones Q3 & Q4 2019

Within the area of Patient Perspective, the Policy Team will continue the pilot project on [vaccine information](#), with a national workshop in Germany in November, reaching out to chronic disease patients and disseminating the translated, lay-friendly information toolkit through their ecosystem. The lay-friendly information toolkit for patients and patient organisations was developed for use in advocacy efforts to spread evidence-based information among patient communities. The information is not disease specific and can be used in the national or local context, as well as by patient groups for specific chronic conditions active at European level.

The **EPF Youth Group** will continue its undertaking in the area of the workplace, making progress on the [W.A.Y.S.](#) (Work and Youth Strategy) project, aiming to identify the challenges faced by young patients when looking for or retaining employment. A set of policy recommendation for employers and employees will be published, together with a short video, illustrating the experience of young patients today when it comes to their social rights. In Q4 the Youth Group will start focussing on the key topic of sexual health and education for young patients with chronic diseases.

Under the scope of Patient Voice, July will see the third edition of our [Summer Training course for Young Patient Advocates](#). 40 young patients aged 18-30, will come together in Vienna over 3 days, to learn how to implement a powerful and effective voice regarding the future of patient advocacy, as our next generation of advocates. This tailor made, high-quality training will cover aspects such as ethics, roles, transparency, responsibilities, representativeness, challenges and opportunities facing young patient advocates today. The programme has been designed with the objective of building and strengthening the patient advocacy capacities of the EPF Youth Group members and young patient advocates, to transfer their acquired knowledge and values to their respective constituencies. An alumni and ambassadors' programme will also be established to gather key patient advocates.

The European Patients' Academy (EUPATI) will launch the fourth edition of the Patient Expert Training Course along with the pilot training on Patient Engagement Training for a variety of stakeholders. A Japanese translation of the EUPATI Toolbox will also be published, the 14th language to be made available.

PARADIGM, PFMD and EUPATI will organise the [second Open Forum on Patient Engagement](#) in September, a two-day event where patient engagement will be explored beyond aspirations in a multi-stakeholder context to make it happen. The Forum aims to provide a holistic perspective on patient engagement, the landscape and actors, and foster collaboration and co-creation while breaking down fragmentation and silos that are often present in patient engagement work.

Our [Capacity Building Programme](#) will continue to support the development of organisational capacities and advocacy skills of our members, by publishing a Toolkit on Empowering Leadership and Positive Governance, following last year's module, and will host the second two-day, face-to-face meeting dedicated to positive organisational governance, in Sofia this September.

The EPF **working group on digital health**, will have their second meeting in autumn, informing EPF's policy in the area of digital health by providing guidance and input to various relevant topics, such as artificial Intelligence, Electronic Health Records and the General Data Protection Regulation. The working group also provides content input into different projects that EPF is involved in, such as EHDEN and DIGITALHEALTHEUROPE.

The [Data Saves Lives initiative](#) will launch the designated website in September, at their health data community meeting. The social media outreach campaign and guiding principles on health data will also be made available.

The Projects Team will advance with their work on project development, project proposals and existing EU Projects such as the **IMMUCAN project**, launching the visual identity, website and publishing the patient guidelines on informed consent, as the leading partner on communications.

Finally, EPF will close 2019 with its first ever [Congress](#) in Brussels, this November. This event, driven by patients and the patient community, is built on the premise that the patient's own unique experiential knowledge is a hugely untapped resource in all areas of the health system and aims to bring about real and lasting change, with tangible learning outcomes. The attendees will be comprised of up to 350 patient representatives across countries and disease-areas, national policymakers and public institutions/authorities, health systems experts, healthcare professionals, researchers and scientists, regulatory experts, payers/health insurance providers, and industry representatives from across the sector. An inspiring event, not to be missed!

Areas of focus in 2020

As mentioned, the first half of 2020 will pave the way for a new horizon at EPF, with the adoption of a new Constitution, an ethics committee, a youth section and the conception of our Strategic Plan for the following seven years. Alongside these new undertakings, EPF will build on its existing projects, notably the follow up on the outcomes of the Congress, implementing the lessons learned and developing the continuous exchange with our member patient organisations, Board and health related stakeholders. Another element that will influence the Work Plan 2020, will be the political environment, analysing how health is taken on board in the European Commission, and the European Parliament, making strategic and tactical choices to identify our foci on the basis of the developments. Our Work Plan 2020 will be finalised in the summer and approved by the board in September, after which it shall be shared with our partners.