



EPF Youth Group Strategy

2021-2026



Background

Why is the young patient voice important?

[The European Patients' Forum](#) (EPF) was set up in 2003 to become the collective patients' voice at the European level. EPF aims to establish patient-centred equitable healthcare which emphasises a patient-centred approach, inclusiveness, non-discrimination, patient empowerment, consultation and independence and transparency. In order for EPF to effectively achieve this goal, it is extremely important to find appropriate ways to listen to and recognise what the real needs of all patients are. This includes being able to effectively understand the specific needs of young patients and value the contribution they can make to strengthen the patient community and promote a more patient-centred approach in healthcare.

The **first EPF Youth Strategy** was created in 2011, with specific aims and objectives, in order to strengthen the representation and involvement of young people with chronic conditions in patient organisations, as well as to create the [EPF Youth Group](#) (YG), to support EPF in delivering the aims of the Youth Strategy.

The EPF Youth Group was created in August 2012, at the first Youth Assembly in Brussels, Belgium with the objective of giving a voice to young patients in Europe and providing a platform for them to learn and become the future leaders of patient advocacy. The Group welcomes young patient representatives between 15-30 years old. They can come from all over continental Europe and represent different chronic conditions and disease areas. Their core goal is to recognise, understand, meet, and effectively represent the needs and expectations of young patients through their meaningful involvement and empowerment.

Milestones & Achievements

Through various events, training courses and different opportunities, EPF has actively advanced on every objective from the previous Youth Strategy. Some of these milestones are:

- The creation of the first structured EPF Youth Strategy;
- The EPF Youth Assembly in 2012, where the EPF Youth Group was established;
- The “Transition from Paediatric to Adult Care” round table, launching one of the first EPF Youth Group projects;
- The first edition of the “[Summer Training Course for Young Patient Advocates](#)”, with a focus on discrimination in the every-day life of young patients;
- The “[Work and Youth Strategy](#)” project – focusing on employment for young people with chronic conditions and disabilities;
- The [EPF Congress](#) on Patient Engagement – where the EPF YG took an active role in showcasing through various interactive methods, key issues faced by young patients;
- An [EPF Board Youth representative](#) with full voting rights, ensuring that the young patient perspective is brought in the governance of EPF as well.
- Growing social media presence on [Facebook](#), [Twitter](#) and [Instagram](#).

In the meantime, the YG members were involved in EPF's day-to-day work and in IMI and HORIZON 2020 projects, where EPF is a partner or member (e.g. PARADIGM, COMPARE-EU, Digital Health Europe and CHRODIS+), while also presenting monthly articles in the EPF Newsletter Youth Group

section and collaborating with EPF members and their youth groups (e.g. EMSP, Coeliac Youth of Europe, World Duchenne Organization).

EPF aims to improve the skills of the YG members, with mentoring, trainings (social media training and policy training by EPF staff) and supporting them to take part in educational programs like [EUPATI](#) and [EHP](#). EPF YG members are frequently representing the young patients' perspective in conferences and different events (e.g. Health Forum Gastein, EFGCP & DIA Better Medicines for Children Conference). They also keep an active role on their social media accounts, making sure that the young patient community is reached in an accurate and easily accessible way.

EPF Youth Strategic Goals 2021-2026

The main aims of the strategy are to make sure the young patient voice is effectively heard when shaping the policy and research agenda within Europe, build a strong core of educated and empowered young patient advocates, and ensure the future of patient organisations and patient representation within Europe. This should be achieved by following through the goals and specific objectives within the strategy.

GOAL 1: Promote the recognition of young patients' needs and expectations within and beyond the health policy area.

The strong voice of young patients, effectively shaping the policy agenda and beyond, within Europe through EPF, with the EPF Youth Group being the most representative, diverse and inclusive young patient voice at a European level.

- Shape a large, diverse and active Youth Group with members capable of running various activities, projects and representing the Group;
- Nurture and develop the cooperation with various stakeholder groups, bodies and institutions and enhance their awareness and understanding of young patient needs;
- Develop various projects, focusing on key issues, faced by the young patient community.

GOAL 2: Build the future of patient advocacy.

Build the capacities and leadership skills of young patient advocates and help the collaboration of older and younger generations of patient leaders for organisational success.

- Provide effective platforms for the continuous dialogue and exchange of ideas between young and senior patient representatives;
- Develop the skills of young patients to become informed patient advocates and potentially patient community leaders;
- Provide high quality courses and trainings to the young patient community, specifically tailored to their needs.
- Identify and select tailored training opportunities for youth group members to strengthen their advocacy and leadership skills.

GOAL 3: Become a reference point for young patients all over Europe.

- Strengthen the cooperation between the EPF YG and other EPF member organisations' youth groups in order to better shape the Youth agenda in Europe together;
- Involve the EPF YG members in EPF activities, working groups, EPF-led events and projects;
- Guide the Group in their various activities, projects and events.

The EPF Youth Group use the above strategic framework to set its priorities and align with the [EPF Strategic Plan](#). The EPF Youth Group develop each year a workplan selecting key activities. It is important to note that the EPF Youth Group is made up by young volunteers and therefore the workplan might change in consideration of their availability and aspirations.

If you would like to know more about EPF Youth Group members or its activities please visit our [website](#).

If you would like to know more or have any questions, feel free to contact the EPF Youth Group Coordinator, Borislava Ananieva at borislava.ananieva@eu-patient.eu.