

EPF Youth Strategy



european**patients'** forum

0. Executive Summary

This document outlines the EPF Youth Strategy. It explains the rationale behind the adoption of a Youth Strategy and outlines the strategic goal and specific objectives which will guide the implementation of the strategy.

A timeline for the implementation of the strategy is also presented. This will be further developed in the first two-year Work Plan implementing the EPF Youth Strategy.

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1. Background: why a young patient perspective?

1.1 Valuing young patients' contribution

EPF was set up in 2003 to become the collective patients' voice at the European level, manifesting the solidarity, power and unity of the European Union. EPF's vision is 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, what are their expectations are not only towards the healthcare system, but also towards patient organisations as entities mandated to formulate and express such needs and expectations. This includes being able to effectively understand the specific needs of young patients and value the contribution they can make to strengthening the patient community and promoting a more patient-centred approach in healthcare, a goal which all patient organisations ultimately strive to achieve.

EPF believes that patient organisations can do a lot to provide better support to young patients by for instance understanding and formulating their needs and integrating them in their mainstream activities.

Having said that, why should a young patient perspective be included in a patient organisation's everyday activities and decisions? EPF viewpoint is that needs and expectations of young patients do not necessarily match those of adult patients. Being a patient inevitably impacts on every aspect of one person's life. For a chronically ill youngster this means that the condition and the way he/she relates him/herself with the condition have important repercussions on his/her growth process and hence on his/her life as a grown up. Chronically ill youngsters enter and go through education as patients, meaning that if they have to miss a lot of classes from school and university because of the condition, this might have strong impact on their learning process as well as on their life, particularly when it comes to entering the labour market. On the other hand, being a chronically ill youngster means that a person is not only different, but is also perceived as such by other young people. Critical stages in young people's growth such as the transition from childhood to adolescence and from adolescence to early adulthood are experienced in a different way by people living with a chronic condition. Apart from ordinary developmental transition, chronically ill young patients also go through a situational transition which is more related to their living with the condition (i.e. from paediatric care to health care). This means that beyond ordinary learning processes all youngsters undergo, a chronically ill youngster also needs to learn to become independent in managing the condition and how to relate him/her-self to the system. This also means that he/she needs to learn a lot that other young people do not need to care about. Moreover, chronically ill youngsters may also have a third transition to face, notably from relative health to illness, depending on the progression of their illness.

These are only some major challenges young chronic patients face in their everyday life that policy makers, institutions, as well as civil society organisations working in the health sector and beyond need to take into account when developing policies, programmes or making decisions that might have an impact on youth.

To be able to effectively address needs and expectations of young patients we need to be able to listen to them and provide them with appropriate tools and avenues through which such needs and expectations can be put forward.

1.2 Involving Young Patients: EPF 2010 Regional Advocacy Seminar

In order to better align our work with the needs and expectations of the young patient community, we decided to dedicate our third Regional Advocacy Seminar for patient leaders to strengthening young patients' representativeness within patient organisations. The seminar, which took place in Budapest on October 25-27, 2010, brought together patient organisations' representatives from Hungary, Romania, Bulgaria, Slovakia, Czech Republic, Greece, Portugal, Italy, Estonia and Lithuania.

The 2010 Advocacy Seminar represented the very first opportunity for EPF to bring young and more experienced patient advocates from different EU countries together to discuss how to promote the meaningful involvement of young patients within patient organisations and how young patients' needs can be better recognised and formulated by patient organisations through the meaningful involvement of young advocates in these organisations.

The third day of the workshop was entirely dedicated to the young patient representatives through an ad-hoc workshop whose purpose was to directly involve young patients in shaping the EPF Youth Strategy.

Looking at the work done and the outcomes produced through the stimulating interaction between young and senior patient representatives we are very pleased to say that this seminar has been indeed a very successful and rewarding exercise.

We have learnt that young patients' involvement in patient organisations is indeed a challenge, but there are many ways in which this challenge can be turned into opportunities. The successful experience of young patients' involvement in patient or other type of organisations which were shared with us by various speakers during the seminar not only gave us food for thoughts on how to implement some of the ideas within EPF and its membership, but they encouraged and motivated us to look into the opportunity to concretely engage with young patients and put a young patient perspective at the very heart of our future work and activities.

This seminar was the first step towards EPF commitment to integrating a youth perspective into our future work plan starting from 2011. The outcomes of the plenary sessions and parallel workshops together with the seminar with young representatives held on the third day of the seminar were therefore also meant to inform the development of this Youth Strategy.

The full report of the 2010 Regional Advocacy Seminar can be accessed through the following link:

<http://www.eu-patient.eu/Events/EPF-Autumn-Regional-Advocacy-Seminar-for-Patient-Leaders/>

2. Methodology for developing the EPF Youth Strategy

In preliminary discussions on how to develop a Youth Strategy for EPF, it was agreed that a bottom-up approach should be favoured. EPF believes that a Youth Strategy can succeed only if young people involved have the ownership of the process. A top-down approach with no preliminary and on-going consultation with the target group is highly unlikely to succeed. EPF also acknowledges that to be successful in effectively engaging young people you also need to find appropriate ways to continuously motivate them by developing activities that match their interests and fine-tuning your communication channels to make sure you are reaching out to them in an effective way.

Young people also want things to happen quickly and decisions to be followed by fast actions. This, however, may conflict to an extent with the way most organisations work where changes may need time to take place. For this reason the EPF Youth Strategy will be developed and implemented through a step-wise approach. Accordingly, the strategy will be developed iteratively with a view to continuously improving it taking into account feed-backs from the young patient community as well as results and outcomes from the implementation of the various activities that have been identified for this strategy. Likewise, the various activities listed under the various priorities for action will be implemented gradually, starting from building up a solid base of young patients – the EPF Youth Group - with the support of EPF membership and then gradually involving this group not only in EPF mainstream activities and policy process but also in new activities which will be specifically designed for a younger audience.

For the purpose of this strategy, the term “young patient representative” does not narrowly refer to chronically ill youngsters only, but it is used more widely to encompass youngsters who are between 15 and 25 years old who fall under at least one out of the four categories listed below:

- a) Young people who are chronically ill patients and are also actively involved in a patient organisation as young advocates
- b) Young people who are chronically ill patients but who are not involved in any patient organisation/patient advocacy activity
- c) Young people who are not patients but are involved in patient advocacy activities, such as volunteering in patient organisations
- d) Young people who are not patient advocates but look after chronically ill patients as informal carers.

By contrast, the term “young patient” is used more narrowly to refer to categories a) and b).

This broad approach to “young patient representatives” reflects the view of the young representatives who participated in the Budapest Workshop who called for actions involving both chronically ill patients, regardless of whether involved in a patient organisation, and not chronically ill youngsters actively involved and interested in patient advocacy and/or looking after chronically ill patients.

While the EPF Youth Group will be made up of young patients from patient organisations which are members of EPF - - and many of the activities envisaged in the work plan implementing this strategy will target the members of this group, specific activities will be designed in order to target and involve other groups included in the definition of “young patient representatives” provided above.

In identifying and delivering the various activities implementing this strategy EPF will, therefore, ensure that all abovementioned categories are appropriately reached out. Particular attention should be paid to youngsters falling under the second category, chronically ill young patients who are not involved in any patient organisation.

Specific attention will be also paid on fostering the cooperation between young patients and other youth groups with a view to strengthening mutual understanding and cooperation between these two groups.

The EPF Youth Strategy looks at medium term and has been developed around a set of goals and specific objectives which should be achieved in the next 4 years (2011-2014). The strategic goals and the specific objectives are presented in the next paragraph. A first work plan implementing this strategy has also been developed. The latter covers the first two years (i.e. 2011-2012) and identifies a number of priorities for action, each contributing to at least one strategic goal.

In line with the bottom-up approach chosen, once the EPF Youth Group has been established this strategy, together with the first two-year work plan, will be discussed with the members of the Youth Group and revised accordingly if needed. The first meeting of the Youth Group is envisaged to take place in mid-April alongside EPF 2011 Annual General Meeting.

3. Scope and priorities of the Youth Strategy

The overall objective of this Youth Strategy is to enable EPF to recognise, understand, meet and effectively represent the needs and expectations of young patients through their meaningful involvement and empowerment. In order to achieve this objective, EPF has identified four main strategic goals which will guide the implementation of the Youth Strategy.

GOAL 1	Strengthening the involvement and representation of young patients in patient organisations
GOAL 2	Promoting young patients' rights and recognition of their needs and expectations within and beyond health policy area
GOAL 3	Promoting a better cooperation between young patient and adult patient advocates
GOAL 4	Strengthening young patient representatives' skills

3.1 Specific Objectives and performance indicators

Based on the four strategic goals a set of specific objectives has been identified.

GOAL 1	Strengthening the representativeness and involvement of young patient representatives in patient organisations
Objective 1.1	Strengthening the involvement of young patient representatives in EPF activities
Objective 1.2	Enhancing the involvement of young patient representatives in EPF Members
Objective 1.3	Strengthening the involvement of young patients in EPF governance structure

The following performance indicators have been identified

- EPF is successful in setting up, motivating and coordinating a Youth Group made up of 15 young patients indicated by EPF members and developing effective mechanisms for ensuring the representativeness and self-governance of the group.
- EPF is able to ensure that young patient representatives are effectively involved in EPF events and activities (specific thresholds will apply to different events/activities).
- EPF manage to raise awareness of and promote the active involvement of young patient representatives, especially young patients within its membership and beyond.
- EPF governance structure and mechanisms enable the participation of a Youth Board Member elected by EPF young people's constituency.

GOAL 2	Promoting young patients' rights and recognition of their needs and expectations within and beyond health policy area
Objective 2.1	Strengthening the understanding of patients needs and expectations towards healthcare and beyond among patient organisations and other health stakeholders
Objective 2.2	Improving the integration of young patient needs into EPF work
Objective 2.3	Increasing the integration of young patients' perspective into Health and Youth Policy developments at EU and national level and youth-friendly healthcare

The following performance indicators have been identified

- EPF identifies and exploits effectively mechanisms and channels for continuously capturing and communicating what young patients' needs and expectations are not only towards the healthcare system, but also towards society as a whole.
- EPF is able to integrate young patient perspective into its policy work and ensure that such perspective is reflected in EU health policy-making process.
- EPF is able to link up with existing young patient groups and promote the cooperation between the latter and the EPF Youth Group.
- EPF develops and nurture cooperation with youth stakeholder groups, bodies and institutions and enhance their awareness and understanding of young patient needs.

GOAL 3	Promoting a better cooperation between young patient and adult patient advocates
Objective 3.1	Enhance the dialogue, trust and mutual understanding between young patients and adult patients
Objective 3.2	Strengthening the cooperation between young and adult patients within patient organisations

The following performance indicators have been identified

- EPF is able to provide effective platforms for the continuous dialogue and exchange of ideas between young and senior patient representatives.
- EPF able to stimulate cooperation between young and adult patients within its membership and beyond.

GOAL 4	Strengthening young patient representatives' skills for them to grow to become
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	patient advocates
Objective 4.1	Strengthening young patients' advocacy and leadership skills
Objective 4.2	Increasing the involvement and active participation of young patients in the healthcare arena at European and national level

The following performance indicators have been identified

- EPF is able to strengthen its outreach activities geared towards enhancing patient leaders' advocacy skills by a) ensuring the active involvement of young patient representatives and b) defining specific learning outcomes for young patient representatives and assess the degree to which have these been fulfilled.
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- EPF is able to strengthen the participation of young patient in events at European and national level
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4. Implementation of the EPF Youth Strategy

In line with the stepwise approach chosen for this strategy, the EPF Youth Strategy will be implemented through subsequent two-year operational work plans outlining specific operational priorities and associated activities, each contributing to at least one of the strategic goals identified for this strategy.

The first operational work plan will cover the years 2011-2012 with two the key objectives:

- a) establishing and consolidating the EPF Youth Group;
- b) implementing actions aimed at strengthening the capacity and the empowerment of the members of this group in order for them to be able to become gradually involved in EPF activities and, in the long run, in EPF governance structure.

To this end, regular skill building activities for young patients will also be implemented. These should include an annual meeting for young patients, the involvement of young patients in EPF regular skill-building seminars at European and national level and, in the medium term (2012-2014), the development of a specific project aimed at strengthening young patients' capacity on how to actively participate in policy-making processes at European, national and local level. Suitable funding opportunities, particularly the EU "Youth in Action Programme", will be explored.

Through the establishment of the Youth Group EPF will also make a concrete effort to foster the participation young patients within its membership, particularly within those organisations where a youth group does not yet exist and/or youth-related issues are either poorly understood or insufficiently considered.

Targeted activities aimed at sharing good practices among patient organisations on young patient involvement in patient organisations will be also implemented in the medium term. These activities will build upon the outcomes of the 2010 EPF Regional Advocacy Seminar, and through cooperation with European and national patient organisations which have been successful in setting up and maintaining a youth group. Strategic cooperation will also be explored with other "non-patient" youth groups and organisations as well as with other health stakeholder groups, i.e. health professionals, policy-makers, etc., with a view to fostering constructive dialogue between the latter and young patient groups.

A number of activities aimed at involving the Youth Group in different EPF activities are envisaged already in 2011. These activities will be carried out alongside the broadening and consolidation of the Youth Group.

Wherever possible, EPF will ensure that other young patient representatives who are not members of the EPF Youth Group will have access to capacity building activities as well as to other activities and initiatives where the involvement of young patients has been envisaged.

In the medium-long term after building their capacity, EPF will consider, in certain cases, seconding a youth representative to an EPF staff or Board member participating to certain events. This would enable young patients to play a very active role by making presentations or participating to panel discussions in EU and national events.

The second two years of this strategy (2013-2014) will be aimed at consolidating and further empowering the EPF Youth Group, particularly through the establishment of a clear governance structure, which will include a "Youth Board" and the identification of a "youth" budget line within EPF budget to ensure the long-term sustainability of the Youth Group. EPF will also explore how best to integrate the "Youth Board" into EPF's governance structure, including the possibility to reserve one board seat for a youth representative to be elected by the Youth Group itself.

5. The EPF Youth Group

In order to be able to achieve the four strategic goals, EPF will establish a Youth Group. This group will be made up of young patients who are associated to EPF member organisations or organisations which are members of member organisations. Young patients will be nominated by EPF members and will be selected according to pre-determined eligibility and selection criteria. It is responsibility of EPF to ensure the highest standard of transparency in the selection process.

In order for EPF to identify suitable candidates for the Youth Group a consultation with its membership will be launched in early 2011. Those members who are willing to have a young patient to represent their organisation in the EPF Youth Group will need to nominate one or more candidates.

In order to be eligible a nominee will need to:

- be a patient
- be between 15 and 25 years of age
- be member of a patient organisation which is member of EPF or a member of an EPF member
- be not employed as a staff member within the patient organisation
- have a working knowledge of English
- be available to attend 1-2 physical meetings every year and quarterly teleconferences
- show strong motivation and willingness to take a proactive role in engaging with the local young patient community

To be eligible a candidate needs to fulfil all the above mentioned eligibility criteria. The final selection will be carried out taking into account the following selection criteria, which are meant to ensure the balanced composition and representativeness of the EPF Youth Group.

The following selection criteria will apply:

- Country of origin (preferably no more than one young patient from the same country)
- Sex (possibly equal number of males and females)
- Age (balanced distribution of ages)
- Disease (good representations of different diseases)

6. Revision of the Youth Strategy

This Youth Strategy will be revised by the Youth Group during its first meeting envisaged alongside EPF 2011' Annual General Meeting to take place in mid-April in Brussels.

A regular annual revision of the Strategy will be done in close cooperation with the Youth Group on the basis of the results achieved through the implementation of the work plans.

Annex A: Members of the EPF Youth Group

Name and Surname	Organisation	Country	Date of Birth
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Annex B Governance and PAG implications of the EPF Youth Strategy

Governance implications

The Youth Strategy outlined above and the work plans that will be developed to implement it will have some direct implications for EPF governance. The purpose of this Annex is, therefore, to present the results of a preliminary assessment of governance implications of this strategy.

Generally speaking, while all specific objectives outlined for this strategy are meant to contribute to the ultimate goal of enabling EPF to recognise, understand, meet and effectively represent the needs and expectations of young patients through their meaningful involvement and empowerment, only a few of them will have direct governance implications for EPF.

The specific objective which is most likely to have direct governance implications for EPF is Objective 1.3. This objective is specifically designed to strengthen the involvement of young patients in EPF governance structure. Objective 1.3 has been conceived as a medium-long term objective as it can only be achieved once the implementation of the Youth Strategy as well as the work and *modus operandi* of the Youth Group have attained a sufficiently adequate level of maturity.

The ultimate goal of Objective 1.3 is to enable a representative of the EPF Youth Group to become a member of the EPF Board. A key requirement is that the youth board member will not be elected according to ordinary procedures governing the election of EPF board members. Instead, the youth board member will need to be nominated by the members of the Youth Group according to the specific mechanisms and procedures that will be defined for this group.

A direct implication of this is that the youth board member will represent the Youth Group and, on a more indirect level, the young patient community at large. This also implies that a senior representative affiliated to the same organisations as the youth board member will still be able to run for EPF board election.

The election of a youth board member will be initially phased-in for one year, by allowing a youth delegate, who will be nominated by the Youth Group, to participate as an observer to all board meetings taking place throughout that year.

EPF is aware that the achievement of this objective and the speediness with which the election of a youth board member will actually take place will strongly depend on the ability of EPF to successfully implement specific skill-building activities to strengthen the advocacy capacity of the members of the Youth Group as well as to ensure the effective integration of the Youth Group into EPF mainstream activities.

Another objective which is expected to yield direct governance implications is Objective 1.2 "Enhancing the involvement of young patient representatives in EPF Members". Through this objective EPF will seek to foster the meaningful involvement of young patients across its membership and the participation of young representatives in EPF meetings and events as well as in other events.

A direct implication of this is that once a young patient becomes member of the Youth Group the organisation he/she is affiliated to will commit itself to having this person participating as a second delegate to those EPF meetings where the participation of youth delegates is envisaged, particularly the AGM. Specific rules will apply to those organisations which have a representative in the EPF board. In such a case the participation of a third delegate will be allowed upon the condition that the

second person is a member of the EPF Youth Group or a proxy appointed by the latter.

In the longer run and as long as the organisation concerned agrees, the young delegate might also participate in EPF meetings and events, including the AGM, as a main delegate for his/her organisation.

Objective 1.2 may also, on a more indirect level, yield some governance implications for EPF members. Through this strategy, the Youth Group and, more specifically, through Objective 1.2, EPF will be seeking to promote the establishment of youth groups within those member organisations where the involvement of young patients is possible.

The establishment of youth groups within our members should in turn enhance the representativeness of the members of the EPF Youth Group, as the latter will be able to act as local leaders, thereby enabling EPF to reach out to a larger number of young patients across EU countries. This will also benefit and strengthen the EPF Youth Group itself as future members of this group could be elected in a democratic way by the various young patient groups set up within EPF member organisations.

Implications for the Policy Advisory Group

One of the declared goals of this strategy is to promote young patients' rights and strengthen the recognition of their needs and expectations within and beyond health policy area (Goal 2). In order to achieve this goal three specific objectives have been set out. Out of these, one is particularly relevant, namely Objective 2.3 "Increasing the integration of young patients' perspective into Health and Youth Policy developments at EU and national level and youth-friendly healthcare". On a more indirect level, both Objective 3.1 "Enhancing the dialogue, trust and mutual understanding between young patients and adult patients and Objective 3.2 "Strengthening the cooperation between young and adult patients within patient organisations" are also relevant in this context.

In order for these objectives to be achieved it is of primary importance for EPF to ensure that young patients are effectively involved in and are given access to venues and platforms where to make their voice heard and listened to.

In 2009 EPF set up a Policy Advisory Group (PAG) tasked with providing advice to the Board and Secretariat EPF on key policy issues being discussed at EU level. Delivering on the declared objectives of this strategy, most specifically Objective 2.3 and 3.1, requires ensuring that the EPF Youth Group is given the possibility to participate in PAG meetings in order to ensure that a youth perspective is thoroughly taken into account in the various health policy dossiers discussed within the PAG.

For this very reason EPF will work to ensure that in the future one seat within the PAG will be reserved to a young patient representing the Youth Group. In the same way as the election of a youth board member, the nomination of a young patient for the PAG will not be carried out according to the ordinary procedures in place for the nomination of PAG members. Accordingly, the youth PAG member will not represent the organisation he/she is affiliated to, but the Youth Group. This also implies that a senior representative affiliated to the same organisations as the youth PAG member will not preclude the possibility for the former to become member of the PAG.

The nomination of a youth PAG member might be initially phased-in for one year, by allowing a youth delegate, who will be nominated by the Youth Group, to participate as an observer to all PAG meetings taking place throughout that year.

Similarly, EPF will ensure that the Youth Group will be given the possibility to participate in policy consultations carried out by EPF anytime the policy issue at stake has direct implications for youth. Such consultations will be done in line with the mechanisms and procedures that will be defined for

the Youth Group.

EPF is aware that the achievement of this objective and the speediness with which the nomination of a youth PAG member will actually take place will strongly depend on the ability of EPF to successfully implement specific skill-building activities to strengthen the advocacy capacity of the members of the Youth Group as well as to ensure the effective integration of the Youth Group into EPF mainstream activities.