

TOOLKIT ON BUILDING NATIONAL COALITIONS OF PATIENT ORGANISATIONS

**STRONGER
TOGETHER**



Author: Camille Bullo

Edition: Nicola Bedlington, Walter Atzori, Jana Hlaváčová, Sofia Crisóstomo

About the European Patients' Forum - EPF is a not-for-profit, independent umbrella organisation of patients' organisations in the EU, currently with 67 member organisations active in public health and health advocacy. Its mission is to ensure the patients' community drives policies and programmes that affect patients' lives, to bring the changes needed to empower them to be equal citizens in the EU.

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1. INTRODUCTION



What is a national coalition of patient organisations?

A national coalition of patient organisations is an umbrella organisation grouping national or regional patient organisations representing individual chronic conditions (Alzheimer's, diabetes, multiple sclerosis...) or groupings of conditions (rare diseases, cancers, mental health conditions etc.). These organisations come together and form an umbrella that should be representative of the collective interests of all patients of one country.

National coalitions can also be referred to as national alliances, or networks of patient organisations. The terms are used interchangeably and there are no formal criteria defining each denomination, but one would tend to use the word "network" when the group of organisations is not legally constituted, and the terms "national coalitions" or "national alliances" when there is a higher degree of formality.

Objectives of the toolkit

This toolkit aims to be a practical step-by-step guide for national, regional and local patient organisations who wish to set up a national coalition in countries where it does not yet exist. Newly created national coalitions will also find insights on how to ensure their sustainability. Furthermore, this toolkit will hopefully also constitute a practical reference for existing well-established national coalitions of patient organisations who wish to raise their profile further, especially in terms of strengthening their legitimacy, representativeness, and accountability.

Other stakeholders at national level such as decision-makers, health professional groups, private companies and their trade associations or insurers might find this toolkit useful to understand better the role of national coalitions as well as the synergies that may be drawn from supporting or partnering with them.

Why is the European Patients' Forum working on this?

National coalitions of patient organisations play a crucial role in a national context: they are best placed to monitor, understand and react to as well as to actively influence national health policies of their respective countries.

For EPF, they are a vital partner, providing us with expertise on country-specific situations, and cascading our messages from and to the national and regional levels.

Supporting the constitution of national coalitions has great political added value, both for the targeted countries and EPF. Indeed, to be effective advocates at European level, we need to have a strong patient voice in each of the European Union's member states.

One of the challenges in rallying national coalitions to our movement is the absence in some countries of a national coalition of patients' organisations. For this reason, national coalition building is one of EPF's focus in terms of development and growth.

Thanks to its experience and its knowledge of the local stakeholders, EPF can support the coalition-building process by providing examples from other countries, acting as a bridge between patient organisations and external stakeholders, and providing tools for the organisational development of the future platforms.

However, in order to be successful, the coalition-building process should be bottom-up and initiated by patient organisations in the country. EPF acts as a facilitator and should in no case be the driving force of an embryonic coalition.

One size doesn't fit all

We recognise that the processes of developing, establishing, and leading non-governmental organisations and specifically patient organisations varies greatly from one country to the other. Our objective is not to deliver a "one-size-fits-all" solution, but rather to propose a pathway for organisations wishing to work together.

Since it was funded in 2003, EPF has had to face and overcome significant hurdles. There is a lot we have learned on this journey. We do not always get things right at first, and we make mistakes too: one of our key learnings is the need for tenacity and persistence, two qualities we hope to inspire through the reading of this toolkit.



2. WHY NATIONAL COALITIONS ?

2.1 LOUDER TOGETHER

Poor management of chronic diseases is a huge burden on society. However, when patient organisations advocate separately, their messages often fail to reach the ears of decision-makers. Here is how creating a national coalition can benefit the patient movement in your country:

- ✓ **It improves the visibility of patient organisations:** by joining forces, the patients' voice is louder, and your actions have a bigger impact. You can attract media attention more easily.
- ✓ **Increased representativeness means more credibility:** the fact that a national coalition represents more diseases increases its credibility towards decision-makers. Your advocacy work has more weight, as you represent more voters.
- ✓ **The national coalition becomes the single point of contact for external stakeholders.** You increase the chances for direct and regular contacts between patient organisations and a diverse set of stakeholders (decision-makers, media...). Ultimately, the national coalition can be recognised as a partner by other stakeholders. Of course, the national coalition only works on cross-cutting issues, enabling disease-specific organisations to focus on their area of specialism.
- ✓ **Speaking for your country on the international stage:** a national alliance is able to provide a country-specific consolidated patients' perspective at European and international level.
- ✓ By pooling together the energy and human resources of the different member organisations, a national coalition can ensure **a continuous presence of patient-related issues in health and social policies and programmes.** It also provides a forum for generating collaborative responses.



2.2 SMARTER TOGETHER

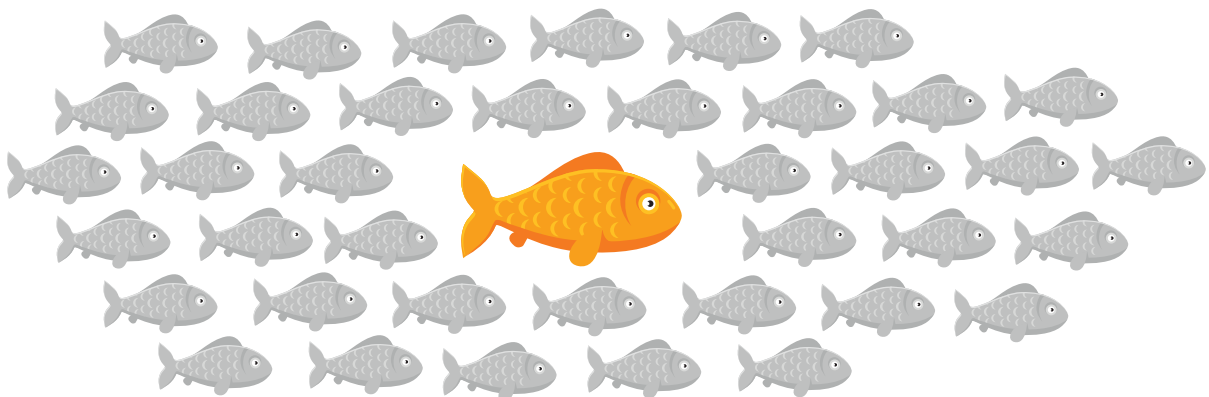
Beyond visibility among decision-makers, the media and the wider public, forming a national coalition of patient organisation means building on the expertise of others, increasing your knowledge and broadening your understanding of the patient community.

- ✓ **Seeing the big picture:** a coalition can provide an overview of overarching patterns and complementary issues. This is beneficial both to the coalition and its members, allowing disease-specific groups to focus on the specific challenges of their disease area.
- ✓ **Expanding your horizons:** one of the added values of a national coalition is that it gives disease-specific organisations the opportunity to understand each other's competing and complementary needs and requirements. It broadens the consideration of issues to include differing values and facts.
- ✓ **Learning from each other:** a forum provides the opportunity to share information, good practices and expertise. It also enables the development of more complete and satisfactory solutions.
- ✓ **Transcending institutional boundaries:** patient organisations often have to deal with different stakeholders and governmental agencies according to the condition they represent. Yet, problems that affect the entire community are best addressed by approaches that involve the resources of the entire community.

2.3 STRONGER TOGETHER, STRONGER ALONE

Being part of a national coalition also means benefits for individual organisations who are a part of it. Thanks to the information exchange and common actions with other patient organisations, **being part of a national coalition results in more and quicker progress for the individual organisations in fulfilling their missions.**

Through concerted efforts, the associations involved also **reduce the duplication of efforts and optimise the use of their own resources.**



2.4 ADDRESSING THE FEAR OF LOSING ONESELF

Some questions may arise when discussing the set-up of a national coalition: one common fear is that one of the stronger organisations may want and take the **leadership of the coalition-to-be** and use its visibility to defend its own interests. This legitimate fear can be addressed by ensuring the representativeness of the coalition and its governing bodies, and putting in place strong governance rules.

Other organisations may not be willing to engage in a national coalition for **fear of losing their own “identity”**, or for **fear of the increased competition for funding** resulting from the creation of a coalition. The perception is that the coalition will take resources away from disease-specific groups.

To address these challenges, you should reassure future member organisations that their own organisations will continue to exist, and that the national coalition will address specific, cross-cutting goals. Similarly, with regards to the fear that the coalition may drain away funding from their own pots, organisations should weigh the risk against the added value of having a coalition that can focus on cross-cutting topics, enabling a more efficient allocation of resources and advocacy efforts.



3. FIRST STEPS TO ESTABLISHING A NATIONAL COALITION

The ultimate decision to build a national coalition of patient organisations can be prompted by a variety of motivations and external factors. Sometimes, it is a violation of patients' rights that motivates patient organisations to ally and take action together; sometimes patient associations involved in an informal collaboration or a project decide that there is added value in pursuing and formalising this cooperation; sometimes, the push to get

together comes from external stakeholders (national Ministry of health, international organisations) wishing to exchange with one single umbrella patient organisation rather than dozens or hundreds of organisations.

The motives for establishing the national coalition will have an impact on how it is shaped, but essentially, the process of establishing a national coalition will go through the following steps.

3.1 COME TOGETHER

So there you are – you want to start a national coalition of patient organisations in your country. Where should you start?

Start with a small working group and build from there

Gather a smaller nucleus (around 8 to 15 maximum) of the most interested and committed patient organisations. They should represent a variety of diseases, so you get diverse point of views (also taking into account geographic, gender and ethnic diversity).

Ability to perceive common interest

This first group of people will shape the rules, mission and vision of the future national coalition. Therefore, you want to involve people who are able to put the interests of the future organisation first, work for the common good and leave their egos at the door.

Build on your legitimacy from the start - the right individuals, with the right values

You want people with motivation, vision, connections and influence in the community and leadership skills. Make sure the people around the table are speaking on behalf of a patient organisation and are not just individuals interested in the patient cause. Indeed, the national coalition will need to be rooted in the patient community to be legitimate and credible.

People who agree to disagree

Most importantly, you need to find people who can rise above the inevitable personality clashes, political and philosophical differences, and territorial turf wars that may emerge.

Although it may be tempting to involve a great number of people from the beginning to ensure a broader consensus and early recognition by external stakeholders, be cautious: attempting to include all interested parties in the group initially can be counter-productive. Also, it is important to keep in mind that not everybody that has a link with your cause will be interested, and that is OK.

Where and when should you meet?

Sometimes the practical issues are the biggest hurdles to realising your project. We recommend to hold coalition-building meetings at a venue that is easily accessible to all stakeholders. You can also take turns in hosting the meetings, which could for instance take place in the meeting room of one of the participating organisations that can accommodate the group. Access to audio-visual equipment for PowerPoint presentations or videos is important.

In the initial stages of formation, the coalition should meet quite frequently. A monthly meeting will enable the group to stay focused and engaged, and to work out any early difficulty that may arise. Meetings should be scheduled as far in advance as possible to get in busy persons' calendars. Make sure you have specific agendas, timings and anticipated outcomes to make the best use of everyone's time.

External facilitator vs. internal moderator

Soliciting an external facilitator's help (for instance external consultant with experience in organisational development) to introduce the topic, moderate the discussions, and keep the process moving smoothly can be a good idea – however it requires resources organisations might not have or be ready to invest at that time. Alternatively, you can designate a person to moderate the discussions to take on that role at each of the group's meetings.



“ Such a coalition is of a huge help for its members, because it provides the credibility required to represent themselves in front of the authorities and policy makers. This power is very high and one must be wary of those who have an interest to use the organization to achieve their own goals. Bear in mind that such a coalition must represent the interests of patients only. ”

The experience of COPAC, the Romanian Coalition of Patients



3.2 WHAT IS ALREADY THERE?

The first meetings of your group should be dedicated to a scanning process of the environment you evolve in. You want to build on what is already there and avoid replicating work that has already been done or leaving potential allies out.

See what you have in common to make sure everyone is on the same page, launch a discussion on the added-value of your cooperation and on the history of the patient movement in your country. Encourage participants to take these questions back to their own organisations for internal discussions to gather additional information for analysis at the next meeting.

- *Is there solidarity across the patient community in your country?*
- *What problems are not addressed if they are tackled from a disease-specific perspective?*
- *What can be gained from a collaborative approach?*
- *Are there precedents of such collaborations? If they did not work, why was that?*

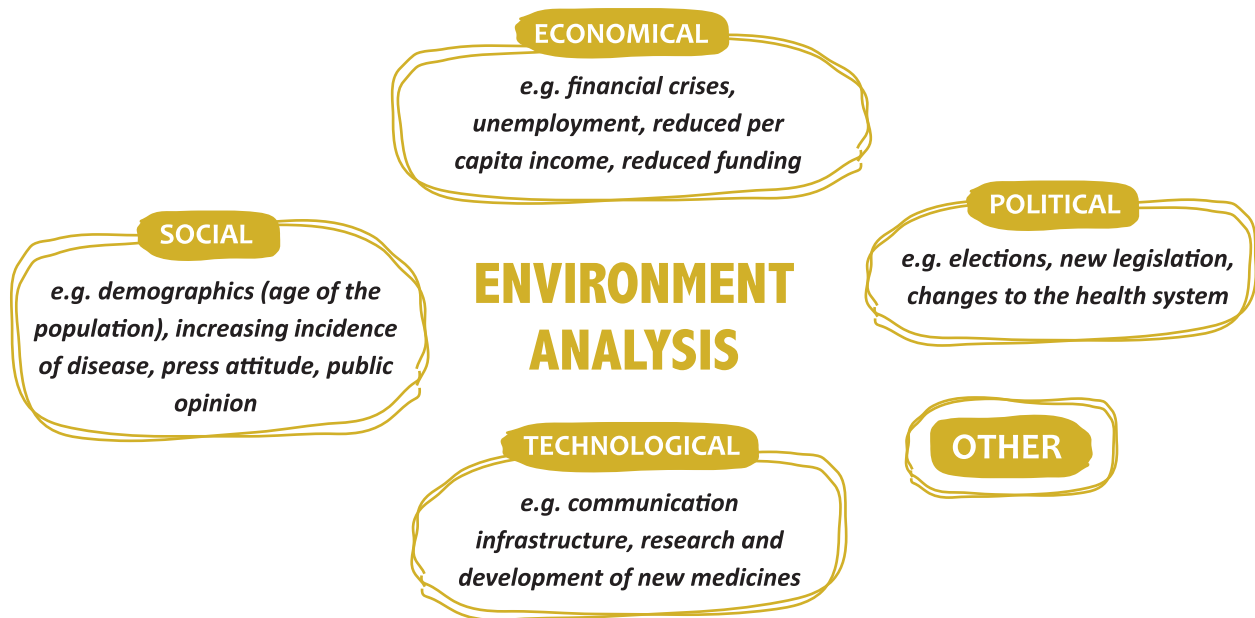
Identify the key stakeholders your coalition will be interacting with, and in what quality. Write down the stakeholders you think are relevant for a national coalition of patient organisations and then divide them into three groups: “Potential members”, “Allies and Partners”, and “Target audience”.

- **Who are your potential members?**
National coalitions are usually composed of organisations active at national level only. Indeed, having to juggle with different levels of organisations can make the democratic process more difficult, as the representativeness of the organisations may vary according to their level of activity. However, according to your national reality, you may want to leave the door open to regional associations, and even to individual members. Plan carefully the role and criteria that each of these stakeholders must fulfil to become a member.
- **Who are your potential allies and partners? Who is likely to support, or conversely, undermine the idea?**
- **Who is your target audience? Whom are you trying to convince?**

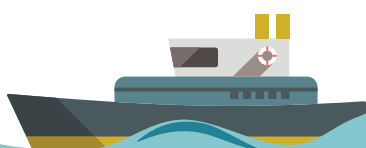


Environment analysis

You need to have a clear idea of the environment you will be evolving in. A good process to do this is to conduct a “PEST Analysis”, looking at the political, economic, social and technological environment and its likely evolution in the foreseeable future. For this exercise to be most useful, assign a “score” based on the level of “criticality” of the factor at stake.



To complete the picture, identify the greatest external opportunities and threats that may help or hinder the work of the coalition. Focus on outside factors that may help the coalition doing its work (opportunities) and the outside factors that may be unhelpful/hinder the work of your coalition (threats). Note that some factors/trends may be both an opportunity and a threat.



3.3 DEFINING WHO YOU ARE: DEVELOPING A MISSION AND VISION

A crucial step for any organisation is to define its ultimate purpose (“raison d’ être”) and ways to fulfil that role. Developing a common understanding among the coalition’s members of who you are and what you stand for is essential to better present yourself to stakeholders, partners, and potential new members.

Your mission and vision explain in a nutshell what problems your coalition intends to address in which way and for whom. Most importantly, they highlight the unique value of your coalition’s approach.



FORMAT

The mission and vision of an organisation are made of a few simple short sentences, free of jargon: easy to understand and easy to remember. They should be understandable by the organisation's staff, its members, but also by a wider audience.

Once you have defined your mission and vision, you will need to sketch out the beginnings of an operational plan with key priority activities for the first couple of years. This can then be developed after the official launch of the coalition, with a proper Strategic plan and work (operational) plan.

see Chapter 7

The vision can be used to lead and inspire your group and organisation in achieving quality results.

It reminds you and your members of why you are doing the work you do.

FUNCTION

The mission is an easy way to communicate to others what you do and how you do it.

It is a tangible tool to help you make decisions about priorities, actions and responsibilities

1. Define the problem that you want to address
2. Imagine an ideal situation in the future: what does it look like when the problem is solved?
3. Describe the ideal situation with key words or a phrase
4. Think of when you want to reach that stage

HOW TO DEVELOP IT

1. State who you are (a non-profit organisation, at national/ regional level)
2. What the organisation aims to do or achieve;
3. For whom do you do it? (the target group)
4. Whom it is done with;
5. Where do you do it?
6. Define how you intend to reach your objective - in broad terms, what methods it uses.
7. What is the expected benefit?

"Our vision is one of empowered patients with a strong voice in a Pancyprian society where high quality health and quality of life are available to all." (Cypriot coalition)

"COPAC's vision is a world with a powerful and influential patients' movement where health and social systems are based on the real needs of patients." (COPAC, national coalition of Romania)

EXAMPLE

"Our mission is to ensure that patients have access to holistic, patient-centred, equitable and social healthcare, by promoting collaboration and building synergies among patient organizations and stakeholders, awareness raising and advocacy to shape health and social policies." (Cypriot coalition)

"COPAC mission is to empower/support patients and patients' organisations to act in unity and efficiently for the protection and promotion of patients' rights." (COPAC, national coalition of Romania)

3.4 YOUR VALUES AS COMPASS

Values are the principles an NGO commits to uphold in all aspects of its work. Values guide your organisation and help you set standards for the quality of your work. Independence, accountability and transparency are examples of crucial values for patient organisations.



It is important to discuss and agree on values that are important to who you are:

Values related to your vision: patient-centred, health in all policies, inclusive...

Values related to the quality of your work: open, consultative, professional...

Values related to how you work with others: transparency, independent, partnership...

Once you have decided what the core values of your national coalition are, make sure they live! Values should not be just written on paper, but be reflected in your daily work, and incorporated by every individual representing your organisation.

3.5 MAKE IT LEGAL

Because they are non-profit, voluntary citizens' groups, patient organisations (including national coalitions) generally choose to register as non-governmental organisations. You now have a good idea of the identity of your coalition-to-be. The next part of your journey will take you to registering your organisation legally.

- ✓ **Setting up task forces to facilitate the process up until the founding or constituent assembly:** at this stage it can be useful to set up smaller working groups which will be responsible to lead on making concrete suggestions and getting information on issues that need to be settled, such as the development of by-laws, membership criteria, finding funding for the constituent assembly, and disseminating information beyond your initial group about the constitution of your group as a national coalition of patient organisations.
- ✓ **Develop the by-laws,** the set of rules under which your national coalition will operate.

In many countries, developing and adopting a set of by-laws is a pre-condition for its official registration with local authorities.

The requirements on what the statutes should include depend on your national law, but they typically include information on the organisation's membership, structure, general assembly's scope and decision-making, board of directors' eligibility, role and nomination process, financial management, consultation process, and the process to amend the by-

laws. The by-laws are self-imposed by the NGO and should therefore fit the needs of your organisation. Think ahead as far as possible: constitutional reforms are arduous processes, so it is better to get it right in the first instance. Anticipate the needs of the organisation in the five to ten coming years.

The by-laws might have a specific European and/or international dimension which could make it easier to cooperate beyond borders (and become an EPF member).

- ✓ **Consultations** after having prepared the suggestions for all aspects mentioned above, a phase of consultations with other patient organisations (not involved in the task force) needs to take place. This builds more awareness about what is being done, why it is important and ensures a transparent and democratic process.
- ✓ **Constituent assembly** – founding member organisations adopt the statutes, rules of procedure, elect the leadership of the organisation and set some common culture for the new organisation by defining expectations. The number of founding members can vary but it is best to have as broad range of patient organisations as possible for the newly created national coalition to be representative.
- ✓ **Register your coalition legally as a non-governmental organisation** - After a name is chosen and the by-laws and articles are written, it is necessary to register the organisation with the country's public authorities. The documents to be submitted vary between countries, but in most cases information about the board members, mission statement, and staff members is required and the articles and/or bylaws are essential.
- ✓ **The Post-assembly period** – this is when the actual work starts. After your coalition has obtained its legal status, you will need to work on issues such as devising a comprehensive operational plan, obtaining funding, securing stable functioning, gaining new members, establishing internal information channels and in the long run acquiring recognition as the main voice of patient interests in the country.



4. STRUCTURES OF NATIONAL COALITIONS

4.1 YOUR MEMBERS, YOUR DRIVING FORCE

The driving force of a coalition of patient organisations is their member organisations. Membership-based organisations usually have several types of memberships, amongst the most common:

- ✓ **Full members:** they hold the highest power within the organisation and have the right to speak, make suggestions and vote in statutory meetings along with nominating people for the governing bodies of the organisation.
- ✓ **Candidate members:** usually hold the same rights as full members except for voting rights. Candidate member status is normally used as a step from “not a member” to becoming a “full member”.
- ✓ **Observer/associate membership:** this status is usually reserved to organisations that do not fulfil all membership criteria or organisations that do not wish to become full members. Observer members usually have the right to be present at statutory meetings, speak there, and make suggestions but cannot vote or nominate a candidate for the governing bodies of the coalition.



4.2 MEMBERSHIP CRITERIA: THE KEY TO LEGITIMACY

Membership criteria determine who can be part of your organisation. Once you start recruiting and new applications to join come in, you need to have a clear idea of whom you can accept and not.

This part is crucial and has a lot of implications on your legitimacy and credibility. As they will be enshrined in your constitution, it is important to take the time to think about it and get this right.

Membership criteria vary from one organisation to the other, depending on the national reality. They usually consist of a combination of requirements that can include:

- ✓ **Level of geographical coverage by the organisation:** do your members have to be national-level organisations? If so, how many municipalities or regions do they have to cover? Will your coalition accept regional organisations and coalitions?
- ✓ **Individuals vs. organisations:** can your coalition accept individual members or should your members be organisations only? Is there a specific category for each?
- ✓ **Representativeness:** how many regional members/individual patients should the candidate organisation represent to be eligible?
- ✓ **Legally registered:** organisations are legally registered as non-profit organisations in accordance to the rules of your country.
- ✓ **Objectives:** the activities and work of the candidate organisation is aimed to the promotion and defence of patients' rights.
- ✓ **Requirement to be patient-led:** the organisation must have patients only/ a proportion of patients in its governing bodies. We consider that a genuine patient organisation should have at least 50%+1 patient representatives in its governing bodies.
- ✓ **Consultation:** the organisation must consult with its members regularly, or the organisation must carry out a certain number of activities per year.
- ✓ **Democracy:** the governing bodies of the organisation are elected by its members.
- ✓ **Transparency:** because the reputation of your members will impact your reputation as a national coalition, you want to make sure that your members behave ethically and are transparent when it comes to their funding sources, but also with regards to their governance, consultation processes, partnerships...



Advisory bodies and healthcare professionals:

Accepting or not organisations that include healthcare professionals in their membership or governing bodies is a tough call. Indeed, to build and preserve the credibility of your coalition-to-be, you want to make sure that it is purely patient-led. However, some patient organisations do allow the presence of one or two healthcare professionals in their Board or as a separate advisory body for scientific and medical advice. Some prefer to create Memoranda of Understanding with relevant healthcare professionals' bodies. In any way, healthcare professionals should not be the key drivers of your organisation. In case of uncertainty, always take the discussion to your Board or membership.

4.3 REPRESENTATIVE BODY

The highest decision-making body of a national coalition – or any organisation, for that matter – is always a meeting that gathers all member organisations. These meetings are normally held once a year and can have different names: General Assemblies, Members' Council...

These meetings mainly have the following responsibilities:

- *Election of executive bodies and other bodies named in the statutes;*
- *Making political and strategic decisions for the national coalition's work;*
- *Making financial decisions: adopting the budget, accepting the annual financial statement;*
- *Adopting and amending the statutes and other working rules (in that case it is called an "Extraordinary" meeting).*



4.4 THE EXECUTIVE COMMITTEE OR THE “BOARD”

The Executive body of an organisation is also called Board, Bureau, Executive Committee, Steering Committee, or Presidium. It is the body that holds the power between General Assemblies. Its main roles and tasks include:

- *Making sure that the organisation is working towards its goals and implementing its work plan;*
- *Ensuring that the organisation has the necessary resources to work and overseeing the financial management;*
- *Supervising the organisation's projects;*
- *Recruitment of the organisation's lead (Secretary General).*

The size and composition of the Executive Body vary depending on the capacity and size of your national coalition. The Board generally consists of a President, a Vice-President, a Treasurer (otherwise referred to as “elected officers”) and Board members that follow specific policy and working areas.

Boards must be elected by the General Assembly and are responsible towards it. The duration of the mandate and the responsibilities of the Executive Committees are defined in your organisation's statutes.

4.5 OTHER WORKING STRUCTURES

Organisations may have other bodies, envisaged by the statutes or the strategic plan, appointed by the board or formed ad hoc according to urgent or momentary developments. These bodies can be named working groups, committees, steering groups, expert groups and are either focused on internal issues (financial control, membership issues, statutes revision...) or based on content (access to care, health policy, discrimination...).

The advantage of these structures is they ensure a better involvement and participation of your coalition's members and provide space for learning and sharing knowledge, and creating a common ground.

The main drawback is that they can make decision-making more complex and lengthy. It is important to carefully define the role of these structures and not create too many of them.

4.6 STAFF AND VOLUNTEERS

While some national coalitions of patient organisations have a large team of professionals to manage their activities and the implementation of decisions, other function entirely on voluntary basis. The size and number of staff depends very much on the financial resources of your national coalition. Regardless of this, the involvement of volunteers from member organisations is always necessary to implement the work of a national coalition.

When the first staff member is recruited, the role of the Executive Committee changes and it has to be less involved in the implementation work and focus more on the governance piece. The division of tasks has to be then re-examined and clear roles and approval processes must be defined to avoid conflicts.

5. ROLE AND ACTIVITIES OF NATIONAL COALITIONS

National coalitions of patient organisations serve as the consolidated voice of patients at national level. A national coalition eases the consultation and information gathering for governmental institutions and other stakeholders and means more weight and unity for organisations advocating for patients' rights.

- ✓ **Representation and advocacy work:** one of the most important roles of a coalition is influencing policies that affect patients' rights. Being organised as a national umbrella means providing the national authorities with one single point of contact for patient organisations. It also is easier to break silos and tackle cross-cutting policies such as employment, discrimination, reimbursement of medicines, research, and to address questions to governmental departments other than health.
- ✓ **Know-how & capacity-building centres:** national coalitions are by nature a privileged place for patient organisations to get and exchange information. They have a role in building-up resources and collecting know-how to support their members' advocacy actions and their own. Umbrella organisations are also in a good position to carry out surveys or research on cross-cutting policies. Expanding on their resource centre role, most national coalitions also tend to provide capacity-building tools for patient organisations, offering trainings or methodological support for their members.
- ✓ **Material support:** in some countries where patient organisations suffer from scarce resources, national coalitions offer working space, equipment and meeting facilities for member organisations, while those are working to build their own sustainability. Of course, at the beginning, one can find the opposite situation, where the national umbrella is hosted by one of the disease-specific organisations.
- ✓ **Awareness-raising and watchdogs:** by working on cross-cutting topics, national coalitions often are front-runners in identifying new topics and areas of work relevant to their communities, thus encouraging their member organisations and governmental institutions to be more aware and reactive to changes affecting patients. National coalitions also have the possibility to draw visibility towards topics neglected by authorities, or to act as watchdogs, monitoring the evolution of patient rights in their countries and calling on public attention when necessary.
- ✓ **International cooperation:** national coalitions of patient organisations act as an interlocutor between disease-specific organisations from their countries and those from abroad, thus providing support in developing international cooperation. They voice the concerns of their countries' patients on the European scene through other NGOs such as the European Patients' Forum or directly to European institutions and agencies such as the European Medicines' Agency.

6. FINANCING YOUR NATIONAL COALITION

Funding and the ability to fundraise play the democratic process more difficult a determining role in the development of your coalition. Once your national coalition is established, one of your primary goals will be to establish a framework where funding allows you to carry out your priorities and objectives... and not the contrary.

6.1 STRUCTURE OF FUNDING

It is important to differentiate project funding from core funding.

- ✓ **Core funding** is used for the day-to-day functioning of the organisation and covers offices, equipment, most of the staff costs and other running costs that are needed for the organisation to function. Ideally these operating costs should be covered by funding from the national government under the form of an operating grant or lump sum (an amount of money covering the overall costs of activities with no breakdown for individual items).
- ✓ **Project funding** corresponds to money allocated for certain actions, activities, policies or projects for which the funding has been granted, and is therefore conditional to the aims and objectives of this specific project. It should be used to fulfil the actions planned within a specific action (organisation of a conference, research project, set up of a database) but can also cover some operational costs linked to the realisation of the project's activities.





6.2 FUNDING SOURCES

The main funding sources for umbrella patient organisations are membership fees, public funding, international funds and private sector funding.

- ✓ **Membership fees:** because coalition of patient organisations are membership-based, membership fee is a common source of income for all coalitions. It sometimes has a symbolic character with little or no impact on the total budget; for some organisations however it is the main source of income.

Public funding: in a number of countries, national coalitions of patients receive funding from the state. State funding is given either as administrative support (operating grants), or through public tenders for project implementation.

- ✓ **European & International funding:** international funding can stream from international organisations like the United Nations and its different organisations, the European Union, foreign countries through their development programmes as well as different foundations or trusts (political foundations, etc.).

The most interesting EU programmes for patient organisations are the Public Health Programme, Horizon 2020 (research activities), the European Structural and Investment Funds, the Programme for Employment and Social Innovation (EaSI), the Justice programme, the Innovative Medicines Initiative (a public-private partnership between the European Commission and private companies) and ERASMUS + (for exchanges).

The management level of these programmes varies so you may need to contact your local and national authorities rather than the European level. Most of the European Union programmes have a co-funding principle and require that your organisation also puts some money on the table, or in some cases, 'in kind' contribution, that is to say contributions of goods or services, other than cash grants. Most programmes will also only fund actions with European added-value.

For further specific information please see the respective programmes and actions.

- ✓ **Private sector funding:** most patient organisations including national coalitions tend to rely mostly on grants from the private sectors, particularly in the earlier years, and especially from the pharma industry but opportunities exist beyond that sector, in the field of medical devices, IT industry, food sector, etc. Before accepting funding from the private sector, make sure you establish guidelines for working with industry or a code of conducts.

6.3 TRANSPARENCY

Ethics and transparency are an absolute priority for patient organisations. This applies to every aspect of an organisation's structure and activities (from membership to governance through communications). However, this is especially crucial when it comes to funding. To protect their independence and their credibility, national coalitions must follow some principles (you may want to check EPF's Toolkit on Fundraising for patient organisations for a more comprehensive overview)

- ✓ **Diversify your funding mix:** patient organisations' funding should come from at least four different sources, ideally across the public, private and international sectors;
- ✓ **Make your funding sources public** by sharing them on your website and in your annual report;
- ✓ **Prefer and promote unrestricted funding:** "Unrestricted" funds are donations that your organisation is free to use for any purpose, while "restricted" funds are earmarked and their use is designated for a specific activity or project.

Make the case for unrestricted funds: talk to your sponsors and explain how increased general operating support can lead to greater impact for your coalition's projects. Moreover, general operating support can help your patient organisation build the fundraising, planning and other systems it needs to strengthen their funding sources and sustain their organisations over time.



“ It is good to create a Code of Ethics to be adopted by all member organisations. It should be based on key principles and ethical standards for the organisation's and its members' activities: democracy, transparency, mutual respect and understanding, social responsibility, equal of opportunities, cooperation with institutions and partners. The document introduces clear rules on fundraising and transparency. ”

The experience of COPAC, the Romanian Coalition of Patients

7. TOWARDS SUSTAINABILITY

The keys to gaining and keeping sustainability

Your national coalition is set up. Congratulations! You now need to ensure its sustainability, to develop the capacity to grow and adapt to a changing environment to have a real impact and reach your goals.

Sustainability depends on several factors: although there is no magic recipe, one can say that:



SUSTAINABILITY =

*strong structure + clear and long-term planning +
sound and diverse funding base + effective communication + ownership*

The basis for a **strong structure** is laid out in your statutes, which you will need to refer to as often as possible. We have talked about **diversity in funding** in chapter 6, so let's have a look at how to tackle good planning, ensure ownership and develop effective communication.

7.1 PLAN STRATEGICALLY

Develop your first strategic plan and action plan

It's hard to accomplish anything without a plan. By writing your organisation's strategic and operational plans, you translate your mission and vision into concrete actions. A strategic plan looks at all the things your organisation could do and narrows it down to the things that you can realistically achieve, and where there is most added value for the coalition to intervene. A strategic plan also helps the coalition's leadership to determine where to spend time, human resources, and money.



STRATEGIC PLAN

OPERATIONAL PLAN

Outlines the organisation's direction for the future and sets a broad framework of goals and objectives to be achieved in line with this direction.

WHAT?

The operational plan details how the organisation will accomplish the goals outlined in the strategic plan during the time covered by the plan (usually one year).

Planning the implementation of your vision and mission, setting out long-term strategic goals.

PURPOSE

Details specific objectives and related activities to be undertaken to implement strategies defined in the Strategic Plan.

3 to 5 years.

TIMELINE

Is a plan for the day-to-day management of the organisation (one year time frame).

- ✓ Vision, Mission and Values.
- ✓ Strategic Goals: defining the direction of the organisations towards achieving the mission.
- ✓ Key areas of work: specific statements detailing what will be accomplished in relation to each goals.
- ✓ Strategies: how the objectives will be achieved. The Strategies must be specific, measurable, achievable, reviewable and time bound.
- ✓ Key performance indicators associated with the goals to be able to monitor and evaluate the implementation of the strategic plan.

WHAT DOES IT INCLUDE

- ✓ What?
Actions: detailed description of the key actions to be undertaken to achieve the strategies set out in the strategic plan.
- ✓ By when?
Timeframe: describes the "due" date for completion of each action.
- ✓ How much?
Financial and human resources implications for each action.
- ✓ Who?
Names the persons/body responsible for carrying out these actions.
- ✓ Key performance indicators associated with the actions to be able to assess the implementation of the operational plan.

The strategic plan, once formulated, tends not to be significantly changed every year.

REVISION

Operational plans may differ from year to year significantly.

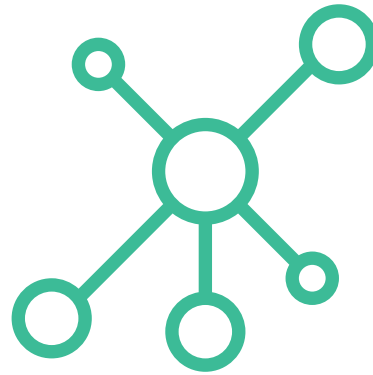
Review, review, review

Not that fast! Your plans must not be documents that end up collecting dust on a shelf. To ensure the plans perform as designed, you must hold formal reviews of the process and refine as necessary. For the operational plan, we suggest a review once a quarter. The strategic plan can be reviewed halfway through its implementation.



7.2 COMMUNICATE EFFECTIVELY

To grow your membership and your circle of influence, you need to communicate on your coalition. Your communication strategy has to be thought through carefully.



Know your target audience:

You do not use the same arguments or the same tone to invite a patient organisation to join the coalition or to convince the Ministry of health to meet with you. Segment your audience, adapt your messages and develop specific material for each of your targets.

Streamline your communication:

Each of the people involved with your organisation may have a different reason why they are doing this, and all of them will surely speak about your organisation and the work you do with third parties, be it in an informal context, at a networking event or when doing a speech at a conference. You also need to make sure that the persons who are going to speak about your coalition to external stakeholders will give the same view of your organisation. Indeed, when promoting the work of your organisation, you should be speaking with a unique voice.

5 key messages about your organisation

During a meeting with members, list the most important things you want other people to know about your coalition.

It may be the vision of your umbrella, the current topics you cover, what it can offer to other people. Reduce the list to five pieces of information and create short and realistic messages that summarise your work and can grab people's attention.

Make sure you disseminate these five key messages throughout the organisation and review them if necessary.

Create an elevator pitch for people with a representation role

An elevator pitch answers the question:

"If you only have a minute or two to talk about your coalition, what would you say?"

This marketing tool prevents you from going into every detail of what your organisation does and to get the attention of an audience in a very limited time. Gather the individuals who are going to represent your coalition externally: these may be Board members, staff members, volunteers...

Develop a short story that will make your coalition's work come alive and demonstrate your impact. Make sure your pitch is clear, concise, credible, concrete and conversational enough!

Invest in internal communication:

A great mistake would be to invest all of your efforts in external communication. Membership-based organisations are complex associations whose members are not sitting together regularly. An open and transparent communication with members is key to ensure the organisations' transparency and democracy. In order to ensure ownership and commitment, you need to put in place user-friendly

communication tools that facilitate the internal information flow.

Examples of internal communication tools include websites, intranet, social media groups (Facebook group), printed or online newsletters for members only, physical meetings, trainings, seminars, emails, phone calls, teleconferences...

7.3 IT'S A LEARNING JOURNEY

A word on organisations' culture

The success of patient organisations is more than the sum of a clear vision, well-thought strategic and operational plans, committed sponsors, a clear vision and dedicated individuals. Your organisation also has to foster a positive atmosphere and a culture of learning, sharing, documenting and communicating openly. Keeping your activities and governance open and transparent is essential to build trust and inspire individuals to volunteer their time for your organisation.

Good governance

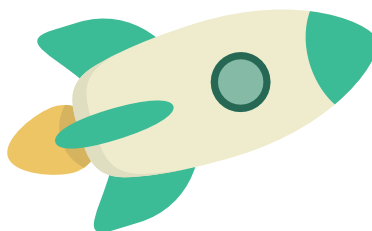
Respecting the rules and ideals you have set up when first constituting your national coalition is important. Good governance isn't about making 'correct' decisions, but about setting up the best possible process for making those decisions. Make sure you follow your own statutes and your country's rules for non-profit organisations. Be responsive, equitable and inclusive, effective and efficient, transparent and participatory.

Standing the test of time

Go back regularly to your vision, mission and values to ensure that the work you are engaging in, the institutions you are partnering with are in line with your identity.

It can also be useful to review the current environment from time to time to ensure that your mission and vision are still fit for the challenges patient organisations face in your country. Check your environment screening the political, economic, social and technological developments (as suggested in Chapter 3) and conduct SWOT analyses to see where your coalition stands and what potential new opportunities and threats need to be taken into account.

Last but not least, do not forget that participatory processes take time, just as establishing a good relationship with institutional stakeholders or building your reputation. Organisations develop, their role evolves, they gain importance or face obstacles, they



occasionally merge with other organisations and they even cease to exist sometimes when the needs of the communities they represent are met, when they fail to motivate or engage with their members, or when the conditions for their existence are no longer met. Work constantly and regularly towards building your coalition, and evaluate your work regularly: asking for and responding to feedback from your own members and partners is the key to progress. Invest in evaluation, check your achievements against your initial goals, repeat what worked well and try out new activities, always making sure they fit your mission and vision.

Next steps

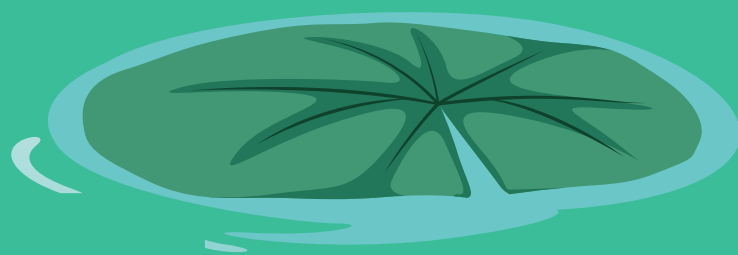
Patients still face barriers today in accessing information, diagnostic, care and treatment. Everywhere in Europe, we still need to defend our right to sit at the table where decisions are made, and to fight for the recognition that we are experts and therefore our opinion is crucial for the definition of research or policy priorities. We at the European Patients' Forum believe that the interests of patients are best served by pooling the expertise available within the patient community and joining forces, across diseases, in Europe and at national level.

The journey towards sustainable patient organisations is a long one. We know that with this toolkit we cover only one of the many steps to becoming a strong and credible partner. As part of our commitment to capacity building, EPF continuously develops and shares resources with our members and will address new topics in the years to come.



“ As a Federation, one of our main achievements is how we managed to strengthen the dialogue with national institutions such as the Ministry of Health, and the Parliament. A significant piece of legislation has been prepared, discussed and passed by the Parliament in early April 2016. The new legislation institutionalises the participation of the Federation in Parliament and now considers it as a key partner with whom the state and several institutions shall consult for health issues. ”

(Pancyprian Federation of Patient Organisations & Friends)



8. REFERENCES



How did we write this toolkit?

The European Patients' Forum wrote this toolkit based on the experience of already established national coalitions. In this regard, we would like to thank the Romanian Coalition of Patients' Organisations for chronic diseases (COPAC), the Bulgarian National Patients' Organisation (NPO) and the Pancyprian Federation of Patients' Associations and Friends for their input and honest feedback of the challenges overcome.

This guide is also based on the work led by EPF within its capacity-building programme and more precisely within the training modules conducted on strategic planning, operational planning, fundraising and transparency. The outcomes of the preliminary coalition-building workshops facilitated by EPF in Italy have also fed into this guide.

Finally, we have drawn advice from similar publications published by other organisations from different sectors on strengthening partnerships and building national coalitions.

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CONTACT US

European Patients Forum (EPF)

Rue du commerce 31
1000 Brussels
Belgium

✉ info@eu-patient.eu

☎ + 32 2 280 23 34

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