European Patients' Forum

Transparency guidelines

CONTENTS

1. INTRODUCTION

Why is the European Patients' Forum (EPF) engaging in this exercise?

The intrinsic nature of patient organisations means that they are under enormous pressure to prove their transparency: patient organisations deal with health, which is a highly sensitive topic. They also evolve in a complex external environment. Their relationships with regulators, healthcare professionals and industry with potential - or perceived - conflict of interests reinforce the need for a high degree of integrity and accountability. This applies across all of the organisation's activities, from membership criteria and governance rules, to its cooperation agreements, its advocacy efforts and its financial resources. But what are the actual rules that one should respect, and what are the processes to implement and monitor them in your organisation?

Supporting and guiding patient organisation's efforts

Transparency is an absolute priority for EPF, and the organisation focused on guaranteeing the highest level of accountability from our creation, back in 2003. Over the years, EPF developed its own cooperation framework with industry and funding partners, a document which inspired many stakeholders in the health environment.

These transparency guidelines are the result of a collective reflection initiated in EPF with a Training Programme on Transparency & Ethics during the summer of 2016. By developing these guidelines, we were clear that our goal was not to enter a "*blame and shame*" game, but rather to identify good practices and encourage patient organisations to take steps towards increased transparency. The objectives of this document are therefore:

> to develop a mutual understanding of what constitutes an ethically sound patient organisation;

> to reflect on the accountability of patient organisations, and how to demonstrate it;

> to provide guidance to patient organisations in becoming more transparent;

> to ensure the highest possible standards for our own network;

> to increase the level of trust and share insights on the added value of patient organisations from other stakeholders.

A mentality shift – We all gain from higher transparency standards

The reason why organisations enter the transparency debate is usually for fear of the negative repercussions that lack of transparency could have on their reputation. With this publication we hope to contribute to a paradigm shift and demonstrate that organisations can actually gain much by proactively working towards higher transparency standards. Improving the visibility, credibility and good governance of your organisation are positive outcomes of undertaking work on transparency, and are more motivating factors than the fear for bad publicity.
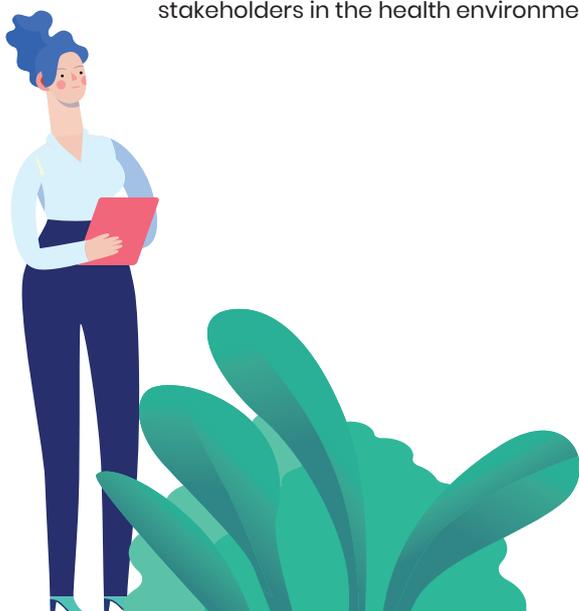
Who is our target audience?

EPF members and the patient community at large are the natural audience of this report. Stakeholders cooperating with patient organisations might also find it useful to understand the perspective of patient organisations and the considerations needed when entering into a partnership, or collaborative venture.

Methodology

This toolkit is based on a training on transparency which took place in September 2016.

The guidelines were further enriched by representatives from EPF members organisations, who contributed to each of the sections by sharing the experience of their organisations or sometimes their own questions. We are especially grateful to:

> Noémi Ambrus, Consultant at Civil Society Support

> Petra Balážová, Project Officer, Association for the Protection of Patients' Rights (Slovakia)

> Yannik Bendel, Policy Officer, Transparency International (until March 2017)

> Monika Benson, CEO, Dystonia Europe

> Marcin Rodzinka, Project Coordinator, Mental Health Europe

> Donna Walsh, CEO, European Federation of Neurological Alliances

It's a learning process for us too

The European Patients' Forum has developed this toolkit to support its members but also our own efforts towards the greatest possible transparency. We are conscious that we still have to develop for own organisation some of the tools that are mentioned in this toolkit. As a learning organisation, we are committed to taking the steps and implement the processes that will enable our organisation to lead by example, in line with our ethical values.
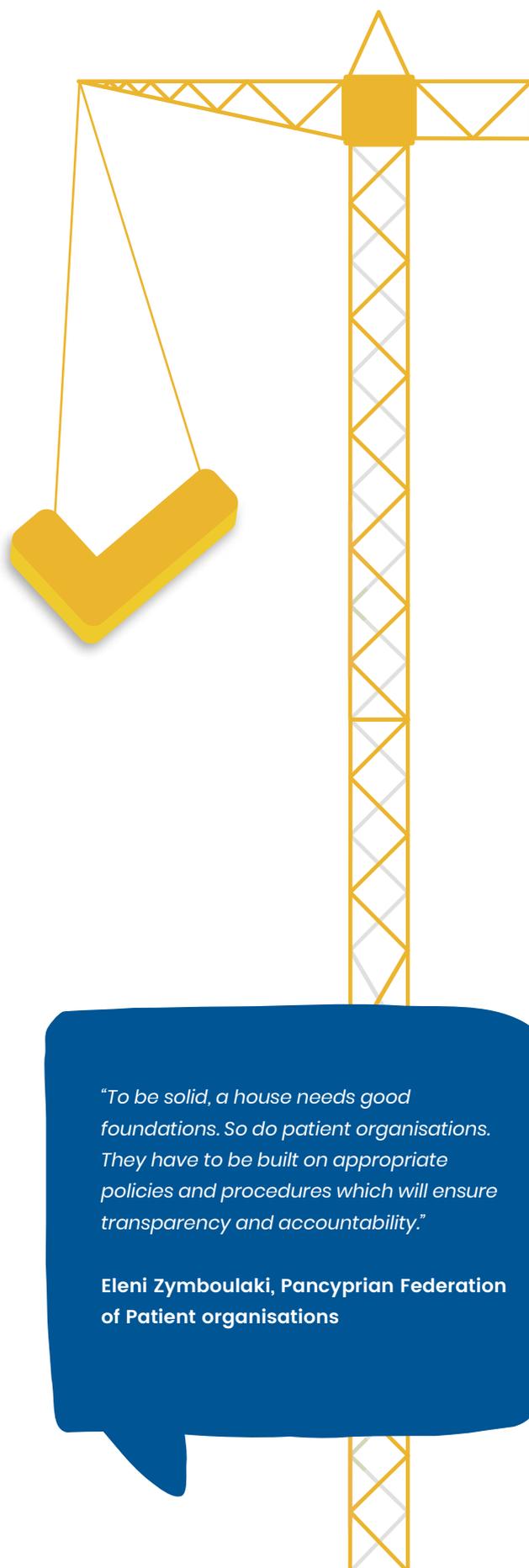
"To be solid, a house needs good foundations. So do patient organisations. They have to be built on appropriate policies and procedures which will ensure transparency and accountability."

Eleni Zymboulaki, Pancyprian Federation of Patient organisations

2. MEMBERSHIP – THE KEY TO YOUR LEGITIMACY

Patient organisations are most often membership-based organisations. As such, you are the sum of your members. Therefore, the legitimacy and transparency of your members affects your own organisation's transparency.

2.1 Membership criteria – who can join you?

The admission of members is usually regulated through membership criteria, spelled out in the organisations' statutes.

Interestingly enough, the membership criteria used to determine the eligibility of your potential members are often similar to the criteria that your organisation has to comply with to be recognised as a legitimate stakeholder in the public scene.

These membership criteria are discussed and approved by the governing bodies of your organisation, but they usually include:

> **Legal basis**: the candidate organisation must be legally registered, most often as a not-for-profit organisation.

> **Geographical relevance**: the candidate organisation is genuinely based (registered) and active in the geographical area represented by your organisation.

> **Representation**: the candidate organisation shall be representative of patients. Some organisations set up a minimum threshold of individuals or organisations that the candidate organisations must represent. Depending on your organisation's type (local, regional, national coalition of patient organisations, or disease-specific organisation), this criterion can also refer to the disease areas covered by the organisation, or the minimum number of regions/countries that has to be covered by the organisation.

> **Governance Structure**: this refers to the organisation's governing bodies (board, executive committee etc). The requirement is usually that these are elected by the organisation's members, and that they shall be patients, their carers, or their elected representatives.

> **Matching vision and convergence of the objectives** of the candidate organisation with the goals of your organisations.

> **Democracy and consultation**: the candidate organisation should be able to demonstrate that they have processes in place to ensure that the organisation's statements and opinions reflect the views and opinions of their own members. Compliance with this criterion is more difficult to verify: you can ask for examples of consultation documents from the candidate organisation to their members, or proofs of internal communications material, which would show that there is a flow of information between the organisation and its members, and a two-way dialogue: from and towards its members.

> **Transparency**: the organisation shall make its sources of funding public. We talk more about this in Section 4.

> **Membership fees**: most membership-based organisations request the payment of a membership fee. This is used as a source of revenues for the organisation's operations, but also to monitor commitment from member organisations. The amount requested can be fixed, linked to the membership category or the members' turnover. It is usually specified in the statutes of the organisation.

2.2 APPLICATION PROCESS

Beyond the membership criteria, the process of accepting a new member organisation is also highly important:

> **Make your membership criteria public**, on your website;

> **Set up a membership review process, and make this public too**: what are the documents that should be provided? Who is the contact person? Who conducts the review? Membership applications are usually reviewed by your organisation's General Assembly (the highest sovereign body of your organisation), based on a recommendation of the board, during its annual meeting. The members with

voting rights decide on whether to accept or not an organisation as a new member.
Make sure that you provide your voting members with all the information they need to make an informed decision on approval of potential newcomers' applications.

Who reviews the applications?

To ensure objectivity, the review of the membership applications should ideally not be left to one person. The reviewers can be a member of the staff or a member of the Board of the organisation. Should there be any hesitation on the eligibility of the organisation, it is important to involve the governing bodies: they are the guarantors of your values.

Sometimes organisations set up a dedicated body tasked to review membership applications. This can be made up of members' representatives, Board members, and/or Secretariat members.

Thus, the European Youth Forum's *"Consultative Body on Membership Applications reviews the complete applications of potential members and presents a motivated report on the membership applications to the Board. Additionally, the Consultative Body on Membership Applications can be addressed by existing members or take initiative in relation to both proposed as well as adopted changes relevant to their membership status, such as changes of statutes and/or legal status."*

In any case, make clear who will assess and review the membership application of the candidate, and also give an indicative timeline to the applicant.

> **Apply the same application process to all candidates** – there should be no favourable treatment: fairness is key for your legitimacy.

> **Communicate clearly the outcome of the decision of the governing bodies.**

> **Keep track of the assessment process for future references**: they are part of the organisation's institutional memory and you may need to get back to these should the legitimacy of one of your member be questioned at a later stage.

2.3 MEMBERSHIP TYPES

Many memberships organisations offer different types of membership, which are linked to different benefits and duties. The most common terms to segment your membership are:

> **Full membership**: this status is granted to an organisation that complies 100% with the organisation membership criteria. Full members have the right and the duty to vote.

> **Associate membership:** this status is granted to organisations that fulfil the most essential criteria but do not comply with all of them. It can be that they involve patient organisations, but not only, or that they do not cover a geographical area that is representative enough. Associate members usually can participate in some of the meetings of your organisation, but not all. They also cannot vote in governance meetings or hold elected position in your organisation. This type of membership allows the candidate organisation to join your community. For your organisation, it means bringing in a different voice while preserving its legitimacy.

> **Provisional membership**: is granted to organisations that do not meet all the membership criteria yet but are likely to do so in the near future. Provisional membership

is a transitory status. In some organisations, this level of membership is also reserved for organisations having been approved by the Board but whose membership still need to be confirmed by the Annual General Meeting, which happens at EPF.

In a membership organisation having different types of membership, disclosing your membership criteria publicly on your website and official documents allow you to:

> be more transparent with your membership and external stakeholders;

> be more inclusive with organisations that are not yet fully complying with your membership criteria but still bring an important added value to your community.

2.4 MONITORING COMPLIANCE OVER TIME

If most organisations have membership criteria in place, little is often foreseen for what happens after a membership application has been accepted. Yet patient organisations are created, they evolve and sometimes become inactive for a while or even disappear. How do you monitor your membership and its compliance with your criteria over time?

Your membership directly affects the representativeness of your organisation: asking yourself how representative you are is the first step towards taking action.

> **Dealing with inactive members**
Some of your members are listed on your membership list, but they are inactive: they no longer participate in your activities, they do not pay their membership fees, or maybe, they do not answer to any of your emails. Can they still be counted as members?

This is an issue that many membership-based organisations encounter at some stage, and that requires some action. First of

all, try to understand what the problem is: it might be that the contact person is wrong and that the organisation is not receiving your communications at all. Make sure you update your contacts list regularly to avoid this kind of situation. Perhaps the organisation is undergoing some structural change, or they momentarily have low resources or capacity, and therefore cannot participate in your activities. Check in regularly with your members to understand what their situation is, and offer to re-contact them at a later stage.

It may also be that their priorities have changed, and that they no longer see the benefits of being a member of your organisation. Exchange regularly – even informally - with your members to understand what their needs are, and how you can best support them, to make sure that the services that you offer have added value for them.

If they are no longer interested in being a member, then make sure to discontinue the membership through the procedure set in your statutes. This often needs to be validated by a vote during a General Assembly.

It should be noted that losing a member is a serious issue for any organisation and the decision cannot be taken lightly. Every effort should be made to keep members on board.

> **Reviewing your members' legitimacy criteria – how to proceed?**
There are different solutions to monitor the compliance of your members with membership criteria: you can set up a "committee" (a body made of a few elected members – or nominated by your Board) with the task of monitoring compliance regularly systematically (every 5 years, for example). Alternatively, if you have fewer resources, review compliance for one or two member organisations selected randomly each year.

Some organisations also set up an ethics Committee who can be contacted when members or external stakeholders suspect one of your members is not meeting the legitimacy criteria.

> **So, one member is no longer meeting the criteria – what should I do?**
The action to be taken by your organisation obviously depends on the gap that exists between your criteria and the situation of your member organisation. If the organisation does not have the legal basis it claims to have, or was misleading about its governance system, then the membership of the organisation is questioned. The governing bodies should decide on the sanction to apply. There again, the statutes should be used as a reference: exclusion criteria should, ideally, be listed therein.

> For minor infringements however, an encouraging and supportive attitude can be the right approach. If the organisation is momentarily not meeting the number of members required to be part of your network, or if they have not published their annual accounts on their website, excluding them might seem slightly disproportionate. Rather than taking a punitive action, try to guide your member, and support them in meeting the criteria again.

2.5 MEMBERSHIP CONSULTATIONS AND INVOLVEMENT OF MEMBERS IN THE DECISION-MAKING PROCESSES

As a membership-based organisation, you represent the collective voice of your members and speak on their behalf. To be credible in the eyes of external stakeholders such as decision-makers, you must ensure that the statements you publish, and the decisions your organisation makes are endorsed by your membership.

How to "consult" with members?

To do this, you must have a process in place to consult with your members. This includes giving them the opportunity to comment on your statements, to express their support or disagreements, and to provide any additional views they may have.

General consultations methods include:
- Face-to-face meetings: General Assemblies, workshops, working groups, teleconferences...
- Surveys, polls.
- Written consultations: you submit a first draft of a statement, and your members can comment on it.
- Collaborative platforms or online shared documents (Yammer, Slack, Google docs...).

How much involvement is "enough" involvement?

For a consultative process to be legitimate, it needs to give your members an appropriate amount of time to answer the consultation. Members sometimes need to consult with their own basis. This can be tricky, especially in policy contexts, when to be impactful, a position statement needs to be published promptly.

Define the consultation process together with your members:

- What are the instances/topics on which your members want to be consulted? What are the topics on which they trust your Secretariat and or board's judgement, based on previous statements and position, the body of evidence available through project work, and the organisation's values base?
- What is an acceptable timeline for them to review the materials/statement you send them?
- What channels do your members prefer to be consulted?

- How many responses are "enough" responses? It is rare that all members of a membership-based organisation participate in all discussions. Some organisations might have joined your network because they do not possess the necessary expertise to take part in the policy processes your organisation is dealing with. Some other organisations might not have the capacity to answer all of your consultations. This is fine, and you need to acknowledge this. As with the other aspects of the consultation process, define with your members what constitutes an ideal/acceptable level of answers.
- What if members disagree? It can also be useful to define a process when there is no consensus, and an organisation has significant and divergent views from the majority of the members. This can be discussed at Board meetings for example, the difference of opinion can also be acknowledged by a foot note in the position paper.

Closing the consultation process: the importance of providing feedback

The consultation process does not stop when you receive answers from your members.
You will need to integrate the comments received by your members, share them with other members, and provide feedback on the comments received, and why the organisation decided or not to include the comments received.

Don't neglect this step! For members to feel the ownership of your network, they need to know that they are shaping its policy work, contributing to its strategy, and that their opinion is taken into account. By dedicating time to build that positive feedback loop, you reduce the distance between the organisation and its members.

3. GOVERNANCE

The management of NGOs including patient organisations consists of three main entities: the Board of Directors (or Executive Committee), the General Assembly, and, for patient organisations having paid staff, the Executive Director or Secretary General.

3.1 GOVERNING BODIES

The General Assembly – Your members in the driving seat

The General Assembly gathers all your organisation's members and is the supreme governing body. It generally meets annually, and makes the most important decisions over the budget, strategic planning, annual planning of activities, membership. The General Assembly elects the Board of the organisation.

The Board – setting the example

The Board (or Board of Directors, or Executive Committee) of a patient organisation is made of several individuals coming from your membership. The Board is responsible for overseeing the organisation's activities and accounts.
Board members are nominated by member organisations and elected by your full members during the Annual General meeting. As such, the board is accountable to your organisation's full membership.
Beyond what is stated in your organisation's statutes, there are some further characteristics to look for in individuals who wish to become Board members that can enhance your organisation's credibility:

"Good governance is a transparent decision-making process in which the leadership of a non-profit organisation, in an effective and accountable way, directs resources and exercises power on the basis of shared values."

European Working Group on Non-profit Governance

> **Knowledge of the patient community & vision**: the individuals present on the Board are expected to champion your cause, and represent your organisation externally. Some Board members are also expected to help fundraising.

> **Commitment**: you are looking for committed candidates who are willing to take the work of your organisation forward. Candidates should be ready to contribute with time and ideas.

> **Expertise**: ideally, you want a board with multidisciplinary and complementary skills within its membership.

The Executive Director (or Coordinator, or Secretary General)

He or she is responsible for the overall direction in which the patient organisation moves, implementing the strategies agreed by the governing bodies, and has overall responsibility for managing the day-to-day activities of your organisation.

3.2 DEMOCRACY

To ensure your organisations' legitimacy, make sure you have strong democratic processes in place.

> **Elections – processes**: here again, it is quite important that you are very clear about the election process:
> • Which organisations are allowed to put forward a candidate (full members only vs. all membership),
> • What is the election process?
> • What happens in case of a tie? This issue can be solved with the nomination of tellers, for example.

> **Board rotation policy** – Set up a review process that will occur annually and provides an opportunity for the Board to reassess not only the contributions of Board members stepping down or standing for re- elections, but also the blend of qualifications and experience and knowledge represented on the board, and to plan board succession accordingly.

> **Length of term and limits in the terms of mandates**: the length of terms for patient organisations' Board members varies from organisation to organisation, but usually ranges from one to three years.

> **Cessation of appointment:** due to the nature of the work and contribution to the workings of an NGO board, criteria for cessation of appointment is also usually set out in the statutes of the organisation. A Board member could cease to be a member if he/she resigns; if he/she no longer has links to the organisations that secured his/her nomination; if he/she is unable to perform the agreed upon tasks; if he/she is unable to work with the other Board members as part of a team; or if a conflict of interest is declared.

3.3 TIPS FOR INCREASING LEGITIMACY AND TRANSPARENCY

› Individuals sitting on the Board of patient organisations are usually not remunerated. This is a role that they take on voluntarily. With regards to the process, it is important that you spell out clearly what is expected from Board members: roles, responsibilities of Board members and the estimated time commitment.

› The number of Board members varies from organisation to organisation: it helps if they are an odd number in case there is a tie during votes.

› Ideally, your organisations' Board is different from its management (paid staff). While many small patient organisations have Board members serving in management positions, the ultimate goal is to have board members separate from paid staff members.

› Board meetings are kept closed. However, written proceedings, reports and summary minutes should be made available on request for transparency purposes.

› Set up a conflict of interest policy: require board members to disclose outside interests conflicting with the interests of your organisation. These potential conflicts of interest include relationships or responsibilities (personal, financial, and others).

› The Executive Director is usually appointed by and reports to the Board. As such, it is best if he/she does not have voting rights at Board meetings.

4. FINANCES AND COOPERATION WITH FUNDING PARTNERS

The funding of patient organisations is such a sensitive matter, this is also one of the first issues to come up when talking about transparency and ethics. In this section we will look at how to improve your transparency when it comes to fundraising and cooperation (involving funding or not) with sponsors.

As in most of the chapters of this publication, one of the key factors influencing the transparency of your organisation when it comes to fundraising is how you communicate it.

Your transparency therefore can be enhanced by looking at the following questions:

> How clear is your purpose, your activities when you fundraise? (4.1)

> Cooperation with sponsors – what are the rules? (4.2)

> Communicating about funding (4.3.)

4.1 TRANSPARENCY OF YOUR PURPOSE: WHAT ARE YOU FUNDRAISING FOR?

Your Strategic Plan as a basis for fundraising

For your fundraising to be successful, you need to know what you are fundraising for. In this context, a crucial tool and your starting point to fundraise is your Strategic plan. The fundraising materials you will develop subsequently should be in line with your strategic plan.

The key principle here is that your purpose dictates your fundraising plan, and not the contrary.

Your strategic plan:

> helps to provide direction and focus for all people involved in the patient organisation – Secretariat, Board, volunteers, etc.;

> provides a sense of direction and outlines measurable goals;

- helps build your competitive advantage (added value);
- is useful when communicating your strategy to staff;
- gives a broad framework to ensure process and outcome evaluation;
- helps prioritising your financial needs; it provides focus and direction to move from plan to action;
- Prior to drafting the strategic plan, conduct a **SWOT analysis** – analysis of your strengths, weaknesses, opportunities, and threats, and an **environmental analysis**, which will enable you to understand the external local, national or international forces that might affect your organisation.

What should your Strategic plan entail?

- A vision statement – it is future oriented; it describes where the organisation is going;
- A mission statement – summarising the aims and values of an organisation;
- Strategic objectives – they are long-term and should be aligned with you organisation's mission and vision;
- Tactical objectives / Action plan – describing how you are going to achieve your strategic objectives, concrete steps;
- Monitoring and evaluation approach – how are you going to measure your success in delivering on your objectives?

Some examples of Strategic plans:

http://www.eu-patient.eu/globalassets/library/strategic-planning/epf-strategic-plan-2014-2020- final.pdf

www.who.intevidence/OMSEVIPNetStratPlan.pdf

4.2 COOPERATION WITH SPONSORS

Fundraising means that your organisation seeks for funds that will enable you to conduct the activities that will bring you closer to its vision (and not the contrary!). The main funding sources for umbrella patient organisations are **membership fees, public funding, international funds and private sector funding.**

Because public funding is scarce and competitive, patient organisations often look for funds from the private sector. In this section we take a closer look at cooperation with sponsors, in particular with industry (in this section, we refer to private partners as "companies", "corporate partners", "industry", "partners from the private sector".)

STARTING ON THE RIGHT FOOTING

If cooperation with private and public partners may translate in financial or in-kind support for your organisation, it is not a decision to be taken lightly.

Because health is a sensitive topic, cooperating with industry will doubtlessly have an impact on the way your organisation is perceived. As before entering any cooperation agreement, you should make sure that the terms of the agreement work for both parties involved. We recommend that you take a little time to think of the broader implications of entering a cooperation with a private partner.

❯ **Take a minute to think of what the benefits for the funding partners (public or private) cooperating with you are**;

❯ **It's not all about the money**: It is important to note that with any sponsor (corporate or not) it is not just about the money, it is about the relationship, common goals and assumed good intent.

❯ **Think creatively**: think of the different ways that partners can support your activities **–** monetary support is only one of the ways that public or private can support your work: they can also provide support in the form of expertise, legal advice, visibility, work time donation.

❯ **Trust your worth**: a lot of patient organisations walk in meetings with funding partners feeling like the "weaker" interlocutor in the discussion. This is a wrong approach. You are not asking for a favour, but you are bringing something at the table. You are offering expertise and a perspective that the company currently does not have. Don't be arrogant, but trust your worth and go into discussions as an equal.

❯ **Can you work with anyone?** Although it is not prohibited, patient organisations would generally not accept funding or support from sources such as the tobacco, alcohol, arms trade industry, for their activities are in contradiction to patient organisation's values.

SETTING UP A FRAMEWORK FOR COOPERATION WITH FUNDING PARTNERS

Before entering into a cooperation with a company, take the time to develop a framework for cooperation (code of conduct). This document will lay out the basis of the cooperation with your funding partners (not with one single partner). Its objectives are to:

❯ Set up principles of ethical collaboration between partners;

❯ Ensure independence and ethical conduct;

❯ Promote transparency and accountability.

Developing your framework for cooperation with industry

The framework for cooperation with industry is usually structured as follows:

❯ **Background, introduction:** in this section you explain whom your organisation is and why it does cooperate with industry.

❯ **Key principles:** this is the most important section of the document, where you explain what the conditions for this cooperation and for acceptance of funding are. These core principles are the conditions under which you will or not enter into a cooperation with your funding partners. They are non-negotiable.

❯ The principles listed in this document reflect your organisations' values.

• Independence – this means that the voice of your organisation remains independent, and that the effect of your position on funders will never be a relevant factor for your organisation's policy development and decision-making process. Sometimes, the topics on which you will be working will coincide with the areas your sponsors are working on.
The key point here is that your organisation's priorities are developed prior to the fundraising, and are not established in function of the support you get.
Similarly, the content of activities and/or events sponsored should be developed independently by your organisation.

• Mutual respect – receiving financial support does not mean you cannot be openly critical towards your sponsors (be they public or private): this freedom of expression and any critique should be underpinned by respectful and responsible dialogue, inherent to the

values of patient organisations, as well as assumed good intent.

- Unrestricted funds – this means that your organisation decides on how to use financial support it receives from funding partners;
- No single company funding – the projects or events should be supported with an unrestricted grant by more than one company, and/or funding source (public).
- Sustainability – the funding support provided by partners should, wherever possible be part of a long-term commitment to funding supported by a written agreement.
- Transparency - a written agreement between the funder and your organisation outlines the nature and amount of the funding and the period covered. The amount of funding received and the sources are included in your organisation's Annual Report and published separately on your website.

❭ **Acknowledgements and benefits for funding partners** – acknowledgements can include: the display of a logo on a publication, or of roll-ups at an event, thank you letters. Benefits can include: priority notice on public events, priority placement or discount on public events, free copies of publications, name and links on the website, right to propose a new partnership, invitation to capacity-building project – as experts for inclusion in national stakeholder discussion, invitation to an industry event.

❭ **Ways of dialogue** – in this section you explain how the structure of the communications between your organisation and the sponsors: e.g. one contact person from both parties, monthly newsletter towards corporate partners, Annual Funder's Meeting, dialogue on health policy issues, attendance at a Funder's events, invitation to the organisation's events, etc.

❭ **Guidelines for non-funding relations**, for example, in-kind support, expertise, etc.
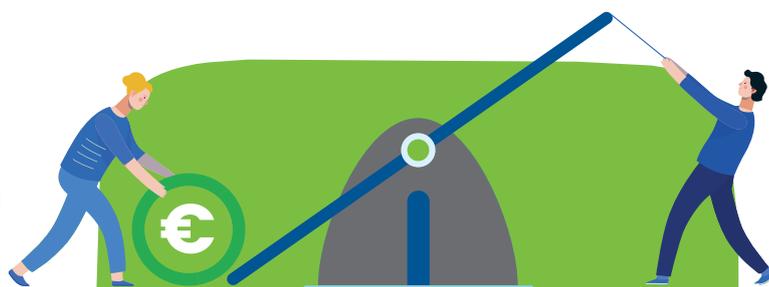
When patient organisations struggle to diversify their funding…

Although diversification of funding is an important objective, it should be noted that this is unfortunately very often challenging for patient organisations: at national level, some governments simply do not award funding to NGOs including patient organisations. At European level, the opportunities for core funding for patient organisations are also very limited. Moreover, some disease-specific patient organisations may have difficulties in initiating a cooperation with multiple funding partners, who do not work in their disease area and therefore do not generally support these patient groups. EPF undertakes a lot of awareness and capacity-building activities to promote diversity and balance in funding among our members and the patient community in general. With this publication we would also like to raise awareness of the challenges met by patient organisations in resourcing themselves, and in balancing the challenge of fundraising with that of credibility and legitimacy. [1]

1   For more on this, please see the EPF "Report on the Added-Value of Patient organisations", http://www.eu- patient.eu/globalassets/library/publications/epf_added_value_report_final.pdf

YOUR ORGANISATION, YOUR RULES

When it comes to individual agreements with funding partners and companies, what is acceptable and what is not? The agreements should of course be in line with your framework for cooperation, but more questions may come up. How to handle activities sponsored by one sponsor only?

What's the rule when there's no rule?

There is not a rule for everything, but here are a few tips on how to handle unknown situations:

> First, set your boundaries. A good rule is that if you are not comfortable with a request, you should probably not be doing this. Draw your red lines, and stick to them. For example, if you do not agree to have your picture or name used in a material from a sponsor, just state clearly that you are not comfortable with it, and do not dread that this will affect the relationship negatively.

> If an offer is not acceptable, state clearly that you cannot engage in the cooperation agreement as it is proposed, and do not hesitate to go back to the sponsor with a counter-proposal on the terms that suit your organisation and your policy.

> There is no such thing as "business as usual" with a patient organisation: as an NGO, make sure that your organisation as an NGO is not treated as any business partner.

Dealing with new types of requests

The explosion in visual communication tools (Twitter posts, leaflets, videos) means - potentially and increasingly in requests from industry to patient leaders to lend their image to their materials - still in line with Codes of Conduct. Again, the rule here is not to commit to doing anything you do not feel comfortable with.
If you decide that the request can be beneficial

to your organisation, make sure you control the different parameters, for example:

> Always ask to be able to review the materials before they are published, and to have the opportunity to change your mind.

> Agree on the context in which your picture or quote is used.

> Set up a timeframe during which the company is able to use your picture (or video interview).

Supporting Documents – Some examples of Codes of Conduct

European Patients' Forum, Framework for cooperation: http://www.eu- patient.eu/globalassets/who-we-are/transparency/framework-for-cooperation-2014.pdf
European Federation for Allergy and Airways Diseases Patients Organisations, Sustainable Corporate Partnership Framework: http://www.efanet.org/images/documents/EFA_Sustainable_Corporate_Partnership_Framework_2 016.pdf
European Multiple Sclerosis Platform, Code of Conduct, http://www.emsp.org/wp- content/uploads/2012/08/Code-of-Good-Conduct-2015-Update.pdf

4.3 COMMUNICATING ABOUT YOUR ORGANISATION'S FINANCES – MAKE THE NUMBERS SPEAK!

Managing your organisation's fundraising and budget in a transparent way are important steps. Once you get these rights, you also need to make sure that the financial information of your organisation is available to external stakeholders.

Here are the documents that you should make available:

> **Financial statements**: financial statements provide information to key stakeholders to evaluate your organisation's financial performance. They can be used to measure

your achievements and successes on a given period of time. Finally, they are useful tools for making decisions regarding engagement in new projects, long-term planning, potential expansion. They can also give you an idea of the fundraising efforts you will need to make in order to realise your plans. There are several types of financial statements:

- **The budget (your plans)**: the budget is a plan for your income and expenditures. It is usually defined on an annual basis and adopted by your General Assembly.

- **The Balance sheet (your results)** – the balance sheet is a picture of the financial position of your organisation at any point in time. It entails your organisation's assets, liabilities and equity at the end of a financial reporting period.

Note! The balance sheet should be made available to external stakeholders (sponsors, general public). On the other hand, budgets are internal: they are used for daily management and decision-making. They do not have to be made public to your wider audience, beyond your membership.

- **The Income and Expenses statement** – reports operating results, such as revenues earned and related expenses covering a certain period of time. Prefer this term to "Profits and Loss", which apply better to the corporate sector.

- (Optional) **Cash Flow Projection** – the cash flow projection presents anticipated income and expenditures during an upcoming period. This is a planning tool.

› **List of sponsors:** your audience is not only interested in your organisations' operations and financial results. To have a complete view of your financial situation, they also want to know where you receive your funding from. Publishing a list of your sponsors (public and private) is key to transparency. Show the breakdown of the sponsorships you receive per project can also be a way for you to demonstrate how you implement the "no single company funding" principle.

› **Are your sponsors transparent?** Most entities –private or public– providing financial support to patient organisations are obliged to display the amount and beneficiaries of the support they provide on their websites. We believe that ensuring compliance with this is not the task of patient organisations. Nevertheless, as a beneficiary, you can check whether the companies or public institutions supporting you report on the grants you receive accurately. You can also advocate for companies' full compliance with their own codes of conduct and additional support and guidance where this is necessary.

› **Audit report (see below)**: Publishing the activity report and independent audit report on the website for the purpose of enlightening the public contributes to accountability and transparency.

MAKE YOUR BUDGET INTELLIGIBLE!
Your organisation's budget can be presented in many different ways. Presenting the information in a format that is easily readable and makes sense to your target audience is also part of transparency work.

Here are some of the ways you can present your budget and balance sheet:
› Thematically or "per project": income and expenditures (planned or actuals) related to your work on patient education, health literacy, mental health;

> According to the income source: public vs. private;

> Per activity: income and expenditures linked to advocacy, capacity-building, communications, fundraising;

> or simply by broader headlines: personnel costs, operations, administrative costs.

Documents:

http://www.eu-patient.eu/library/Annual-Reports111

4.4 AUDIT – A HEALTH CHECK FOR YOUR ORGANISATION

An independent audit has the important function of securing necessary level of transparency and accountability and in building trust.
An audit is the examination of the financial report of an organisation by someone independent of that organisation. In most countries, conducting an external audit is compulsory for organisations exceeding a certain turnover. Audits are usually performed once a year after the completion of your organisation's fiscal year.

Beyond the legal obligation, audits are also a way to have a systematic, independent and objective feedback on the financial management of your organisation and to get advice on how to improve the effectiveness of your risk management, control and governance processes.

Internal audits: some organisations do not have the resources to pay for or warrant an external audit. Think of an alternative: in some small organisations, two ordinary member representatives (not board member) with financial expertise can be nominated to review the accounts.

What do auditors look at?

Auditors do not only look at the money spent by your organisation. They also review the processes that led to the expenditures, and whether these were efficient and conform to your organisation's governance rules:

> They analyse your books, operations and confirm their effectiveness;

> They evaluate the internal controls and review compliance with procedures in place;

> They evaluate the risks for your organisation.

The result

Based on what they learn during the audit they will produce an "Audit Report", certifying the conformity of your financial statements with the law and with your organisation's internal rules. The audit report may also entail recommendations aimed at the management and board on how to improve your organisation's financial management.

Finances, but not only

Although a financial statement audit is the most common type of external audit, external auditors may also conduct special purpose audits which might include social audits (making sure your organisation's human resources policy complies with the legal obligations), performing specific tests and procedures and reporting on the results, a less intensive review, and compilations.

4.5 FUNDRAISING EXPENSES: HOW MUCH DO YOU ACTUALLY SPEND ON GETTING MONEY?

Fundraising means increasing the organisation's income, but it also has a cost! If you are looking at improving your fundraising activities, it is interesting and important to estimate the percentage of your budget that is spent on generating income for the rest of your activities.

Financial expenses related to fundraising can include:

❯ **Staff costs linked to fundraising:** in case you have one person in charge of fundraising, it is this person's salary. It could also be a portion of the time of several members of your staff. Here are some examples of activities linked to fundraising:

- Worktime spent on a fundraising strategy linked to the overall strategy;
- Grant-writing;
- Paper work linked to compliance and written agreements;
- Maintaining donor mailing lists – sending letters;
- Organisation of fundraising events and campaigns;
- Writing materials that will be used for fundraising;
- Initiating and maintaining relationships with funding sources.

❯ **Costs linked to fundraising events:**

- Annual industry funders' meeting;
- Conducting fundraising campaigns;
- Conducting fundraising events;

❯ **Communications costs:** printing/mailing publications and fundraising materials.

❯ **Administrative costs:** postage and printing, telephone and internet charges.

5. ADVOCACY – TRANSPARENCY IS YOUR CURRENCY

The word "advocacy" comes from the Latin 'advocare' and literally means "to call out for support". Today it is used to describe the process where individuals or groups of people take actions to try to influence those who make decisions that affect our lives.

5.1 WHY IS TRANSPARENCY IN ADVOCACY IMPORTANT?

Defining advocacy

When it comes to exerting influence in policy-making, advocacy is often used interchangeably with the term "lobbying", which Transparency International defines very practically as "Any direct or indirect communication with public officials, political decision-makers or representatives for the purposes of influencing public decision-making and carried out by or on behalf of any organised group".

Health advocacy and lobbying is at the heart of the work of many patient organisations (whether it is local, national or European). Their mission statement often includes promoting a political, regulatory, and societal environment that are more patient-centred.

This means that patient organisations engage in lobbying activities on a regular basis. They do so by contributing the specific perspective of patients and people with chronic condition to legislative processes, but also by pushing for the

"Advocacy is an iterative, informal game built on personal ties and trust."

(Yannick Bendel, Transparency International, September 2016).

recognition and for actions on topics that are not necessarily yet on the political agenda (proactive advocacy). This is for example what the European Patients' Forum did with its Campaign on Patient Empowerment in 2015-2016, when asking European decision-makers for a European Strategy on Patient Empowerment.

In its Guide on "Responsible Lobbying", Transparency International Ireland lists common lobbying activities:

> ❯ Submitting formal written responses or draft legislation to government for proposed policies or laws;

- Appearing before parliamentary bodies considering draft laws or particular issues;
- Face-to-face meetings with politicians, elected representatives and officials;
- Taking part in expert or advisory groups set up by government or public bodies to recommend changes to policies or laws;
- Engaging in formal structures, like multi-stakeholder partnerships which regularly discuss laws and policies with public officials or elected representatives;
- "Grassroots" campaigns encouraging individuals to write to their elected representatives or government officials;
- Publication of research and policy papers aimed at influencing public officials' views on a topic." [2]

What are the risks associated to advocacy?

Going back to the etymological definition of the word, "advocacy" is actually a very legitimate and democratic process that feeds public policy: that of voicing the concerns of a group that you represent.

The risks associated to advocacy arise when this process is abused. Here are some of the occasions in which this abuse may take place, as identified by Transparency International:

- Bribery - making payments to public officials and decision-makers to influence government decisions;
- Manipulating evidence, lying or misleading policy makers or the public;
- Trying to hide your advocacy activities and influence in secret;
- When disproportionate levels of influence exist, meaning the balance of interests is not respected.

It is crucial to understand that for many of the situations associated with "unethical advocacy" do not mean that the organisation does not respect the law. Transparency International Ireland captures this nuance very well in its definition of Responsible Lobbying: "[It is based on the understanding that regulations and laws, while important, are not enough on their own]."

5.2 TIPS TO ENHANCE YOUR TRANSPARENCY IN ADVOCACY ACTIVITIES

Reputation is an essential currency for advocacy, and transparency is key in keeping this reputation intact. It grants you access to policy-makers and enables you to build alliances.

Here are some easy ways to engage in advocacy activities "responsibly".

STATE WHO YOU ARE AND SET YOUR LIMITS

- Develop a **Conflict of Interest Policy**, and always fully disclose any conflict of interest you may have, either in previous or current positions;
- Develop and implement a **Gift and Hospitality Policy:** in this policy which should be developed and voted by your Board, you define what is acceptable in terms of gifts and hospitality (food, drink, and other privileges offered for example in the framework of an event). Generally, there should not be any offering or receiving gifts from decision-makers and/or companies. With regards to hospitality, you should define what is acceptable or not in terms of nature of the hospitality, value. A good compass is that it should be bona fide and socially acceptable and not allow for any impression of improper influence over the political process or the execution of their professional duties.

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2   Transparency International Ireland, "Responsible Lobbying, a short guide to ethical lobbying and Public Policy Engagement for Professionals, Executives and Activists", 2015, https://transparency.ie/sites/default/files/15.12_responsible_lobbying_guide.pdf (accessed December 2017).

5. ADVOCACY – TRANSPARENCY IS YOUR CURRENCY

> **If you are active on the European scene, register on the EU Transparency Register:** in order to increase the transparency of the activities of the Members of the European Parliament and of the European Commission's high officials, the EU has set up a Transparency Register. The transparency register is a database that lists organisations that try to influence the law-making and policy implementation process of the EU institutions. The register makes visible what interests are being pursued, by whom and with what budgets.

The system is operated jointly by the European Parliament and the European Commission and will soon also be adopted by the Council.

When registering onto the EU's Transparency Register, provide a complete and up-to-date entry. Ideally, this would include not just the basic information, but also proactive publication of further, optional information.

Are there any comparable initiatives to the Transparency Register in your country? Make sure you register onto them too.

SAY WHAT YOU DO, AND BE TRUTHFUL ABOUT WHAT YOU SAY

> **Use information that is evidence-based, up-to-date and reliable to support your claims;**

> **Make your (adopted) positions available:** publish online position papers and other direct inputs to the decisions-making process. Being transparent about lobbying is essentially about being transparent about the interests and position an organisation represents. For this reason, the written input a lobby organisation submits to influence an important decision should be made public.

SAY WHOM YOU ARE MEETING

The EU Institutions set up the Transparency Register to respond to citizens who demanded more accountability from them on whom they were meeting.

Transparency International recommends organisations who engage in advocacy activities to do the same and publish dates, participants, and topics of meetings with public officials and other decision-makers, just as some EU institutions already do. [3]

Supporting Documents

European Union Transparency Register:
http://ec.europa.eu/transparencyregister/public/homePage.do Transparency International, Code of Ethical Advocacy,
https://www.transparency.org/whoweare/accountability/commitment_to_ethical_advocacy/3 (accessed November 2017).

Looking for inspiration? Check the European Commission's and the European Parliament's policies:
Communication from Vice-President Šefčovič to the Commission on Guidelines on Gifts and Hospitality for the staff members (2012):
https://ec.europa.eu/info/sites/info/files/communication-to-the- commission-guidelines-on-gifts-and-hospitality_2012_en.pdf

Code of Conduct for Members of the European Parliament with respect to financial interests and conflicts of interest:
https://www.europarl.europa.eu/pdf/meps/201305_Code_of_conduct_EN.pdf

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3   http://transparency.eu/lobbyresponsibly/

6. COMMUNICATIONS – THE CROSS–CUTTING ACTIVITY

6.1 WHAT SHOULD YOU COMMUNICATE ON?

Developing measures towards greater transparency in membership, governance, finances and advocacy is a crucial step. However, for the new processes and tools you have created to be effective and meaningful, you need to make sure that they reach their target.

Communicating widely about these efforts will also enable you to reap the benefits of your investment and "transform it" into increased trust capital for your organisation.

Here is a list of the tools and processes we mentioned above:

"If it's not on your website, you're probably hiding something"

There is a bit of a negative assumption that anything that is not made public is hidden.

For example, during the EPF Training on transparency & ethics which took place in September 2016, the European Network of (Ex)–Users and Survivors of Psychiatry (ENUSP) reported how they were suspected of receiving funding from shifty sources, and not reporting them because they did not mention any funding source on their website, or annual report. And for good reason, because ENUSP did not receive any external funding, relying solely on volunteers' and pro-bono work. What is more, the fact of not receiving external funding is a conscious choice of the organisation, which prefers to rely on committed individuals.

According to Noémi Ambrus, this experience teaches us that transparency does not only mean bringing forward the potential sticky points, be they funding sources, conflicts of interests, governance issues. Transparency simply is about communicating on the choices made by the organisation. In the case of ENUSP, indicating clearly on the website the resources (or lack thereof) of the organisation would also help getting a better picture of its culture and commitments.

Communicate on figures, but also on impact!

As we have tried to demonstrate throughout this publication, transparency for patient organisations cannot be confined to publishing your financial statements on a regular basis. This is about communicating about who you are and what you do.

In an article published in the web-based news outlet "Devex" in February 2017, Tim Middlemiss, Communications Director at Agency, a communication agency focused on community and civil society explains that "*a foundational concern, particularly for international organizations, is how to talk about impact.*" [4] Communicating about impact is especially difficult in the field of advocacy, where successes and failures in managing to get a piece of legislation must be relativized: they are usually long-term processes stretching over several years and involving several players.

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4 Cornish, Lisa (16 February 2017) "In an era of declining trust, how can NGOs buck the trend?", https://www.devex.com/news/in-an-era-of-declining-trust-how-can-ngos-buck-the-trend-89648 (accessed November 2017)

6. COMMUNICATIONS – THE CROSS-CUTTING ACTIVITY

Area	Documents to make public	Target audience
General	• Statutes of the organisations (including elections processes, membership criteria) • Vision and mission statements • Strategic plans (multi-annual plan) • Annual Work plans • Annual reports	All stakeholders (decision-makers, general public, health stakeholders...)
Membership	• List of members • Membership criteria • Membership review process	All stakeholders (decision-makers, general public, health stakeholders...) Of specific interest for: members, potential members
Governance	• Members of the Board • Conflict of interest policy and Declaration of interests from Board members, key staff and key members/ambassadors of your organisation	All stakeholders
	• Minutes of the Annual General Meeting	
Finances and cooperation with funding partners	• Framework of cooperation ("Code of conduct") with industry/funding partners • Annual Balance sheet • List of assets and liabilities • List of sponsors • Audit report	
	• Budget	
	• Cashflow projection	
Advocacy	• Conflict of interest policy	
	• Gift and Hospitality Policy • Registration number on the EU Transparency Register (or on the transparency register of your organisation's country) • List of meetings with high-level public officials	

Level of publicity
Fully public
Fully public
Fully public
Members only
Fully public
Members only
Board members
Fully public

The following resources give some ideas on how to square the circle of measuring impact in advocacy:

Jones, Harry (2011) A guide to monitoring and evaluating policy influence, Background Note, Overseas Development Institute [Online]. Available at http://www.odi.org.uk/resources/docs/6453.pdf (Accessed November 2017).

The Annie E. Casey Foundation, Baltimore, Maryland, "A Guide to Measuring Advocacy and Policy", 2007, http://www.aecf.org/m/resourcedoc/aecf-aguidetomeasuringpolicyandadvocacy-2007.pdf

LabStorm: Measuring the Impact of Advocacy, http://feedbacklabs.org/blog/labstorm-measuring-the- impact-of-advocacy/ (Accessed November 2017).

Innovation Network Inc., Measuring Influence: Advocacy Evaluation Challenges and Successes, 2006, http://www.pointk.org/resources/files/advocacy_eval_series_grantstation.pdf, (Accessed November 2017).

Save the Children, Monitoring and evaluating advocacy, http://www.open.edu/openlearncreate/pluginfile.php/128097/mod_resource/content/1/Monitoring%20and%20evaluating%20advocacy.pdf

6.2 CHOOSING THE RIGHT TOOL

6.2.1 YOUR WEBSITE, YOUR WINDOW

Your website is your organisation's visiting card. It is also often the first contact that external stakeholders will have with your organisation. As such, you want to make sure that it reflects who you are and what you currently do.

All documents publicly available should also be available on your website. This goes for your statutes, financial statements, list of members, membership criteria and application process.

Here are some tips to make sure to make a good first (virtual) impression:

> Make sure your website is **navigable,** meaning that it is structured in a logical way, and that people do not have to go through a hundred pages before finding the information they are looking for. Your website should also be **responsive**, meaning that it automatically resizes to the screen size it is being viewed on.

> Make sure your website is **accessible**: be aware that your target audience may experience problems when using the web because of different kinds of disabilities, functional limitations, environmental factors or technology matters. As a patient organisation striving for inclusiveness, you must set the good example and work towards making sure that your website and communications are readable and accessible to the largest number.

> **Update your website regularly and remove outdated contents**: you must strike the balance right between giving your target audience enough information on the history of your organisation, and not losing them by flooding them with too much information or outdated contents, which may just lead to more confusion;

> **Make your website "personable"**: identify persons of contact for each area, so that people browsing on your website know whom to contact for more information. Adding pictures and creating "a human face" for your organisation will also help creating a link between your target audience and your organisation.

6.2.2 ANNUAL REPORT – COMMUNICATING YOUR ACHIEVEMENTS

Another crucial communications tool of your organisation is your annual report: it provides information on the activities of your organisation over the past fiscal year.

If presented well, it also serves to reinforce the accountability (trustworthiness) of your organisation. It can be used to raise awareness

about your "brand", what you do, and to attract and retain, sponsors and donors. In terms of accountability, it also constitutes an opportunity to thank those who enable you to fulfil your mission. Finally, it demonstrates the value of membership towards current and potential members.

Annual Report – what to consider?

> Who is your target audience? In general, the audience of your annual report is quite broad: you are looking at addressing all of your potential audience: members, donors, policy-makers, potentially regulators. This means you should not include information that is relevant for one of these sub-groups only.

> Keep the following in mind: "What message you want to convey and to whom?";

> Identify a few key accomplishments, trends or stories to focus on;

> Find a red thread to ease the reading: is there a cross-cutting theme that might be fitting?

> State clearly your mission and relate the contents of your annual report to your mission. The annual report should answer clearly to the question: how did your activities this year contribute to coming closer to your vision and achieving your strategic goals?

> Give a clear statement of performance objectives and targets and link them to the mission;

> Disclose your organisation's risks, issues and challenges in the context of the mission;

> Don't let it become a presentation brochure: if you need one of these, make it a separate document.

6.3 COMMUNICATIONS TOOLS AND DATA PROTECTION

6.3.1 THE EU COOKIE POLICY

What are cookies anyway? Cookies are a kind of short term memory for the web. They are stored in your browser and enable a site to 'remember' little bits of information between pages or visits.

Almost all websites use cookies - little data files - to store information in peoples' web browsers. Some websites contain hundreds of them. If your organisation owns a website, it also stores cookies. You will need to make sure it complies with the law, and this usually means making some changes.

The EU Cookie Law – By "Cookie law", we actually refer to the EU Directive that was adopted by all EU countries in May 2011. Each country then updated its own laws to comply.

This Directive is a piece of privacy legislation that requires websites to get consent from visitors to store or retrieve any information on a computer, smartphone or tablet.
It was designed to protect online privacy, by making consumers aware of how information about them is collected and used online and give them a choice to allow it or not.

What it means for you:

If you don't comply you risk enforcement action from regulators. In exceptional cases this can mean a fine. However, non-compliance could also have other, perhaps more serious consequences than enforcement. There is much evidence that consumers avoid engaging with websites where they believe their privacy is at risk, and there is a general low level of trust about web tracking by the use of cookies.

And so what? It is not illegal to use cookies but you must make sure that you inform the users of your website that your website uses cookies, and what you have the user consent.

Compliance with the cookie law comes down to three basic steps:
> Work out what cookies your site sets, and what they are used for, with a cookie audit;
> Tell your visitors how you use cookies;
> Obtain their consent with a tool (pop-up window for example) and give them some control.

6.3.2 ISSUES ON THE HORIZON
EU General Data Protection Regulation (GDPR)

There are some changes on the horizon with regards to data protection. Approved on 14 April 2016, the EU General Data Protection Regulation (GDPR) replaces the Data Protection Directive 95/46/EC and was designed to harmonize data privacy laws across Europe, to protect and empower all EU citizens data privacy and to reshape the way organizations across the region approach data privacy.

The enforcement date is set for 25 May 2018.

What data is concerned?

According to the law, "personal data is any information relating to an individual, whether it relates to his or her private, professional or public life. It can be anything from a name, a home address, a photo, an email address, bank details, posts on social networking websites, medical information, or a computer's IP address."

What is new?

The new EU General Data Protection Regulation reinforces the existing Directives and Regulations on data protection and sets up new rights and concepts: the "right to be forgotten", (right to erasure), the need for consent, data breach notification, and "privacy by design".

The Regulation also calls for the setting up of national data protection authorities, and of a "European Data Protection Board", meant to ensure the consistent application of the Regulation.

The GDPR is applicable in the EU or for data concerning EU citizens. Its scope is far-reaching, and its implementation is seen as a real revolution.
For patient organisations, its relevance is to be found not only in the field of communications, but also in the field of digital health: a lot of the new technologies applied to health involve or even are based on the storage of data. A lot is at stake in terms of information to patients and patient consent in this area.

For more information on the GDPR, we recommend you check **EPF's guide for patient organisations:** European Patients' Forum, the new EU Regulation on the protection of personal data: what does it mean for patients?
http://www.eu-patient.eu/globalassets/policy/data-protection/data-protection-guide-for-patients-organisations.pdf

The following sources may also be helpful:
https://www.eugdpr.org/
https://ec.europa.eu/commission/priorities/justice-and-fundamental-rights/data-protection/2018- reform-eu-data-protection-rules_en

7. SOME IDEAS FOR IMPLEMENTING CHANGE

Introducing new processes and new tools can be challenging for a patient organisation. Because working on transparency implies making changes in several strategic and operational areas within your organisation, this can be a tricky task.

The topic of "change management" would deserve a dedicated publication, and this is not the topic of these guidelines, but let's address some key tips on where to start with the implementation of the transparency tools and processes mentioned in this guidance.

Step 1 – Recognising the need for change: what is the need for change? Who is calling for change? What is the practice you are trying to correct? Or the objective you are trying to reach?

Step 2 – Set up a team to lead the change process: define the seniority level required, the number of participants, and whether the work of that task force is public or internal.

Step 3 – Research: How do others do? What are the good practices out there?

Step 4 – Be explicit! Define the purpose and the scope of the procedure you are developing, the objectives and guiding principles, key terms, procedures. Set up clear responsibilities for all parties involved. Make sure you are specific about whom the policy applies to. Define what is acceptable and what is not. Define what happens

in case of a breach of policy. Identify a monitoring and review process.

Step 5 – Draft the policy: the wording is very important. Review, revise and recirculate as many times as needed to make sure there is clarity and full buy-in from the parties involved.

Step 6 – Implement! As already mentioned in the previous section, a key aspect of implementation is to make sure that your target audience is aware of the policy, therefore, spend some work on a dissemination strategy. If necessary, hold a webinar or a meeting to inform your members

Step 1: Recognise the need for change
Step 6: Implement
Step 7: Maintenance
Step 2: Set up a team
Step 5: Draft
Step 3: Research
Step 4: Be explicit!

and other key stakeholders involved. You could even organise a training if you feel this can be beneficial: your members could become the "ambassadors" of your policy and help you spread the word.

You can also organise a sort of "ceremony" to materialise the commitment of your organisation and its members to the policy. You could for instance have all your members and individuals to which your policy applies confirming and acknowledging it with their signature.

Step 7 – Maintenance: do not forget to include some elements about monitoring the implementation of your policy. Set up review dates, and apply the sanctions you have planned if needed.

Some tips to conclude:

> The values of your organisation are at least as important as the policies themselves;

> Differentiate the following aspects: why you need to do this (policy), what is required (standard, quantifiable measures), how you do it (procedure = steps);

> Organise regular training for your Board members;

> Revisit your rules regularly – This is not a one-time thing

> Organisations are deemed trustworthy when their communication feels open, honest, spontaneous, personal and to the point.

> … Remember! Transparency is a lot about communicating what you do anyway.

8. RESOURCES

General
EPF Breakfast briefing on transparency:
https://www.youtube.com/watch?v=uY5thu7O1Zc

EPF toolkit on building national coalitions:
http://www.eu-patient.eu/globalassets/library/toolkits/epf-toolkit_nationalcoalitions.pdf

EPF Report on the Added Value of Patient Organisations:
http://www.eu-patient.eu/globalassets/library/publications/epf_added_value_report_final.pdf

Younger, Rupert, "*5 steps to build trust in your organisation*",
https://www.bond.org.uk/news/2018/01/5-steps-to-build-trust-in-your-organisation (Accessed January 2018).

Membership
Hudson, James R., and Patricia A. Hudson, 2002, Getting Started: The Founding of Membership- based Organizations. Paper presented at ARNOVA Annual Conference, Montreal, Canada
https://knowhownonprofit.org/organisation/operations/membership
http://www.ema.europa.eu/docs/en_GB/document_library/Regulatory_and_procedural_guideline/2009/12/WC500018099.pdf
http://www.eu-patient.eu/globalassets/membership/membership-procedure.pdf

Governance
https://www.501c3.org/nonprofits-board-directors-board/
Hudson, Mike, "Managing without profit", 1999.

Fundraising
European Patients' Forum, EPF toolkit on fundraising,
http://www.eu-patient.eu/globalassets/library/epf_broch2016_v5blow.pdf
https://www.councilofnonprofits.org/tools-resources/ethical-fundraising
http://www.institute-of-fundraising.org.uk/code-of-fundraising-practice/guidance/accountability-and-transparency-guidance/

Advocacy
OECD (2012), Lobbyists, Governments and Public Trust, Volume 2: Promoting Integrity through Self- regulation, OECD Publishing.
http://dx.doi.org/10.1787/9789264084940-en (accessed December 2017).

Transparency International, Code of Ethical Advocacy,
https://www.transparency.org/whoweare/accountability/commitment_to_ethical_advocacy/3 (accessed November 2017).

Transparency International, "Keep your head. Lobby responsibly" (published 3 October 2016),
http://transparency.eu/lobbyresponsibly/ (accessed December 2017).

Transparency International

Transparency International Ireland, "Responsible Lobbying, a short guide to ethical lobbying and Public Policy Engagement for Professionals, Executives and Activists", 2015,
https://transparency.ie/sites/default/files/15.12_responsible_lobbying_guide.pdf
(accessed December 2017).

Transparency International Ireland, "Responsible Lobbying in Europe – An overview of voluntary lobbying standards and practice", 2015,
https://transparency.ie/sites/default/files/15.12_responsible_lobbying_europe_report.pdf
(accessed December 2017).
Vigeo, Transparency and Integrity of Lobbying: A New Challenge for CSR (Paris: Vigeo, June 2013)

On Communication:

Euroblind,
http://www.euroblind.org/publications-and-resources/making-information-accessible-all
(accessed July 2017)

European Telecommunications Standards Institute, Accessibility requirements suitable for public procurement of ICT products and services in Europe,
http://www.etsi.org/deliver/etsi_en/301500_301599/301549/01.01.02_60/en_301549v010102p.pdf
(accessed July 2017)

Other useful resources:

Edelman, Edelman Trust Barometer 2017,
https://www.edelman.com/trust2017/ (Accessed July 2017)

EUPATI Guidance for patient involvement in industry-led medicines R&D:
https://www.eupati.eu/patient-involvement/guidance-for-patient-involvement-in-industry-led-medicines-rd/

EUPATI Guidance for patient involvement in HTA:
https://www.eupati.eu/health-technology- assessment/guidance-for-patient-involvement-in-hta/

EUPATI Guidance for patient involvement in regulatory processes:
https://www.eupati.eu/patient- involvement/guidance-for-patient-involvement-in-regulatory-processes/

The European Patients' Forum (EPF) is the united patient voice in Europe. Since 2003, we work with patients' groups in public health and health advocacy across Europe. Our 72 members are national coalitions of patients or represent specific chronic disease groups at EU level.

EPF

European
Patients
Forum