



United Patients Transparency Toolkit



Transparency is an Health NGO's Brand

Health is a political issue that is in the interest of all people which means that health NGOs are under particular pressure to be as open and transparent as possible.

Health NGOs not only engage with ministries of health but also with companies that have financial interests, health NGOs also need to protect the interests and data of the population they serve. All of these factors means that our transparency has to be clear to our constituents, the policy makers we engage with and the donors from whom we receive funds.

The aim of this toolkit is to create a step-by-step approach to addressing guidelines to ensure that health NGOs can meet the highest standards of transparency, can learn from some best practices and can increase the level of trust between the health NGO and the many stakeholders with whom they engage. This toolkit hopes to help health NGOs protect their reputations and effectively represent the needs of the populations and patients that they serve.

To whom is this toolkit directed?

Health NGOs who work on policy issues, receive donations and help vulnerable populations and patients. Any group who is interested in entering a new relationship with a policymaker, funder or constituent should assure that their code of ethics is clearly stated and communicated and this is the goal of this tool.



STEP 1: GOVERNANCE

A health NGO should be governed by a well-managed Board of Directors and should have a clear staff/volunteer management process

The Board of Director – getting it right!

The Board of Directors is responsible for overseeing the organization's activities and finances. Board members are nominated and elected by other members of the Board of Directors. The Board of Directors is accountable for the effective management of the organization and manages the Executive Director.

Recruitment:

Here are some characteristics to look for in an individual who would be an effective Board of Directors member:

- Passion deep interest in the mission of your organization.
- **Vision and Leadership** the ability to see the big picture and the courage to set direction to achieve the organization's mission.
- **Stewardship** the integrity to serve the interests and pursue the goals of your organization, as well as the interests of the public and your organization's intended beneficiaries.
- **Knowledge** knowledge of your constituents and operations and organizational and managerial acumen.
- **Diligence** dedication and commitment to fulfilling your organization's goals.

Ensuring Board Independence:

Key to an NGO's legitimacy it is important to define a democratic process for Board of Directors selection.

Best practices for Board Member selection:

- Selection processes--It is important to have election and nomination process
- Board Terms policy Set up a review process and term limits.
- Clear Terms of Reference—There should be a Terms of Reference for board members so they know what is expected from them, their term, meeting schedule and committee appointments.



TOP TIPS FOR EFFECTIVE GOVERNANCE!

- Executive Director reports to the Board of Directors and therefore cannot vote at meetings.
- With a health NGO, a Board of Directors member is usually not remunerated. It is a voluntary post.
- Nominate an odd number of members to the Board of Directors to assure that there is not a tie during any of the votes
- Stagger the terms of the members so that there is not a year when all the members are up for election
- Make sure that the Terms of Reference includes a Conflict of Interest clause.
- Board of Director members should not be paid staff of the organization.
- Meetings should be closed but minutes and outcomes should be available



STEP 2: VALUES

A health NGO should be have clear ethical guidelines for governance, funding and staff management. Having a Code of Ethics can assure that the values at every level of its operations.

Code of Ethics

Having a code of ethics or statement of values helps attract talented employees, recruit board members, retain donors, and of course ensure that all transactions are aligned with the values of the organization. Transparency inspires confidence. Beyond what the law requires, a health NGO can demonstrate its commitment to ethical practices by being entirely transparent with financial information and fundraising practices.

What is the content of a Code of Ethics?

The Code of Ethics summarizes the policies and priorities integral to the organization.

- The conflict-of-interest policy. Most organizations have adopted a conflict-of-interest policy for directors and officers, but the conflict-of-interest policy should also be created for staff including issues around nepotism, procurement and hiring.
- **Human resource policies.** Certain human resource policies deal only with business issues, but others such as policies prohibiting discrimination and harassment speak to the moral character of an organization. By placing these policies in the code of conduct, the organization can highlight its commitment to them.
- Financial integrity. Nonprofit organizations must be good stewards of the donations they receive.
 Therefore, the code of conduct should call for everyone connected with the organization to adhere
 to the highest standards of financial integrity. For example, the code of conduct should address
 whether employees may receive gifts from vendors; when the organization will reimburse the
 expenses incurred by directors, officers, employees and volunteers; and the importance of filing
 accurate financial reports.
- Nonprofit requirements. In addition to complying with the same legal requirements as other
 organizations, nonprofits may have special legal standards they must meet with respect to political
 activity.



What is the process for developing the Code of Ethics:

The Board of Directors should take the lead in developing a Code of Ethics in order to demonstrate the Board's support and commitment to the code. At the same time, the Board should work with senior management to develop a code that reflects the day-to-day activities of the organization. Once the Code of Ethics is developed, it should be approved by the Board of Directors.

An audit committee or a similar board committee should be responsible for updating the Code of Ethics when necessary and ensuring that the organization is in compliance. Senior management should be responsible for communicating the code to the organization's employees and volunteers. It is generally considered a good practice to have each employee sign a statement reflecting that he or she has received a copy of the code and has reviewed its contents. Thus, if an employer needs to terminate an employee for violating one of the code policies, the employee cannot claim that he or she never received a copy of it.



TOP TIPS ON ETHICS!

- Communications must be accurate and honest.
- Never include information or images of patients that could be considered personal identifying information.
- A fundamental financial transparency practice is to make it easy for visitors to a health NGO website to find information about the nonprofit's budget-size and its sources of revenue
- Clear information about its Board of Directors, as well as programs, outcomes/impact, staffing, and donors (protecting the identity of those who wish to remain anonymous).
- There are certain documents that tax-exempt health NGO MUST make available to the public.



Step 3: FUNDING

A health NGO should have clearly defined relationships with its funders

The fundraising is a complicated process and sometimes can lead to issues that can be addressed with some easy steps to portray a health NGO's transparency. A key factor of transparency is how a health NGO fundraises, from whom and for what—equally important is how a health NGO communicates about its funding sources.

Your transparency can be enhanced by answering at the following questions:

- Is our fundraising furthering the Mission of the organization?
- Is it clear to our donors/sponsors what they can expect from this collaboration?
- How do we communicate our funding sources?

Key Question:

Is this funding supporting our Mission and aligning with our Strategic Plan?

A Strategic Plan Includes:

- A Vision statement it is future oriented; It answers the question "Where is our organization going?:
- A Mission statement Summaries the aims and values of an organization; It answers the question "What is the reason that our organization exists?
- Strategic objectives-they are long-term and connect to the Mission and Vision
- Tactical objectives / Action plan Actions, projects and programs that will allow your organization to reach its Strategic Objectives. The Action Plan should include concrete steps and a timeline
- Monitoring and evaluation
 — Answers the question "How is the organization going to measure its success?"



Funding Base

Funding should always have a "Mission Match" meaning that the funds will help the health NGO reach its own Mission, not only the objectives of the donor.

Primary sources of funding are the public, the government, foundations, major donors and the private sector. As funding is difficult to obtain, many times health NGOs receive funds from the private sector and since these organizations work in the healthcare issues, the primary private sector funders tend to be from pharmaceutical companies who have an interest both in patient care and in access to treatment.

Recommendations on How to Work with the Pharmaceutical Industry:

Recommendation 1:

Create a Code of Ethics:

This Code of Ethics will include guidelines for receiving funding from the pharmaceutical industry:

What does a Code of Ethics need to include:

- Assurance that the health NGO is receiving funding to pursue its Mission goals
- · Clear ethical principles for the collaboration
- Independence of health NGO in content, data and program planning/implementation
- Promotion of mutual transparency and accountability

Questions that the Code of Ethics consider:

- What do we allow when receiving funding from the pharmaceutical industry?
- Does our organization allow for restricted funding arrangements?
- · What are the conditions that will exclude receiving funding?
- Are there any industries we cannot accept funding from?
- How do we assure that we are not achieving only the business goals of the pharmaceutical industry?
- · How does our organization maintain independence in content, management and implementation?
- How are donations recognized and communicated?
- Do we require multi-funders for all projects?



Recommendation 2:

Put it all in writing:

Having written support for the donor relationship will allow for further transparency and will allow both sides the benefit of having a clear understanding of the arrangement.

- Create a written agreement: A written agreement outlines the amount of the funding, activities planned, and the period covered.
- Make the benefits to the donor clear: Benefits can include display of logo on website, at events, on publications, and invitations. Additional benefits can include priority notice on NGO events, priority placement or discount on NGO events, free copies of publications, and the right to propose a new partnership,
- Recognize funding publicly: The funding received and the sources should be included in the health organization's Annual Report and published separately on the website

Recommendation 3:

The numbers should be public:

Managing the organization's fundraising and budget in a transparent way are important steps. The organization will also need to make sure that the financial information of the organization 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 organization's financial performance. 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 realize your plans.
- The Balance sheet— the balance sheet is a picture of the financial position of your organization at any point in time. It entails your organization's assets, liabilities and equity at the end of a financial reporting period
- List of sponsors—Stakeholders and donors are not only interested in your organizations' 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.



Recommendation 4:

Make sure your donors are being transparent

Most entities -private or public- providing financial support to health NGOs are obliged to display the amount and beneficiaries of the support they provide on their websites. As a beneficiary, the health NGO can check whether the companies or public institutions supporting you report on the grants that they receive accurately.



TOP QUESTIONS FOR ASSESSING A DONATION FROM INDUSTRY:

- Does this funding help my organization further our Mission?
- Do we share common values with the donor?
- Would our organization do this project with unrestricted funds?
- Do we trust the representative from the company?
- Are there any other resources that this company may have as an in-kind donation?
- Are there any industries that our organization cannot accept money from?
 (e.g. tobacco, alcohol, high calorie foods)
- How would our organization appear if this donation appeared in a public forum?
- Is the company reporting accurately about the donation?



STEP 4: COMMUNICATIONS

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.

Recommendations for Communication Channels that Support Transparency:

Recommendation 1:

Put it on the Website

The health NGOs website is a public facing tool that often is the first contact that stakeholders will find on the organization.

A successful website should:

- Make all documents publicly available which includes .statutes, financial statements, Code of Ethics, and program evaluations.
- Be navigable by being structures in a logical way so that the user will not need to click through many links before they are able to find the information they are looking for. Related to transparency, if information is hidden in a website it may raise concerns.
- Updated and relevant for the user and strike a balance between giving the target audience enough information on the history of the organization and not overwhelming them too much information or outdated contents.
- Personable demonstration of the organizations brand and how it wants to be portrayed publicly. Having a human face to the organization and health condition also helps destignatize the condition for the public.



Recommendation 2:

Communicate Success and Donations in Annual Report

ANNUAL REPORT – COMMUNICATING YOUR ACHIEVEMENTS

Another important communications tool of a health NGO organization is the Annual Report which provides information on the activities of the organization over the past fiscal year. If presented well, it also serves to reinforce the accountability (trustworthiness) of the organization. It can be used to raise awareness about the "brand" and what the organization does. A good Annual Report can also attract and retain, sponsors and donors. In terms of accountability, it is an chance to thank those who enable the organization to fulfil its mission.

A successful Annual Report should:

- Take into consideration the audience who will be reading the Annual Report. Since it may reach a public that is not familiar with the health NGO it should not use too many acronyms or jargon. The content should try to be relevant to donors, policy makers, and people interested in the cause.
- State clearly the mission and relate the contents of the annual report to the mission of the organization.
- Demonstrate how did activities the fiscal year contributed to reaching the Vision and Mission of the organization. It should also give a clear statement of performance objectives
- · and targets and link them to the mission.
- Since this is not a marketing tool an Annual Report should also discuss the health NGOs risks and challenges in the context of the Mission



STEP 5: ADVOCACY

A health NGO should demonstrate transparency in every part of its operations in order to demonstrate that it can advocate with policy makers to benefit the public that the organization serves.

Health advocacy is at the essence of the work of many health NGOs and should be included in its Mission statement. This means that health NGOs engage in advocacy activities on a regular basis. They offer the opinions and perspective of patients and people with chronic condition to legislative processes. Reputation is an essential currency for advocacy, and transparency is key in keeping this reputation intact.

Advocacy activities can include:

- Submitting formal written responses draft legislation to policymakers
- Appearing before parliamentary bodies as they draft laws
- Face-to-face meetings with politicians, elected representatives and other policy makers
- 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 representative;
- "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."

Unethical advocacy activities can include:

- Bribery by making payments to public officials and decision-makers to influence their decisions
- · Manipulating evidence, lying or misleading policy makers or the public
- Trying to hide the organization's advocacy activities and influence in secret



TOP TIPS TO SHOW TRANSPARENCY IN ADVOCACY!

- Use information that is evidence-based, up-to-date and reliable to support advocacy activities
- Have an up to date Conflict of Interest Policy included in the Code of Ethics to always fully disclose any conflict of interest the organization may have
- Create a policy related to what is acceptable in terms of gifts and hospitality including travel. Generally, there should not be any offering or receiving gifts from policy makers
- Make advocacy positions publicly available by putting position papers and any advocacy materials available online
- Have an up to date record of with whom the health NGO
 has met that can be made available for those interested