



## Contents

---

### **About this guide**

*This guidance document is designed to provide practical advice for patient group organisations and advocates to support them in creating positive change for the communities they represent.*

*The recommendations included in this guide are based on the experiences and work of Samuel Wiafe, Founder of the Rare Disease Initiative in Ghana, in building advocacy for rare disease patients in a low-middle income country.*

For more information about Samuel's advocacy work on behalf of the rare disease community, please visit: <https://www.ieepo.com/en/about-ieepo/domain-of-engagement/change-domain.html> to watch the full case study videos.

# 1.

**Defining your goals and priorities**

# 2.

**Engaging with stakeholders**

# 3.

**The importance of patient-led data generation**

# 4.

**Working with multidisciplinary stakeholders**

- Working with regulators
- Working with health ministers
- Engaging healthcare professionals

# 5.

**Securing funding**

# 6.

**Working with national and international patient organisations**



## Defining your goals and priorities

### 1. How would you recommend that an organisation defines their goals for what they want to achieve?

- It is important to ensure that your goals are defined by a needs assessment, and ideally based on data. Engaging and collaborating directly with patients, clinicians, researchers, policymakers and other decision makers is important to co-create these goals together to ensure moving in the same direction and creating mutual value.

### 2. What advice would you give to organisations who have competing goals and priorities?

- Ensuring that goals are simple, measurable, achievable and realistic is important, but making sure your short term goals fit into what you ultimately want to achieve together will help you in the long term.
- Identifying goals which need less resources or logistics that you can achieve more easily is key, as well as looking for broader opportunities for how you can partner to achieve the bigger initiatives - using a 'top-down and bottom-up' approach.



## Identifying and engaging with stakeholders: where to start

### 3. What advice would you give to an organization at the very start of their journey?

- If an organisation is unsure where to begin, it is important to understand which resources/stakeholders are easy to access, are free, and can help you with the goal you have in mind.
- Your key stakeholders may also be able to contribute in ways that do not involve funding or grants: they can contribute advice, support with a campaign, get engaged in collecting information and/or, relevant data, identifying further volunteers or help with activities such as a website.
- Registering your organisations as a legal entity is important to ensure you avoid any compliance issues but also helps to build trust among stakeholders.

### 4. How would you recommend a patient organisation identify and prioritise the different stakeholders that they should be engaging with?

- Every stakeholder is important in the healthcare ecosystem, and you should have open arms to all.
- Identifying the needs of your stakeholders and what they can help you drive should be the first step so that you can tailor your approach to them with them.

- Some stakeholders that you identify may not be able to help you immediately drive your initiatives but they may be important to consider to help draw up and be part of the story you want to tell.
- Assess what and how much a stakeholder can contribute to your cause before you approach them e.g. what government can offer will differ from what industry can offer.



## How to approach patient-led data generation and why is it important?

### 5. What tips do you have for organisations who want to create patient-led evidence?

- Many patient organisations are started through passion. It is critical for organizations to understand the value of data in order to drive their mission.
- Before you embark on creating patient-led data, it is first very important to have a plan for collecting and protecting the data, as well as implementing a governance around it.
- Deciding on what is the most important data to collect will vary from organization to organization and it may be worth focusing on common data between organisations before gathering more unique data for your particular organisation.

### 6. How can organisations use patient-led data?

- Understanding how different stakeholders may view different aspects of data will help you engage more effectively with them. For example, policy and decision makers are interested in healthcare costs and system structure efficiencies, laboratories are interested in research, industry may be interested in the epidemiology of a disease.
- Data needs to be aligned with what stakeholders want to hear and their own priorities.
- Having reliable patient-led data can be key to securing funding initiatives for your organisation.

### 7. Why should you collaborate to generate patient-led data?

- It is best to collaborate with partners for data generation as unity will provide greater strength and integrity of the results, as well as the ability to be more open with other organisations.
- Collaborating with other organisations or partners for data collection also means shared costs and resources, allowing for greater efficiency and opportunities to work together.



## Working with regulators

### 8. What should patient organisations consider to effectively engage with healthcare regulators?

- Patient organisations are advocates that can largely protect the interests of the patient. Knowing how to work most effectively with healthcare regulators and maintaining good relationships with these bodies is a very important part of our work.
- Researching and understanding existing guidelines and ongoing patient programmes is very important before approaching regulators, in order to discuss what might be possible.
- For example, in Ghana, we knew we didn't have an orphan drug designation guideline back in 2017 when we started, but that there was a named patient programme. Along the line, as we engaged the FDA in Ghana, on this existing named patient programme to expand it and provide more support to more patients and we now have a guideline for registering orphan drugs.

Also, we currently do not have a designated rare disease act or policy, instead we have the disability act and the new National Health Policy which provides some answers to the rare diseases patients. We will continue to depend on these until we have a dedicated law or policy in place for persons living with rare diseases.

- It is important to keep in mind that relationships with regulators are likely to be gradual, and you should build this into your approach to keep a positive relationship. Regular communications will help develop these relationships, such as email updates, invitations to meetings or as speakers. Try and find a key contact or gateway which will help you open up these relationships.

## Working with health ministers

### 9. What are your top 3 tips for approaching and working with health ministers?

- *Data.* Patient organisations must have enough data to make a case to the Ministry of Health, to convince them to make an informed decision, based on evidence. They are less likely to make decisions based on more emotional information.
- *Know the policies.* Ensure to be knowledgeable on existing regulations and policies and think about how your organisation can use what already exists.

- *Focus on solutions.* Ministries do not want to be approached with a problem, approach your interactions with solutions or ideas for pilot projects that you could undertake together now or in the future.



## Engaging with healthcare professionals on educational initiatives

### 10. What are the best ways for patient organisations to approach educating healthcare professionals (HCP) about specific unmet patient needs?

- It is important to understand the gaps in the knowledge of the HCP, and target the education accordingly. For example, the gap may not be in knowledge but in capacity to diagnose.
- Understanding the needs of the HCPs will help you tailor educational initiatives more effectively. For example, understanding their daily challenges when dealing with people living with rare diseases, where treatment and care is not always available.

### 11. How do you target and engage with HCPs for your educational initiatives?

- Identifying interested individuals or groups and working with them to become trainers within their communities is key.
- Engaging HCPs to consult on projects or initiatives can also be mutually beneficial as they also start to understand the burden on the patients more fully.
- It is important to offer HCPs incentives to attend training as they may already be very stretched for time, especially in low-middle income countries.
- Considering ways that your organisation can equip HCPs with support services to help their patients can also provide a huge help to HCPs in their daily challenges and provide key learnings for them.

## Evaluating and securing funding for your organisation

### 12. What tips would you give to patient organisations to help them secure funding for their cause?

- Evaluate what you consider to be 'funds' for your organisation. Funding does not necessarily have to be money and can also be in kind, i.e. include things like office space, resources, IT support etc which can help you run an effective organisation.
- There are several sources of funding that organisations can apply for. These can include public and/or private grants or donations, crowdfunding, and partnerships where funding is only one part of the engagement.

- Ensuring that your organisation is legally registered and has a good financial management system will help you be seen as a compliant organisation which will build trust with stakeholders, as well as helping you in your grant or funding applications.

### **13. What are the most important compliance requirements that organisations should be aware of?**

- Having a good financial management system in terms of records, auditing and internal governance policies around funding will ensure you are compliant. Tracking your finances and how they are being used is of utmost importance in order to be/become a trusted partner for sustainable change.
- Understand how to manage the organisation's funding, no matter how big or small. Working with partners or with larger organisations can help provide support in ensuring compliance.
- Ensure you understand the compliance needs of the country/region you are operating in. If you are looking for specific training, several organisations run free training programmes and support for non-profits such as:  
<https://www.nonprofitready.org/>



## **Working with national and international patient organisations**

### **14. How should patient organisations approach working with other national and international organisations?**

- In order to approach global organisations, you should ensure that your organisation goals are relevant to the global challenges and priorities too.
- Understand that your work locally can align to a bigger, global picture and it is important to add your work at a community level to what is happening at the international level.

### **15. Why are these partnerships important?**

- Working in partnership with other organisations can be very beneficial in terms of building capacity, as well as ensuring your governance and compliance is always meeting international standards.
- Adding your voice to national or international projects can help ensure the sustainability of your organisation, building credibility and increasing your profile that will help your engagement with key stakeholders.
- Working in a global organisation can be a source of motivation and continued learning for your team and the community that you support, to be part of international projects. It may also provide you with access to resources that you wouldn't usually have.

- Working with a global organisation is important to help shape global priorities through local experiences and needs. Global health policy should be shaped by what is happening locally too.

###

### **About IEEPO and the CHANGE domain**

The CHANGE domain and Changemaker video series is an initiative launched by the International Experience Exchange with Patient Organisations (IEEPO). IEEPO is a platform of engagement for the international patient community.

IEEPO aims to support the global patient community by providing learning opportunities around global trends in healthcare systems, creating a forum for experience exchange and co-creation, fostering connections with stakeholders from across and outside the healthcare ecosystem, and empowering patient communities to be strong and impactful partners in transforming the future of healthcare ecosystems.

The IEEPO CHANGE domain enables patient communities to hear how different experts and advocates have affected health policy and created healthcare transformation and positive change for their communities. This is reinforced by the concept that global health policy is shaped by what is happening on the ground through evidence based patient advocacy; a 'Think globally, act locally' approach.

As part of the CHANGE domain, the Changemaker video series will showcase the work of patient organisation leaders, to inspire and provide practical advice for patient group leaders advocating for change for their own patient communities around the world. The videos will be hosted on [www.IEEPO.com](http://www.IEEPO.com)