



International Alliance of  
Patients' Organizations

A global voice for patients

# Working with partners and stakeholders

Patients' organisation toolkit



Funded by Novo Nordisk  
International Operations

The contents of this folder are to be used in conjunction with the interactive Patients' Organisation CD (included).

## Contents

### Section 1: Welcome

<b>Welcome</b> .....	<b>1</b>
Forward from IAPO.....	2
IAPO involvement.....	3
Novo Nordisk involvement.....	4
Pope Woodhead involvement.....	5

### Section 2: Collaborating with stakeholders

<b>Collaborating with stakeholders</b> .....	<b>6</b>
Framework for interaction.....	7
Collaborating with other patients' organisations.....	8
– Examples of how patients' organisations can work together.....	9
Collaborating with healthcare professional associations.....	11
– Top tips for collaborating with other patients' organisations and healthcare professional associations.....	12
– Example of how a patients' organisation and healthcare professional associations can work together.....	13
Collaborating with government.....	14
– Top tips for collaborating with government.....	15
– Examples of how patients' organisations can work with government.....	16
Collaborating with industry.....	18
– Top tips for working with industry.....	19

### Section 3: Working with pharmaceutical companies

<b>Working with pharmaceutical companies</b> .....	<b>21</b>
Benefits for working with pharmaceutical companies.....	22
How to work with pharmaceutical companies.....	23
– Frameworks and agreements explained.....	24
– Working with industry partners: framework for interaction template.....	26
– Roadmap to working with pharmaceutical companies.....	31
– Top tips for working with pharmaceutical companies.....	41
– Checklist for working with pharmaceutical companies.....	42
Case studies.....	44
– Case studies: working effectively with pharmaceutical companies.....	45
Pharmaceutical industry perspective.....	54

## Section 4: Key patients' organisations activities

<b>Key patients' organisations activities</b> .....	<b>55</b>
Strategic planning .....	56
– How the external environment can affect a patients' organisation's strategy.....	58
– Top tips on developing strategic objectives .....	59
– How to develop policies .....	60
Advocacy and raising disease awareness.....	64
– Advocacy .....	66
Fundraising.....	67
Communication .....	68
– Press release template .....	70

## Section 5: 'How to...' guides

<b>'How to...' guides</b> .....	<b>71</b>
Planning projects .....	72
– Project plan template .....	73
Managing projects .....	76
– Step-by-step guide to project management .....	77
Running meetings.....	78
– Meeting invitation .....	80
– Agenda template .....	81
– Meeting thank you letter .....	82
– Meeting minutes template.....	83
– Step-by-step guide to planning and running a meeting.....	84
Preparing and giving presentations .....	85
– Top tips on preparing presentations.....	86

## Section 6: Other tools and resources

<b>Other tools and resources</b> .....	<b>87</b>
--	-----------

## Section 7: Other information

<b>How to use the toolkit</b> .....	<b>89</b>
<b>Acknowledgements</b> .....	<b>90</b>



International Alliance of  
Patients' Organizations

A global voice for patients

# Working with partners and stakeholders

## Patients' organisation toolkit

**Section 1**  
Welcome



Funded by Novo Nordisk  
International Operations



# Working with partners and stakeholders

## Patients' organisation toolkit

### Welcome

Patients' organisations are important patient advocates that truly understand patients' needs. While there are other stakeholders who, like patients' organisations, want to improve the health and quality of life of patients, they are not fully aware of patients' needs or how best to address them. Therefore establishing partnerships between patients' organisations and other stakeholders can help provide real benefits to patients, their families and carers.

This toolkit has been designed specifically to support patients' organisations develop effective relationships with key stakeholders. It contains information and tools to help understand and overcome challenges that they sometimes experience when working with external parties.

The design and content of the toolkit has been developed by an independent third party (Pope Woodhead and Associates Ltd; see [Pope Woodhead involvement](#)) in consultation with the International Alliance of Patients' Organizations (IAPO; see [IAPO involvement](#)). The case studies were provided by IAPO member organisations. Novo Nordisk, a pharmaceutical company, provided project funding (see [Novo Nordisk involvement](#)).

### Useful links

[How to use the toolkit](#)

[Site map](#)



# Working with partners and stakeholders

## Patients' organisation toolkit

### Foreword from IAPO

The International Alliance of Patients' Organizations (IAPO) is a global alliance representing patients of all nationalities across all disease areas. Our members are patients' organisations who work to help patients, their families and carers.

We are committed to assisting patients' organisations develop their patient services and are delighted to have had the opportunity to help develop this toolkit (IAPO involvement).

The toolkit outlines how patients' organisations, both large and small, can work effectively with a range of partners and stakeholders, including the pharmaceutical industry. It provides guidance and examples of how to develop long-term partnerships with these stakeholders, while retaining the independence of your organisation.

We hope that these materials will assist you in developing your organisation's infrastructure and capabilities, as well as further enhancing your relationships with key stakeholders.

A handwritten signature in black ink, appearing to read "J Groves", written over a horizontal line.

**Joanna Groves**  
Chief Executive Officer, IAPO

A handwritten signature in black ink, appearing to read "Hussain Jafri", written over a horizontal line.

**Hussain Jafri**  
Chair of Governing Board, IAPO



# Working with partners and stakeholders

## Patients' organisation toolkit

### IAPO involvement

The International Alliance of Patients' Organizations (IAPO) is a unique global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare worldwide. Their members are patients' organisations working at the international, regional, national and local levels to represent and support patients, their families and carers.

IAPO's vision is that patients throughout the world are at the centre of healthcare.

IAPO had full editorial control over this toolkit. Its role in the development of the toolkit included:

- reviewing and commenting on the design, core content and download documents
- obtaining feedback on the toolkit's contents list from a group of their member organisations
- contributing to the patients' organisations' case studies
- providing key IAPO documents for inclusion in the toolkit.

For more information about IAPO and their work, please refer to their [website](#).



# Working with partners and stakeholders

## Patients' organisation toolkit

### **Novo Nordisk involvement**

Novo Nordisk is a global pharmaceutical company with 87 years of innovation and leadership in diabetes care. The company also has leading positions within haemophilia care, growth hormone therapy and hormone replacement therapy.

Novo Nordisk is committed to providing patient-centred healthcare and is working actively to increase patient focus. They recognise the key role that patients' organisations play in raising disease awareness and promoting patient-centred health policy, treatment access and quality of care. Consequently, Novo Nordisk is dedicated to building effective partnerships with, and supporting patients' organisations.

As part of their commitment to support patients' organisations, Novo Nordisk funded the toolkit project. However, the content has been created by an independent third-party provider in consultation with IAPO.

For further information, please refer to Novo Nordisk's [website](#).





# Working with partners and stakeholders

## Patients' organisation toolkit

### Pope Woodhead involvement

Pope Woodhead is an independent, healthcare consultancy with a 30-year heritage in communications.

Throughout the world, healthcare can affect or be affected by a wide range of groups including patients, patients' organisations, healthcare professionals/associations, government bodies and pharmaceutical companies. Pope Woodhead uses its understanding of healthcare systems and policies to help many of these groups engage more effectively with one another. For example, they have assisted patients' organisations with communications and their interactions with government bodies.

Pope Woodhead has worked closely with the International Alliance of Patients' Organizations on the development of the concept, design and content of this toolkit.

For further information on Pope Woodhead's patients' organisation and external affairs activities, please visit their [website](#) or contact [beverly.barr@popewoodhead.com](mailto:beverly.barr@popewoodhead.com)



International Alliance of  
Patients' Organizations

A global voice for patients

# Working with partners and stakeholders

Patients' organisation toolkit

## Section 2 Collaborating with stakeholders



novo nordisk®

Funded by Novo Nordisk  
International Operations

## Collaborating with stakeholders

Patients' organisations share the aim of improving health and quality of life for patients with many other stakeholders. Building relationships with these other stakeholders can be valuable and mutually beneficial.

While there are several **benefits** of collaborating with other healthcare stakeholders, like all relationships, there are also **challenges**. One way to support the development of effective partnerships and overcome these challenges is to have a **Framework for interaction**.

### Benefits

The main benefits of collaborating with other healthcare stakeholders are to:

- gain a greater understanding of respective needs
- obtain advocacy support to shape policy and increase disease awareness
- share skills and expertise
- gain access to information and data
- secure funding and resources.

### Challenges

Common challenges of collaborating with other healthcare stakeholders are:

- differing expectations or goals
- maintaining independence and understanding boundaries
- external changes and influences that impact the partnership
- working within local laws and regulations
- public opinion and scrutiny.

This section focuses on building relationships with four key stakeholders:

- **Other patients' organisations**
- **Healthcare professional associations**
- **Government**
- **Industry**.

Refer to the section **Working with pharmaceutical companies** for more detailed information on collaborating with the pharmaceutical industry.

While this toolkit considers collaborations with individual stakeholders, it is important to be aware that some patient-support initiatives will involve multi-stakeholder collaborations.

## Framework for interaction

### What is a framework for interaction?

- A framework for interaction is a set of principles or policies, or a code of conduct/practice, that governs how your organisation interacts with external stakeholders, e.g. industry and healthcare professional associations.
- It defines the boundaries for interaction and the rules for engagement.
- For an example refer to IAPO's principles for industry support within the [IAPO Healthcare Industry Partners Framework booklet \[PDF\]](#).

### Why is a framework for interaction important?

- It helps both partners to work together in a transparent and accountable way, while maintaining their independence.
- It enables you to be open and transparent about how you conduct business.
- It allows for better understanding of partnerships, and instills public confidence.

### Communicating and implementing the framework

- Plan how to communicate your framework to internal and external audiences.
- Provide information and training (where possible) about the framework to all internal staff.
- Consider if, how and when you wish to communicate with the media about your framework.

## Collaborating with other patients' organisations

Patients' organisations can include any non-governmental, not-for-profit organisations representing patients at any level. Working with these partners has many benefits.

For example, working with other **local patients' organisations**:

- gives a united voice that is stronger than a single voice
- enables you to share experiences
- avoids duplication of efforts (e.g. you can produce shared educational materials)
- is more cost effective.

Partnerships with **national, international, regional** and other **umbrella patients' organisations** provide benefits such as:

- support for your work, including visibility and publicity
- guidance and training for your members
- representation and ability to impact policy at a national/international level
- opportunities to share resources (such as staff and equipment), communication materials and best practice.

### Local patients' organisations

Local patients' organisations represent groups of patients specific to a city, town or district, rather than a large geographical area. Patients usually have a particular condition (or group of closely-related conditions). Sometimes a local patients' organisation acts for groups of patients with different diagnoses but within a limited geographical area.

### National patients' organisations

National patients' organisations represent groups of patients at a country level (e.g. Brazil, South Africa). National organisations may be disease specific or work across many disease areas.

### International patients' organisations

International patients' organisations represent groups of patients at a worldwide level (e.g. International Alliance of Patients' Organizations [IAPO]). These can also be umbrella patients' organisations.

### Regional patients' organisations

Regional patients' organisations usually refer to organisations that represent groups of patients at a continental level (e.g. European Haemophilia Consortium), but can alternatively refer to a region within a country. These can also be umbrella patients' organisations.

### Umbrella patients' organisations

Umbrella patients' organisations represent groups of patients' organisations either with related diseases (e.g. the International Diabetes Federation or the World Federation of Hemophilia) or with non-specific conditions (e.g. European Patients' Forum). As well as running international projects, umbrella organisations provide resources and training to their member organisations.

## Useful documents

[Top tips for collaborating with other patients' organisations and healthcare professional associations \[PDF\]](#)

[Examples of how patients' organisations can work together \[PDF\]](#)

## Examples of how patients' organisations can work together

### Twining

Several umbrella organisations, including the International Alliance of Patients' Organizations (IAPO) and the World Federation of Hemophilia (WFH), provide twinning services. In these services they introduce and connect compatible patients' organisations that go on to develop a working partnership. Umbrella organisations co-ordinate the twinning but do not get involved or play an active role in the partnerships. They may, however, give advice or support, and seek feedback on how the partnership is progressing.

Twinning encourages patients' organisations to share knowledge and practices, and to collaborate on specific projects, e.g. advocacy campaigns or disease education programmes.

Participating patients' organisations find that twinning is a mutually beneficial experience that enables knowledge sharing and motivates staff and volunteers.

Partnering with another patients' organisation could help your organisation to (for example):

- review its strategy and needs
- develop an advocacy campaign or fundraising strategy
- increase its knowledge on policy areas, patient needs or disease-related issues
- organise events, e.g. to raise publicity, host educational meetings or camps.

Member organisations should refer to the IAPO and WFH websites for more information on their twinning services.

### UK Lysosomal Storage Disorders (LSD) Patient Organisation Collaboration

LSDs are a group of rare, genetic metabolic disorders. In the UK there are many LSD patients' organisations, each representing patients with different disorders. Five of these organisations have decided to work together, forming the UK LSD Patient Organisation Collaboration. This collaborative group works and lobbies on behalf of LSD patients and their families in the UK.

The objectives of this group are to:

- “enable the development of a stronger voice with which to influence national policy, stimulate interest and further the knowledge and understanding of LSDs”
- “encourage close working relationships between member associations in order to facilitate the sharing of information and the effective use of resources”
- “oversee the provision of clinical care for those affected by LSDs; to promote clinical efficiency and best practices in the health service”
- “share information regarding potential therapies and treatments for LSDs; to support and encourage all those affected by LSDs in accessing treatments and therapies”
- “seek to provide a positive influence, leading to increased engagement in the delivery of government policy on LSDs and other rare diseases”
- “consider ways of encouraging new initiatives, including the commissioning of further research into the causes and possible treatments of LSDs”.

To achieve these objectives the UK LSD Patient Organisation Collaboration plan to:

- share information, ideas and examples of good practice with researchers and healthcare professionals
- provide advice and information regarding LSDs to all interested parties
- establish links with stakeholders (including industry, researchers, healthcare professionals and individuals) with an interest in LSDs
- campaign to highlight the need for effective, accessible and safe therapies for LSDs and better need for health and social care
- lobby government and other stakeholders to improve the clinical standards of care for people affected by LSDs
- contribute to updating and improving the standard of clinical care
- raise awareness of LSDs amongst health and social care professionals and the public.

### Collaborating with healthcare professional associations

Healthcare professional associations support and educate healthcare professionals in specific disease areas so they can provide optimum care to patients. They may have similar objectives to patients' organisations. Sometimes, healthcare professional associations and patients' organisations combine (e.g. [Associação Nacional de Assistência Ao Diabético](#)).

The benefits of working with healthcare professional associations include:

- sharing information
- understanding respective needs
- presenting a united voice in a disease area or on a particular issue.

#### Useful documents

[Top tips for collaborating with other patients' organisations and healthcare professional associations \[PDF\]](#)

[Example of how a patients' organisation and healthcare professional associations can work together \[PDF\]](#)

## Top tips for collaborating with other patients' organisations and healthcare professional associations

1. Collaborate with other patients' organisations/healthcare professional associations that share similar goals and ambitions to that of your own organisation, e.g. to raise disease awareness in a given disease.
2. Agree the scope, objectives and timeframe of any collaboration in advance of starting any project or alliance.
3. Review the scope and objectives of the project or alliance at regular intervals to ensure that things are running as planned, and to identify ways that the collaboration could be improved if required.
4. Where possible explore how best to share resources, e.g. educational materials, access to information.
5. Assign clear roles, responsibilities and tasks for any project or alliance and ensure that they are clearly communicated to the relevant individuals.
6. Ensure that each party is appropriately acknowledged for their input or contribution.
7. Work together to maximise each party's strengths and be sensitive to any limitations or constraints they may have.
8. Be prepared to invest time, effort and resources in establishing, building and maintaining any relationships.
9. Ensure that you keep in regular communication using emails, telephone and face-to-face meetings. Any written communications should be as clear and concise as possible.
10. Appoint one individual to take responsibility and manage the collaboration on behalf of your patient organisation.
11. Be flexible and willing to discuss how to resolve any potential areas of conflict.
12. Always be open, transparent and ethical.
13. Develop an agreement specifying:
  - the objectives and scope of the project/interaction
  - the roles, responsibilities and tasks of each party
  - timelines
  - the amount and source of any relevant funding
  - how each party will be acknowledged for its contribution and involvement.

## Example of how a patients' organisation and healthcare professional associations can work together

### The UK Haemophilia Alliance

The UK Haemophilia Alliance is a union between the patients' organisation, the Haemophilia Society, and several healthcare professional associations including the Haemophilia Centre Doctors Organisation and the Haemophilia Nurses Association.

The mission of this alliance is to “work together with the aim of continually improving standards of care and support for all patients with haemophilia and other inherited bleeding disorders and their families throughout the UK”.

Through this formal partnership the alliance developed the ‘National Service Specification for Haemophilia’, which promotes best practice and tries to standardise care throughout the country.

The alliance also works with an unofficial parliamentary group (All Party Parliamentary Pressure Group on Haemophilia), which promotes and keeps the Government informed of haemophilia issues, and ensures that haemophilia is kept on the political agenda.

### Collaborating with government

Collaborating with government may involve working with individual members of government or interacting with governmental bodies such as health policy teams, regulatory bodies, and health technology assessment teams.

The benefits of working with government members or bodies include:

- creating, shaping or educating around health policies
- impacting treatment guidelines and access to treatment
- ensuring that the disease area and issues that affect patients are kept on the political agenda.

Additionally, in some countries, governments may help fund patients' organisation activities, either directly or via government initiatives.

#### Useful documents

[Top tips for collaborating with government \[PDF\]](#)

[Examples of how patients' organisations can work with government \[PDF\]](#)

## Top tips for collaborating with government

1. Use the internet or your network of contacts to conduct research to:
  - identify the most appropriate government department, body or group to contact
  - identify the most appropriate person within the department/body to contact
  - understand what policies, initiatives or projects they may be working on that directly impacts or affects your disease area or patient population.
2. Remember that most government policies are general; therefore it may be difficult to identify the policies that could have an impact on your organisation or patient members. For example, a patients' organisation for Alzheimer's Disease may be interested in general policies on improved health in people aged more than 65 years, or anything on neurological disease in general.
3. Make sure all communications are clear and concise. Always ensure that you provide accurate and factual information about your disease and your organisation.
4. Be certain of your policy position(s) and messages and be able to demonstrate the evidence behind them.
5. Establish in advance clear objectives and goals for all communications and collaborations/projects.
6. Be clear on the level and type of input you need from the government body/contact person.
7. While you may need to be persistent to establish contacts, always be professional and polite in your interactions. Listen to what is being said to you and try to understand the other person's point of view.
8. Remember that you may need to be flexible and willing to compromise to reach an agreement or achieve the next step in the relationship.
9. Always follow up any meeting or teleconference by sending a thank you letter/email and summarising the key points and actions from the meeting/call.
10. At all times be open, transparent and ethical, and ensure that you adhere to the mission of your organisation.

## Examples of how patients' organisations can work with government

Patients' organisations can work with individual members of government, such as members of local, national or regional government. They can also work with specific government bodies, including:

- government organisations, such as health departments
- regulatory bodies
- health technology assessment (HTA) teams.

### Working with individual members of government: putting patient healthcare issues on the political map

By involving and inviting a member of the government to patients' organisation activities, you can raise the political profile of the disease area and the patients your organisation represents. It can also help attract media coverage of your events.

For example, the European Liver Patients Association (ELPA) is working with the Members of the European Parliament, Dr Thomas Ullmer and Mr Aljóz Peterle, to raise the political profile of hepatitis. As part of World Hepatitis Day activities, ELPA and the European Association for the Study of the Liver (EASL), together with Dr Ullmer and Mr Peterle, organised a policy lunch debate in the European Parliament. Its purpose was to assess what needs to be done by the European Union and to identify policy initiatives that could be of importance when fighting challenges associated with hepatitis. At the session, ELPA conducted free liver tests for members of the European Parliament and their staff to raise awareness among policy makers of the need for targeted screening of viral hepatitis among risk groups. For more information on this interaction refer to ELPA's website: [www.elpa-info.org](http://www.elpa-info.org).

### Interaction with regulatory bodies

Regulatory bodies are government agencies that decide whether a new drug can receive a licence and be marketed in a particular country or countries. Examples include the Pharmaceuticals and Medical Devices Agency (PMDA) in Japan and the Central Drugs Standard Control Organization (CDSCO) in India. Many of these regulatory bodies now work with patient groups to consider the patient perspective when making licensing decisions. Some examples are given below.

#### European Medicines Agency (EMA)

EMA is a decentralised body of the European Union that evaluates and supervises the use of specific medicines including drugs that are used to treat HIV/AIDS, cancer, diabetes, neurodegenerative disorders and autoimmune diseases. EMA has set up a Patient and Consumer Working Party to provide recommendations to the agency and its associated groups on all matters of interest to patients in relation to

medicinal products. Representatives from many patients' organisations, including the International Alliance of Patients' Organizations (IAPO), International Diabetes Federation (IDF) and European Organisation for Rare Diseases (EURODIS), are on the working party. For further information, refer to EMA's website:

[www.ema.europa.eu](http://www.ema.europa.eu).

### **Food and Drug Administration (FDA)**

The FDA is an agency within the United States Department of Health and Human Services. It is responsible for protecting public health by assuring the safety, efficacy and security of human drugs, biological products and medical devices. The agency has established a Patient Representative Program, which is responsible for providing the FDA and its associated committees with the perspective of patients and family members who are directly affected by a serious or life-threatening disease. Patient representatives serve on advisory committees that review products and therapies for the diagnosis and treatment of several diseases including diabetes. For further information, refer to the FDA's website: [www.fda.gov](http://www.fda.gov).

### **Collaboration with HTA teams and the development of national treatment guidelines**

Many governments employ health technology assessment (HTA) teams to evaluate and identify the best quality of care and treatment procedures for patients in their country. HTA teams usually consider the effectiveness, costs and the broader impact on healthcare when evaluating new drugs or therapies. National treatment guidelines are written once the best practices have been identified. Patients' organisations are often involved in the evaluation of new therapies and the development of treatment guidelines, thus representing patients, their families and carers in decisions that impact their healthcare.

An example of a HTA and guideline development body is the National Institute for Health and Clinical Excellence (NICE), which is part of the National Health Service in the UK. NICE is responsible for developing national treatment guidelines to ensure that everyone in England and Wales has 'equal access to medical treatments and high quality care from the NHS'. As part of a commitment to involving patients and their carers in the development of clinical guidance, NICE frequently consults patients' organisations. For example, several members of Diabetes UK represented patients and carers in the development of the diabetes clinical guidelines.

In Argentina, the Institute for Clinical Effectiveness and Health Policy (IECS) collaborates with public and non-governmental organisations to identify strategies to improve accessibility and quality of health care, to promote the efficient utilisation of health care technologies and to reduce unnecessary costs and expenditures.

The Centro Nacional de Excelencia Tecnológica en Salud (CENETEC) in Mexico collaborates with patients' organisations to collect information required for health technology assessments.

## Collaborating with industry

Patients' organisations can have beneficial collaborations with a variety of industry partners:

- pharmaceutical companies (see [Benefits of working with pharmaceutical companies](#))
- medical device companies
- industry in related areas (e.g. food companies)
- industry in non-related areas (e.g. banks) as part of their corporate social responsibility.

You may collaborate with more than one type of industry partner. Click [here](#) for an example.

### An example

Many patients' organisations partner with several different types of industry. For example, Diabetes UK partners with:

- pharmaceutical companies
- pharmacy companies, i.e. high street pharmacies that sell or dispense drugs
- food companies
- opticians
- diet support companies
- banks.

The general benefits of working with industry include:

- securing funding
- access to other resources, e.g. IT equipment, literature, fundraising events, printing services
- skills sharing.

### Useful documents and links

[Top tips for working with industry \[PDF\]](#)

[Working with industry partners: framework for interaction template \[Word document\]](#)

[Working with pharmaceutical companies](#)

## Top tips for working with industry

1. Use the internet or your network of contacts to conduct research to:
  - understand the company structure
  - identify the most appropriate person to speak with. A good point of contact is usually the national office within your country. There is usually a specific person responsible for external relationships. If there isn't, then ask who is the most appropriate person.
2. Be clear in your initial conversation what type and level of support you are seeking.
3. Make sure that your organisation and the industry partner maintain their independence. This helps to keep public and patient confidence.
4. Be accountable for your actions. Accountability is important for both the organisation's relationship with its members and their partnership with industry.
5. Remember that collaborations/interaction should be beneficial to both parties. Partnerships conducted in this way are most likely to be successful.
6. Undertake projects that will help you meet your organisation's objectives. Make sure that the outcomes of the collaboration are in line with the needs of your patients.
7. Always conduct any partnerships in an open and transparent way.
8. Establish in advance clear roles and responsibilities for each party. Also consider who has ownership of any of the information produced.
9. Be respectful of the company's policies and working processes.
10. For each project/interaction have an agreement, signed by both parties, that:
  - states the objective of the project/interaction
  - outlines the scope of the project/interaction
  - defines the roles, responsibilities and timelines
  - specifies the amount of funding and any non-financial contribution
  - describes how each party will be acknowledged.

### 3. Working with pharmaceutical companies

- For each project, agree the roles and responsibilities for yourself and the pharmaceutical company. For example, if the project involves running an educational meeting, the patients' organisation could be responsible for deciding the content of, and selecting speakers for the meeting, while the pharmaceutical company could be responsible for supplying information and logistical support.
- Agree project/interaction objectives at the start of the project/interaction.
- Develop a project plan and sign a project agreement.
- Be transparent and accountable for the actions of your patient organisation.
- Agree use of materials, information and logos, and how the parties will be acknowledged before initiating a project.
- Hold mid-project reviews and meetings to ensure the project is on track, and that each party is working to the agreed framework and project plan.
- Review and evaluate project/interactions.



International Alliance of  
Patients' Organizations

A global voice for patients

# Working with partners and stakeholders

Patients' organisation toolkit

## Section 3

Working with pharmaceutical companies



novo nordisk®

Funded by Novo Nordisk  
International Operations

### Working with pharmaceutical companies

Pharmaceutical companies are key partners in improving patients' health and quality of life. In addition to providing new therapies and drugs, pharmaceutical companies are also an:

- excellent source of expertise, information and contacts
- important funding source for patients' organisations.

The pharmaceutical industry is heavily regulated in most countries. These laws may even extend to what and how pharmaceutical companies can communicate to patients. It is important to be aware of, and comply with, any local or national laws and regulations that affect how pharmaceutical companies can interact with patients and patients' organisations.

This section provides:

- an overview of the [Benefits of working with pharmaceutical companies](#)
- general guidance on [How to work with pharmaceutical companies](#)
- a selection of [Case studies](#)
- a [Pharmaceutical industry perspective](#) of working with patients' organisations.

## Benefits of working with pharmaceutical companies

In addition to securing funding, resources and skills sharing, other benefits of working with pharmaceutical/healthcare industry partners include:

- access to information, educational materials, scientific data and equipment
- knowledge of country-specific markets and barriers to treatment access
- better and more timely understanding of regulatory and safety issues about specific drugs
- information about pipeline products and planned and ongoing clinical trials
- access to networks of contacts, including access to key opinion leaders
- informal pharmaceutical/healthcare industry advice or opinion
- an additional voice for lobbying policy makers
- opportunities to attend conferences, workshops and other professional development events
- greater understanding of options for managing health conditions.

Some of these benefits may extend beyond the life of the relationship.

## How to work with pharmaceutical companies

Partnerships with pharmaceutical companies should be based on the four pillars of engagement: **compliance**, **patient focus**, **mutual benefit** and **respect**.

### Compliance

Interactions between pharmaceutical companies and patients' organisations may fall under local laws, regulations, frameworks or codes of conduct. It is the responsibility of both parties to ensure that all interactions comply with local laws, regulations, frameworks and codes.

### Patient focus

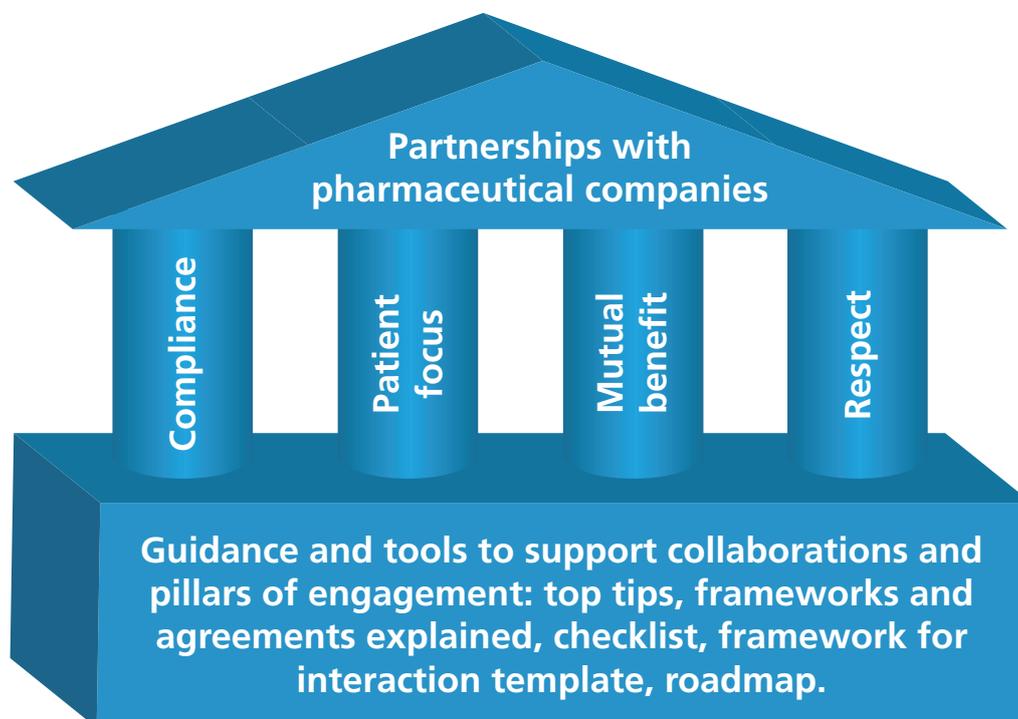
Interactions must ultimately benefit the patient.

### Mutual benefit

Interactions must be mutually beneficial.

### Respect

Partnerships must be based on respect. Interactions must be transparent, ethical and maintain the integrity/independence of both parties.



Guidance and tools that can be used to support your interactions with pharmaceutical companies are:

- [Top tips for working with pharmaceutical companies \[PDF\]](#)
- [Frameworks and agreements explained \[PDF\]](#)
- [Checklist for working with pharmaceutical companies \[PDF\]](#)
- [Working with industry partners: framework for interaction template \[Word document\]](#)
- [Roadmap to working with pharmaceutical companies \[PowerPoint\]](#).

## Frameworks and agreements explained

Maintaining independence and showing transparency are key factors when interacting with industry partners. There are two key documents that will help to ensure transparency and protect each party's independence:

1. Framework for interaction
2. Project agreement.

### Framework for interaction

A framework for interaction is a set of general principles or policies, or a code of conduct/practice, which governs how one party will interact with another, e.g. how your patient organisation will interact with industry partners. It can be used to guide your organisation in setting up relationships with industry partners, including pharmaceutical companies. The framework sets out the boundaries of interaction, and specifies the rules of engagement. They **are not** usually project or collaboration specific.

When working with industry there may be two frameworks for interaction that need to be taken into consideration and followed:

1. **Patients' organisation**

It is recommended that your patients' organisation has its own policies, principles, or code that it adheres to when working with industry partners. If your organisation does not already have a framework for interaction, you can develop one using the framework for interaction template, provided in the '*Working With Partners And Stakeholders*' toolkit.

2. **Industry partner**

The industry partner that you are collaborating with may also have its own set of policies, principles or a code that it adheres to when working with patients' organisations. It is important to be aware of these, and try to work within their framework while maintaining the independence of your organisation. If you are concerned in any way, do have a discussion with the industry partner and try to resolve any issues.

### Project agreement

A project specific agreement is a signed document that defines the purpose of the project/interaction, the responsibilities of both parties and provides an overview of the project plan. Each project/interaction should have its own specific project agreement.

Ideally, for each collaboration, a detailed project plan should be developed. Once this plan has been agreed, it should be written up into an agreement and signed by both parties. The agreement should include:

- Name of the project
- Names of the involved parties
- Approach/type of project, e.g. meeting, information campaign, unrestricted funding
- Purpose/objectives
- Roles, responsibilities, tasks and deliverables
- Level and source of financial support
- Scope and content of non-financial support
- Timelines
- Sign-off process
- Acknowledgements (i.e. how each party will be acknowledged for their contribution)
- Co-endorsement (use of logos and other identifying symbols).

## Working with industry partners: framework for interaction template

### 1. What is a framework for interaction?

A framework for interaction is a general set of principles, rules, policies or a code that guides your patients' organisation in setting up relationships with industry partners, including pharmaceutical companies. The framework should apply to all interactions. In this context an interaction would be defined as any type of activity undertaken with an industry partner, including, for example, providing a quote for a press release, speaking at an industry event, collaborating on the production of educational materials or events, participating in a clinical trial, or seeking financial support for a patient-support activity. This would apply regardless of whether or not there is a transfer of funds, other material goods or knowledge.

The framework clearly specifies to partners what types of interactions are acceptable (boundaries of interaction), how the partners will work together (rules of engagement) and how the relationship will be communicated to others (transparency). A framework for interaction can be documented in the form of a code of conduct, guiding principles or policy statement.

A framework for interaction also provides the basis for developing specific agreements for defined projects that form part of your interaction.

For further information, refer to the document '*Frameworks and agreements explained*'.

### 2. What are the benefits of having a framework for interaction?

A framework for interaction:

- helps your organisation clarify the ways in which it will and will not interact with industry partners
- helps to ensure openness and transparency about your organisation's interactions with industry
- communicates your organisation's principles to industry partners, provides the basis for negotiations and acts as a reference for partnership activities
- improves patient, public and other stakeholder understanding of, and confidence in, your patient organisation-industry partnerships.

### 3. Purpose of this template

This template is designed as a **starting point** to help your organisation develop its own framework for interaction.

The template highlights key topics and provides some general policy and principle suggestions that you may wish to consider when developing a framework for interaction. The policy and principle suggestions are based on common themes identified following the review of several patients' organisation partnership frameworks (including the International Alliance of Patients' Organizations [IAPO], World Federation of Hemophilia [WFH] and the European Patients' Forum [EPF]).

While this template provides some **ideas** and **suggestions**, it needs to be adapted accordingly for your particular organisation. Ideally a formal framework for interacting with stakeholders should be created in line with your organisation's procedure on developing internal policies (refer to the '*Working With Partners And Stakeholders*' toolkit for guidance on developing organisational policies). The framework should also take into account any local legal requirements.

#### 4. Communicating the framework for interaction

Once a framework for interaction has been agreed it needs to be documented and communicated (refer to '*Working With Partners And Stakeholders*' toolkit for guidance on writing position statements). It is important to inform members, internal staff and volunteers, the public and external stakeholders of your organisation's position on industry relationships. Different methods may be required to effectively communicate the framework to the various audiences (refer to '*Working With Partners And Stakeholders*' toolkit for guidance on communication).

#### 5. Template

##### **Patients' organisation vision and mission**

<To complete>

##### **Reasons for seeking industry support**

<Insert rationale for seeking industry support.>

<Examples include:

- *create a diverse funding source*
- *obtain funding to:*
  - *build core capabilities*
  - *support patient service activities*
  - *help initiate new activities*
  - *help expand existing activities*
- *build relationships and share knowledge with other healthcare stakeholders about issues that affect patients.>*

##### **Purpose of this framework**

<Insert reason(s) for developing a framework for interaction with industry partnerships.>

<Reasons could include to:

- *ensure openness and transparency of interactions with industry partners*
- *specify the types of interactions with industry partners that are acceptable, and those that are not, to:*
  - *ensure interactions are compatible with the organisation's mission, values, goals and objectives*
  - *ensure interactions do not jeopardise the organisation's integrity and ability to act independently*
  - *recognise and deal with actual or perceived conflicts of interest*
- *ensure interactions contribute to the organisation's positive public image and credibility*
- *clearly communicate the organisation's policy on interactions with industry.>*

### **Framework for interaction**

<State agreed policies or principles for interaction. Some examples taken or adapted from IAPO, WFH and EPF are given below that you can select and adapt for your organisation. Please note that not all policies/principles have to be adopted – choose and amend those that are suitable for your patient organisation.>

### **Policies/principles: general**

Delete or amend the following

1. All collaborations with industry partners will be compatible with the mission of *<name of patients' organisation>*.
2. All collaborations must be assessed to ensure that they follow this framework for interaction and approved by the *<name of patients' organisation>* responsible body.
3. *<Name of patients' organisation>* will not enter into an interaction with an industry partner that may potentially have an adverse effect on the organisation's credibility or integrity.
4. *<Name of patients' organisation>* will not engage in projects with industry partners where there is an implicit expectation or obligation to promote a branded, commercial product. In some circumstances, however, the organisation may independently choose to support a specific (branded) product or service following informed analysis of scientific data and patients' needs. (For example, when speaking to a regulatory authority or independently lobbying a government body to improve patients' access to treatment.) Testimonials or support for a specific (branded or unbranded) product will be prepared and presented by *<name of patients' organisation>* based on its own informed analysis of scientific data, patient input and independent expert opinion. All activities and references to products will comply with local laws.

5. *<Name of patients' organisation>* will ensure that all uses of its name, logo and other identifying symbols are compatible with the organisation's mission and values. *<Name of patients' organisation>* responsible body will have final approval on all uses of its name, logo and identifying symbols.
6. *<Name of patients' organisation>* will appropriately recognise company sponsorship. Recognition should not be interpreted as endorsement of particular policies or products.
7. *<Name of patients' organisation>* will gratefully accept product donations. However only products that are licensed by a recognised regulatory body such as the US (FDA), European (EMA), or Japanese regulatory agencies will be accepted.
8. *<Name of patients' organisation>* will follow all local laws and regulations *<insert details if appropriate>* in relation to interactions with the pharmaceutical industry.

### **Policies/principles: transparency**

#### **Delete or amend the following:**

1. *<Name of patients' organisation>* will ensure that all industry partners are familiar with the framework/principles/policies for interaction outlined in this document.
2. Where possible, *<name of patients' organisation>* will disclose all financial support and other benefits from industry partners on request, and will publish the amount and source of all funding in their annual report and/or website.
3. *<Name of patients' organisation>* will require a written and signed project agreement with all industry sponsors prior to initiation of the collaboration.

### **Policies/principles: maintaining independence**

#### **Delete or amend the following:**

1. *<Name of patients' organisation>* will maintain an independent position on all issues that impact patients, based on its own informed analysis of scientific information, patient input and independent expert opinion.
2. *<Name of patients' organisation>* retains the right to withdraw from the collaboration should the terms of agreement be broken.
3. *<Name of patients' organisation>* retains the right to publically object to positions or actions of the industry partner.
4. *<Name of patients' organisation>* will only accept restricted sponsorship if it retains full control of the event, publication or project.
5. *<Name of patients' organisation>* reserves the right to receive sponsorship support from multiple companies where possible, to avoid the appearance of alliance with any one company, its products, political agenda or regulatory concerns.

## **Policies/principles: funding**

### Delete or amend the following:

1. *<Name of patients' organisation>* is committed to having a diverse range of funding sources where possible. Projects funded by a single company must be aligned with *<name of patients' organisation>* strategic plan, agreed by the responsible body and comply with local laws and regulations.
2. Companies that provide unrestricted funding will be given priority for all additional sponsorships.
3. Restricted funds for activities that are inconsistent with *<name of patients' organisation>* vision, mission or strategic plans will not be accepted.



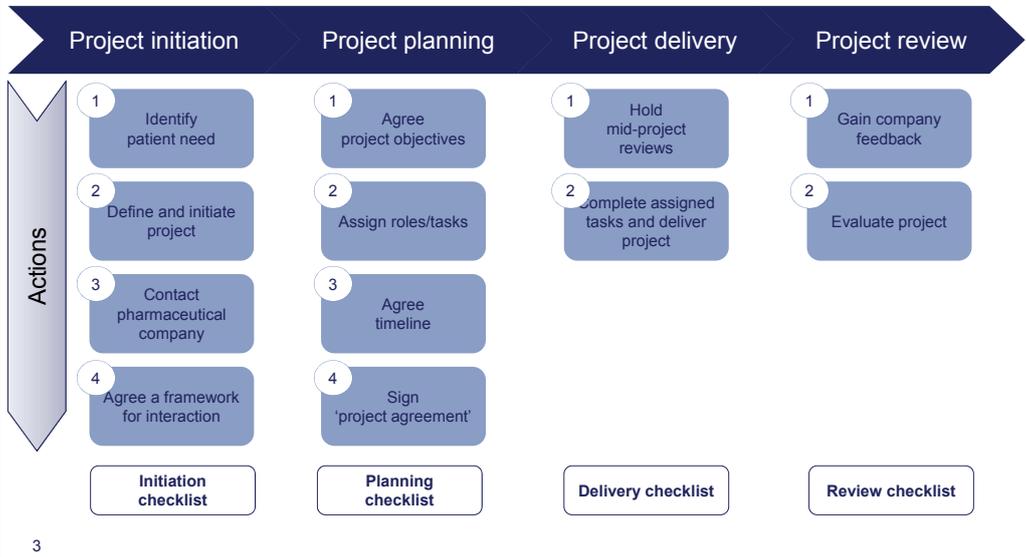
# Roadmap to working with pharmaceutical companies

## Introduction

- This presentation guides patients' organisations through the process of working with pharmaceutical companies from project initiation to project delivery and review
- This is only one of many ways to work with pharmaceutical companies and the guidance should be adapted to suit your organisation
- The guidance given is also applicable to working with other external stakeholders such as other patients' organisations, healthcare professionals associations and government
- This document can also be used to present how your organisation works with external partners to staff, volunteers and members
- The presentation contains buttons (hyperlinks), particularly on slide 3 - see example on right. To use the buttons to move between slides, view the presentation as a slide show

Agree  
timeline

## Overview: roadmap to working with pharmaceutical companies



[Back](#)

### Project initiation: identify patient need

- Identify patient need through:
  - internal research/knowledge
  - request from patients
  - change in health policy/law
  - known disease area need

## Project initiation: define and initiate project

- Develop:
  - draft objectives
  - project ideas
  - project outline, e.g. identify key stakeholders, deliverables
- Identify possible funding sources and decide whether to approach a pharmaceutical company for support

## Project initiation: contact pharmaceutical company

- Identify a suitable pharmaceutical company to collaborate with (if you are not already aware of a potential company to partner with)
- Approach the pharmaceutical company to discuss the potential project
- Take notes and keep records of meetings with the pharmaceutical company
  - send meeting minutes to the pharmaceutical company for agreement

## Project initiation: agree a framework for interaction

- Discuss and agree the boundaries for interaction
  - If available, share your patient organisation's framework for interaction with the pharmaceutical company
- Discuss expectations and limitations/constraints of the collaboration with the pharmaceutical company
- Establish how both parties will:
  - maintain independence and integrity
  - work in a transparent fashion and benefit from the interaction
- Agree:
  - key contacts
  - total amount of funding (if applicable)

## Project initiation: checklist

- Do you have a framework for interaction, describing how your organisation interacts with pharmaceutical companies?
- Is the pharmaceutical company aware and respectful of your organisation's framework for interacting with industry?
- Does the proposed project advance the mission of your patient organisation?
- Does the proposed project comply with local laws, codes and/or regulations?
- Have you identified any other stakeholders that need to be involved?
- Will the project provide benefit to both your patient organisation and the pharmaceutical company?
- Have you assigned a specific person to look after this partnership?
- Does the project focus on external affairs or disease area support? (Avoid collaborative projects that support a particular medicine.)
- Have the use of materials, information and logos, and how the parties will be acknowledged been agreed?

## Project planning: agree project objectives

- Objectives must be:
  - in line with the mission/aims of your patient organisation
  - agreed by the pharmaceutical company
  - long term
  - achievable
  - measurable
- Identify parameters to measure the success of the project

## Project planning: assign roles/tasks

- When assigning roles/tasks, take into consideration:
  - all applicable frameworks for interaction
  - limitations/constraints of both parties
  - how to maintain the independence of both parties

## Project planning: agree timeline

- Develop a feasible timeline, incorporating mid-project reviews, meetings and reports
- Consider limitations/constraints when agreeing the timeline

## Project planning: sign 'project agreement'

To ensure transparency and clarity, the collaboration should be defined in writing. The agreement could include, for example:

- name of the project
- names of the involved parties
- approach/type of project, e.g. meeting, information campaign, unrestricted funding
- purpose/objectives
- assigned roles, responsibilities, tasks and deliverables
- level and source of financial support
- scope and content of non-financial support or significant indirect support
- timelines
- sign-off process
- acknowledgements (i.e. how each party will be acknowledged for their contribution)
- co-endorsement (use of logos and other identifying symbols)

## Project planning: checklist

- Have clear project objectives been agreed?
- Has a project plan been agreed?
- Is the project plan in line with your patient organisation's framework for interaction?
- Have clear roles and responsibilities for each party been agreed?
- Is the project plan feasible for both parties?
- Has an agreement been signed and copies filed?

## Project delivery: hold mid-project reviews

- Have regular meetings and/or prepare reports to ensure project is progressing as planned, is on time and on budget
- Keep meeting minutes and project reports to track progress, and to promote transparency and accountability
- Identify if and where timeline and budget over-run may occur. If required, agree a new timeline and budget, or stop the project

## **Project delivery: complete assigned tasks and deliver project**

- The project should be delivered on time and according to the agreed project agreement
- Acknowledge contribution by the pharmaceutical company and the patients' organisation appropriately (to ensure transparency)
- Adhere to the agreed sign-off process and co-endorsement

## **Project delivery: checklist**

- Have regular meetings/reports been scheduled?
- Are meeting minutes written, filed and distributed to the pharmaceutical company?
- Have revised timelines and budgets been issued (if required)?
- Is the pharmaceutical company respecting and adhering to your organisation's framework for interaction?
- Is the project agreement being adhered to?
- Has the contribution from both parties been appropriately acknowledged?

## Project review: gain company feedback

- Share feedback with the pharmaceutical company
  - How did you find working with pharmaceutical company?
  - How did they find working with your patient organisation?
- Review the success of the collaboration – establish if anything should have been done differently in terms of improving the collaboration

## Project review: evaluate project

- Evaluate the project in terms of:
  - whether objectives were achieved on time and on budget
  - benefit to patients
  - benefit to your patient organisation
- Identify key learnings from the project
- Write and publish a short project report, e.g. publish a summary of the project on your patient organisation's website

## Project review: checklist

- Were the project goals/objectives achieved?
- Was the investment of time, resources and people worthwhile in terms of improved patient-centred healthcare?
- Has feedback from the pharmaceutical company been obtained and recorded?
- Has a project report been written and published?
- If appropriate, has information about this collaboration been made publically available (e.g. has it been published on your website)?
- Is there an opportunity to continue working with the pharmaceutical company?

## Top tips for working with pharmaceutical companies

Here are some top tips for patients' organisations on developing strong partnerships with pharmaceutical companies. These top tips will help your organisation work effectively with the pharmaceutical industry while maintaining your independence.

They have been divided into three sections:

1. Supporting interactions with industry
2. Selecting projects and opportunities for interaction
3. Working with pharmaceutical companies.

### 1. Supporting interactions with industry

- Develop a framework for interaction that describes the basic principles, rules or policies of how your patient organisation interacts with industry. This framework can be used to help your patient organisation set up relationships with industry partners including pharmaceutical companies.
- Have a sponsorship programme that outlines how pharmaceutical companies can work with your patient organisation.
- Assign one person to look after all industry interactions.
- Publish information about your interactions with pharmaceutical companies (e.g. on your website or in a newsletter) to help ensure transparency.

### 2. Selecting projects and opportunities for interaction

- Make sure that the proposed project/interaction advances the mission of your organisation and benefits patients.
- Check that the proposed project/interaction is in line with the laws and regulations in your country.
- Partner with companies that respect how you work with industry and support your need to maintain independence.
- If possible, partner with multiple companies to help maintain independence and secure funding.
- Ensure that the interaction benefits both parties – your patient organisation and the pharmaceutical company.
- Projects should focus on external affairs and disease area activities (e.g. disease awareness campaigns). Avoid collaborative projects that support, or could be perceived to be supporting, a specific medicine. Do not engage in projects with industry partners where there is an implicit expectation or obligation to promote a branded, commercial product.
- Try to have long-term partnerships and, where possible, consider long-term projects and activities that align with your strategic plan.

## Checklist for working with pharmaceutical companies

Each partnership/interaction with a pharmaceutical company will be unique, and you should consider the unique circumstances and features when building the relationship. However, there are a number of key considerations that you should take into account.

The following checklist highlights key questions that should be considered and addressed when working with pharmaceutical companies.

Checklist sections:

- Project initiation
- Project planning
- Project delivery
- Project review.

### Project initiation

1. a. Do you have a framework for interaction, describing how your organisation interacts with pharmaceutical companies?
  - b. Is the pharmaceutical company aware and respectful of your organisation's framework for interacting with industry?
2. Does the proposed project advance the mission of your patient organisation?
3. Does the proposed project comply with local laws, codes and/or regulations?
4. Have you identified any other stakeholders that need to be involved?
5. Will the project provide benefit to both your patient organisation and the pharmaceutical company?
6. Have you assigned a specific person to look after this partnership?
7. Does the project focus on external affairs or disease area support? (Avoid collaborative projects that support a particular medicine.)
8. Have the use of materials, information and logos, and how the parties will be acknowledged been agreed?

## Project planning

1. Have clear project objectives been agreed?
2. Has a project plan been agreed?
3. Is the project plan in line with your patient organisation's framework for interaction?
4. Have clear roles and responsibilities for each party been agreed?
5. Is the project plan feasible for both parties?
6. Has an agreement been signed and copies filed?

## Project delivery

1. Have regular meetings/reports been scheduled?
2. Are meeting minutes written, filed and distributed to the pharmaceutical company?
3. Have revised timelines and budgets been issued (if required)?
4. Is the pharmaceutical company respecting and adhering to your organisation's framework for interaction?
5. Is the project agreement being adhered to?
6. Has the contribution from both parties been appropriately acknowledged?

## Project review

1. Were the project goals/objectives achieved?
2. Was the investment of time, resources and people worthwhile in terms of improved patient-centred healthcare?
3. Has feedback from the pharmaceutical company been obtained and recorded?
4.
  - a. Has a project report been written and published?
  - b. If appropriate, has information about this collaboration been made publically available (e.g. has it been published on your website)?
5. Is there an opportunity to continue working with the pharmaceutical company?

## Case studies

Sharing knowledge and experiences of working with pharmaceutical companies is a great way of developing new ideas for collaborations. It also helps to identify the best ways to interact with pharmaceutical companies – establishing what works and what doesn't.

This selection of [Case studies \[PDF\]](#) provides you with examples of how a range of patients' organisations have successfully worked with pharmaceutical companies. The case studies also highlight what the patients' organisations have learnt in terms of how best to collaborate with pharmaceutical companies. However, it is important to note that patients' needs vary between disease areas, and from country to country, and this impacts on the types of interaction you may have with pharmaceutical companies.

## **Case studies: working effectively with pharmaceutical companies**

## Contents

Introduction .....	47
The Symposium on Patient Communication project .....	47
The Patient's University programme in Peru.....	49
Oncology workshop project.....	51
The Great Lakes Positive Handbook project.....	52

## Introduction

There are many different ways that patients' organisations and pharmaceutical companies can work together. How your organisation interacts with pharmaceutical companies will depend on many factors including:

- patient needs in your country
- local laws and regulations governing how pharmaceutical companies and patients' organisations can interact
- your organisation's mission, strategy and policies on working with industry partners.

While each patients' organisation-pharmaceutical company relationship will be unique, sharing knowledge and experiences of working with industry partners is a great way of developing new ideas for collaboration. It also helps to identify the best ways to interact with pharmaceutical companies.

This selection of case studies provides a range of examples of how patients' organisations have successfully worked with pharmaceutical companies. They show what can be achieved through collaborating with the pharmaceutical industry, as well as highlighting how best to overcome common challenges such as maintaining independence and being transparent.

## The Symposium on Patient Communication project

Information kindly supplied by Kin-Ping Tsang, Chairman of the Alliance for Patients' Mutual Help Organizations (APMHO).

*This project provides a good example of how patients' organisations can develop an advanced communication programme through a variety of initiatives and stages, in order to ensure effective patient engagement in policy decision-making. It demonstrates just what can be achieved through establishing common objectives and developing a successful partnership with the pharmaceutical industry – a venture that provides invaluable support for the patients' organisation, whilst maintaining its independence and integrity.*

## Background

The Alliance for Patients' Mutual Help Organizations (APMHO) is an umbrella group for most of Hong Kong's patient groups. It has many advisors, including physicians and healthcare workers, academics and lawyers. There are approximately 100 patients' organisations in Hong Kong, but most of them are small bodies and have only limited means of communicating with the media, the public and their patient members. Importantly, they need support in areas such as policy discussions and advocacy.

## The project

APMHO held the Symposium on Patient Communication in 2010, to assist their member organisations with communication issues. The purpose of the symposium was to highlight the importance of communication in patient engagement, and the impact that advanced technology can have. In addition, APMHO is developing a communications website for use by member organisations and other external partners, such as political bodies, doctor associations and pharmaceutical companies either in Hong Kong or in the West Pacific region.

APMHO has co-organised the overall project and the symposium with the Chinese University of Hong Kong (CUHK), with support from the International Alliance of Patients' Organizations (IAPO) and sponsorship from a pharmaceutical company. The symposium's popular talks and roundtable discussions attracted approximately 60 patients, together with doctors, administrators, corporate executives and medical students from Hong Kong, mainland China and Taiwan. The meeting was an excellent opportunity for the launch of the patient communication website (<http://www.i-patients.org.hk>). This regional bi-lingual site is moving forward quickly and is now being piloted for two years. Already it provides a forum for patients' organisations to discuss common issues and areas of concern, and is on track to achieve its ultimate goal of bringing about patient-centred healthcare.

## Positive outcomes from the partnership

Support from the pharmaceutical company has been invaluable for APMHO. They efficiently and successfully sponsored the symposium and website expenses, relieving the financial burden on APMHO. They also provided important practical assistance with the symposium's organisation, including helping to provide keynote speakers. In addition, they enabled APMHO to forge valuable links with CUHK, and also to enhance communication with patient groups in mainland China and Taiwan.

APMHO is very positive about its partnership with the pharmaceutical company. The process works well and independence and integrity are easy to maintain. The industry partner provides advice but does not interfere with decision-making. Both parties have a common understanding with regard to patient-centred healthcare, and support for patient engagement in healthcare policy discussions. There has been no pressure from the pharmaceutical company to include commercial promotion or product advertising.

## The Patient's University programme in Peru

Information kindly supplied by Eva Maria Ruiz de Castilla, Executive Director, Esperantra, Peru.

*This programme demonstrates how patients' organisations can improve healthcare access by enlisting support from the pharmaceutical industry. It shows that even where regulations have limited the amount of funding that companies can supply, this Peruvian patients' organisation has been able to take maximum advantage of its partnership with industry to help create a large and highly influential, ongoing programme. This case study highlights also the advantages and results of securing funding from multiple industry partners.*

### Background

Esperantra is an umbrella patients' organisation set up in Peru to help reduce cancer mortality and improve the quality of life of people suffering from cancer and other chronic diseases. It aims to protect patients' rights, advocating for equal access to quality treatment in a country where there is only limited medical help, particularly for those without private healthcare. Esperantra is strengthening healthcare access for cancer patients in Peru by working with government officials to keep relevant issues on the political agenda.

## The project

The Patient's University (PU) is an ongoing programme that started in April 2006, and has been developed by Esperantra with support from various organisations, including a wide range of pharmaceutical companies. The project's main activities last for seven months each year, involving approximately 2,000 cancer patients. It is primarily a training programme for these patients and their relatives. It consists of a series of workshops held in Lima, which patients can attend when coming to the city for treatment. They not only learn about the latest available treatments, but also about their rights to receive medical help. The workshops allow patients to exchange experiences and ideas, and encourage them to develop self-help networks. In addition, the PU provides administration and management training for patients' organisations, whilst inspiring individuals to become leaders and powerful stakeholders in the decision-making process for the State's medical policy.

The PU also provides a range of materials – guides, manuals, and online communications – which bring together all of the latest information on cancer therapy, making it accessible to all.

Conflict of interest between industry and Esperantra has been easily avoided in this project as no single company has a dominant influence. Seven pharmaceutical companies provide basic, non-specific funding for no more than a total of 20% of the costs of the project, which is the maximum amount allowed by the State and the international co-operation organisations. International co-operation organisations provide the rest of the funding.

Corporate support is more than just basic funding. Through their media contacts, pharmaceutical companies can ensure high visibility for Esperantra and the PU. They are also important providers of access to the best scientific information for patients and decision makers.

## Positive outcomes from the partnership

Co-operation between Esperantra and the pharmaceutical industry has helped to make this huge project a great success. The PU mobilises, informs and trains cancer sufferers – it makes patients more aware of their rights and more active in directing and managing their own healthcare. As a result of the PU, the urgent need for a national cancer institute is now well recognised by all, and work is ongoing to develop this much needed resource. Esperantra continues to work towards gaining long-term support from industry as this will be important to ensure the PU's continued success.

## Oncology workshop project

Information kindly supplied by Jolanta Bilińska, President of the Patient Safety Foundation (PSF), Poland.

*This Oncology workshop project shows how, through a small pilot programme, a recently-established patients' organisation can begin to achieve its long-term goals through a strong, but ethical partnership with a pharmaceutical company that shared these aspirations, namely to help and empower patients.*

### Background

The Patient Safety Foundation (PSF) is an organisation set up in 2006 in Poland to help patients gain access to the best and most effective treatments. It also encourages medical authorities in Poland to recognise patient needs and ensure that they provide the necessary treatment. To achieve its goals, PSF organises educational sessions, workshops and conferences for both patients and medical staff. In addition to its work in Poland, the PSF is also involved in overseas charity work.

### The project

During 2010, the PSF successfully partnered with a pharmaceutical company in the development of an educational project to help oncology patients with treatment problems. The industry partner funded the project, which consisted of monthly, hospital-based workshops for patients and their families. It provided printed materials for these meetings, including a patient education booklet and a diary for patients to record treatment notes. In addition, psychologists were present to offer valuable psychological support for the patients.

Working with an industry partner has ensured useful funding for this important patient support programme. Project set-up was straightforward; the PSF made the first contact with the company, and meetings were set up to discuss requirements and to agree the funding package. Throughout the project, co-operation between the PSF and the company was good. Whilst the company funded the project, it made no attempt to influence either the running or the content of the workshops. Specific products were not mentioned either during the workshop or in the educational materials provided.

### Positive outcomes from the partnership

Media reporting of the project has helped raise PSF's profile. At the same time, the project has raised the awareness of the Polish authorities to the problems faced by cancer patients.

With its initial success in partnering with a pharmaceutical company, PSF now plans a similar project for 2011 – this time not just in oncology, but also for other patient groups.

## The Great Lakes Positive Handbook project

Information kindly supplied by Mariam Regina Namata Kamoga, Country Manager Community Health and Information Network (CHAIN).

*This project shows how a well-coordinated and successful partnership between a patients' organisation and industry has provided major benefits and significantly empowered patients in one African region. Establishing firm agreements and timelines at the outset, and providing simple and straightforward access to funds, were crucial to the success of this project.*

### Background

The Community Health and Information Network (CHAIN) was initially set up in 1998 to improve the lives of people living with and affected by HIV and AIDS in Uganda. CHAIN works with a variety of other organisations to provide prevention, treatment and care services for people living with and affected by HIV. CHAIN is also a drug distribution centre for HIV positive patients.

### The project

Through collaboration with a pharmaceutical company during 2006–2007, CHAIN developed the Great Lakes Positive Handbook. This pocket-sized booklet provided up-to-date information about anti-retroviral (ARV) therapy. It was designed for use by the uniformed forces (which include the army, police and prison staff) in Uganda and other countries bordering the Great Lakes. Members of the uniformed forces living with HIV and AIDS find it difficult to adhere to treatment due to their unique working environment. There was much need for clear, relevant and easy-to-access guidance regarding the use of ARVs, and about maintaining health when infected with HIV.

CHAIN was responsible for planning, co-ordinating, implementing, monitoring and evaluating this important project. The industry partner's role was to provide funding. They paid for the expenses of the steering committee that developed the handbook content, and for handbook's production (in two languages, English and Swahili) and printing.

Whilst the pharmaceutical company gave very significant financial support, it did not influence the content of the handbook, and CHAIN was given total autonomy to implement the project. This allowed the patients' organisation to adhere to its guiding principles and maintain its independence and integrity. For CHAIN, working with the pharmaceutical company was particularly successful because access to funds was simple, and there was only a limited need for reporting.

### **Positive outcomes from the partnership**

The project raised CHAIN's profile and visibility within the Great Lakes region. It greatly increased its capacity to develop educational materials, as well as to form partnerships with the pharmaceutical industry and the uniformed forces. Most importantly, it enabled CHAIN to achieve its objective of promoting treatment understanding and disease awareness to vulnerable people, and in so doing, empowering them to take control of their condition.

Based on their experiences from this project, CHAIN believes that firm agreements with the pharmaceutical company need to be put in place at an early stage. It is very important to establish how much money will be provided, and when, so that there is good co-ordination between the stages of funding and the project's timelines. Where possible, patients' organisations should aim to secure long-term funding commitments; where this is not possible, they need to identify and put in place additional sources of funding early in the project.

### Pharmaceutical industry perspective

Pharmaceutical companies work to improve patients' health and quality of life, and so have similar goals to patients' organisations. While pharmaceutical companies are primarily a business, their work extends beyond developing, manufacturing and providing drugs, to include providing patient support, disease area education and advocacy.

Working with patients' organisations allows pharmaceutical companies to:

- gain a better understanding of diseases and patients' needs, so they can develop new and/or adapt their existing therapies, or provide services accordingly
- increase the impact of their patient advocacy and patient services
- broaden their capacity to work on different types of **social responsibility projects**.

#### **Social responsibility projects**

Pharmaceutical companies recognise their responsibility to society and patients. Many pharmaceutical companies have departments dedicated to ensuring that their company acts responsibly and ethically. These departments often run projects that provide direct benefit to society and patients (e.g. charitable foundations, sponsorship and educational programmes) and in some countries can provide product donations.



International Alliance of  
Patients' Organizations

A global voice for patients

# Working with partners and stakeholders

## Patients' organisation toolkit

### Section 4

#### Key patients' organisations activities



Funded by Novo Nordisk  
International Operations



# Working with partners and stakeholders

## Patients' organisation toolkit

### Key patients' organisation activities

Patients' organisations have to perform and manage a range of related activities to ensure that the organisation runs effectively and that objectives are achieved. Some common activities include:

- **Strategic planning**
- **Advocacy and raising disease area awareness**
- **Fundraising**
- **Communication.**

This section provides information and advice on these tasks, as well as tools to help fulfil them. For further links to information and guidance on these topics, refer to the **Other tools and resources** section.

## Strategic planning

All patients' organisations should have a strategic plan that provides an overview of what the organisation wants to accomplish over the next few years (typically 2–5 years) and how this is going to be achieved.

Plans may be detailed or give top-level information. They differ depending on the size, leadership, experience and culture of the organisation. The strategy can also be influenced by the external environment.

Strategic planning is often based on achieving specified goals. It starts with developing the organisation's **vision** and **mission**. Strategic plans vary, but tend to include:

- **strategic goals**
- **strategic objectives**
- **key outcomes and activities.**

### Vision

An organisation's vision describes its ideal future. For example, IAPO's vision is that "patients throughout the world are at the centre of healthcare".

### Mission

An organisation's mission is a short statement describing its overall purpose or tasks. For example, IAPO's mission is "to help build patient-centred healthcare worldwide by:

- realising active partnerships with patients' organisations, maximising their impact through capacity building
- advocating internationally with a strong patient voice on the relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies
- building cross-sector alliances and working collaboratively with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives".

### Strategic goals

A strategic goal is a statement of what an organisation wishes to achieve over the period of the strategic plan (e.g. IAPO's strategic goal is "to strengthen the impact of the global patient voice in decision-making processes globally").

### Strategic objectives

Strategic objectives help to provide guidance on how the organisation can fulfil or move toward the strategic goals. See [Top tips for developing strategic objectives \[PDF\]](#).

### Key outcomes and activities

Each strategic objective may have several key outcomes, which can be listed separately. In addition, activities or steps to achieve the outcomes can be stated.

External stakeholders may be consulted when developing your strategic plan. However, the final version must always be in line with your organisation's overall vision and mission.

Plans can also be used to guide:

- [healthcare policies and position statements](#)
- [internal organisational policies and procedures](#)
- [periodic reports](#).

#### **Healthcare policies and position statements**

Healthcare policies ensure that the patients' organisation has a considered and agreed position on issues that are important to patients (e.g. new controversial therapies or a governmental decision regarding access to treatments). Once a policy has been agreed, a position (or policy) statement should be written to communicate the organisation's view or opinion on the healthcare issue to its members, public and other key stakeholders.

Tools: [How to develop policies \[PDF\]](#); [IAPO guidelines on policy statements \[PDF\]](#); [IAPO Policy Framework \[PDF\]](#);  
[Example policy statement: IAPO Policy Statement on Patient Involvement \[PDF\]](#)

#### **Internal organisational policies and procedures**

Organisational policies and procedures state how the organisation is going to work. Examples of key policies and procedures are: how the organisation is run and managed, how it engages with its members, and how it works with industry partners.

Tools: [How to develop policies \[PDF\]](#); [IAPO Guidelines on policy statements \[PDF\]](#)

#### **Periodic reports**

Periodic reports are important as they:

- communicate achievements of the patients' organisation to the public and stakeholders
- highlight areas that need to be addressed
- can be used to evaluate and reflect upon the progress and achievements of the patients' organisation.

Example of a periodic report: [IAPO strategic plan 2010–2014 – Progress in 2010 \[PDF\]](#)

### **Useful documents and links**

[Planning projects](#)

[How the external environment can affect a patients' organisation's strategy \[PDF\]](#)

[Example: IAPO strategic plan 2010–2014 \[PDF\]](#)

## How the external environment can affect a patients' organisation's strategy

Current and future strategies of a patients' organisation can be shaped not only by the external environment but also by internal and external stakeholders.

External environment pressures, for example changing healthcare policies or government forces (through changes in policy, taxation, spending etc.), will inevitably affect your strategy. Similarly, anything that affects your organisation's stakeholders may also impact on your strategy.

For example:

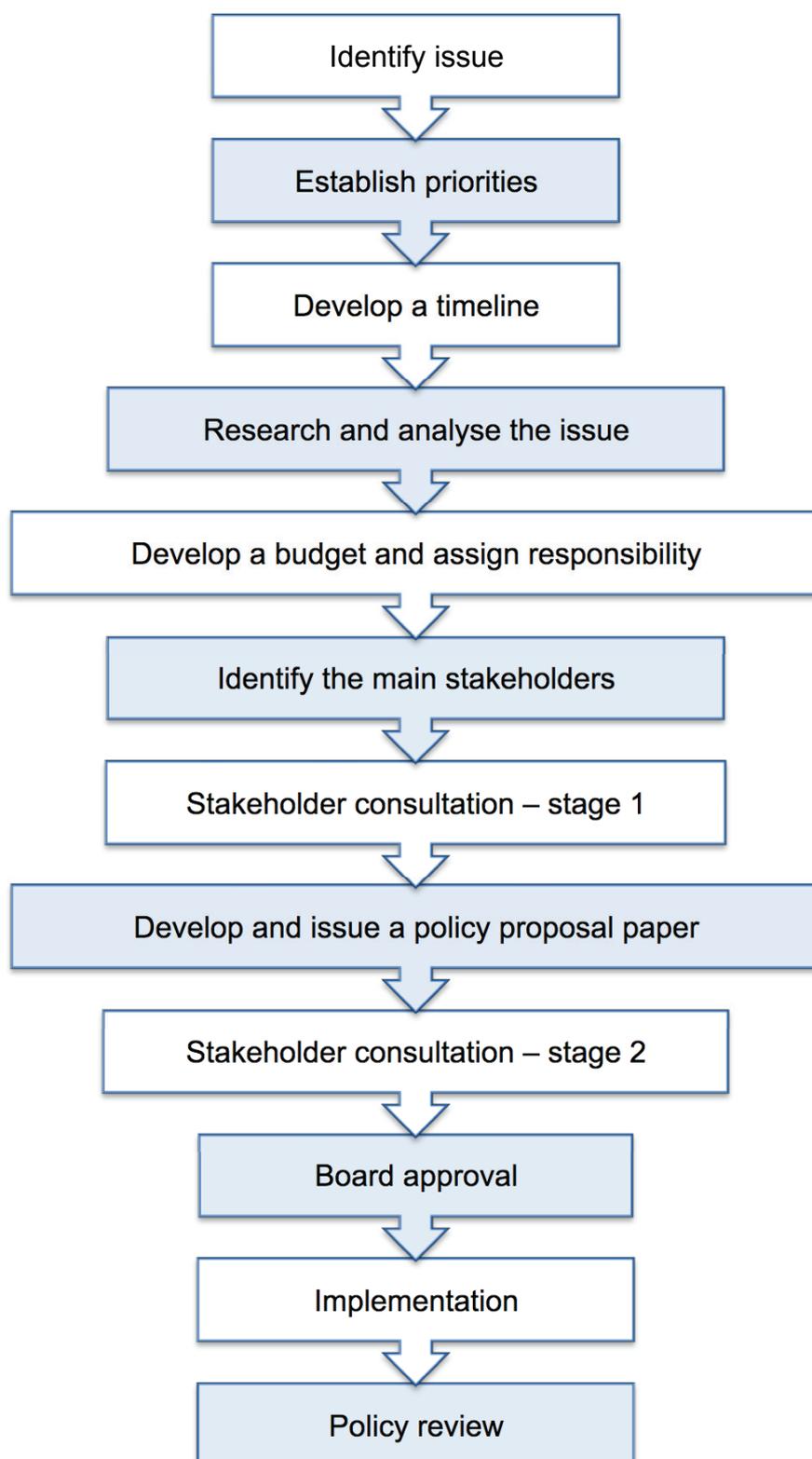
- You receive industry funding from a particular sector, which may be reduced or cut in the future due to greater industry regulation, downsizing or mergers.
  - How will you find an alternative source to replace these funds?
- Your member patients' organisations may be at different stages of development in terms of infrastructure and skills.
  - How will you help them develop in line with requirements and build this into your strategy?
- Patients (one of your key stakeholders) are difficult to communicate with because they are located in diverse geographical regions and there are many different languages to consider.
  - How will you address these needs within your strategy?
- Changes in government policy in a particular country may affect the supply of products to patients.
  - How will you change/develop your strategy to raise awareness of this and/or what actions will you take to ensure that individuals receive the best care?

## Top tips for developing strategic objectives

1. Remember that strategic objectives are the goals that will lead to the success of your organisation.
2. Consider which issues will be most critical to your organisation in making its preferred future a reality.
3. Ideally, have no more than five or six key strategic objectives. These should reflect the issues, projects and ideas that your organisation considers to be most important to advancing its preferred future.
4. You may wish to consider the following categories when developing your objectives:
  - current and future status – what is the current status of your organisation and where do you want to be in the future?
  - innovation – what (if any) new services will you need to put in place?
  - human resources – do you need to acquire and/or train people to get the job done?
  - financial resources – what funding do you need?
  - physical resources – do you need to acquire buildings/facilities?
  - productivity – are your resources are being used efficiently?
5. When developing any objectives, make sure they are SMART – specific, measurable, achievable, realistic, and time bound.
6. Be able to articulate exactly how a strategic objective will benefit your organisation. Ideally all projects you undertake will be aimed towards meeting some of your key objectives.
7. Avoid expanding the purpose of the objective to accommodate a wide variety of demands from numerous internal or external stakeholders.

## How to develop policies

Several steps are required to develop policy, as shown in the diagram below. Each step is explained on the following pages.



## 1. Identify issue

Something may happen that will identify a policy issue; for example, a new law or a complaint by a patient or member organisation. When an issue is identified, you need to review your policies and decide which of the following apply:

- there is a gap in your policies and therefore a new policy needs to be developed
- an existing policy partly addresses the issue but needs to be adapted in some way
- an existing policy is sufficient to cover the issue and no amends are required.

## 2. Establish priorities

It is useful to establish the priority of policy development and related projects. This is usually done at the most senior level in the organisation; for example, the governing board/responsible body. If the policy or project is unexpected, a decision may need to be made to revise the organisation's priorities and resource allocation.

## 3. Develop a timeline

Identify any legal or statutory deadlines that will affect the development and implementation of the policy. For example, the policy may be driven by a change in law that will take place at a specific time.

Remember to allow time to:

- develop and revise the draft policy
- get approval from the senior people or board/responsible body in your organisation
- implement the policy.

## 4. Research and analyse the issue

Always conduct research into the issue and analyse its effect.

For example, if the policy is being driven by a new law or a change to an existing law you could:

- look at any the relevant laws and regulations or court judgments
- identify any related policies
- talk to your umbrella patients' organisation to find out if they have any similar policies or experience
- talk to experts in the field
- identify any potential obstacles and/or implementation issues.

## 5. Develop a budget and assign responsibility

A clear budget may need to be created for the work and an individual assigned to the policy development, research etc.

## 6. Identify the main stakeholders

Ideally each stakeholder (e.g. the patients' organisation, the industry company sponsor) should have a representative involved in the policy development process or be consulted when a policy is adapted or changed. These stakeholder representatives need to clearly understand their role and be able to express the view of the stakeholder rather than their own opinions.

It should be the responsibility of the person managing the process to identify all stakeholders and decide who else will input into the policy. It is also their role to determine:

- who needs to review the policy before it goes to the board/responsible body for final sign-off, e.g. legal representatives
- how the policy is distributed
- who monitors the policy after it has been adopted and how this will be done
- what infrastructure is required.

## 7. Stakeholder consultation – stage 1

Stakeholder consultation tends to occur in two stages (see point 8 for stage 2).

During stage 1, you inform all the stakeholders of a new or change to a policy. At this point you find out how this may impact/affect them, and get their feedback. Feedback should be provided in written format, e.g. email or Word document.

After internal consultation, and if appropriate, incorporate some or all of their suggested feedback. This feedback can help to improve your policy and could also identify issues that you had not previously considered. In addition, it will identify areas of agreement and disagreement. Sometimes it may be necessary to hold a workshop or face-to-face meeting or focus group to help identify different options for resolving issues. The whole process needs to be carefully co-ordinated and a deadline given to receive responses. Remember you do not have to incorporate all of the comments received – only consider those that you agree with and that are appropriate.

## 8. Develop and issue a policy proposal paper

Develop a draft policy proposal for consideration of senior personnel/the board/responsible body. This should:

- be clear and concise and consistent with your values
- align with your other policies
- consider the needs of users and stakeholders.

Ideally it should state:

- why the policy is needed (background)
- a summary of the draft policy (plus a copy of the actual draft policy)
- its likely impact
- the main points/the main changes
- what you want the board/responsible body/senior people to do.

Attach a list of people it is being circulated to and identify their function in the process, e.g. 'review only' or 'review and sign-off'.

## 9. Stakeholder consultation – stage 2

At this stage the policy is almost final and the real intention of a second consultation stage is to give notice of an intended policy change. While stakeholders can still provide feedback, changes should be kept to a minimum. Only implement those changes that you agree with and that are appropriate. The result will be a final draft policy for consideration of the board/responsible body.

## 10. Board approval

Once the policy is approved by the board/responsible body or general assembly, it should be communicated to the intended audience, e.g. placed on your website or sent out by email.

## 11. Implementation

Carefully consider how the policy may be implemented. For example this may include:

- new procedures
- allocation of resources
- training/communication.

## 12. Policy review

Regularly review and monitor your policies. You need to consider whether they have become out of date, unclear, or inconsistent with your other policies and those of your member organisations.

## Advocacy and raising disease area awareness

Advocacy involves speaking or acting to ensure that your, or someone else's, voice is heard.

Patients' organisations are important advocates, representing patients and their families/carers, and as such, take action to ensure their views are expressed and that needs are addressed.

By providing advocacy services, patients' organisations enable patients, families and carers to participate in healthcare decisions that affect their lives.

Provision of a good advocacy service should ideally include:

- **increasing disease awareness**
- **researching issues that are important to patients**
- **developing policy positions**
- **lobbying stakeholders.**

### **Increasing disease awareness**

Increasing disease awareness is a great way to get the public and stakeholders to support patients. It also helps to identify previously undiagnosed patients so that they can access treatments and become aware of your organisation.

### **Researching issues that are important to patients**

It is important to research topics that affect patients and to understand patients' views on these issues. This research will ensure that the correct messages and information are communicated. Research may involve speaking with patients and other stakeholders on a one-to-one basis or in groups, conducting surveys and/or conducting literature and internet searches.

### **Developing policy positions**

To help provide a good advocacy service, an organisation should develop policy positions. For example, patients' organisations can formulate researched and agreed policy positions that reflect patients' opinion on healthcare related issues.

### **Lobbying stakeholders**

Patients' organisations can help to shape laws and health policies by lobbying governmental bodies and educating policy makers.

## Stakeholder support

Stakeholders, including **other patients' organisations**, **healthcare professional associations**, **government** and **industry**, may be able to support your organisation's advocacy activities or be patient advocates themselves. By working with them, you can increase the impact of your advocacy voice.

### **Other patients' organisations**

Working with other patients' organisations (with similar objectives) on advocacy projects can create a strong, united voice. This united voice will have much more impact and influence than that of a single patients' organisation. Working in partnership may also help solve any resourcing or cost issues.

### **Healthcare professional associations**

Healthcare professional associations are a useful source of medical information, which may be required to support an advocacy project. They can speak effectively on behalf of patients – by collaborating with healthcare professional associations, you can create a strong, united patient voice.

### **Government**

Contact the government to introduce your organisation and find out about healthcare policies and issues that affect your members. You can strengthen your advocacy campaign by asking for support from a member of government or a government body employee. This could take many different forms, such as writing an introductory letter of support or a foreword for a report or other publication.

### **Industry**

Industry is a good source of funding for advocacy projects. Pharmaceutical companies are also disease area and patient advocates, and are often keen to sponsor or support advocacy campaigns. In addition, pharmaceutical companies can provide information on drug-related issues and introduce you to key opinion leaders or policy makers.

### **Useful documents and links**

[Advocacy \[PDF\]](#)

Additional useful documents can be found in [Other tools and resources](#).

## Advocacy

There are many different ways to be an advocate for patients. Generally, advocacy in patients' organisations aims to facilitate the relationship between individuals and their healthcare. This can take many forms, depending on the capabilities of the organisation and country specific requirements.

For any particular disease (or disease area), advocacy could include:

- creating greater awareness of the condition
- bringing about a considerable behavioural change regarding health issues
- offering advice about insurance or reimbursement
- providing a reliable education source.

You can also use others to initiate advocacy for a disease area. For example, you could encourage people working in the health sector, community leaders, government and other national or influential people (e.g. a national sports person or entrepreneur) to become your advocates. They can disseminate disease area messages, such as earlier diagnosis, early initiation of treatment, or better access to healthcare.

In addition, you can use different advocacy approaches, such as holding an event for the media at a local level, or organising a roundtable discussion at a national level. These events will raise awareness of the disease among a variety of groups, such as government organisations, healthcare workers and the general public.

## Fundraising

Fundraising can be hard work and frustrating, but also very rewarding. It requires effective **project planning** and **management** and **communication**, plus creativity and good business practices.

Fundraising is about asking donors to **contribute financially** to help achieve your organisation's mission. There are a variety of funding sources and a many ways in which organisations can raise funds. These vary between organisations depending upon their needs and regulations.

### Contribute financially

Donors may contribute financially to a patients' organisation through a donation, gift, bequest, contribution, grant, subsidy, sponsorship or endowment.

#### Potential funding sources

Government
Foundations and donor agencies
Pharmaceutical companies/Industry
Religious institutions and community groups
Individual donations/Public support for an event

#### Types of fundraising

Grant seeking
Major gifts and legacies
Annual appeals or specific campaigns (using direct mailings or emailing, telemarketing, door-to-door or street canvassing)
Special events or fundraisers (e.g. raffles, dinners, auctions, sponsored events, sport tournaments, car washes)
Membership services (such as publications)

When you approach a potential donor, be clear about whether you are applying for **unrestricted funding** or **sponsorship for a specific activity**. Always thank donors, but ask for permission before publicising any financial contributions.

### Unrestricted funding

Unrestricted funding is where the donor provides money that your organisation can use for any of its activities.

### Sponsorship for a specific activity

A donor can sponsor a specific activity by providing funding for a one-off project that is agreed in advance.

Refer to **Other tools and resources** for further information on fundraising.

## Communication

Good communication underpins all other tasks. It requires careful planning and expertise. Your communication plan should support your organisation's overall strategic objectives and activities. To begin, define your **communication objectives** and decide what your **key messages** will be. The plan should also identify potential partners who can help with your communications, and outline priorities, responsibilities and timelines.

### Communication objectives

Communication objectives are the specific outcomes you would like your communications to achieve (e.g. to increase awareness of a specific disease to the general public through targeting the media).

### Key messages

Key messages are core messages that you want your target audiences to hear and remember. They should be:

- short, concise and active (one memorable sentence, avoiding jargon and acronyms)
- credible and believable (backed up by evidence)
- positive (stating what you can do, not what you can't)
- distinctive (offering clear competitive awareness)
- specific (addressing a particular challenge/issue and audience)
- consistent (with your organisation's strategy).

Ideally you should test your key messages with an appropriate external audience.

An example of a key communication message is: 'The European Parkinson's Disease Association is the advocate for the rights and needs of 1.2 million people with Parkinson's and their families in Europe'.

It is vital that you communicate effectively and consistently to your:

- internal audiences (e.g. staff, volunteers, members, board members)
- external audiences (e.g. existing and potential partners, the public, political players and the media).

For each communication activity, you should be clear about:

- **what you want to say**
- **who you want to say it to**
- how you want to say it (i.e. **the most appropriate channel and format**)
- **how you will measure the effectiveness of the communication.**

### What you want to say

You should identify consistent key messages, and define your standard terminology (e.g. the European Parkinson's Disease Association use the term *people with Parkinson's*, not *Parkinson's Disease patients*), and use these messages and terms across all of your communications.

### Who you want to say it to

Define your audience for each communication activity, and adapt your language for them (e.g. use non-scientific language for patients).

### The most appropriate channel and format

For each communication, identify the most appropriate channel and format. For example, by letter, email, poster, the media (newspapers, magazines, radio, TV), telephone call, a personal presentation, social networking sites (Facebook, Twitter). You should adapt the style of the writing to suit the chosen format (e.g. briefer and more visual for the internet).

### **How you will measure the effectiveness of the communication**

Define how you will measure the effectiveness of each communication. For example, you could test draft materials with groups of people who will receive the communications (e.g. doctors, patients), ask for feedback and measure success.

### **Useful documents**

[Press release template \[Word document\]](#)

[Press release example: IAPO 2004 \[PDF\]](#)

## Press release template

<Insert your logo>

### PRESS RELEASE

Use either **FOR IMMEDIATE RELEASE** or **EMBARGO UNTIL** <Insert date and time>

### Headline

<Insert headline>

Be creative and keep it to one sentence. Remember you are trying to grab the attention of the media.

### Paragraph 1

<Insert physical location (country, state, city), day, month, year>

Begin with a strong introductory paragraph that captures the reader's attention and contains the information most relevant to your message. Keep all information factual.

This paragraph should summarise the news story and tell your entire message. It should also have a 'hook' to get your audience interested in reading more. If possible these should include Who, What, When, Where, and Why.

### <Paragraphs 2, 3, 4...>

This is the body of the press release and should be more than one paragraph. Following on from the information in your first paragraph, use these paragraphs to provide more detailed information. If possible include quotes from key staff, or disease area experts/opinion leaders – but get their permission to use them before you issue the release.

The final paragraph should restate the key points of your release. Ideally any press release should not exceed 500 words in total.

### Additional 1

Provide background information about your organisation, if appropriate.

### Additional 2

Include a contact for more information about the press release (include the contact's name, title, email, telephone, website). Make sure the person is able answer questions about the release.

End with either of the characters immediately below

#### or \*\*\*\*



International Alliance of  
Patients' Organizations

A global voice for patients

# Working with partners and stakeholders

Patients' organisation toolkit

## Section 5 'How to...' guides



Funded by Novo Nordisk  
International Operations

## 'How to...' guides

This section provides practical advice on core skills and activities for working with partners and stakeholders.

Core skills and activities covered in this section are:

- **Planning projects**
- **Managing projects**
- **Running meetings**
- **Preparing and giving presentations.**

Tools and templates are also provided to support you in these activities.

## Planning projects

Projects require careful planning to ensure that they run smoothly and are successful. A well planned project is much more likely to achieve the desired goals on time and on budget than a poorly planned project.

When planning a project it is important to:

- set clear project objectives
- agree a project budget and identify a funding source
- identify all stakeholders and parties who need to be involved
- agree the end product or outcome (e.g. a conference or educational materials)
- identify tasks and allocate responsibilities – including the responsibility of project management
- define a timeline, specifying when each task should be completed.

A project plan should be written describing all of the above. The template provided will help you to plan your project and to check that all important factors have been considered.

### Useful documents

[Project plan template \[Word document\]](#)

## Project plan template

<Insert project name>

---

<Insert version number and creation date, author, organisation>

### 1. Background

<Summarise the background to the project, including the need for it, why it is important, and any relevant previous work.>

### 2. Aims and objectives

<Define the aims and objectives of the project.>

### 3. Approach

<Describe the approach that will be taken to achieve the objectives defined above. This could include the strategy and/or methodology, any important issues, the agreed scope and critical success factors.>

### 4. Project outputs

<List the items that need to be delivered at the end of the project.>

### 5. Project outcomes

<Describe the desired outcomes from the project.>

### 6. Stakeholders

<List the stakeholders, including what their interest is, and how important they are to the project's success.>

### 7. Issues identification

<Identify any potential issues that might affect the project's success. Describe how they will be prevented or managed if they occur.>

### 8. Project team

<List all members of the project team, including their contact details. Describe the roles and responsibilities of each member in relation to the project. Assign tasks to each team member. An example of a project to develop educational materials is given overleaf.>

<b>Name and title</b>	<b>Role in project</b>	<b>Contact details</b>	<b>Key responsibilities</b>	<b>Tasks</b>
<i>Name 1</i>	<i>Project manager</i>	<i>Telephone number and email address</i>	<i>Main point of contact for the team. Responsible for managing the project, keeping it within the scope, budget and timeframe</i>	<i>Write and circulate project plan. Organise project meetings</i>
<i>Name 2</i>	<i>Editorial manager</i>	<i>Telephone number and email address</i>	<i>Responsible for the content of all educational materials produced in connection with the project</i>	<i>Review all educational materials</i>

## 9. Budget

*<Give the budget for the project, attaching any costing sheets as an appendix to this document.>*

## 10. Funding source

*<List the funding source(s) for the project.>*

## 11. Timelines

*<Describe the timelines for the project, detailing the start and end date, and the person assigned to each task. An example project plan for developing some educational materials is given overleaf.>*

Task:	Responsible person (insert initials)	Month											
		1	2	3	4	5	6	7	8	9	10	11	12
<i>Project initiation</i>		X											
<i>Research</i>		X	X	X									
<i>Development of first draft</i>					X	X							
<i>Review of first draft</i>							X						
<i>Development of second draft</i>								X					
<i>Review of second draft</i>									X				
<i>Development of final version</i>										X			
<i>Final approval for print</i>											X		
<i>Print</i>												X	
<i>Distribution</i>													X

## Managing projects

A project must be carefully managed to ensure that:

- the agreed project plan is followed (see [Planning projects](#))
- timelines and budgets are adhered to
- required tasks are completed
- issues are identified early and appropriate action is taken, e.g. changing timelines or reassigning tasks.

Manage projects by:

- holding regular meetings to discuss the progress of the project and any issues
- maintaining good communication within the project team
- checking the progress of the project against the agreed project plan
- adapting the project plan to avoid problems or resolve issues
- having an organised project documentation system, e.g. filing meeting minutes and the project plan.

## Useful documents

[Step-by-step guide to project management \[PDF\]](#)

## Step-by-step guide to project management

### 1. Define the scope, objectives and deliverables

Clearly define the scope, objectives and deliverables of the project. It may take several drafts before all of the stakeholders agree what these are.

### 2. Prepare a comprehensive written plan

A thorough plan describes the various tasks and activities and the order they'll be undertaken, who is responsible for each task, how long each will take, and when they'll start and finish. It also includes the project deliverables, timeline and budget.

The plan will need to be updated regularly, as issues are identified and appropriate action(s) taken.

### 3. Maintain good communication with the team

Good communication is vital for successful project management. It ensures that the whole team knows the status of the project, they understand what they should be working on, and it also helps to get their support.

Hold regular meetings with the team to discuss the project's progress and any issues that arise.

### 4. Measure project performance

Regularly check the progress of the tasks and activities against the project plan.

- Is the project still within the defined scope?
- Is the project's timeline being met?
- Is the project within budget?

If the answer to any of these questions is 'no', the plan may need to be adapted, and the team members and the stakeholders should be informed.

### 5. Complete the project

### 6. Review, and follow-up

Hold a formal project closing meeting. This meeting will indicate the completion of the project, and review its successes and failures. Identify what worked well and what could be improved – and follow-up on these findings. Thank the team for their work.

## Running meetings

Meetings are usually conducted **face-to-face** or by **teleconference**. Occasionally, **video** or **web** conferencing services may be used.

### Face-to-face

At face-to-face meetings all participants meet in person at an agreed location. Face-to-face meetings are usually reserved for large important meetings, e.g. meetings with new partners to discuss a potential collaboration.

The benefits of face-to-face meetings:

- it is much easier to communicate with people face-to-face than, for example, by telephone
- they are often more productive and easier to chair (or manage).

The disadvantages of face-to-face meetings:

- they are more difficult to organise
- they are more time consuming due to travelling time
- they are more expensive due to costs such as travel expenses, room hire and refreshments.

### Teleconference

Teleconference meetings are conducted over the telephone. If participants are based in more than two locations, a conferencing service will be needed that allows three or more people or groups to connect to the call. Industry partners usually have a conferencing service – if you are having a teleconference with a company, ask them to provide the telephone number and dial-in details. Teleconferences are often used for project update meetings.

The benefits of teleconferences:

- they are cheaper and logistically easier to run than face-to-face meetings
- they are easy to use
- participants can join the meeting from all over the world.

The disadvantages of teleconferences:

- they are more difficult to chair than face-to-face meetings and discussion may be more stilted
- they require a conferencing service.

### Video conference

Video conference meetings are very similar to teleconferences. However, in addition to communicating with participants on the telephone, you can also see them on a television or computer screen.

The benefits of video conferences:

- they are cheaper and logistically easier to run than face-to-face meetings
- participants can join the meeting from all over the world.

The disadvantages of video conferences:

- they are more difficult to chair than face-to-face meetings and discussion may be more stilted
- they require internet connection and a specialist conferencing service.

### Web conference

Web conferences are meetings that are conducted over the internet, allowing all participants to view a specific document, such as a PowerPoint slide presentation.

The benefits of web conferences:

- they are cheaper and logistically easier to run than face-to-face meetings
- participants can join the meeting from all over the world
- you can share and present documents.

The disadvantages of web conferences:

- they are more difficult to chair than face-to-face meetings and discussion may be more stilted
- they require an internet connection and a specialist conferencing service.

Whatever the format of the meeting, it needs to be carefully organised to ensure that:

- all important issues are discussed and the meeting objectives are achieved
- all participants have the opportunity to speak
- conclusions are agreed
- tasks are assigned.

When organising a meeting, one person should be appointed to lead the meeting. This person is called 'the chair'.

Invitations stating the purpose, time and type of meeting should be sent prior to the meeting. This should be followed up with a copy of the meeting agenda. After the meeting, thank-you letters should be issued to all participants, along with a copy of the meeting minutes. Use [Meeting invitation \[PDF\]](#), [Agenda template \[Word document\]](#), [Meeting thank you letter \[PDF\]](#) and [Meeting minutes template \[Word document\]](#) to help with these tasks.

### Useful documents

[Step-by-step guide to planning and running a meeting \[PDF\]](#)

## Meeting invitation

[letter only]

< Insert participant's address >

Dear <insert participant's title and name>

I would like to invite you to a meeting/teleconference <delete as appropriate> to discuss <describe purpose of meeting>.

[For a face-to-face meeting:]

The meeting will take place on <insert date>, starting at <insert time> and finishing at <insert time>. It will be held at <insert location and address>. Please can you confirm whether you will be able to attend the meeting by <insert date>.

[For a teleconference:]

The teleconference will take place on <insert date>, starting at <insert time> and finishing at <insert time>. Please dial <insert number and dial in details> to join the call. It would be very helpful if you could confirm whether you are able to participate in the teleconference by <insert date>.

I have enclosed <insert number> additional documents which provide some background information on <insert details>. An agenda will also be sent to you shortly.

I look forward to hearing from you.

Kind regards

<Insert name>

<Insert contact details>

<Insert position/title in organisation>

If the invite is being sent by email, write the meeting's name in the subject title.

The first paragraph states the main purpose of the meeting.

Give the time and date of the meeting. If it's a face-to-face meeting, include the location, providing directions and a map if necessary.

For a teleconference, you need to provide the telephone number to phone, and any dial in details. If participants are joining from different countries, give the time local to their country.

Describe any documents they will receive (e.g. meeting agenda, introductory information), and/or any preparation they should do prior to the meeting. It may also be useful to let them know who the other participants will be.

## Agenda template

<Insert meeting name>

---

<Insert date and time of meeting>

### Purpose of meeting

<Insert purpose and main objectives of meeting>

Number	Item/Topic	Owner	Duration

## Meeting thank you letter

[letter only]  
<Insert participant's address>

Dear <insert participant's title and name>

On behalf of <insert your organisation's name>, I would like to thank you for your participation in the meeting on <insert date>, which discussed <insert topic of meeting>.

<Insert specific meeting details>

I hope you'll agree that the meeting was very productive and I thank you once again for contributing to such a successful meeting.

Kind regards

<Insert name>  
<Insert position/title in organisation>  
<Insert contact details>

The first paragraph states the purpose of the thank-you letter.

You could give more information about the meeting in the next section, such as the meeting's key outcomes. This section could also describe the next actions and anything you wish to follow-up on.

Finish the letter by summarising the general nature of the letter.

Make sure the letter or email sounds sincere, so that it does not seem like it's been written from a template. It should have a formal but pleasant tone.

[This document is part of the IAPO toolkit 'Working with partners and stakeholders', which can be accessed from the IAPO website.]

## Meeting minutes template

**<Insert meeting name>**

---

*<Insert date and time of meeting>*

### **Purpose of meeting**

*<Insert purpose and main objectives of meeting>*

### **Attendees**

*<Insert attendees and apologies>*

Agenda item	Key discussion points	Action items	Owner and target date

### **Date and time of the next meeting**

*<Insert date and time of the next meeting>*

### **Agenda items to cover**

*<Insert any items that need to be discussed at the next meeting>*

## Step-by-step guide to planning and running a meeting

### 1. Define the purpose of the meeting

Every meeting should have a clearly defined objective or purpose. The best way to consider this is to ask: “At the end of the meeting, I want to know/achieve...”

### 2. Decide on the type of meeting, date and time, and invite participants

First, decide on the best format for the meeting, e.g. teleconference or face-to-face. This will usually depend on what you want to achieve.

Before setting the date and time for the meeting, get an idea of what's best for the participants. Providing some suggested dates/times is likely to get a better response than asking for suggestions. Once decided, send out a formal invitation with the date, time, telephone/dial-in number or venue, together with the purpose of the meeting.

### 3. Develop an agenda for the meeting

Send an agenda to all the participants 2–3 days in advance of the meeting. This document is crucial to the success of the meeting as it clarifies the objectives, lists each item and how long should be spent on each, and provides direction during the meeting.

Put the most important issues at the top of the agenda so that these are covered first, and remember to add breaks into long meetings, providing refreshments if necessary.

### 4. Run the meeting

Assign a person to be the chair. This person is responsible for ensuring the meeting runs to time, that all the items on the agenda are considered, and that everyone has the opportunity to share their opinion. He/she may also greet the participants and thank everyone at the end.

There should also be someone responsible for taking the meeting's minutes. These should include the next steps or 'actions', the person who will be responsible for each of them and any set deadlines. The minutes should also note any new issues that are raised, but not resolved, to cover in the next meeting.

### 5. Write the minutes and follow up on agreed actions and responsibilities

Minutes should be written and sent to all the participants, within 1–3 days of the meeting. Monitor assigned tasks/actions to ensure that they are being done.

## Preparing and giving presentations

There may be several instances where you need to prepare and give a presentation on behalf of your patients' organisation. For example:

- for a symposia or conference
- when applying for funding or sponsorship
- during a project meeting (internal or external).

Giving presentations can be intimidating, therefore it is important to give yourself plenty of time to prepare. When preparing a presentation it is important to consider the:

- audience and the level of their background knowledge
- objective of the presentation
- message or story that you want to communicate.

### Useful documents

[Top tips on preparing presentations \[PDF\]](#)

## Top tips on preparing presentations

### 1. Set your goal

- Decide what you want to happen as a result of your presentation, such as to inform or persuade the audience.
- Think about your key messages – what do you want the audience to take away with them at the end?

### 2. Consider your audience

- Use the right language for your audience, and explain any terms and acronyms.
- Think about who the audience is, what they will want to know and what they already know.

### 3. Tell a story

- Start by outlining what you are going to say, go through the story, and to finish reiterate/remind them again of the key points.

### 4. Prepare answers

- Think about what questions the audience might ask you, and prepare your answers in advance.

### 5. Use slides wisely and only when necessary

- If you use slides at all, use them to highlight and emphasise key points. They should not be used to write large amounts of information and you should not read the content word for word.
- Remember, the audience should be listening to you not just reading the slides.

### 6. Think about how to keep your audience engaged and interested

- Making eye contact with your audience and varying the tone of your voice will help to keep your audience engaged.
- Consider how you can interact with you audience. For example, if you feel comfortable, you could get the audience involved by asking questions.

### 7. Practice the delivery

- Practising the presentation will help you to gain confidence and be more relaxed on the day.
- You can also check that it's the right length of time and get used to hearing your own voice.

### 8. Arrive in good time

- Arrive in good time and familiarise yourself with the room and the audio-visual equipment.

## Other tools and resources

There is lots of additional useful information on the internet, including guidance and tools. Umbrella organisations are also a useful source of information. Here we provide a selection of links to some of these websites and tools.

### Umbrella organisation websites

[Europeans Patients' Forum](#)  
[International Alliance of Patients' Organizations](#)  
[International Diabetes Federation](#)  
[World Federation of Hemophilia](#)

### Pharmaceutical codes of conduct

Examples of regional and national codes of conduct that govern how pharmaceutical companies can work with patients' organisations:

[ABPI \[PDF\] \(UK\)](#)  
[EFPIA \[PDF\] \(Europe\)](#)  
[National codes of practice on relationships between the pharmaceutical industry and patients' organisations](#)

### Patients' organisation basics

[Multiple Sclerosis International Federation: How to develop a National MS Society \[PDF\]](#)

### Collaborations and partnerships

[Leeds Health Action Zone: Partnership self-assessment toolkit \[PDF\]](#)

### Working with pharmaceutical companies

[Consumers Health Forum of Australia/Medicines Australia: Working together, the guide \[PDF\]](#)  
[European Parkinson's Disease Association Toolkit: Working with the industry \[PDF\]](#)  
[EPF: Framework for cooperation \[PDF\]](#)  
[IAPO: Corporate Partnerships Programme](#)  
[IAPO Healthcare Industry Partners Booklet \[PDF\]](#)  
[IAPO: Register of Codes of Conduct](#)  
[WFH: Corporate relations guiding principles \[PDF\]](#)

### Strategic planning

[CIVICUS: Communication and Planning Toolkits](#)  
[Free Management Library](#)  
[IAPO Policy Framework \[PDF\]](#)

### Advocacy and raising disease awareness

[IAPO: Outside of the European Parliament: who and how of policy making by outside groups \[PDF\]](#)  
[IAPO: Worldwide examples of successful advocacy \[PDF\]](#)  
[Multiple Sclerosis International Federation - How to Influence Public Policy \[PDF\]](#)  
[NCVO: Tips on good practice in campaigning \[PDF\]](#)  
[University of Aberdeen: Producing information about health and health care interventions \[PDF\]](#)

## **Fundraising**

British Heart Foundation: Do it for us [PDF]

CIVICUS: Communication and planning toolkits

European Parkinson's Disease Association Toolkit: Fundraising [PDF]

Idealist: How can I find sponsors for an event?

World Federation of Hemophilia: Fundraising [PDF]

## **Communication**

Business Link: PR the basics

CIVICUS: Communication and planning toolkits

European Parkinson's Disease Association Toolkit: Working with the media [PDF]

IAPO: Press release checklist [PDF]

MediaTrust: Communication: your survival toolkit [PDF]

NIH NCI: Making health communication programs work [PDF]

The Plain English Campaign: Tips for clear websites [PDF]

## How to use the toolkit

This toolkit '*Working With Partners And Stakeholders*' has been specifically developed for patients' organisations to help you understand why it is important to build and strengthen your partnerships and collaborations with stakeholders, including the pharmaceutical industry. It has been designed to address issues faced by all types of patients' organisations, whether large and managed by paid staff members, or small and run by a few patient volunteers.

The toolkit provides:

- general information and examples
- advice
- **Case studies**
- '**How to...**' guides, covering key organisational activities
- tools and templates that can be adapted by patients' organisations for local use.

The **Site map** lists all of the pages within the toolkit.

The resource is modular in design allowing for complete flexibility in the way that you use it.

You can use the resource in various ways, for example:

- as an individual or organisational training resource, defining stakeholders and providing background information on how to develop partnerships
- as an organisational planning and implementation tool, providing a framework and templates for local adaptation
- as a quick reference tool for specific issues relating to stakeholder partnerships and collaborations.

## Navigating around the toolkit

The navigation bar at the top of the page shows the main topics covered in the toolkit – click a button to view the topic of interest. To view the sub-sections within that topic click the links in the menu on the left-hand side of the page. Click the 'Back to...' link in the bottom right-hand corner of the sub-section page to view the main section page for that topic.

Some sections have pop-up boxes that are revealed by clicking on the purple-coloured text.

To print the screen text and associated pop-up boxes, click the 'Print-friendly text' link at the bottom left-hand side of the page. This will open a PDF of the current page (including any pop-up boxes) that you can print.

In addition, underlined text is linked to a different section of the toolkit, a document or website.

Use the **Other tools and resources** section to find links to information and guidance on specific topics from other organisations.

Download any of the documents or templates and print off as many copies as you need. Use and adapt them in ways that work best for you and your organisation.

If you are having difficulties finding the page you need, try the **Site map**. This lists and links to all of the pages within the toolkit.

## Acknowledgements

IAPO helped to develop this toolkit. Its board members and staff reviewed the designs, core content and download documents, advised on toolkit's contents list, and provided patients' organisations' case studies. We would like to thank the following IAPO board members and staff for their contribution to this toolkit.

Jolanta Bilińska, IAPO Board Member and President of the Patient Safety Foundation (Poland)

Joanna Groves, IAPO Chief Executive Officer

Hussain Jafri, IAPO Chair and Secretary General of the Council for Alzheimer's Pakistan

Regina M.N. Kamoga, IAPO Board Member and Country Manager of the Community Health and Information Network (Uganda)

Jeremiah Mwangi, IAPO Policy and External Affairs Director

Eva Maria Ruiz de Castilla, IAPO Board Member and Executive Director of Esperantra (Peru)

Caroline Staffell, IAPO Senior Membership Officer

Kin-Ping Tsang, IAPO Secretary and Chairman of the Alliance for Patients' Mutual Help Organizations (Hong Kong)

Durhane Wong-Rieger, IAPO Chair Elect and Head of the Consumer Advocare Network (Canada)