Budget and planning for a newly established patient organisation

(Please note that there may be other authorities you need to consider in your area/country)

This toolkit is designed to help newly established patient organisations understand and manage risk as they grow. Below are key areas to consider, including legal structure, insurance types, and practical steps to protect your members, board, volunteers, and activities.

1. Start-up costs

- **Legal registration:**
  Registration as a non-profit organisation (depending on the country, this may be national, state or local).
- **Insurance:**
  Liability insurance, board and executive liability insurance (D&O).
- **Legal advice:**
  Help with articles of association, GDPR/compliance, tax status (e.g. 501(c)(3) in the US, registration as a charity in the UK, etc.).
- **Bank account:**
  Set up a bank account in the name of the organisation (often requires articles of association and minutes).

1.1 Legal registration

What does this mean?

Registering your patient organisation as a **non-profit** (charitable or public benefit organisation) in the country where you are based. This makes you **formally recognised** and gives you access to:

- A bank account in the name of your organisation
- Apply for funding and donations legally
- Sign contracts, e.g. cooperation agreements
- Protect your name and work

How do you do it?

It depends on the country, but here are some general guidelines:

Country	Authority / Registration Portal	What You Need to Register
USA	IRS + State Authorities	Bylaws, registration form, official address, Employer ID Number (EIN)
UK	Charity Commission (for charities) or Companies House	Governing document, list of trustees, bank account
Germany	Vereinsregister (via local district court)	Bylaws, founding meeting minutes, board member information
France	Préfecture (local authority)	Statutes, board member details, CERFA registration form
Finland	PRH (Finnish Patent and Registration Office)	Rules (säännöt), application form, minutes from founding meeting
Sweden	Skatteverket (Tax Agency – registration optional)	Organization rules, minutes from general meeting
Denmark	(For reference) Not legally required, but can register via virk.dk	Bylaws, founding document, board member details

Tip: *If you are in doubt, search for - register a nonprofit organisation in [your country]*

When should we do it?

As soon as possible when you:

- o Have chosen a name and purpose
- o Have at least 2–3 people ready to form a board
- o Want to be able to receive support or open a bank account

What do you need to register?

Typically, you will need to have the following ready:

1. Name of the organisation
2. Purpose and articles of association/statutes (describe why you exist and how you make decisions)
3. List of board members
4. Founding protocol or meeting minutes
5. Address and contact person, if applicable

Where can I get help?

Local volunteer councils, NGO networks or pro bono law firms

1.2. Insurance

Is it necessary? It depends on what activities you do and where you are registered – but it is often strongly recommended, especially if you have a board, hold physical events or work with volunteers.

Types of insurance to consider;

Type - When it's relevant - What it covers

- D&O Insurance (Directors & Officers) When you have a board Personal liability if the board makes mistakes
- Liability insurance (General liability) If you hold meetings, events or have an office If someone is injured or you cause damage
- Volunteer insurance If you use volunteers Covers if volunteers are injured while performing tasks

Type	When It's Relevant	What It Covers
D&O Insurance (Directors & Officers)	When you have a board of directors	Personal liability of board members in case of decisions or mistakes made in good faith
General Liability Insurance	When you hold physical events or have office space	Injuries to participants or damage to property during your activities
Volunteer Insurance	When volunteers help with your projects	Covers accidents or injuries that may happen to volunteers while helping the organisation
Professional Liability Insurance *(optional)*	When giving advice, training, or public information	Covers legal claims resulting from advice, educational content, or guidance shared

Tips for Choosing Insurance

- Start with the minimum needed to cover your main risks – you can expand later.
- Look for insurers who specialise in non-profits or offer discounted NGO rates.
- Some umbrella organisations or national NGO networks offer group policies at lower cost.
- In some countries, grant funders or donors may require proof of insurance before approving support.

Liability Insurance (General Liability Insurance)

What is it?

Liability insurance protects your organisation if someone is injured or something is damaged during one of your activities or events. It covers the legal and financial consequences**,** such as medical bills or compensation claims.

Typical coverage includes:

Scenario	Example
Bodily injury	A participant trips and falls at one of your in-person workshops and needs medical attention.
Property damage	You accidentally damage rented equipment or a venue during an event.
Legal fees	Someone makes a claim against your organisation, and you need legal representation.

It does **not** usually cover:

- Injuries to your own staff (requires separate employee insurance)
- Board members' decisions (covered under D&O insurance)
- Errors in professional advice (see professional liability)

When Do You Need It?

You should seriously consider liability insurance if:

- You host in-person events, workshops, support groups, or meetings
- You rent venues, even temporarily (some landlords require it)
- You work directly with the public, volunteers, or vulnerable groups

Even a small gathering in a public library or town hall may involve risks.

Tips

- Ask your **venue** if they already have liability insurance – it may cover you partially.
- Check if your **umbrella organisation** or national NGO platform offers group insurance deals.
- If you're only running online events, liability risks are very low – you may not need this yet.

Volunteer Insurance

What is it?
Volunteer insurance protects your organisation and the individuals who volunteer for you in case of **accidents, injuries, or damages** that happen **while they are performing volunteer tasks**. It helps cover medical costs, legal claims, or damage to personal belongings — without making the volunteer personally liable.

What Does It Cover?

Covered Risks	Examples
Accidental injury to volunteer	A volunteer falls while setting up chairs at an event and sprains their ankle.
Damage to a volunteer's belongings	A volunteer's laptop is damaged while supporting an online activity.
Accidental harm to others caused by a volunteer	A volunteer unintentionally causes someone else to trip and get injured.
Legal costs	If a volunteer is involved in an incident that leads to a legal claim.

Important: It usually does not cover deliberate misconduct or actions outside of the volunteer's assigned tasks.

When Do You Need It?

You should consider volunteer insurance if:

- You regularly work with **volunteers at in-person events**, meetings, or community activities.
- You **rely on volunteers** for support tasks (e.g. fundraising, admin help, patient support).
- You want to **protect your organisation from liability** linked to volunteers' actions.

Even if your volunteers are only helping occasionally, insurance sends a message that you take **safety and responsibility** seriously.

Tips

- Keep a list of **active volunteers** and the types of tasks they perform.
- Provide a short **volunteer agreement or code of conduct**, so roles and expectations are clear.
- Check if your **general liability insurance** includes any volunteer coverage – some do, some don't.
- In some countries, **public volunteer support programs** include free insurance (e.g. Germany, the UK in some regions).

1.3 Legal Advice

Risk Management Toolkit for New Patient Organisations. This toolkit is designed to help newly established patient organisations understand and manage risk as they grow. Below are key areas to consider, including legal structure.

Why it's important

Getting legal advice early helps ensure your organisation is set up correctly and avoids problems later. It's especially useful when creating your **articles of association** (also known as bylaws or statutes), understanding **data protection laws** (like GDPR in the EU), and making sure your **tax status** is correct. Getting legal advice early helps ensure your organisation is structured correctly and avoids serious complications later.

Legal Setup and Registration

Why it's important: Registering your organisation formally gives you legal status, access to bank accounts, funding opportunities, and increased credibility.

What you need (varies by country):

- Articles of association or bylaws
- A founding meeting with minutes
- A board of directors (minimum 3 members recommended)
- Registration with a national or regional authority (e.g., Charity Commission in the UK, IRS in the US, PRH in Finland)

Examples by region:

- **USA:** You may need help applying for **501(c)(3)** status to gain tax exemption and eligibility for foundation grants.
- **UK:** Registering as a **charity** with the Charity Commission allows you to benefit from Gift Aid and access special funding.
- **EU countries:** Legal guidance helps ensure compliance with **GDPR** if you manage personal data, such as member lists or health information.
- **Global:** Understanding cross-border collaboration agreements or international funding requirements may also require legal support.

Tip:

You don't always need a lawyer. Some countries offer **free or low-cost legal help** for non-profits, or you can use trusted templates and guides from NGO networks.

1.4 Bank Account

Why it's important:

Opening a bank account in your organisation's name allows you to receive donations, pay expenses, and keep finances separate from personal accounts – which is crucial for transparency and trust.

What you usually need to open one:

- Your **articles of association** or bylaws
- A copy of the **minutes** from your founding meeting
- Proof of registration (if applicable in your country)
- Names and IDs of authorised signatories (often board members)

Opening a bank account in your organisation's name is essential for managing money transparently. It allows you to:

- Receive donations and grants
- Pay bills and reimbursements
- Keep finances completely separate from personal or board member accounts
- Build trust with donors, partners, and auditors

Without a dedicated account, managing finances becomes confusing and risky – especially when reporting to members, funders, or tax authorities.

Other possible requirements:

- A physical address (not a P.O. box)
- A taxpayer or registration number (depending on your country)
- In some countries, a minimum number of board members may be required to act as co-signers

Tip:

Choose a bank that understands non-profits and offers features like ***low fees***, ***online access***, *and* ***multiple signatories***. *Some countries require a* ***minimum number of board members*** *to open an account.* Some banks also offer advice, starter packages, or donation tools tailored for new organisations.

2. Operations and Administration

- **Website and domain:** Purchase of domain name, hosting fees, basic website development.
- **Accounting tools:** Simple accounting software (e.g., Wave, QuickBooks for Nonprofits, Xero).
- **Communications:** Newsletter tools (e.g., Mailchimp), social media presence, branding materials.
- **Office supplies:** Basic materials for administration and communications (printer, paper, IT equipment).
- **Membership management:** CRM system for managing member information and renewals.

2.1 Website, Domain & Social Media

Your online presence helps people find, trust, and engage with your organisation. Even in the early stages, a simple website and active social media profiles give your group credibility and make it easier to grow your community.

A website gives your organisation **credibility**, makes it easier for people to **find and trust you**, and helps you **share your story, mission, and events**. It's also useful for collecting donations, signing up members, or sharing resources.

What you need:

- A **domain name** (e.g. yourorganisation.org) – usually costs around **10–20 EUR/USD per year**
- A **hosting service** – where your website's content is stored (from free plans to about **10–30 EUR/USD per month**)
- A basic **website builder** or developer – you can use simple platforms like:
    - Wix.com (very user-friendly)
    - WordPress.com (flexible and popular)
    - Squarespace.com (clean design, all-in-one)
    - Carrd.co or Notion (good for simple one-pagers)

Tip:
You don't need to hire a developer to start. Most platforms offer ready-to-use templates. Focus first on a **clear homepage** with:

- Who you are
- What you do
- How people can join, donate or contact you

2.2 Accounting tools

Accounting tools for patient associations and non-profit organisations

Using a simple and reliable accounting tool helps you keep track of your finances, ensure transparency and make it easier to report to your board, members and donors.

It reduces the risk of errors, saves time and strengthens trust in your organisation.

Popular tools:

1. **Wave** *(free and user-friendly)*
   - Good for small organisations.
   - Offers bookkeeping, invoicing and reports.
   - Has features for bank account integration and expense tracking.
2. **QuickBooks for Nonprofits**
   - Professional accounting software for NGOs.
   - Allows you to track donations, projects and volunteer work.
   - Good for both small and larger associations, but requires a licence fee.
3. **Xero**
   - Cloud-based and easy to use.
   - Suitable for associations with an international focus or a need for multi-currency handling.
   - Includes dashboards, automatic bank feeds and integration with payment systems and CRM, for example.

What to look for:

- Ability to create budgets and follow up on project finances.
- Support for multiple users (e.g. accountant, treasurer and chairperson).
- Easy access to reports and annual accounts.

- Integration with banks and, if applicable, membership or donation systems.

Tips:

Consider getting help from a volunteer with accounting experience to choose the right tool and set it up.

Make sure to save all receipts digitally and take regular backups.

2.3 Communications

Communication for patient associations and non-profit organisations

Effective communication is crucial for informing members, engaging new supporters, raising awareness of your cause and building credibility with partners and sponsors. A well-thought-out communication strategy strengthens both community and influence.

Newsletters and email systems

Tools

Mailchimp, Brevo (formerly Sendinblue), TinyLetter, MailerLite

Advantages

- Enables you to send professional-looking newsletters.
- Segmentation: Tailor content to different target groups (e.g. members, donors, press).
- Automatic sign-up via your website.
- Statistics: See who opens, clicks and engages.

Use

Share news, events, project updates and invitations. Use fixed templates for recognisability and to save time.

Social

Platforms

Facebook, LinkedIn, Instagram, X (Twitter), YouTube

Advantages

- Reach new and existing followers quickly.
- Creates visibility for your activities and messages.
- User-friendly and (usually) free.

Tips

- Make a fixed plan with posts, e.g. 1-2 times a week.
- Use images, videos and quotes from members or activities.
- Also share other people's content, e.g. posts from partners, relevant news or campaigns.

Branding materials and visual identity

Examples

- Logo, colour palette, fonts, PowerPoint templates, flyers and banners.
- Graphic elements for use on your website and social media.

Purpose

Create recognition and a professional appearance. Make it easy for volunteers and partners to communicate on your behalf.

Tips

*Create a mini brand guide with your colours and logo rules. Use free tools such as **Canva** to design posts, presentations and brochures. Reuse templates to save time and ensure consistency.*

2.4 Office supplies – Office supplies and administrative equipment

Although many associations work digitally and from home offices, there is still a need for basic office supplies and equipment to handle daily administration, communication and documentation efficiently and professionally.

Examples of necessary materials and equipment:

- **Printers and printer cartridges** – for printing contracts, minutes, flyers, etc.
- **Paper, folders and plastic sleeves** – for physical filing and meeting materials.
- **IT equipment** – e.g. laptop, headset, webcam, external hard drive.
- **Writing materials and whiteboard** – for meetings and planning.
- **A stable internet subscription** – especially important when holding online meetings and webinars.

Tips:

Look for offers or non-profit discounts from IT and office suppliers.Consider joint purchases with other associations. Remember to budget for ongoing expenses such as ink, paper and minor repairs.

2.5 Membership management – Member management and CRM systems

A good member management system helps you keep track of members, payments, communication and engagement. It strengthens both relationships and administrative efficiency – and is a prerequisite for growth and transparency.

What a CRM system can be used for:

- Register member information (name, contact details, interests, payments).
- Send automatic reminders about membership renewals.
- Segment members (e.g. active, passive, volunteers).
- Keep track of participation in events and projects.
- Generate reports for the board, accounts and grant applications.

Popular CRM solutions for small/medium-sized associations:

- **SumUp Team & Memberships**, **Wild Apricot**, **Hello Club**, **CiviCRM**, **TidyHQ**, **Mailchimp Audience + Tags** (for very small networks).
- Several of these can be integrated with your website and email tools.

Tips

Choose a solution that suits your needs and technical level. Consider whether the system should also be able to handle donations and newsletters. Make sure you are familiar with the **GDPR** when processing personal data – e.g. consent, access restriction and deletion.

Both office supplies and member management are fundamental to running an association professionally, efficiently and responsibly. These are investments that can quickly free up time and create overview, allowing you to focus on your core task: making a difference for your members and patient group.

3. Activities and Programs

- **Meetings**: Annual General Meeting (AGM), board meetings, and membership meetings.
- **Events**: Educational webinars, conferences, patient cafés, workshops.
- **Advocacy**: Participation in external advocacy activities (travel, event fees, promotional materials).

Activities and Programs

The association's activities are at the heart of your work. They create community, strengthen skills, ensure member involvement and make it possible to influence decision-makers and society. Below is a more detailed description of the three most important categories of activities

3.1 Meetings

Meetings ensure good governance, democracy and transparency in the association. They provide opportunities for decision-making, strategic direction and member involvement.

Types of meetings:

- **Annual General Meeting (AGM):**

  - A mandatory meeting held once a year, where members vote on the articles of association, accounts and elections to the board.
  - Provides an opportunity for joint reflection on the year and direction for the coming year.

- **Board meetings:**

  - ○ Regular meetings (e.g. monthly or quarterly) where decisions are made on operations, finances and activities.

- **Member meetings:**

  - ○ Meetings or networking events for members, where they can provide input on the association's work, share experiences and strengthen relationships.

Practical:

Expenses may include venue hire, catering, transport, digital meeting tools (Zoom, Teams) and minute-taking.

3.1 Events – Events and learning activities

Purpose

Events are a way to engage and strengthen members, create visibility and share knowledge – both internally and externally.

Examples of events:

- **Webinars and online courses:**

  - ○ Topics may include patient rights, health technology, self-help, research or patient involvement.

- **Conferences and theme days:**

  - ○ Physical or hybrid events with speakers, panel discussions and networking.

- **Patient cafés and networking meetings:**

  - ○ Informal meetings where patients and relatives can share experiences and get support.

- **Workshops and training:**

o Activities focusing on skills such as advocacy, communication, data literacy or participation in health research.

Practical:

The budget should take into account speaker fees, technology, platforms, marketing, materials, catering and any travel expenses.

3.3 Advocacy

Purpose

Advocacy is about creating change by influencing policy, research, healthcare and society. This is often done by making decision-makers aware of patients' needs and experiences.

Examples of activities

- Participation in **roundtable discussions, hearings, panel debates, stakeholder meetings**.
- Visibility at **political conferences**, industry events or NGO platforms.
- Production and distribution of **position papers, debate contributions or campaigns**.
- Cooperation with other associations and networks to create a common voice.

Costs may include:

- **Travel expenses, accommodation and subsistence** when participating in national and international events.
- **Event fees** or admission tickets.
- **Production of materials**, e.g. flyers, roll-ups, presentations, graphic design or merchandise.
- **Time fees** for patient representatives.

These activities and programmes create concrete value for members, strengthen the voice of patients in society and contribute to information, empowerment and change. They should be continuously evaluated and adapted to the needs and strategic goals of members.

4. Organizational Development

The strength and sustainability of associations depend to a large extent on their internal organisation, direction and capacity. The following three areas contribute to creating a robust, well-functioning and effective organisation

- **Board development:** Training on governance, patient advocacy, fundraising basics.
- **Strategic planning:** Facilitation for defining vision, mission, and 1–3 year strategic plan.
- **Working groups and committees:** Set up special interest groups, advisory councils.

4.1 Board Development – Development of the board of directors

Purpose

An active and competent board is crucial to the success of an association. This requires that members have the necessary knowledge and understanding of their roles and responsibilities.

Typical topics for training and development:

- **Good association management and governance:** Insight into statutes, areas of responsibility, impartiality and decision-making processes.
- **Patient advocacy:** Training in speaking professionally on behalf of patients, both within the healthcare system and in relation to politicians and partners.
- **Fundraising and financial sustainability:** Introduction to grant applications, sponsorships and membership-based income.
- **Team dynamics and collaboration:** Tools for effective meeting management, conflict management and strength-based collaboration.

Methods

Workshops, online courses, board seminars, e-learning and experience sharing with other associations.

4.2 Strategic Planning – Strategic planning

Purpose

Strategic planning helps you set a clear direction and prioritise resources so that your work creates the greatest possible value for your members and the cause you are working for.

The process may include

- **Vision and mission**: What is the overall goal and why does the association exist?
- **Values and principles**: What fundamental attitudes should characterise your work?
- **Goals for the next 1–3 years**: Specific goals for e.g. membership growth, projects, political influence or knowledge development.
- **Success criteria and follow-up**: How will you know if you are successful – and what will you do if you are not?

Practical:

- It may be a good idea to get outside help to facilitate the process.
- Involve members, volunteers and any partners so that the plan reflects broad ownership.
- Create a one-page overview for communication and a detailed action plan for internal use.

4.3 Working Groups and Committees

Purpose

Working groups and committees make it possible to engage more people and utilise different skills without involving the entire board in everything. This creates momentum and ownership – and makes the association less vulnerable.

Types of groups:

- **Professional interest groups**: E.g. for young patients, men with chronic diseases, relatives or specific diagnoses.
- **Thematic committees**: E.g. communication, research, equality in health, fundraising or event planning.

- Advisory councils: For example, composed of health professionals, researchers and patient representatives who provide input on strategy and content.

Advantages:

- More people become involved and take responsibility.
- The board can focus on overall strategy and decisions.

- Space is created for innovation and specialised knowledge.

Practical

- Ensure clear terms of reference: What is the purpose, the tasks and the framework?
- Provide support and recognition – and ensure regular contact with the board.
- Consider including members who have not previously been active – this strengthens inclusion and diversity.

These three elements – **board development, strategic planning and working groups** – are fundamental building blocks of a modern and sustainable patient association. They create **clarity, decisiveness and long-term commitment**, which are essential for making a real difference to patients and their relatives.

Risk Management Toolkit for New Patient Organisations

This toolkit is designed to help newly established patient organisations understand and manage risk as they grow. Below are key areas to consider, including legal structure, insurance types, and practical steps to protect your members, board, volunteers, and activities.

Key Information and Compliance to Prepare

Structure

- **Bylaws/Constitution**: Define purpose, governance structure, decision-making processes, board member terms, conflict of interest policy.
- **Board formation**:
    - At least 3–5 members recommended: Chair/President, Vice-Chair, Treasurer, Secretary, and possibly additional members.
    - Some countries require independent board members.
- **Meeting minutes**: Keep records of board meetings and general meetings (especially important for transparency and future grants).

Financial Management

- **Annual financial report**: Prepare and approve annually by the board or general assembly.
- **Audit or financial review**: Depending on country and size, may require independent review.
- **Fundraising registration**: Some countries require registration to legally solicit donations.

Data and Privacy

- **GDPR or local data protection compliance**: Manage personal data correctly, including member lists and event registration data.
- **Transparency**: Publicly share information about activities, governance, and financial status where applicable.

Things to Consider Early

- **Member recruitment strategy**: Start building a strong and engaged member base early.
- **Sustainable growth**: Focus on a few key programs instead of trying to do everything at once.
- **Partnerships**: Build alliances with hospitals, other NGOs, researchers, and professional societies.
- **Funding sources**: Diversify between memberships, grants, sponsorships, and donations.

Summary Checklist for a New Patient Organization

- ☐ Legal registration completed
- ☐ Bank account established
- ☐ Bylaws/constitution adopted
- ☐ First board of directors appointed
- ☐ Basic insurance coverage arranged
- ☐ Website and communications tools set up
- ☐ Financial management system in place
- ☐ Membership recruitment plan ready
- ☐ First general meeting or launch event planned