

EFA CAPACITY BUILDING PROGRAMME 2018 GOVERNANCE IN PATIENT ORGANISATIONS

Elena Balestra, EPF Membership &
Capacity Building Manager

@eupatientsforum
@elenabalestra



29 October 2018

“ A STRONG PATIENTS’ VOICE TO
DRIVE BETTER HEALTH IN EUROPE ”



For a strong European Patient Movement...



Our Vision!

“All patients with chronic conditions in Europe have access to high-quality, patient-centred health and related care.”



Our Mission!

“be the collective influential patient voice in European health and related policies and a driving force to advance patient empowerment and equitable patient access to care in Europe.”



Our Strategic Goals



Health Literacy



Healthcare Access and Quality



Patient involvement



Patient Empowerment



Sustainable Patients' Organisations



Non-discrimination

Strengthening Patients' voice in the EU

2003-2007

Influencing **policy developments** at EU-level



From 2008

EPF partnering in **EU projects** to gather evidence-based knowledge



2012 – present

Capacity Building and targeted activities for patient leaders, e.g. EUPATI



Evolution from 1 to 3 “pillars”

Strengthening policy impact

EPF
Capacity
Building
Programme



EPF Capacity building programme (CB)

What, how, for whom?





European Patients' Forum Live Stream
European Patients Forum



2018

SUMMER TRAINING COURSE
FOR YOUNG PATIENT ADVOCATES



Empowering
Leadership
&

Positive
Governance

National Coalitions Meeting



16-17 October 2017
Brussels



The European Patient Academy

- a pan-European project implemented as a PPP by a collaborative multi-stakeholder consortium from the pharmaceutical industry, academia, not-for-profit, and patient organisations; (IMI project)
- EUPATI has already trained 96 patient experts on **medicines development, clinical trials, medicines regulations, health technology assessment.**
- <https://www.eupati.eu/>
- <https://www.eupati.eu/what-is-the-toolbox/>

Governance

What do we mean by governance?

The first rule of any game is to know you are in one.



©Maxims4Mavericks.com

Ken

Why governance is key?

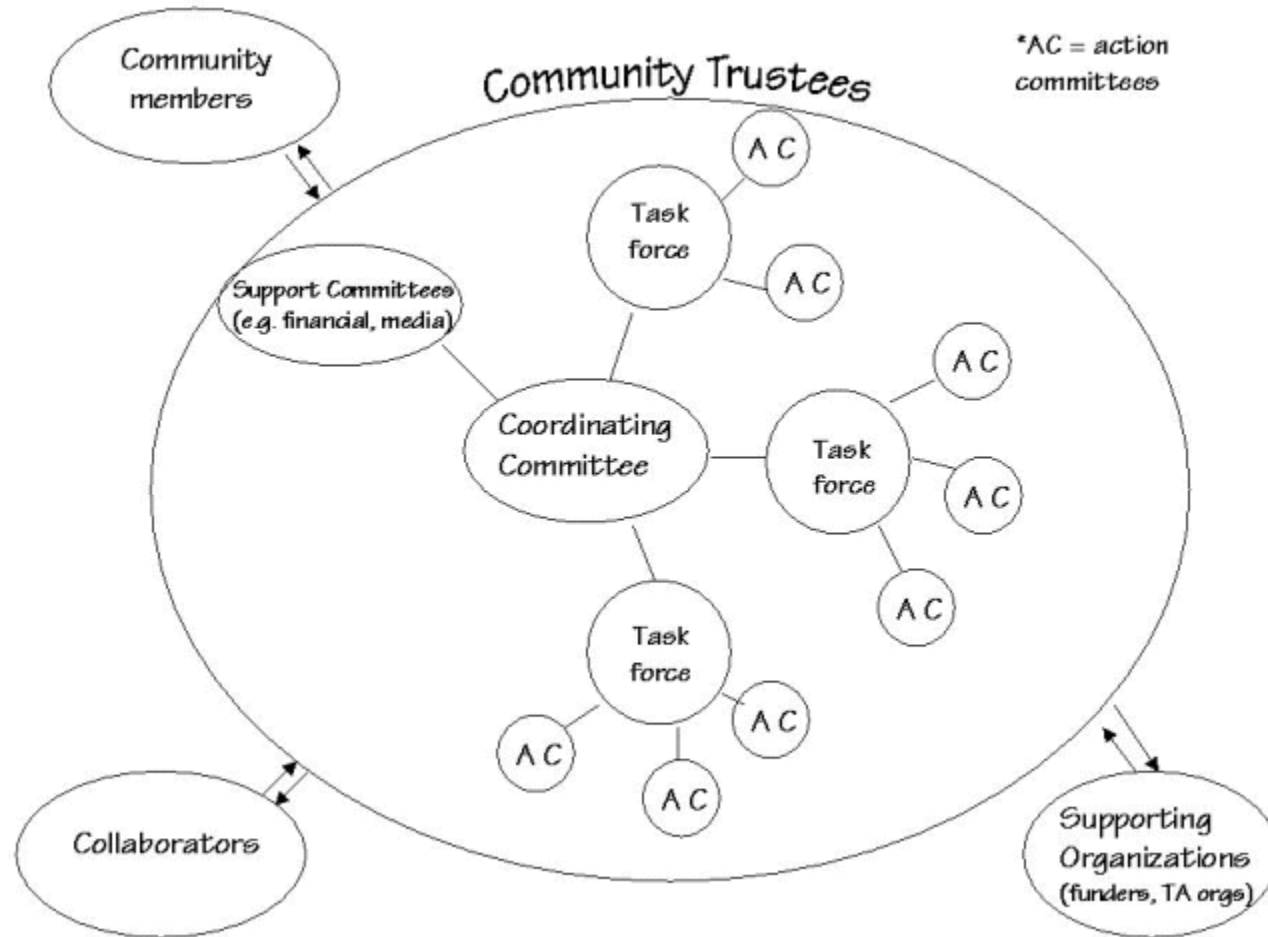
- **Structure gives members clear guidelines for how to proceed.** A clearly-established structure gives the group a means to maintain order and resolve disagreements.
- **Structure binds members together.** It gives meaning and identity to the people who join the group, as well as to the group itself.
- **Structure in any organisation is inevitable** - an organisation, *by definition*, implies a structure.

Key aspects to consider



Dopey Bashful Sneezy Sleepy Happy Grumpy Doc

How complex my governance structure should be ?



- Constitution are the written rules that control the internal affairs of an organisation. Constitution generally define things like:
 - ✓ the group's official name, purpose, requirements for membership, officers' titles and responsibilities, how offices are to be assigned, how meetings should be conducted, and how often meetings will be held.
 - ✓ govern the way the group must function as well as the roles and responsibilities of its officers.
 - ✓ Constitution serve as the legal guidelines of the organisation



Why should your organisation have one?

- Provide the answers to tough questions;
- Save enormous amounts of time, help you define your mission, or structure the organisation to correspond to that mission;
- It is necessary in some countries if your organisation wants to apply for non-profit status;
- It keeps your organisation focused on its intended purpose by specifically defining that purpose.

General Assembly

The highest representative body of your organisation

These meetings mainly have the following responsibilities:



- ✓ Election of the executive bodies and other bodies named in the Constitution;
- ✓ Taking political & strategic decisions for the organisation work;
- ✓ Making financial decisions: adopting the budget, accepting the annual financial statements;
- ✓ Adopting & amending the statutes & other working rules;

Board of Directors

Aka Bureau, Executive Committee, Steering Committee, Presidium

- Made of several individuals coming from your membership;
- They are elected by your full members during the Annual General Assembly;
- The board is accountable to your members;

What does it do?

- Making sure that the organisation is working towards its goals & implementing its work plan;
- Ensuring that the organisation has the necessary resources to work and overseeing the financial management;
- Recruitment of the Organisations' Lead (Secretary General/ CEO);

Board of Directors

Key characteristics

- Knowledge of the patient community;
- Commitment;
- Expertise;



- Manages the day to day operations of the organisation;
- Implements the strategy designed by the governing bodies;
- Manage the relationship with the board and the members;

How to ensure democracy & transparency within your organisation

Positive, transparent, effective, accountable

Describe processes and leave no room to ambiguity

- Elections processes
- Board rotation policy
- Length of term and limits in the terms of mandates



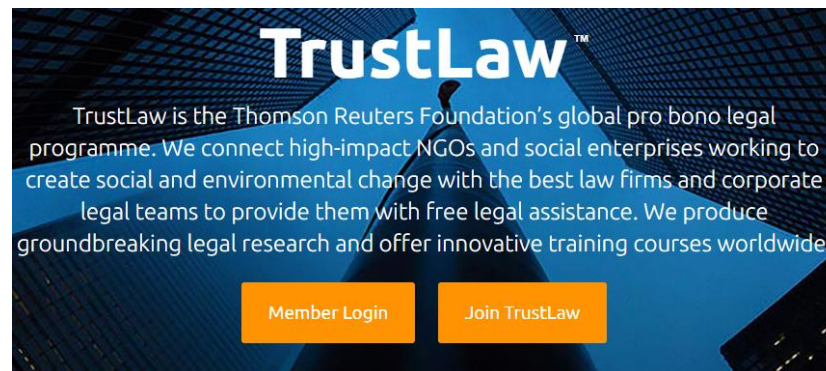
Ask yourself questions

- What happens in case of cessation of appointment?
- Board members should be different from paid staff
- Do you have a conflict of interest policy?



Constitution

- Think forward when developing it;
- Make it last;
- Gather examples of Constitutions of similar organisations for reference;
- Look for templates;
- Ask for legal advise;



General Assembly

- Prepare it and make the most out of it;
- Engage your members regularly during the year;
- Focus on the key issues and achievements;
- Send all the material well upfront;
- Make it interactive;
- Take minutes and prepare a report to be shared afterwards;

Board Members

- Spell out clearly what is expected from them: roles, responsibilities of board members & estimated time commitment;
- It helps if your board members are an odd number in case there is a tie during votes;
- Ideally, your organisations' board is different from its management (paid staff). While many small patient organisations have board members serving in the management position, try to bring some separation in the roles;
- Board meetings are kept close. However, written proceedings, summary minutes should be made available upon request;
- Develop a conflict of interest policy and ask board members to disclose any possible conflict of interest (personal, financial and others).

Tips and tricks

- Make sure he/she has the right level of autonomy;
- Make sure he/she receives support from the board;
- As he/she is generally appointed by the board and reports to them > it's best he/she doesn't have voting rights at board meetings;
- Make sure he/she is not over-worked;

Questions? Ideas?



THANK YOU FOR YOUR ATTENTION!

Follow us on Social Media!



/europeanpatientsforum



/eupatient



/eupatientsforum



eu-patient.eu/blog

@elena.balestra

More information

www.eu-patient.eu

info@eu-patient.eu

“ A STRONG PATIENTS' VOICE TO
DRIVE BETTER HEALTH IN EUROPE ”