

# BUILDING NATIONAL ALLIANCES: STRONGER TOGETHER

Camille Bulloot, Director of Operations & Engagement

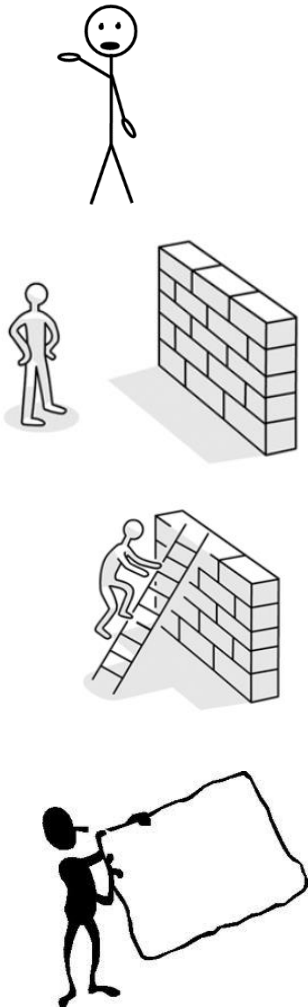
13/07/17

Meeting of National Brain Councils

 @eupatientsforum

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

**EPF**   
European  
Patients  
Forum



- Who is the European Patients' Forum?
- Why building national alliances?
- Overcoming challenges: towards sustainability and engagement
- The cooperation between national alliances and European organisations in Advocacy

Who is EPF?



# For a strong European Patient Movement...



## Our Vision!

“All patients in the EU have **equitable** access to **high quality, patient-centred** health and social care.”



## Our Mission!

“To ensure that the patient community drives health policies and programmes that affect them.”

# Our Strategic Goals



Health Literacy



Healthcare Access and Quality



Patient involvement



Patient Empowerment



Sustainable Patients' Organisations



Non-discrimination

# Evolution of EPF activities 2003-2016

## 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

# Why national coalitions?





# The rationale of building national alliances

## Louder together

- Improving the **visibility** of the cause you are defending
- Increased **representativeness** means more credibility
- The national coalitions as a natural **single point of contact for external stakeholders**
- Speaking for your country **on the international stage**
- Continuous presence of brain-related issues in health and social policies and programmes – and beyond



# The rationale of building national alliances

## Smarter together

- **Seeing the big picture:** a coalition can provide an overview of overarching patterns and complementary issues
- **Freeing up time for “your own issues”** – allows each stakeholder to focus on their own specific challenges
- **Expanding your horizons:** broadens the consideration of issues to include differing values and facts



# The rationale of building national alliances

## Smarter together

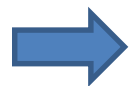
- **Learning from each other:** a forum provides the opportunity to share information, good practices and expertise.
- **Transcending institutional boundaries:** each stakeholder has to deal with different governmental agencies according to the field they represent. Yet, problems affecting the entire community are best addressed by approaches that involve the resources of the whole community.



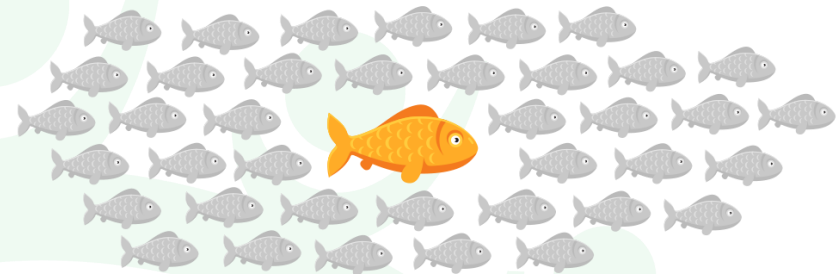
# The rationale of building national alliances

## Stronger together, stronger alone

- Being part of a national alliance means benefits for individual organisations that are a part of it:
  - Information exchange;
  - Common actions;
  - Reduction of the duplication of efforts
  - Optimisation of the use of their own resources



More and quicker progress for the individual organisations in fulfilling their missions.



# Overcoming Challenges: towards Sustainability and Engagement



# Challenges of national alliances...

## Addressing the fear of losing oneself

- **Struggle for leadership**  
The fear that one organisation will use the visibility of the alliance to defend its own interests.



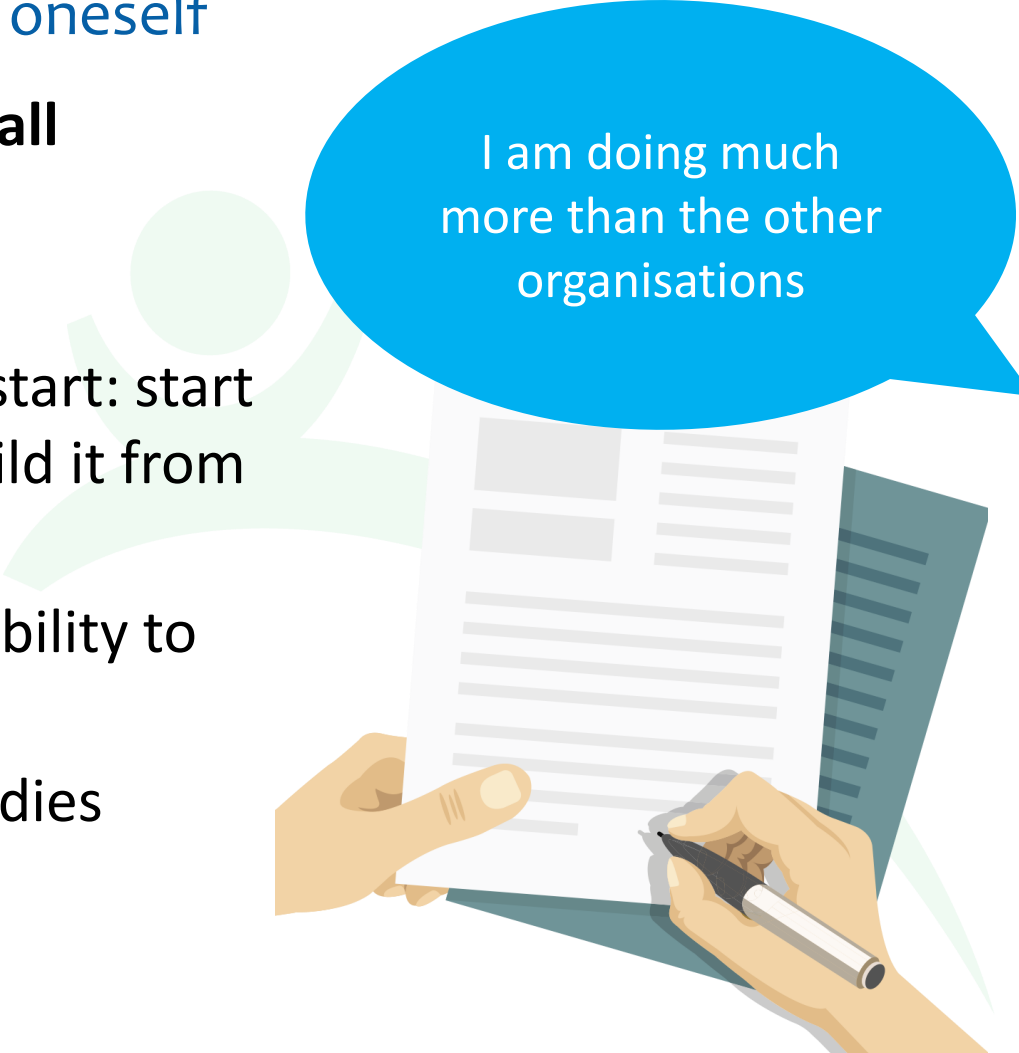
What if... one of the stronger organisations takes the leadership of the alliance-to-be?

- Ensure the representativeness of the organisation through well defined membership criteria
- Ensure the legitimacy of the governing bodies through strong governance rules

# Challenges of national alliances...

## Addressing the fear of losing oneself

- **Unequal commitment by all members of the alliance**
- ➔ Set up the rules from the start: start with a small group and build it from there.
- ➔ Choose partners with an ability to perceive common interest
- ➔ Rely on your governing bodies



I am doing much more than the other organisations

# Challenges of national alliances...

## Addressing the fear of losing oneself

- **The fear of losing your own identity**

- ➔ Reassure members of the alliance: their own organisations will continue to exist.
- ➔ Define the remit of the national alliance to specific, cross-cutting goals (vision, mission, values, strategic goals...)

What if... I lose my own identity?





# Challenges of national alliances...

## Addressing the fear of losing oneself

- **Lack of resources**

The perception is that the coalition will take resources away from each of the members of the alliance.



What if... setting up a new alliance results in increased competition for funding?

→ **Weigh the risk against the added value** of having a coalition that can focus on cross-cutting topics, enabling a more efficient allocation of resources and advocacy efforts

→ A coalition brings **more visibility, more interest to your cause**

# A word about fundraising

Fundraising requires you have clear ideas about what you want to do!

Before you engage in any fundraising activities:

- Draft your strategic plan
- Draft your operational plan
- Fundraising plan
- Estimate the costs for each activity you plan to undertake



# A word about fundraising

Fundraising works if you have the right tools:

- Campaigns, social media...
- Letters, one-to-one meetings: make it personal
- Regular updates: retain your donors!



# A word about Fundraising

## Funding sources

- **Membership fees**
- **Public funding:** operating grants, public tenders for project implementation?
- **European and international funding**
  - Need to demonstrate EU added value
  - Co-funding: need to put money on the table
  - Reporting!
- **Private sector funding:** think behind the pharma sector
- **Don't forget about pro-bono support!**



# A word about fundraising

## Transparency as your compass

- **Transparency across the board:** from membership to governance, to communications.
- **Diversify your funding mix:** at least 4 different sources, ideally across the public, private and international sectors;
- **Make your funding sources public:** on your website, and annual reports
- **Prefer and promote unrestricted funding**



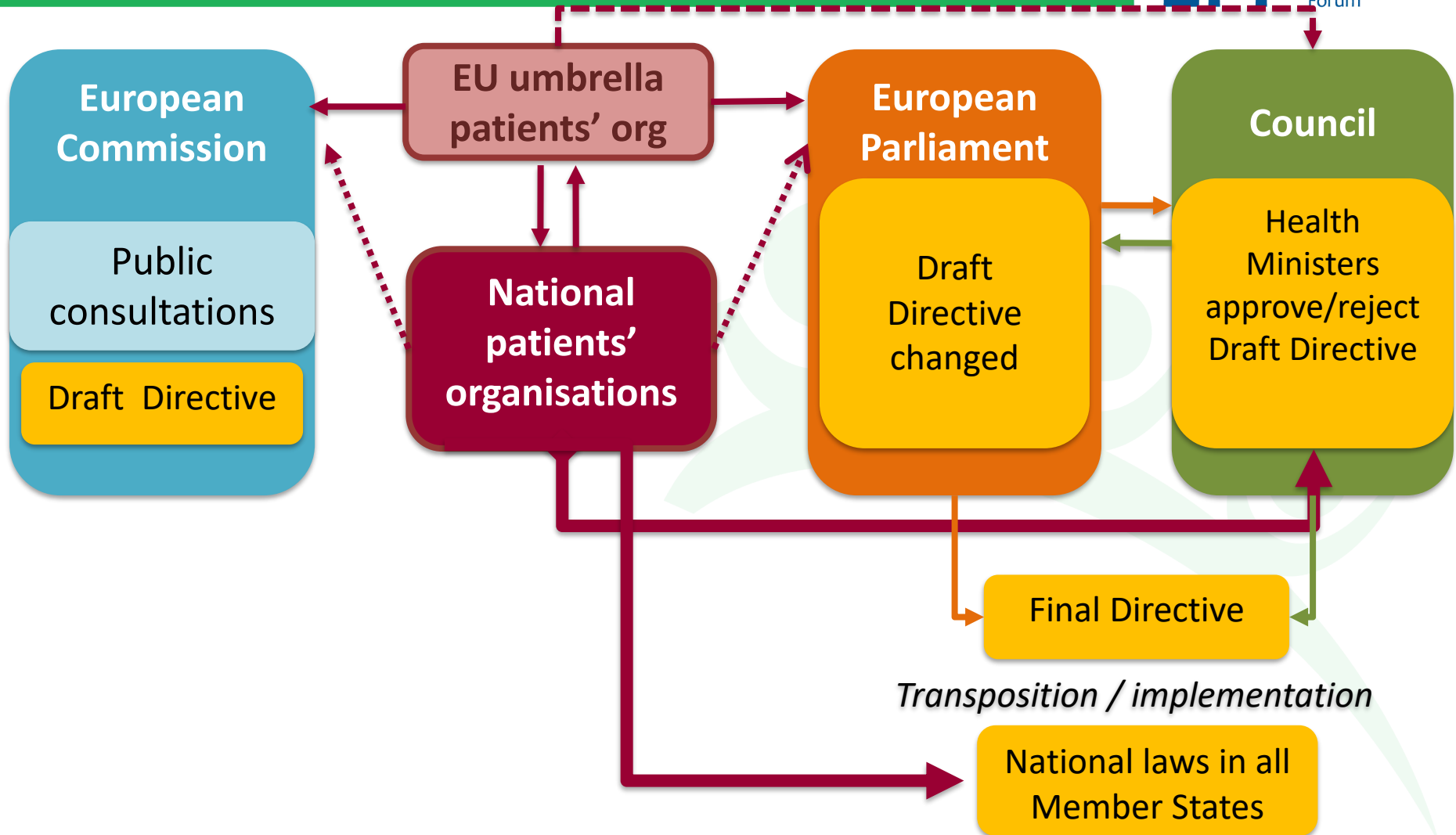
The cooperation between  
national alliances and European  
organisations in Advocacy

The example of patient  
organisations

# Our place in the EU legislative process



**EPF** European Patients Forum



# Complementary levels of action!

## European POs

- Closer to European decision-makers (better access to the European Commission, European Parliament's Committees)
- In a better place to monitor the legislation at EU level
- Have a better "overview", able to compare situations and transfer best practices whenever possible

**Influence**

**Knowledge**

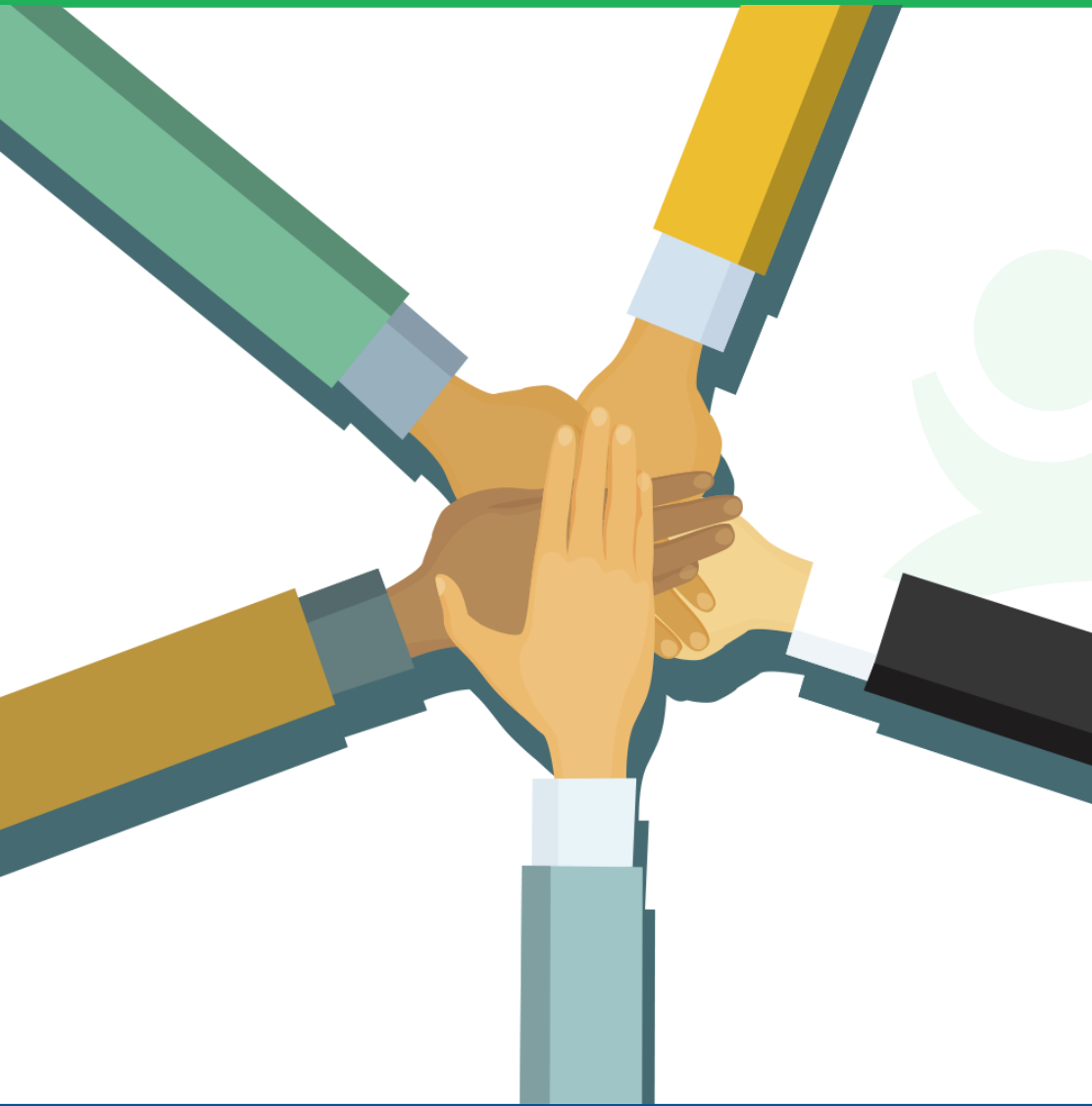
## National Alliances

- Closer to national decision-makers (including Council of the EU)
- Have a greater influence on MEPs from their country (they are voters!)
- Know about national-specific situations, realities
- Know about national legislation
- Closer to patients



Conclusion

# Conclusion



- Alliances are a great opportunity for advancing your cause
- Alliances also have benefits for the individual organisations involved
- Most challenges can be addressed through early thinking and the right provisions in rules of governance
- With regards to advocacy, the European/national levels are complementary levels of action

# THANK YOU



[www.eu-patient.eu](http://www.eu-patient.eu)

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