

## Report

MEETING BETWEEN ITALIAN PATIENT ORGANISATIONS

AND THE EUROPEAN PATIENTS' FORUM (EPF)

10 DECEMBER 2014, ROME (I)



## Annexes

- List of participants
- Agenda of the meeting

## Welcome

Camille Bulot (EPF) welcomed and thanked the participating organisations for their presence. The meeting began with a roundtable during which all the participants were invited to introduce themselves.



## Background of the day

Several Italian organisations have expressed interest in becoming members of EPF. Given that EPF's statutes foresee that its membership shall be composed of pan-European disease-specific organisation and national coalitions of patient organisations representing ten or more diseases, EPF was not able to give a positive answer to these requests.



However, EPF is interested in cooperating with Italian patient organisations for a series of reasons: getting support from Italian patient organisations would be an asset to influence the European legislative process (notably EPF's work with the Council of European ministers). Moreover, the building of a national coalition in Italy would be a major step towards uniting the patient movement across Europe.

Building a national coalition in Italy would also and foremost benefit Italian patient organisations. This is further developed in a specific section below.

## Objectives of the day

- Networking: developing further contacts between EPF and Italian Patient organisations;
- Taking stock of the issues Italian Patient organisations have to deal with currently, identifying issues where intervening at national level would make more sense;
- Introducing the work and activities of EPF to Italian Patient organisations;
- Discussing the benefits of national alliances;
- Exploring opportunities for cooperation between EPF and Italian organisations.

## Presentation of EPF

Camille Bulot, EPF Membership Officer, presented the structure, strategic objectives and activities of EPF.

Filippo Buccella (Parent Project), part of the National Liaison Team of EUPATI, presented the latest development of the EUPATI programme in Italy.

## Discussion

- **Is it possible for an organisation of being a member of both a European umbrella organisation and a national coalition? (Sandra Frateiacci, ALAMA)**

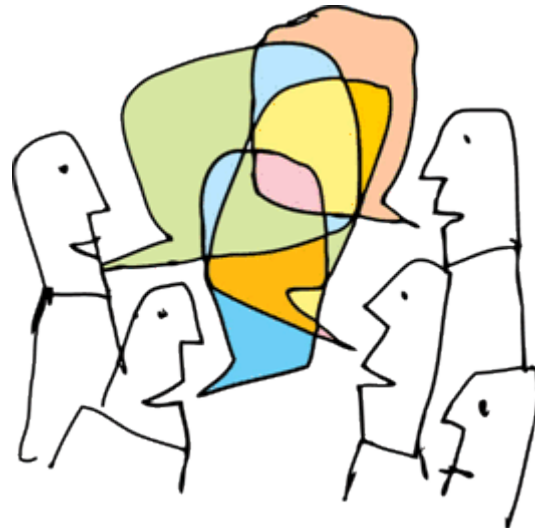
- **What is the added-value of national coalitions at European level? (Davide de Persis, FAVO)**

Memberships of umbrella organisations and national coalitions are not exclusive. In other words, becoming a member of a national coalition does not prevent you from continuing to contribute to/joining the European organisation active in the specific disease area you work in.

Pan-European organisations are experts of one condition (or disease area), and they will focus their work on advancing the patients' rights in the specific disease area they work in.

National coalitions will have different objectives: they are in a better position to advise and assert their concerns to the national stakeholders acting at European level (Italian representatives in the Council of Ministers, Italian Members of the European Parliament).

At national level, they have a unique role in dialoguing with the national institutions.



- **Does the existence of multiple European umbrella organisations not make the advocacy work of patient organisations less efficient? Is there not a risk to “confuse” decision-makers by flooding them with messages from different (disease-specific) messages? (Davide de Persis, FAVO)**

European umbrella organisations based in Brussels and in Europe acknowledge each other's presence and cooperate on a regular basis. When it comes to campaigning, there is usually a coordination of efforts. In that sense, the presence of a number of pan-European patient organisations is not a threat, but an opportunity for the patient movement. EPF also ensures that the advocacy tools are relayed by the national coalition of patient organisations.

- **The EUPATI Italy is creating a patients' platform. Why do we need a separate Italian national coalition? Is it not duplication? (several participants)**

The patient's platform set up by EUPATI does not appear as a suitable structure that could serve as a national coalition as it is a joint initiative by patients' organisations, academics and the industry.

The idea is that the Italian national coalition should be completely independent and be a forum where patient organisations can exchange views between themselves. Independence (being a patient-only structure) is also a criterion to become a member of EPF in the future.

However, the fact that the EUPATI patient's platform is currently being set up is definitely an opportunity to start a coalition and synergies between the two initiatives should be explored.

## Interactive discussion around the building of national alliances

Participants split into groups of 3 people and reflected on a number of issues around the building of national alliances. Inputs were then shared and discussed.



### 1 - Potential benefits of alliances

- Visibility
- Increased representativeness, and therefore more credibility
- Fighting together for a common cause, increased impact, louder voice
- One interlocutor for external stakeholders (media, decision-makers)
- Sharing information, good practices and expertise
- Optimisation of resources (human and economic): to work together is to work less and better!
- Continuous presence in health programming policies
- Recognition as partner by other stakeholders (doctors, industry, decision-makers)

### 2 - Potential challenges and how they might be overcome

- **Individualism of member organisations**
  - ⇒ To overcome this challenge: setting common goals and fighting common battles
- **Ensuring representativeness of the coalition and of the coalitions' governing bodies: how do you ensure coherence between the governing bodies and the base?**
  - ⇒ Solution: requires a culture change (awareness that together you can reach higher goals)
  - ⇒ Solution: setting good governance rules (criteria for participation, "one organisation, one vote")
- **Fear of losing own identity in the coalition**
  - ⇒ To address this, reassure member organisations that their own organisations will continue to exist, and that the national coalition will address specific goals



- **Building trust and ensuring transparency**
  - ⇒ Can be solved through good communication
- **Consultation within the organisation: how to manage to speak with one voice?**
  - ⇒ Solution: explain and communicate to the membership base the importance of the coalition
  - ⇒ Solution: set clear democratic rules.
- **How to avoid interferences by professional bodies (società scientifiche)?** In Italy, a number of patient organisations are created by societies of health professionals and used to validate the arguments advanced by a category of health professionals.
- **Resources?** Who puts in the resources to build the alliance? (time, funds, human resources)



### 3 – Issues that alliances, rather than individual groups, might represent

- Equal access (to care, therapies, medicines, etc.)
- Cross-cutting themes
- Social inclusion, welfare

### 4 – Resources that might be needed for building and managing an alliance

- Economic resources
- Human resources and training
- Cultural change (working together)

### Conclusions & Next steps

- **CONCERNS** - The participants also have concerns about the setting up of this initiative. The main concerns are:
  - Governance: risk of the initiative to be taken over by larger organisations deciding to join the project.
  - Patients only: risks of having mixed organisations (or influenced organisations) joining the initiative.
  - Resources: time and funding?
- ⇒ **NEXT STEP:** The risks mentioned above could be mitigated by agreeing (and adopting) clear governance rules at an early phase of the initiative's development.
- **ENTHUSIASM** - The participating organisations show enthusiasm, openness to participate in building a national coalition. In particular, this would be an opportunity for them to become visible at national level and start a dialogue with decision-makers and industry. For now, this dialogue, when it exists, is not continuous and very much based on personal relationships.

⇒ **NEXT STEP:** One of the main objectives would be to have a democratic process for patient consultation at national level.

- **SYNERGIES WITH EUPATI:**

⇒ **NEXT STEP:** it is decided to follow the development of the EUPATI patients' platform as this is a very good opportunity for the organisations interested to meet.



- **RULES OF GOVERNANCE, BUT ALSO CONCRETE OBJECTIVES:** it is noted that the rules of governance, which should help mitigate the risks of the project being captured by the interests of a minority of organisations should not be the sole axis of development of the initiative.

⇒ **NEXT STEP:** To trigger interest and motivate patient organisations involved, the participating organisations should define a concrete project and precise objectives to work on, as a “cooperation pilot”. These objectives and first concrete actions should be defined over the next months.

⇒ **NEXT STEP:** There is interest from several participants to work around the Chapter 5 of the Italian Constitution (“Titolo quinto”) which introduced the regionalisation of healthcare services, a modification which many of the participating patient organisations see as a barrier to equal health care.

- **LEGAL STRUCTURE of the project:** participants are concerned the legal status for non-profit organisations in Italy does not offer them the freedom to assess legitimacy criteria of candidate members for their national coalition. Some participants are concerned formalising the structure of the initiative would endanger the cooperation: indeed, in the past, most initiatives were stopped when faced with paperwork to formalise the initiative (becoming an association “onlus”).

⇒ **NEXT STEP:** in a next meeting, participants should discuss of the added-value of formalising the cooperation in an association, and of the practical details and timeline to do so.

- **NEED FOR CLARIFICATION OVER THE SCOPE OF THE PROJECT:** at the end of the meeting, participants still do not agree on the objectives pursued with the building a national coalition: for

some, it is about advocating at national level and uniting the patient's movement in Italy. For some others, building a national coalition is a gateway to join organisations such as EPF and becoming active at European level.

- **ADVICE FROM EPF & OTHER ORGANISATIONS:** participants express the wish to benefit from advice from other national coalitions on rules of governance, priorities, and practical matters (funding, time and investment required). EPF offers to facilitate this exchange of best practices.

CB, 11<sup>th</sup> December 2014

Draft Agenda  
Meeting between Italian Patient Organisations  
and the European Patients' Forum (EPF)

**Meeting venue:** Rome (I) – Exact meeting venue to be determined

**Proposed date:** 10<sup>th</sup> December (11 am – 4pm)

**Meeting language:** English/Italian

#### Tentative Timetable

**11:00-11:30 Welcome and introductions**

**11:30-12:00 What is the European Patients' Forum (EPF)?**

**12:00-13:30 Interactive discussion around the building of national alliances**

- *Potential benefits of alliances*
- *Potential challenges of alliances and how they might be overcome*
- *Issues that alliances, rather than individual groups, might represent*
- *Resources that might be needed for building and managing an alliance*

**13:30-14:15 Lunch Break**

**14:15-15:30 Exploring opportunities for cooperation**

- *Between Italian Patient organisations*
- *Between Italian Patient organisations and EPF*

**15:30-16:00 Conclusions and Next steps**

#### Objectives of the meeting

- Networking: develop further contacts between EPF and Italian Patient organisations;
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- Introducing the work and activities of EPF to Italian patient organisations;
- Discussing the benefits of national alliances;
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#### Registration




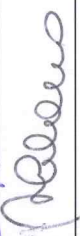




To register, please send an email to Camille Bullo, [camille.bullo@eu-patient.eu](mailto:camille.bullo@eu-patient.eu).



**MEETING BETWEEN ITALIAN PATIENT ORGANISATIONS AND THE EUROPEAN PATIENTS' FORUM (EPF)**

Rome (I), 10 December 2014

List of participants

First Name	Name	Organisation	Signature
Felice	Bombaci	Gruppo ALL Pazienti Leucemia Mieloide Cronica	
Filippo	Buccella	Parent Project	
Camille	Bullot	European Patients' Forum (EPF)	
Antonella	Celano	APMAR	
Davide	De Persis	FAVO	PRESENT
Sandra	Fratesiaci	ALAMA Onlus FEDERAZIONE ALLERGIE ONLUS	
Valeria	Germini	Parkinson Italia	(NO)
Linda	Henderson	ATTA Lazio Onlus	
Elisabetta	Iannelli	FAVO	(NO)
Stefano	Nervo	Diabete Forum	
Silvia	Starita	Parent Project	

MASOMILIANO	CONFORTI	EFAC ONLUS	Massimiliano Conforti
MADDALENA	REAGALLI	APMAR ONLUS	Maddalena Reagalli

# THE EUROPEAN PATIENTS' FORUM

Camille Bulot, Membership Officer

Meeting with Italian Patient Organisations  
Rome (I), 10<sup>th</sup> December 2014

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

# Today...

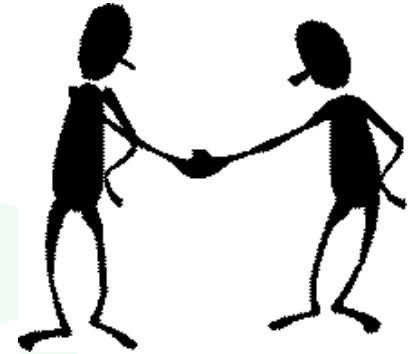
What is EPF?



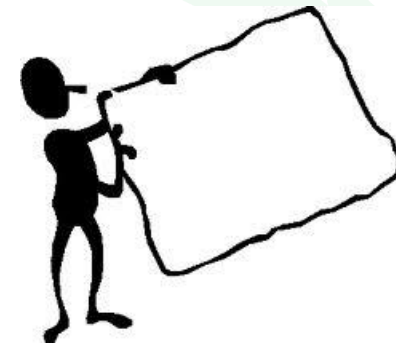
Interactive discussion around the building of national alliances



Exploring opportunities for cooperation




Conclusions and Next Steps




# Who is EPF?

Independent & non-governmental  
advocacy organisation  
Representing 64 members

Created in  
2003



National-level  
Non-disease-specific  
Patients' organisations



EU-level  
Disease-specific  
Patients' organisations

...On **CROSS-CUTTING** issues relevant to  
**ALL PATIENTS** in Europe

# EPF Membership



**National Coalitions**  
(10 diseases, 1 country)

**Pan-European organisations**  
1 disease, 14+ countries

## 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 are adapted for their final users, patients.”

# What do we work on?



Health Literacy



Healthcare Access and Quality



Patient involvement



Patient Empowerment



Sustainable Patients' Organisations



Non-discrimination



# Evolution of EPF activities

## Strengthening Patients' voice in the EU

### Policy & Advocacy 2003-2007



### Gathering evidence through projects



From 2008

### Capacity Building 2012 – present



Evolution from 1 to 3 “pillars”

Strengthening policy impact

# Example 1 – EPF Elections 2014 Campaign



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

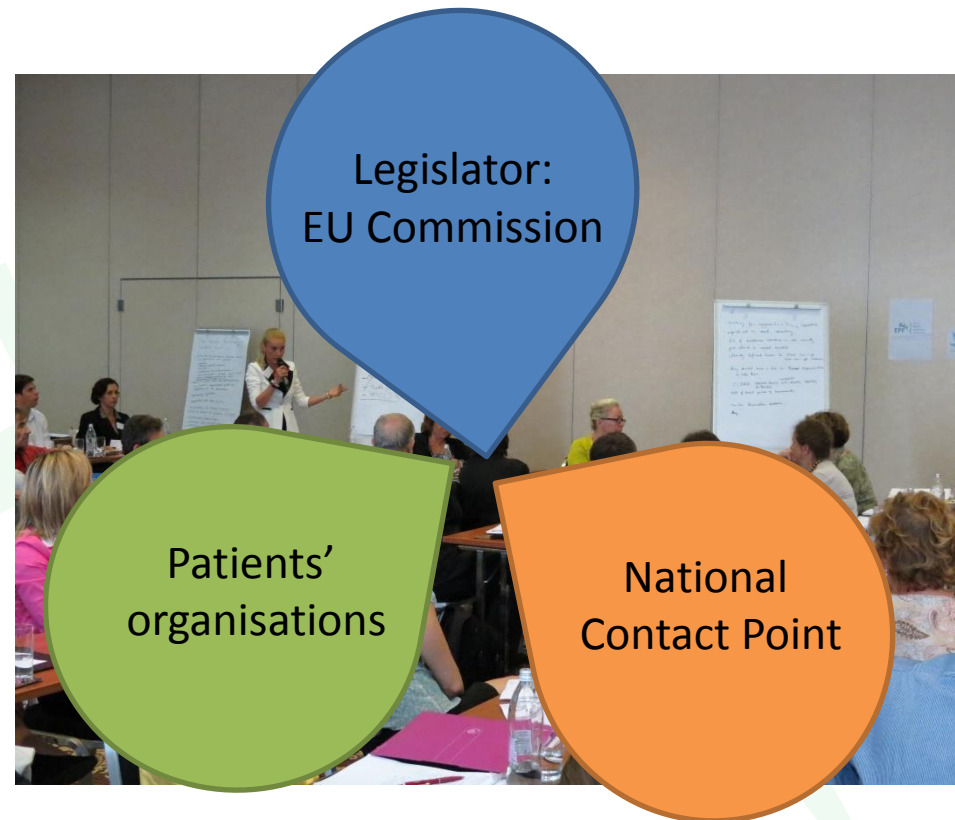
# Example 2 – Regional CBHC Conferences

## Directive on Cross-border Healthcare

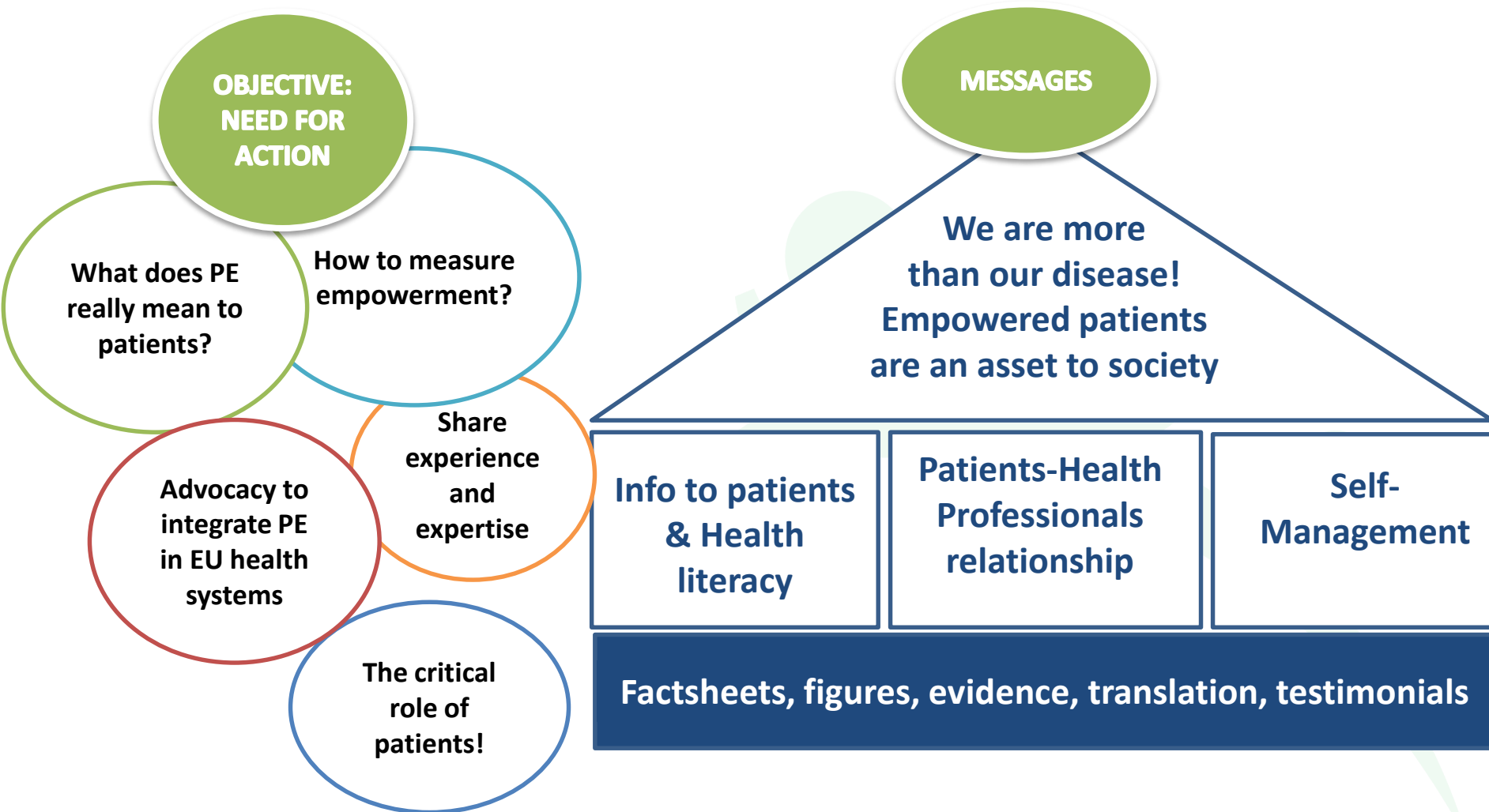
- 4 Conferences (Brussels, Athens, Ljubljana, Tallinn)
- Patient organisations from 20 countries

### Objectives:

- Building knowledge about the directive
- Share and discuss good practices
- To create an informal network of patient leaders to monitor developments over the coming years.

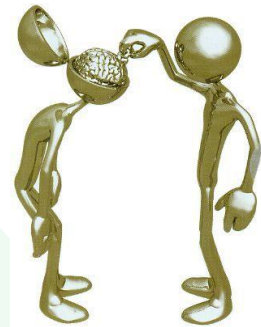


# Example 3 - Patient Empowerment Campaign



So what did we achieve?

- **Legislation is more demonstrably patient-centred**, thanks in part to our advocacy work
- **Soft law and policy:** a clearer, more nuanced patient perspective
- **Real evidence for change** (thanks to our investment in solid project work)



# EPF engagement with our Members



## Three major events each year

- EPF Spring Conference
- EPF Annual General Meeting
- EPF Autumn (Regional) Advocacy Seminar



## EPF Capacity Building Programme (2012-2014)

# EPF engagement with our Members



Weekly (virtual) coffee  
with EPF -

a coffee is worth  
1000 emails!



**Weekly Coffee with EPF!**

## EPF on the Spot! Visiting our members







# Alliance Building and cooperations

IAPO  
International Alliance of Patients' Organizations

WHO  
European Region

European Medical technology industry association (Eucomed)

Health professionals' organisations (EFN, HOPE...)

European Union Agency on Fundamental Rights (FRA)

The European Union Health Policy Forum (EUHPF)

European Health Forum Gastein

European Network on Patient Empowerment (ENOPE)

# EUPATI: an innovative training model



**An unprecedented collaboration:** Patient organisations, health professionals, health tech experts, health NGOs, pharma industry

- ▶ Funded by IMI (PPP between EC and EFPIA)
- ▶ Launched Feb 2012
- ▶ Runs for 5 years
- ▶ Consortium of 29 members – led by EPF



Will develop and disseminate **objective, credible, correct and up-to-date information** on medicines R&D in 7 European languages

Will **build competencies & capacity** among patients & public to get involved

Will **facilitate patient involvement** in R&D to support academia, industry, authorities and ethics committees



# Audiences: patients and the wider public



## EUPATI Certificate Training Programme

**Patient Ambassadors** in committees, HTA agencies, industry, regulatory bodies, academia etc

**Patient Journalists** raising awareness

**Patient Trainers** for patient communities and networks

**100**  
**patient**  
**advocates**

## EUPATI Educational Toolbox

Educational tools for patient advocates (print, slide shows, eLearning, webinars, videos) for patient advocates

**12.000**  
**patient**  
**advocates**

## EUPATI Internet Library

Patients & lay public at large, e.g. on specific aspects of the development process of medicines for patients with low (health) literacy

**100.000**  
**individuals**

# THANK YOU FOR YOUR ATTENTION!

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**More information**

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

[info@eu-patient.eu](mailto:info@eu-patient.eu)

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

# Building National Coalitions

## Interactive discussion

1

Potential benefits of alliances

*I potenziali benefice di una coalizione*

2

Potential challenges of alliances and how they might be overcome

*Le potenziali sfide e come superarle*

3

Issues that alliances, rather than individual groups, might represent

*Ruolo delle coalizioni rispetto ai gruppi individuali*

4

Resources that might be needed for building and managing a coalition

*Le risorse di cui abbiamo bisogno per costruire e gestire una coalizione*

# Exploring opportunities for cooperation

## Between Italian Patient organisations

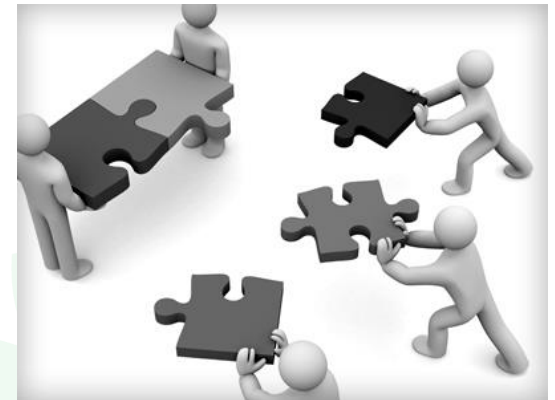
- Motivation check?
- What objectives?
- What cooperation? What form?
- You decide on the rules!
- Timeline?



# Exploring opportunities for cooperation

## Between EPF and Italian Patient organisations

- Your input is important and valuable
- For EPF: all organisations are equal



# EPF and Italian Patient Organisations

## On the short/medium-term

### Process of building a national coalition

- Networking / Facilitation
- Good practice examples
- Informal support, network with other national coalitions

1



## On the longer-term:

### Once the national coalition is formed

- Stronger cooperation with EPF (capacity-building, advocacy...)
- Participate in EU projects

2

