

EUROPEAN PATIENTS' FORUM LEADERSHIP MEETING

Brussels (B)
4 February 2016

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

THE EUROPEAN PATIENTS' FORUM


Nicola Bedlington,
Secretary General

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


Who is EPF?

Independent & non-governmental
advocacy organisation
Representing 63 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

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

Strengthening Patients' voice in the EU

2003-2007

EPF focusing on policy developments (e.g. Pharma Forum)

**From 2008
(Value +)**

EPF gathering evidence based information with projects

2012 – present

Capacity building Programme and targeted activities for patient leaders (Regional Advocacy Seminars, EUPATI project)

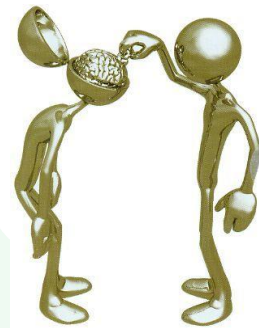
Evolution from 1 to 3 “pillars”

Strengthening policy impact

Your Achievements as EPF

And why does it matter

- **Legislation is demonstrably more 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)



The Current Environment

- A Commission of 'Big Things' –Jobs and Growth
- Commission Work Programme 2016
...No time for business as usual
- Framed around “challenges” slower economic recovery, instability and insecurity.. Brexit, Grexit
- Almost no direct mention of health
 - Health and safety of workers
 - Anti-microbial resistance
 - HTA
- NOTHING on Patients - Invisible Citizens



‘Our business’ as the collective voice

- **Use the hooks** – e.g Semester Process, Digital Single Market, Sustainable Development Goals
- Interact differently with the main EU Institutions
- Engage with WHO-EUROPE and relevant EU agencies
- **Advance on implementation** – “full circle approach”
- **Create an enabling environment**
 - Patient Empowerment, Patient Access and Patient Engagement
- **Prepare for the next Programming period**



SESSION 1 - ENSURING THE SUSTAINABILITY OF PATIENT ORGANISATIONS

Walter Atzori,
Director of Programmes and Operations

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Objectives of the session

- Identifying challenges for patients' organisations funding and long-term sustainability and solutions to overcome them
- Understanding which funding opportunities are available/untapped
- Exploring perspectives of working together to develop a long term strategy for engagement



- **Ever-growing need for patient input:** advocacy, projects, regulatory (EMA), HTA etc.:

Capacity

Impact?

Prioritisation

- **Need to meet this growing demand:** funding, especially long-term, remains a challenge for our sustainability
- **Core grants:** European Commissions' grant - added-value, challenges, sustainability, rules governing them.
- **Working group emerging from EMA-PCWP** to develop a long-term strategy on patient/public health organisations' role and sustainability: role, mandate, expectations...

Setting the scene

- **Role of POs in delivering EU programmes / contributing to key projects:**



- IMI funding: our experience so far – current challenges; how to ensure that more patient groups are represented in key projects?



- **PPP in medicine development**, potentially in other areas, and role of patient groups
- **Cooperation with industry:** corporate sponsorship, challenges, sustainability, transparency and accountability / public perception



Setting the scene

- **Unexplored paths for national and local groups** (structural funds)
- **Mid-term review of the Multi-annual Financial framework** – more funds for patient organisations
- **The role of EPF, and members,** in driving our strategy on funding and sustainability



- Challenges for **patients' organisations funding and long-term sustainability** and solutions to overcome them
- Understanding which **funding opportunities** are available/untapped
- Exploring perspectives of **working together to develop a long term strategy** for engagement



SESSION 2 - COORDINATING ADVOCACY STRATEGIES

Kaisa Immonen-Charalambous
Director of Policy

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Objectives

- Get a picture of ongoing initiatives related to chronic diseases at European level (COM, EP, Council...)
- Identifying and “clustering” strategic priorities across EPF membership
- Understand where synergies are possible
- Sharing our (cross-cutting) key policy and advocacy priorities for 2016 and beyond



A picture of PO's initiatives

Interest groups & other initiatives in the European Parliament (non-exhaustive list)

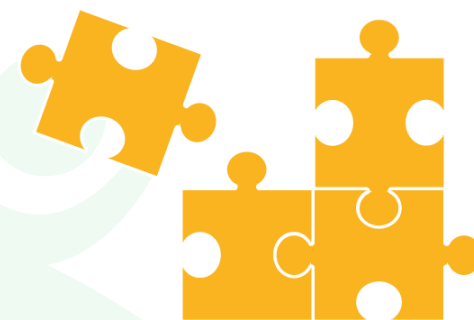
- Interest Group on Mental Health (GAMIAN)
- Interest Group on Access to healthcare (EPF)
- Interest Group on Allergy and Asthma (EFA)
- Interest Group on Brain, Mind and Pain (EFNA, PAE, EMSP)
- Interest Group on “European Patients’ Rights and Cross-Border Healthcare” (ACN)
- MEPs Against Cancer (ECPC)
- Interest Group on Carers (EUROCARERS, EPF participates)
- Interest Group on Innovation in Health (EUROFEDOP)
- Towards access to employment debate in the EP (EMSP)



Commission's expert groups (PSQC, workforce, Health policy Forum...)

Topics for cooperation (2016 and beyond)

- Patient empowerment & chronic disease management
 - Self-management, technology, enablers (e.g. professional training, health literacy)
- Access: towards a “fair access framework”
- Cross-border directive & its diverse impacts
- New ways of thinking and doing:
 - Adaptive pathways, systems innovation, integrated care, culture change, personalised medicine, big data....
- Non-discrimination & inclusivity
- HSPA (outcomes), EU Semester (access, quality)...



Opportunities for bottom-up actions

- **Collaboration** between stakeholders

- PACT
- Riga Conference & Roadmap -
- Informal groups e.g. pricing discussions
- Connect with international organisations e.g. OECD, WHO



- **EPF campaigns** → patient community advocates for its priorities

- Empowerment & Access
- Aim to define the terms of the conversation
- Bridging EU and national/local



- Potential items for discussion:
 - How to exploit synergies between policy initiatives interest groups
 - Can we learn from each other's experiences?
 - Listing Health/patient-friendly MEPs and allies?
 - Supporting each other's campaigns, initiatives?
 - Signing off the work of others rather than reinventing the wheel?

SESSION 3 - THE ROLE OF PATIENT ORGANISATIONS TODAY AND TOMORROW

Camille Bulloot,
Membership & Stakeholder Relations
Manager

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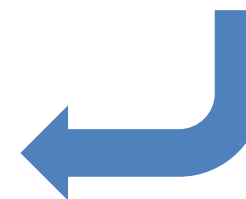
The changing roles of patient organisations



Understanding the specific role of patient groups in today's changing societies



To discuss the role of EPF and patient groups in advancing health status at global level



Some questions for you

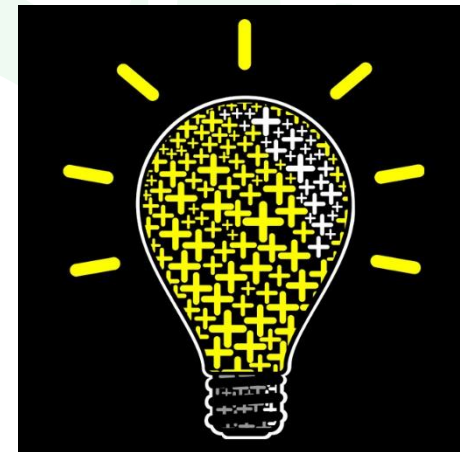
- What is a patient organisation? Who we are...
 - Emergence of online communities
 - Do we need a definition?
 - Positive definition rather than exclusion



NEW

Definition

[def-uh-nish-uh n]



Some questions for you

- What kind of challenges do we collectively meet?
 - Have these changed over the years?
 - What are our responsibilities/roles with regards to the global health challenges (migration/WHO Millenium Development Goals...)
- How can we contribute/solve these challenges?
 - Capacity-building?
 - Reinforcing our role as a watchdog?

SESSION 4 - DIFFERENT CAPACITY AND STRENGTHS

Ensuring balance and representativeness of patient groups

Nicola Bedlington,
Secretary General

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Objective of the session

How can EPF best support our members in achieving their respective missions and our collective mission?



Different capacities, different strengths

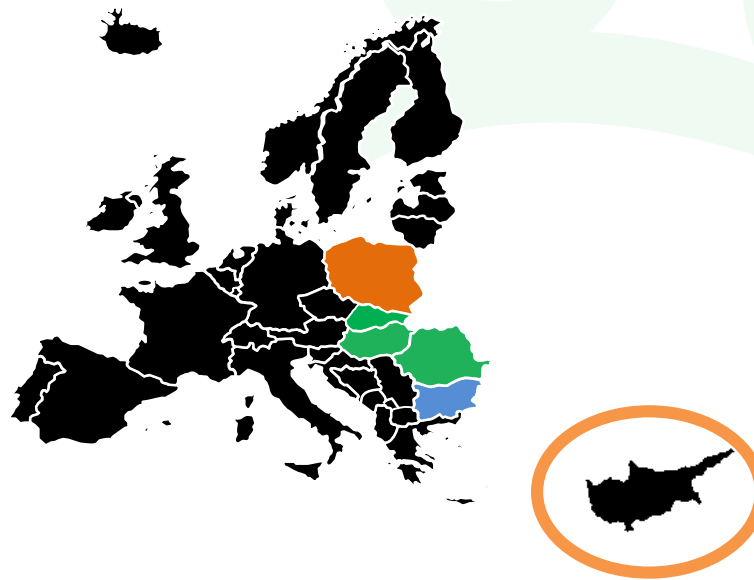
- Recognition that the EPF membership is diverse



- Different profile, different needs, different expertise, different capacity to contribute

Some areas to explore

- Capacity Building
 - at European level: patient safety – transparency in 2016
 - at National level – 6 countries



Some areas to explore

- Horizon – scanning and informing
- Signposting, facilitating links between consortia and members
- Robust patient engagement strategy H2020/IMI
- Overarching non-disease specific IMI projects – ‘ring-fencing’ resources to enable our members to participate and contribute
- And

Balancing the pillars

Strengthening
Patients' voice in the
EU

INFLUENCING
POLICY

GATHERING
EVIDENCE
THROUGH
PROJECTS

CAPACITY
BUILDING

More than ever, we are aware of the interdependence between the pillars

Building capacity to contribute with policy input

Necessity to develop our presence in other EU countries to reinforce our influence on the Council

THANK YOU FOR YOUR ATTENTION!

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More information

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