

EUROPEAN PATIENT'S FORUM

Annual General Meeting

2016

Brussels

22-23 March 2016

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



THE YEAR IN REVIEW: 2015 HIGHLIGHTS FROM EPF

Nicola Bedlington
EPF Secretary General

22.03.2016

EPF Annual General Meeting



@eupatientsforum

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

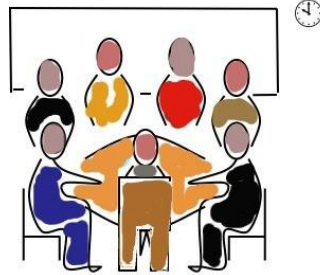


Access

Tackling access barriers

EPF Access Working Group

We strengthened our **positions and activities on access**



WE CARE

We contributed a strong patient perspective on investing in the future of healthcare



We had strong political impact on the **EU access Agenda:**

PACT voted most successful follow-up to Vilnius declaration



RIGA ROADMAP

Health Technology Assessment



EPF HTA Working Group



Module on HTA principles and practice



Patients' role in the next Joint Action

In 2015 EPF placed the focus on **strengthening and coordinating patients' perspective on HTA**



Strengthening the patient movement

Patient safety and quality of care

- **6 Amendments incorporated** in the European Parliament report “Safer healthcare in Europe”
- Contribution to the Council’s position on **medical devices**: safety and quality, transparency, and patient involvement
- **PASQ Joint Action** completed:
 - ✓ Provides a key set of good practices on patient safety for professionals and healthcare organisations [in the PASQ Wiki](#)
 - ✓ Patient involvement as a criteria



The BMJ  [SUBSCRIBE NOW](#)

Nicola Bedlington: Patient involvement in medical devices— an opportunity we may be missing

2 Jul, 15 | by BMJ



Patient involvement in health and social care is a fundamental right, and an operating principle of European healthcare systems. In the area of medicines patients are recognised as experts and are participating in many aspects of access, innovation, safety, and transparency, thanks, not least, to the commitment to patient involvement of the European Medicines Agency. However, in the area of medical devices a change of mind-set is needed.



Involvement

- **Discrimination in healthcare position published in 2015** → Increased cooperation with NGOs representing vulnerable groups (e.g. undocumented migrants)
- **Focus on multimorbidity** as part of the JA CHRODIS
- **Focus on young patients** through a future position paper on equal treatment in education and employment



CHRODIS
ADDRESSING CHRONIC DISEASES & HEALTHY AGEING ACROSS THE LIFE CYCLE

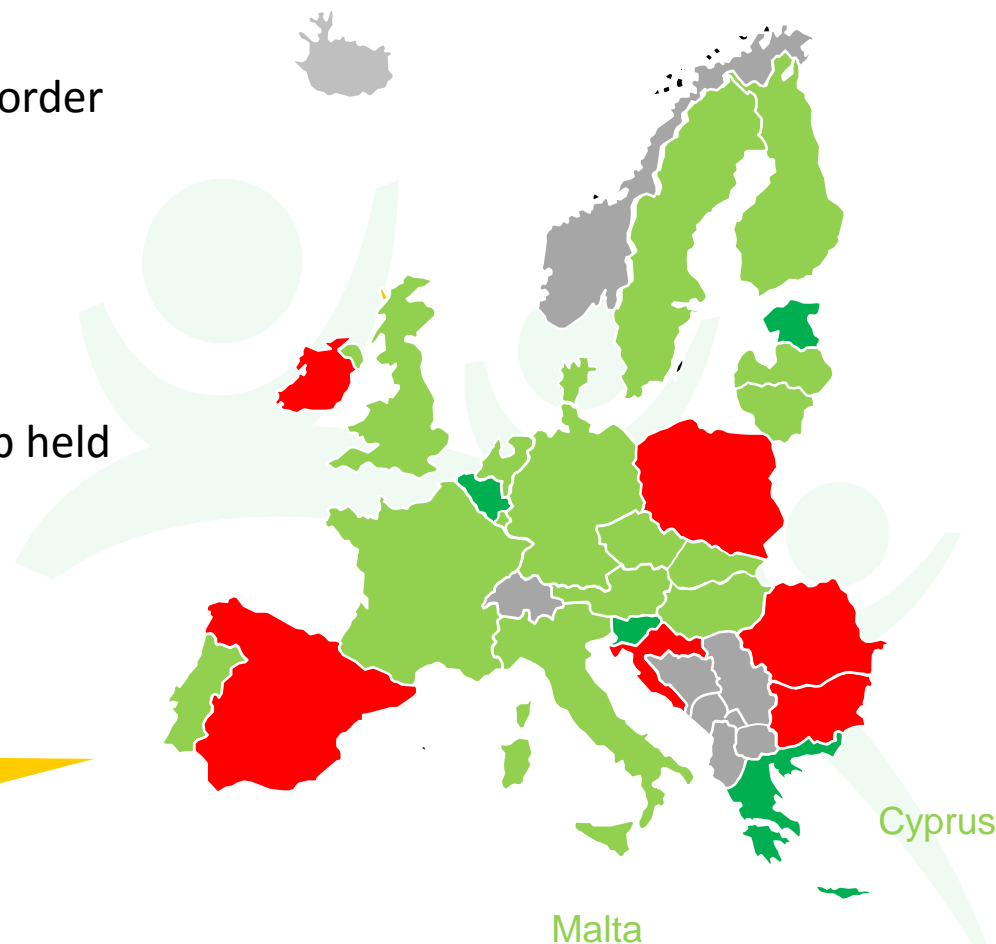


Diversity

Bringing cross-border healthcare closer to home

-  Countries where EPF held a conference/workshop on cross-border healthcare since December 2013
-  Countries who participated to a regional conference
-  Cross border healthcare workshop held in 2015
-  Non EU countries

Building an EU wide patient expert network



Cross-border healthcare

- Summary report of regional & national events 2013-15
 - ✓ Key barriers for patients
 - ✓ The “ideal” National Contact Point
 - ✓ The patient journey mapped: information & support needs
- Conference in Brussels, 2 July
 - ✓ Focus on key concerns: information; quality and safety of care; equity of access
 - ✓ Political message to and from the Commission



Empowerment

Conference on Patient Empowerment



- Education
- Expertise
- Equality
- Experience
- Engagement

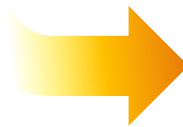
Patients Prescribe E⁵ for Better Health Systems

Lay summaries of clinical trials

EPF recommendations

To help foster an open, inclusive and accountable system, EPF makes the following recommendations:

1. EPF calls for a set of guidelines to be developed at EU level, with the involvement of patient organisations, to ensure that the lay summaries written for the EU database adhere to a common set of quality standards. The existing *core quality principles*¹¹ could be used as a starting point. In addition, existing guidance on lay summaries should be reviewed and used to arrive at the common set of guidelines.
2. Our members who responded to the consultation would prefer the guidelines to be drafted by a **dedicated working group hosted at the European Medicines Agency**, with a sufficient number of patient representatives and involving the European Commission, regulators and industry. This would enable in-depth discussion and ensure that patients and patient organisations are engaged with the process from the beginning. A specific topic could focus on the user-friendliness of the electronic interface.
3. Once proposals are made, an **EU-wide consultation** should follow in order to invite



Terms of Reference

EU Taskforce for the development of guidelines on summaries of clinical trial results for lay persons



Adherence and concordance

- From blaming patients to *developing solutions*
- Better information and health literacy, with shared decision-making
- Ongoing, integrated support - all professionals play a role
- Self-management support including empowering technology
- Patient reporting of adverse drug reactions

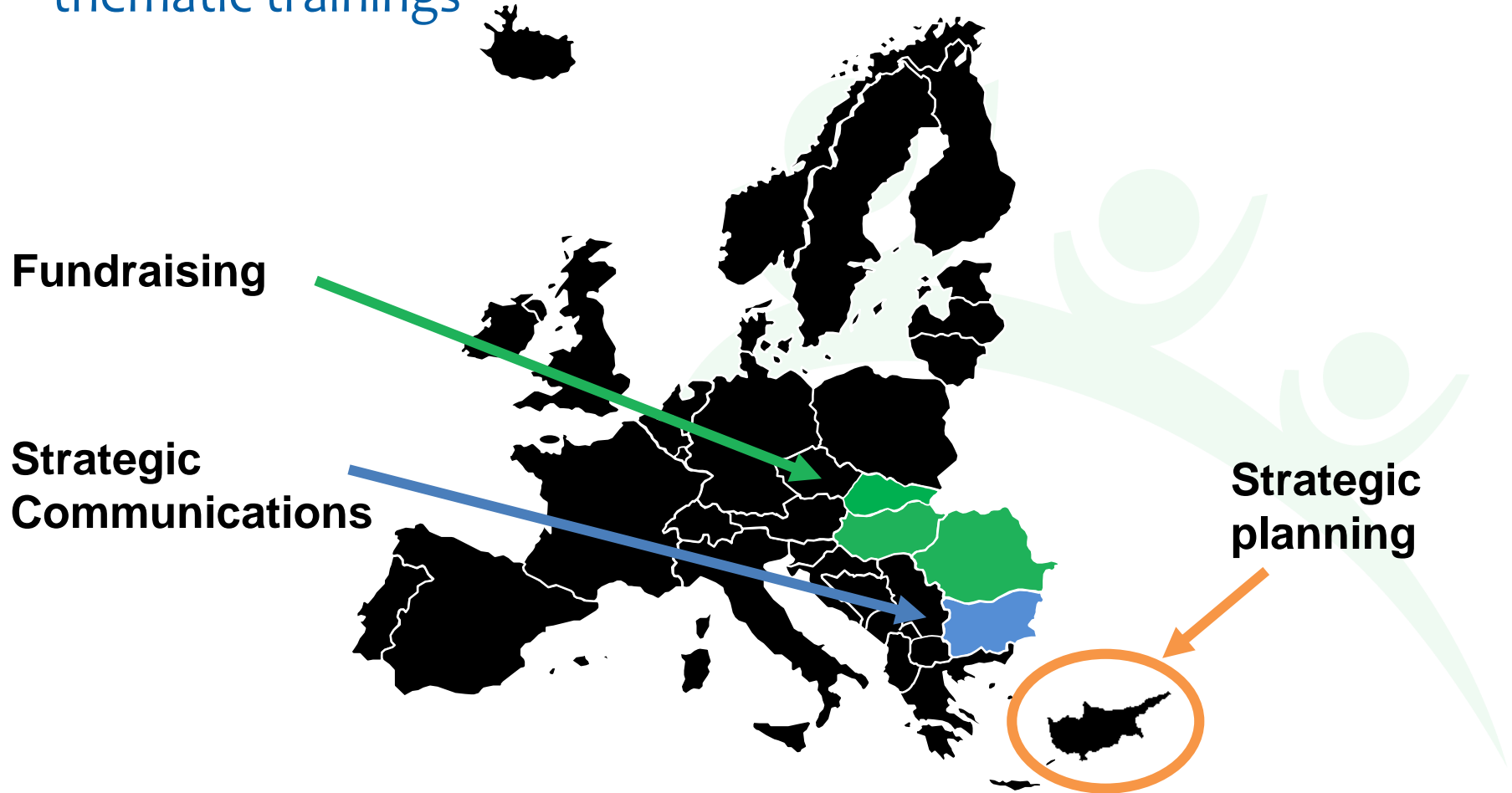
Development of EPF Principles on adherence and concordance



Capacity-Building

EPF Capacity Building in 2015

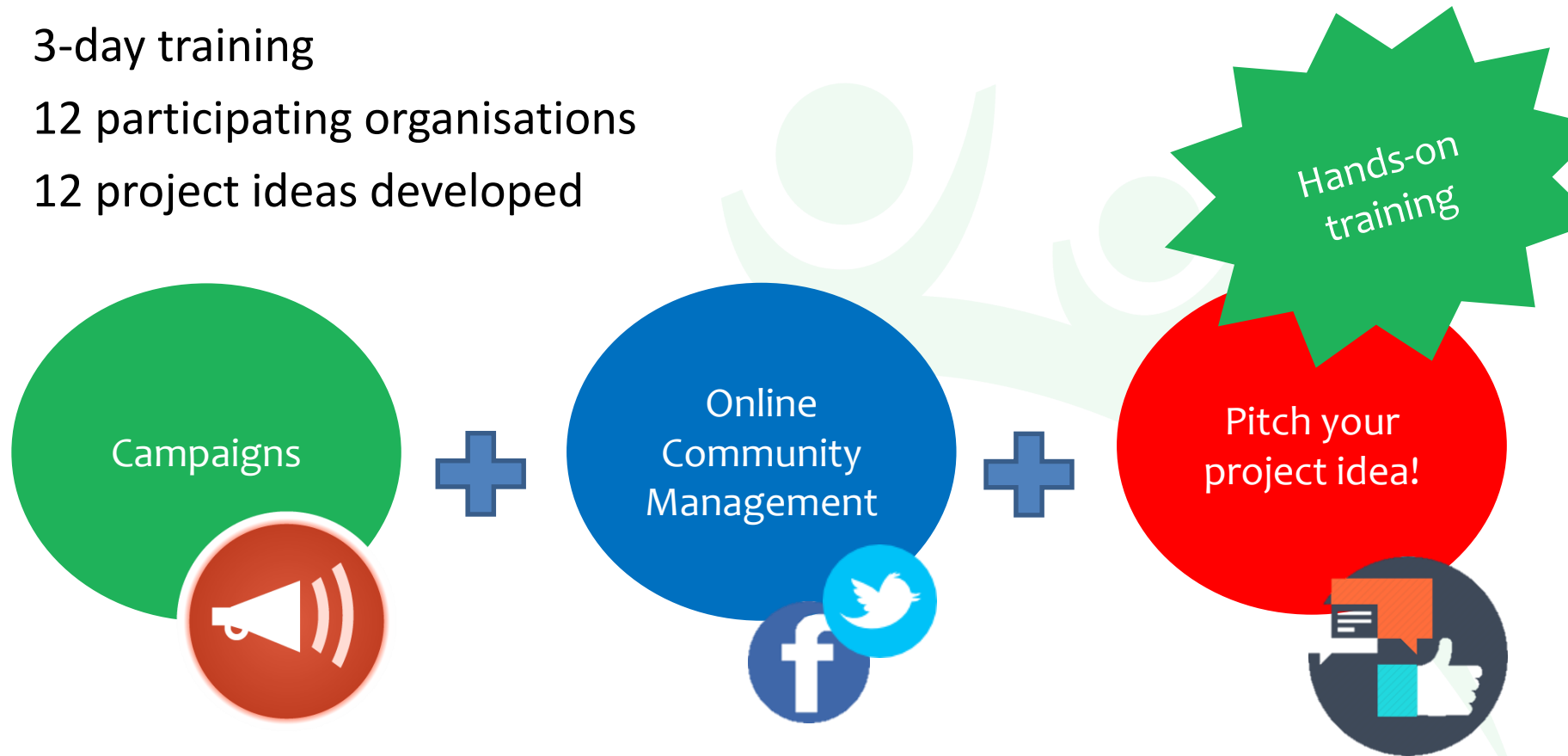
At national level: moving from organisational development to thematic trainings



EPF Capacity-Building in 2015

At European level: Strategic Communications

- 3-day training
- 12 participating organisations
- 12 project ideas developed



Evaluation and lessons learned

- Take more into **account the capacity and resources** of the participating organisations
 - **Need to adapt the training curriculum to the local context** and to simplify tools
 - **Flexibility with the approaches** used and expected outcomes
- More face-to-face meetings
 - Shorter, practical, hands-on training
 - Accepting that... sometimes it takes time!



Communications

EPF Communications at a glance

EPF was represented at **190** events in 2015 and **4300** readers subscribe to our newsletter.



5.194 likes on Facebook
2.703 followers on Twitter

Our campaign videos were viewed **36.227** times and the campaign hashtag **#patientsprescribe** was used **1812** times.



EPF CAMPAIGN ON PATIENT EMPOWERMENT

Laurent Louette
Communications Officer

22/03/16

Brussels



#PatientsprescribE

@eupatientsforum

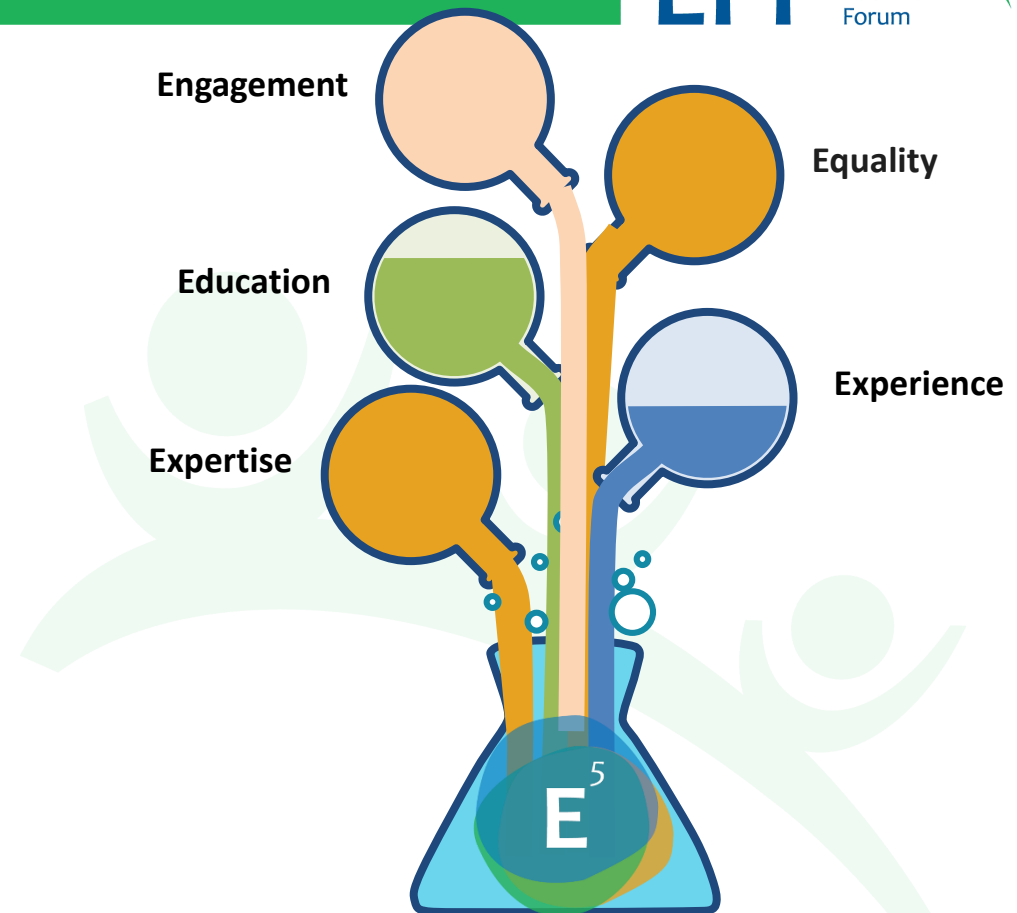
@laurentlouette

“ A STRONG PATIENTS’ VOICE TO
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Patients Prescribe E⁵

- 01 Education
- 02 Expertise
- 03 Equality
- 04 Experience
- 05 Engagement



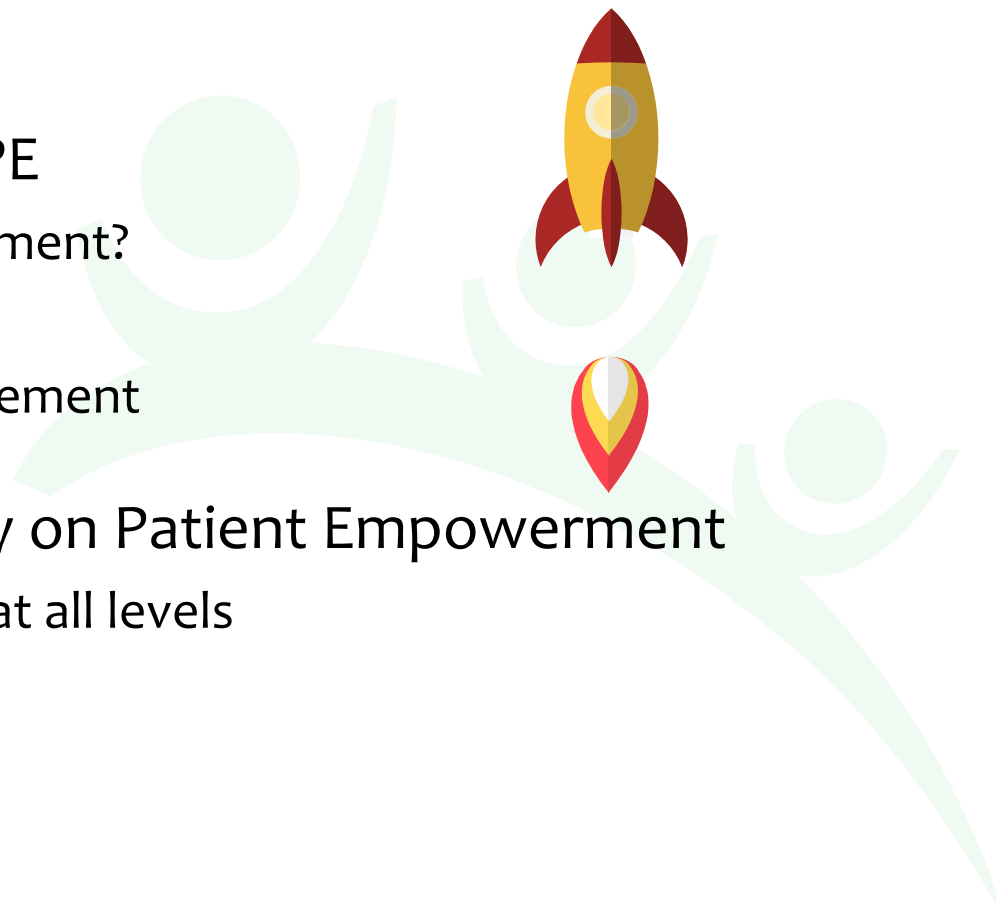
→ Patients prescribe E⁵ for Better Health Systems!

Patient Empowerment Campaign

Launched in May 2015

What were our objectives?

- Raise awareness about PE
 - What is Patient Empowerment?
 - Critical role of patients
 - Collective patients' involvement
- To call for an EU Strategy on Patient Empowerment
 - Advocate for integration at all levels
 - Share good practices
 - Propose concrete actions

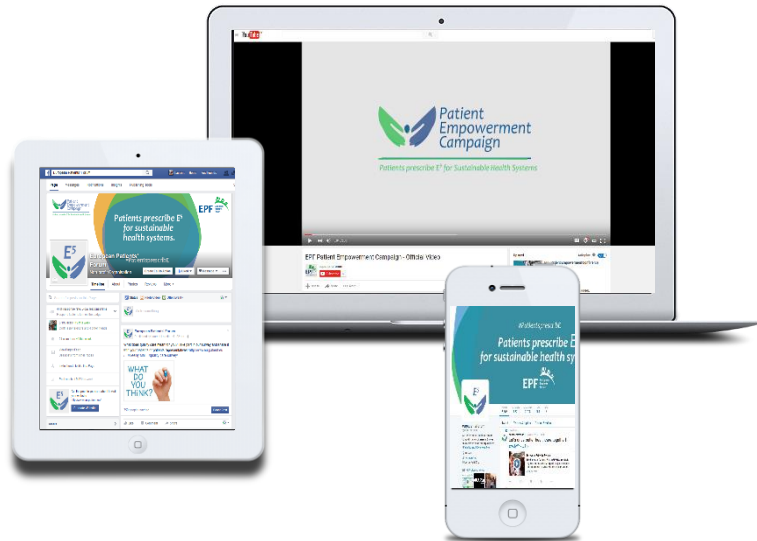


What did we achieve?

Campaign reach out

- The campaign was presented at **22 events** in **10 countries**
- EPF and supporters of the campaign helped raise awareness on the campaign with publications in different media. In total, the EPF campaign was mentioned in **35 articles/publications**

The campaign in numbers



193 pledge supporters



36.311 views in total for 8 campaign videos



1,873 tweets from 563 handles



Leaflet available in **18** different languages

2,167,289 Impressions

Next steps?



You can still get involved!

Share the campaign material and talk about the campaign

On social media



 #PatientsprescribE

At events



You can still get involved!

Campaign leaflet

The leaflet is available in many EU languages, send it to your contacts and share it on social media



You can still get involved!

Support the campaign pledge

Online

Act now for Patient Empowerment!



I believe that empowered patients can make a difference for the sustainability of healthcare systems. To make real progress, I call on decision makers to adopt an EU strategy on patient empowerment.

I stand with millions of patients and I prescribe E5 for better health systems.

Sign the pledge:

Full Name *

Name of Organisation

Country *

PLEDGE

Print



eupatientsforum @eupatientsforum · 5h
David supports our #PatientsprescribE campaign! And you? ow.ly/UeeBO



You can still get involved!



Write an article

EPF Website



Why Empowerment matters – a medical student's perspective



For a long time, doctors were the experts in healthcare. They knew what's wrong with the patient and there was little to no argument about their decisions and advice. But now this is changing, and some may fear it, because it questions what so far has been unquestioned.

Even though it might seem a little challenging from a doctor's perspective, it is invaluable to empower patients. Active patient empowerment

...knowledge that patients can be experts as well. They are the ones living with the daily searching for information on how to deal with their condition, so they often

...rs who are trained to know as much as possible about the human condition and admit that a patient knows more about their specific condition than



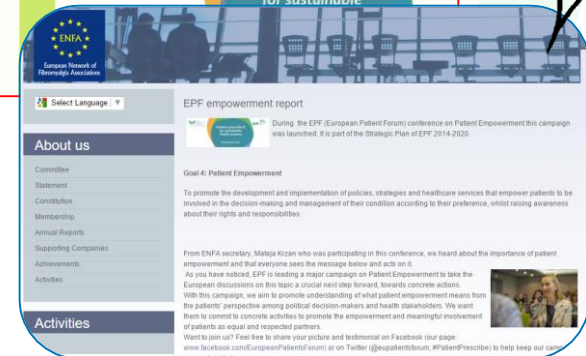
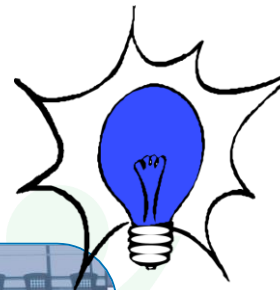
Your website!



A video on Patient Empowerment from EPF

Posted on October 27, 2013 by Lupus Europe blog

The European Patients' Forum launched their Patient Empowerment Campaign earlier this year. Here is the video accompanying the campaign and showing what patient empowerment might mean for different people.



How to engage in 5 steps

Share good practices

Good practices on patient empowerment

"Seize the moment - It is time to get patient empowerment onto the policy agenda."



As part of the EPF Patient Empowerment Campaign, we are collecting information on good practices that aim to promote patient empowerment at different levels and to gather more evidence on activities that are already happening in Europe.

To go to the data collection form click [here](#).

What is the objective of collecting information on good practices?

The objective of collecting information and good practices on patient empowerment is to enable EPF to gather more evidence on the good practices that are already happening in different parts of Europe, initiated by different stakeholders. Eventually, we aim to share the information via an online repository, as inspiration for others who may wish to take action.



THE PATIENT EMPOWERMENT CHARTER

Kaisa Immonen-Charalambous
Director of Policy

Brussels

22 March 2016

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

The Patient Empowerment Charter

“What really matters” to patients

1

I am more than my health condition

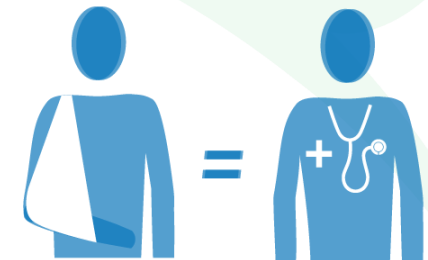


2

I am empowered to the extent I wish to be

3

I am an equal partner in all decisions related to my health

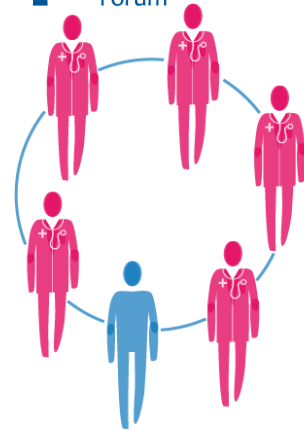


The Patient Empowerment Charter



“What really matters” to patients

- 4 I have the information I need in an easily understandable format, including my own health records
- 5 My health professionals and our health system actively promote health literacy for all
- 6 I have the ongoing support I need to manage my own care



The Patient Empowerment Charter

“What really matters” to patients

- 7 My experience is a vital measure of healthcare quality
- 8 I can participate in evaluating and co-designing healthcare services so they work better for everyone
- 9 Through patient organisations, my voice becomes part of a bigger, united voice
- 10 Equity and empowerment go hand-in-hand - I want a fair deal for all patients



Questions?



FINANCIAL REPORT FROM THE TREASURER

Radu Ganescu
EPF Treasurer

22.03.2016

EPF Annual General Meeting



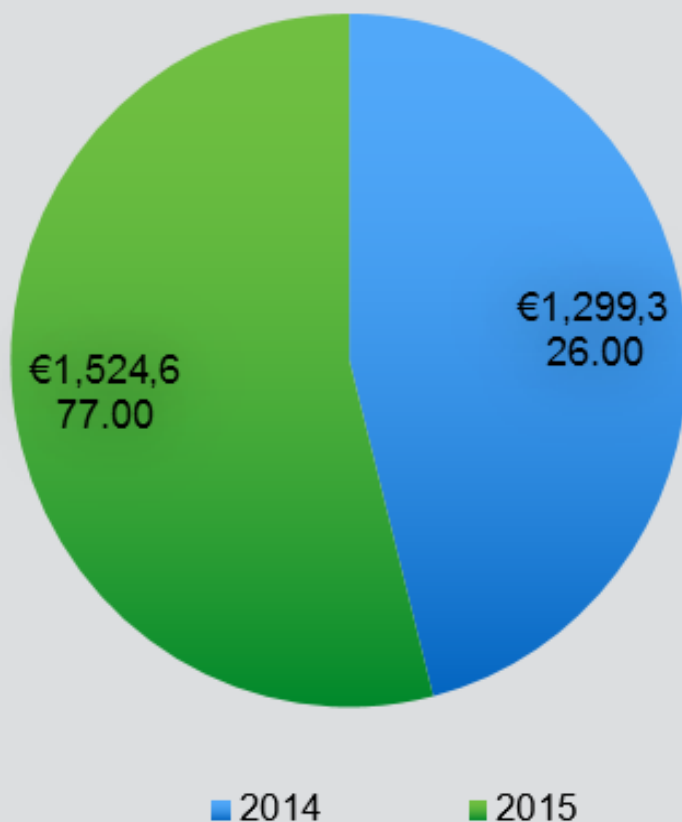
@eupatientsforum

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2015 Balance Sheet: ASSETS

ASSETS

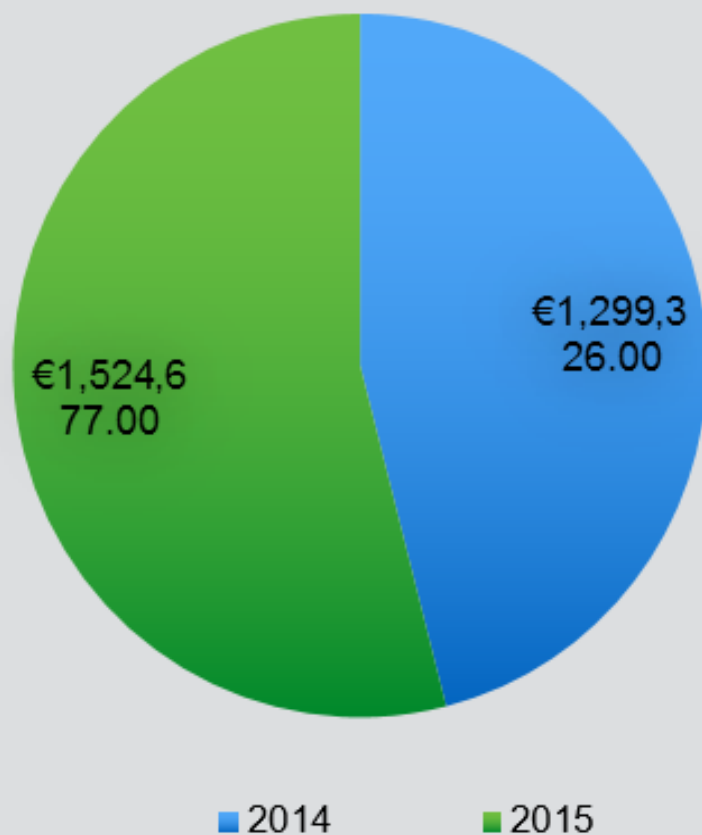


I Fixed Assets	2014	2015
Leasehold	48,474	44,438
Furniture, ICT, Equipment	23,783	21,802
Guarantees	50	50
TOTAL	72,307	66,290

II Current Assets	2014	2015
Accounts receivable	562,887	784,079
Cash in Bank	637,262	669,073
Prepaid expenses	26,870	5,235
TOTAL	1,227,019	1,458,387

2015 Balance sheet: LIABILITIES

LIABILITIES

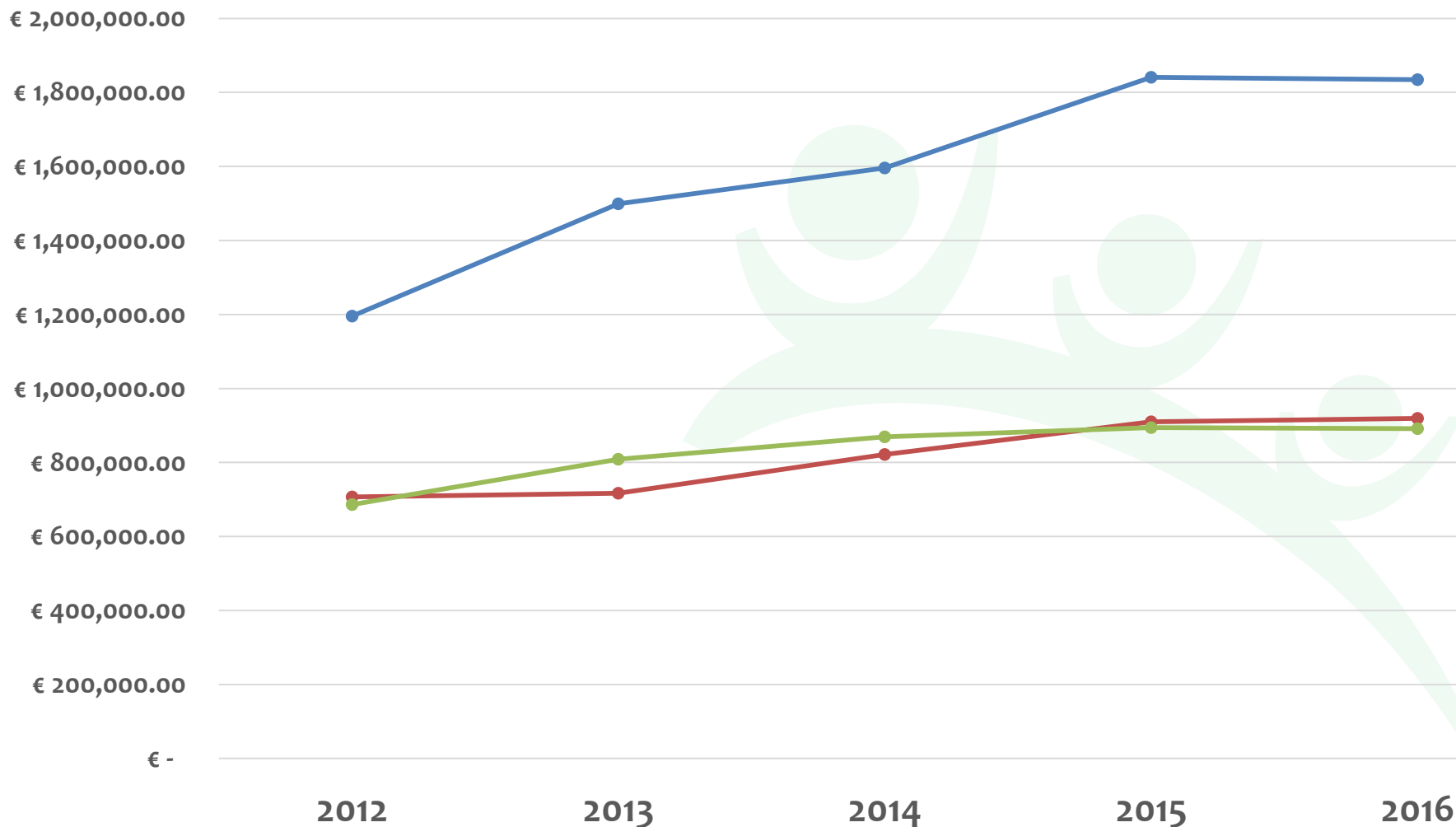


I Reserves	2014	2015
Funds brought forward	394,521	392,620
Surplus/Deficit	-1,901	112,887
TOTAL	392,620	505,507

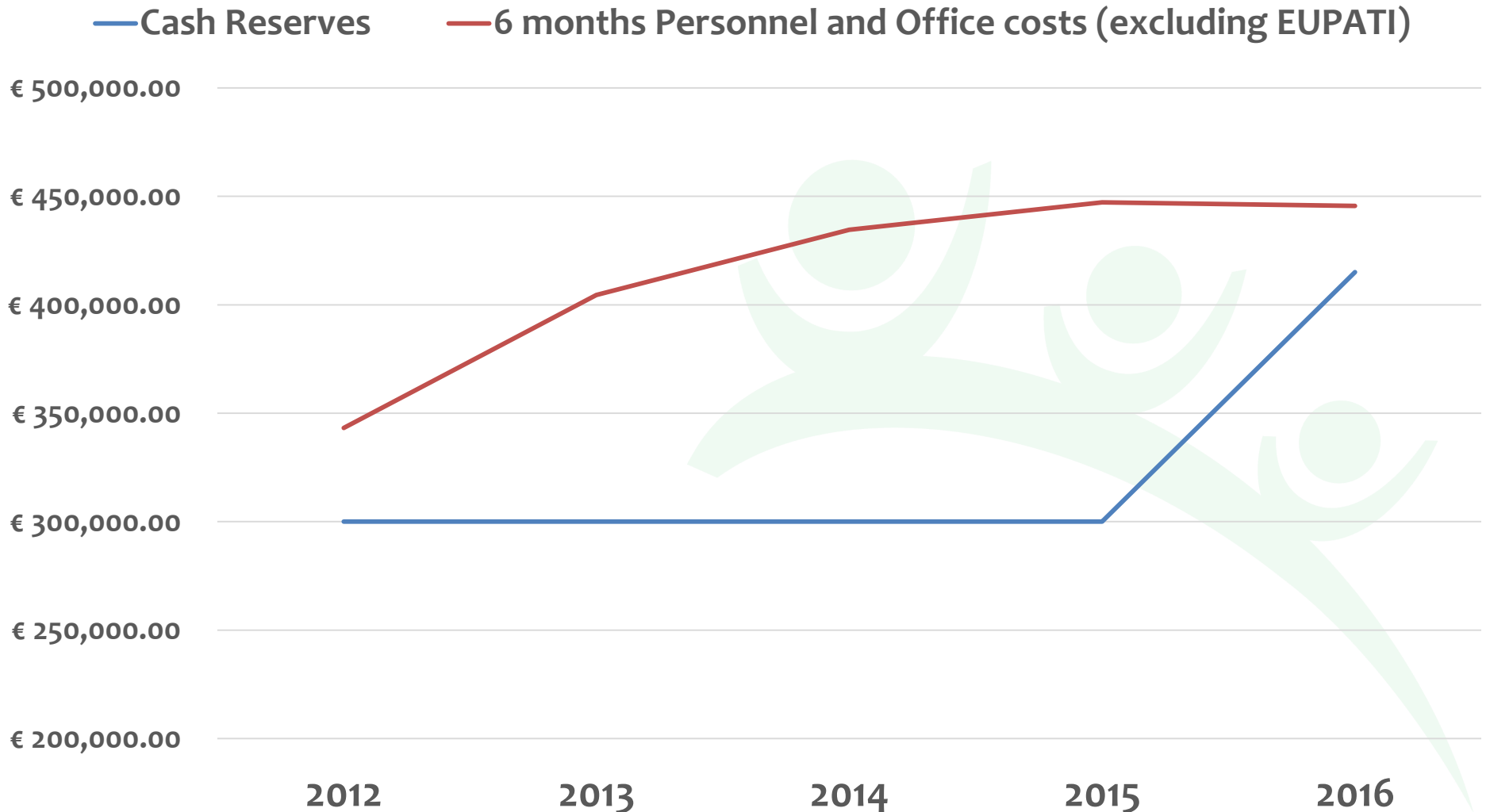
II Current Liabilities	2014	2015
Accounts payable	99,437	76,551
Deferred income	755,500	753,224
Income to be allocated to project partners	51,769	189,395
TOTAL	906,706	1,019,170

Evolution EPF budget 2012-2016

—●— Total EPF expenditures —●— TOTAL OG —●— Personnel and Office costs (excluding EUPATI)



Evolution cash reserves vs 6 month reserve policy 2012-2016



2015 expenditures: budget vs. actuals

Budget line	2015 budget	2015 actuals
Operating Grant	EUR 910.265	EUR 913.802
EU project (including EUPATI)	EUR 493.740	EUR 471.238
Capacity Building Programme and Empowerment Campaign	EUR 367.271	EUR 141.282
Project development	EUR 64.586	EUR 53.464
Other costs	EUR 41.000	EUR 98.494
TOT	1.876.870	1.838.318

2015 INCOME

INCOME



TOTAL INCOMES

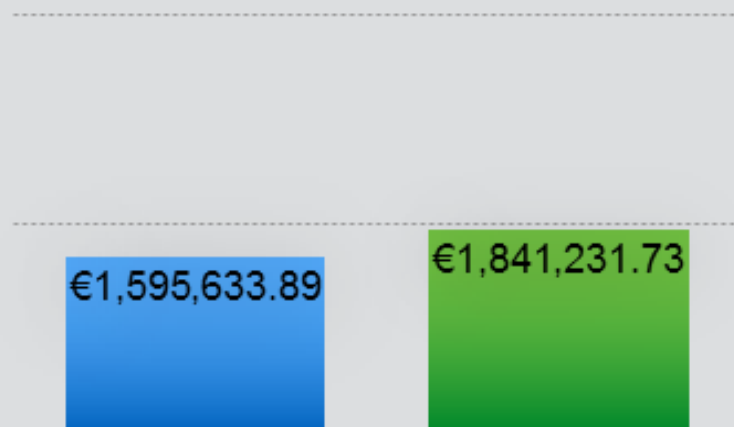
■ 2014 ■ 2015

	2014	2015
Membership fees & Bosch Foundation		
Operational Work Programme	11,000	11,000
Contribution to EU projects	3,650	4,132.31
R. Bosch Foundation Grant to Empowerment Campaign	-	125,000
TOTAL	14.650	140,132.32

	2014	2015
Funding Public Sector		
Operational Work Programme	653,966	728,212
EU Projects	164,180.54	97,060.59
EUPATI (IMI JU contribution)	229,748	262,397.62
TOTAL	1,047,894.54	1,087,670.21
Funding Private Sector		
Operational Work Programme	156,500	171,000
Co-Funding to EPF Projects	145,815.06	49,595.65
Projects Developments/Other Costs	-	248,011.24
Capacity Building Programme	120,943	141,282.34
Contribution to EPF Empowerment Campaign	-	34,586.61
EFPIA contribution to EUPATI	78,777	60,856.11
TOTAL	502,035.06	705,331.95

2015 EXPENDITURES

EXPENDITURES



TOTAL EXPENDITURES

■ 2014

■ 2015

ADMINISTRATION COST	2014	2015
Staff Costs	975,018.51	966,587.13
Office Costs	169,334.61	176,220.78
Depreciation	18,898	14,239.39
Travel	53,816.67	58,645.98
TOTAL		

EVENTS	2014	2015
Annual General Meeting	61,574.14	41,664.34
Regional Advocacy Seminar	-	35,909.49
Youth Meetings	8,265.46	13,759.07
Patients Evidence Workshop	12,227.24	-
Capacity Bulding Programme	108,356.75	105,773.27
Cross-Border Healthcare Regional Events	80,760.18	79,089.36
Development of New Projects/ Other Costs	-	235,856.16
EPF Campaigns	106,186.38	112,841.21
Bank and Financial Charges	1,195.95	645.55
TOTAL		

EPF MEMBERSHIP

Camille Bulot

Membership & Stakeholder Relations Manager

Brussels

22 March 2016

“ A STRONG PATIENTS’ VOICE TO
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4 New Membership Applications



Dystonia Europe



International Federation for Spina Bifida and Hydrocephalus

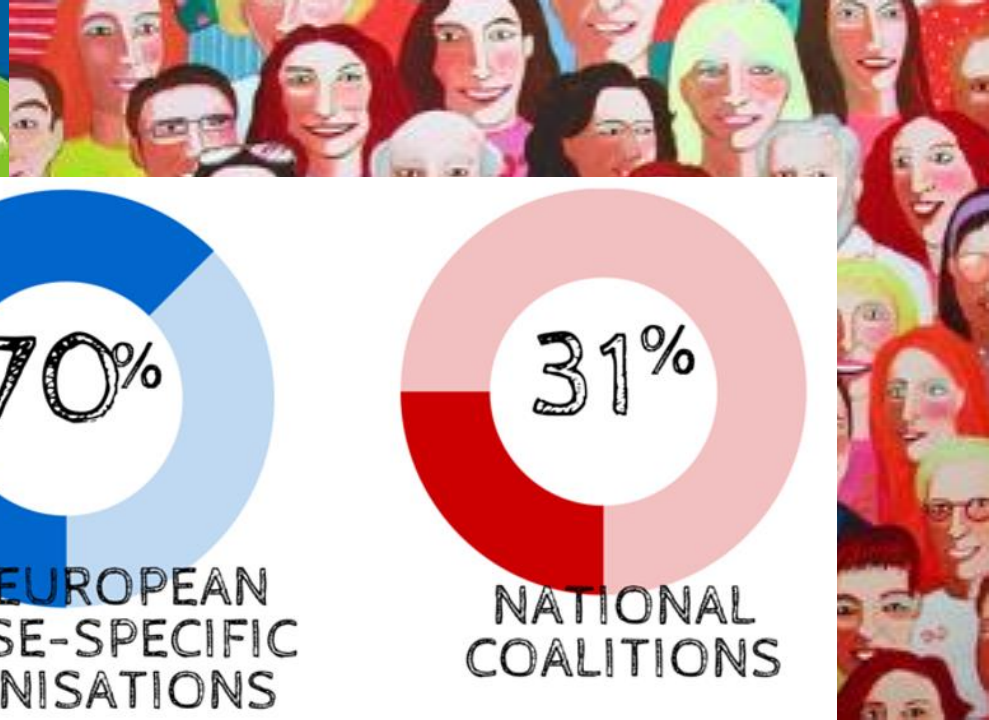


International Bureau for Epilepsy

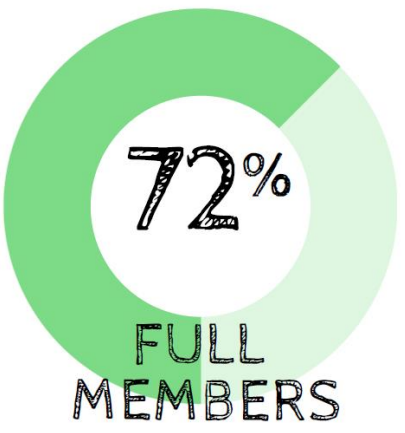
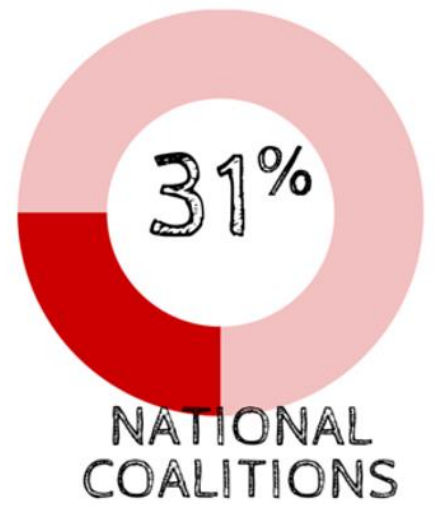
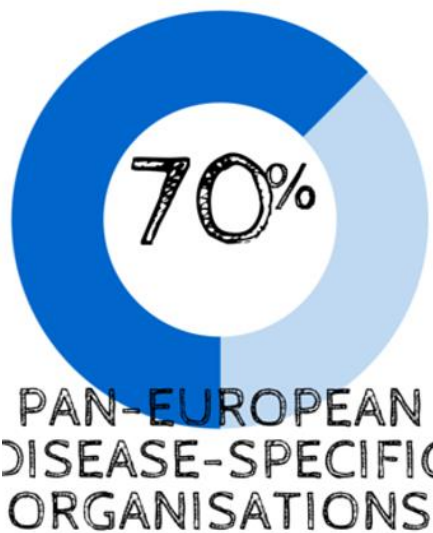


Alliance of Patient Organisations (FYROM)





67 MEMBERS





10 REASONS to be a member of the European Patients' Forum!



Attended/
spoke at 9
members'
events



20
Weekly
Coffees





EPF

European Patients Forum

EPF
A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

Skype Contacts Conversation Call View Tools Help

Camille EPF
Skype me for a Weekly Virtual...

Search

Home

Call phones

CONTACTS RE

Kirsten
23:35

ng contact o

THE YEAR AHEAD: 2016 WORK PLAN

Nicola Bedlington
EPF Secretary General

22.03.2016

EPF Annual General Meeting



@eupatientsforum

“ A STRONG PATIENTS’ VOICE TO
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Access

Strengthening our knowledge on health inequalities

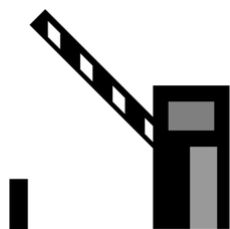
- In 2016 the Working Group will work towards developing a survey on patients' access to healthcare
- Questions designed by patients, for patients
- Gaining more knowledge on current situation as to access for patients in the EU
- Contributing to the Patient Access Partnership



**Evidence
based**

A campaign to call for a fair access EU strategy

In the 2nd Semester 2016, EPF will develop a campaign on access to health and social care to be launched in 2017:



Identify concrete
barriers



Show the “human
face”



Collect good
practices



Patient centred
recommendations

Calling for
action

Anti-discrimination

- **Building relationships** with organisations and EU decision-makers active in the field of education and employment
- Launch of an EPF **internal task force** on inclusiveness in patient organisations
- Collaboratively with fundamental rights NGOs we will develop an internal **roadmap for inclusiveness in patient organisations**



Focus on patient safety and quality of care

- **EPF Survey on quality of care** from the patients perspective to contribute to debates on Health System Performance Assessment
- **Smartcare:** piloting integrated care services
- Building capacity on medical devices and in vitro diagnostics through a series of **factsheets**
- Continuing commitment to **patient safety** as a priority at EU level



Building and sharing expertise

Empowerment

Information to patients

- Review of "core quality criteria" (2008)
- Synergies with other areas:
 - Clinical trials
 - (e) Health literacy
 - Patients' rights
 - Shared decision-making
 - Self-management
- EPF position on quality of information



Patients' rights... and responsibilities?

- Participatory model of medicine
 - Patients, consumers, citizens...
 - Discourse on individual responsibility for health
 - Building on EC report, various lists of patient rights
 - EPF Working Group – consultation paper
- ➔ Consensus position on rights and responsibilities



"You have to learn about thousands of diseases, but I only have to focus on fixing what's wrong with ME! Now which one of us do you think is the expert?"



Finalisation of draft paper

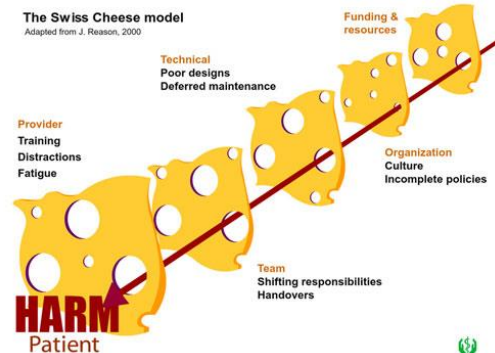
- ✓ Exploring the potential of technology to support patient empowerment
- ✓ Building on evidence from several projects – Renewing Health, SUSTAINS, Chain of Trust + Policy Advisory Group and Empowerment Working Group



Patient empowerment in safety

- Need for change in healthcare practice and culture, including **real partnership** with patients
- **Patient involvement** can improve safety and quality of care
- Major **high level conference**
➔ Launch of process to develop **core competencies** for patients and families (implementing CR 2009)

“When I read through my medical record, I found two mistakes!”



“Safety for patients includes medicines and devices - patient safety and regulatory bodies need to talk to each other.”

Capacity-Building

A programme in constant evolution

At national level

- Thematic modules + mid-term assessment of strategic plan developed in 2012-2013
- Slovakia: partnership with the local trade association



At European level

- July: Training module on patient safety, in link with our Conference
- September: Training module on transparency, codes of conduct, and definition of bona fide patient organisations



Capacity Building in 2016

Making the link between strengthening patient movement and our advocacy work

- **Organisational development allows us to do meaningful thematic trainings**
- **Synergies between EUPATI and CBP**, especially in countries where we have EUPATI national platforms!
- At European level: training on key areas to reinforce our advocacy work



EPF Leadership meeting 2016

Key messages

1

Financial sustainability a key issue for EPF and its members

→ Creation of a working group on sustainability to prepare the mid-term review of the PHP and develop a long-term strategy



2

There are synergies between the advocacy work of EPF members: let's share good and bad practices even more

→ Online platform a good place for that?



3

We need to work even more towards the recognition of patient organisations as crucial contributors to the public health debate



EPF BUDGET 2016

Walter Atzori, Director of Programmes &
Operations

Brussels

22 March 2016

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

EPF 2016 Budget: main features

- **Continue to receive an Operating Grant** (2nd year under the Framework Partnership Agreement with the EC)
= 50% of our budget = EUR 919.557
 - **Funding structure same as previous years 80% EC funds, 19% Corporate Sponsorships, 1% membership fees**
 - **What does the OG cover?**
 - Policy advocacy work
 - Costs linked to administration, operations, IT and finance – related costs
 - Communication and membership
 - External representation
 - Core events (AGM, Regional Advocacy Seminar, Patient Safety Conference, Internal meetings - PAG, Working Groups)
 - Youth Group activities

EPF 2016 Budget: main features

- **EUR 40.000** carry over from 2015 (Capacity Building Programme, project development and Empowerment Campaign)
- **EPF staff in 2016 :**
 - Staff 12.5 Full Time Equivalents (FTE), including EUPATI Munich-based secretariat and Communications Officer
 - 13 people in the Brussels Secretariat (two being recruited) + 4 people EUPATI + Youth Intern

EPF Budget 2016 - overview

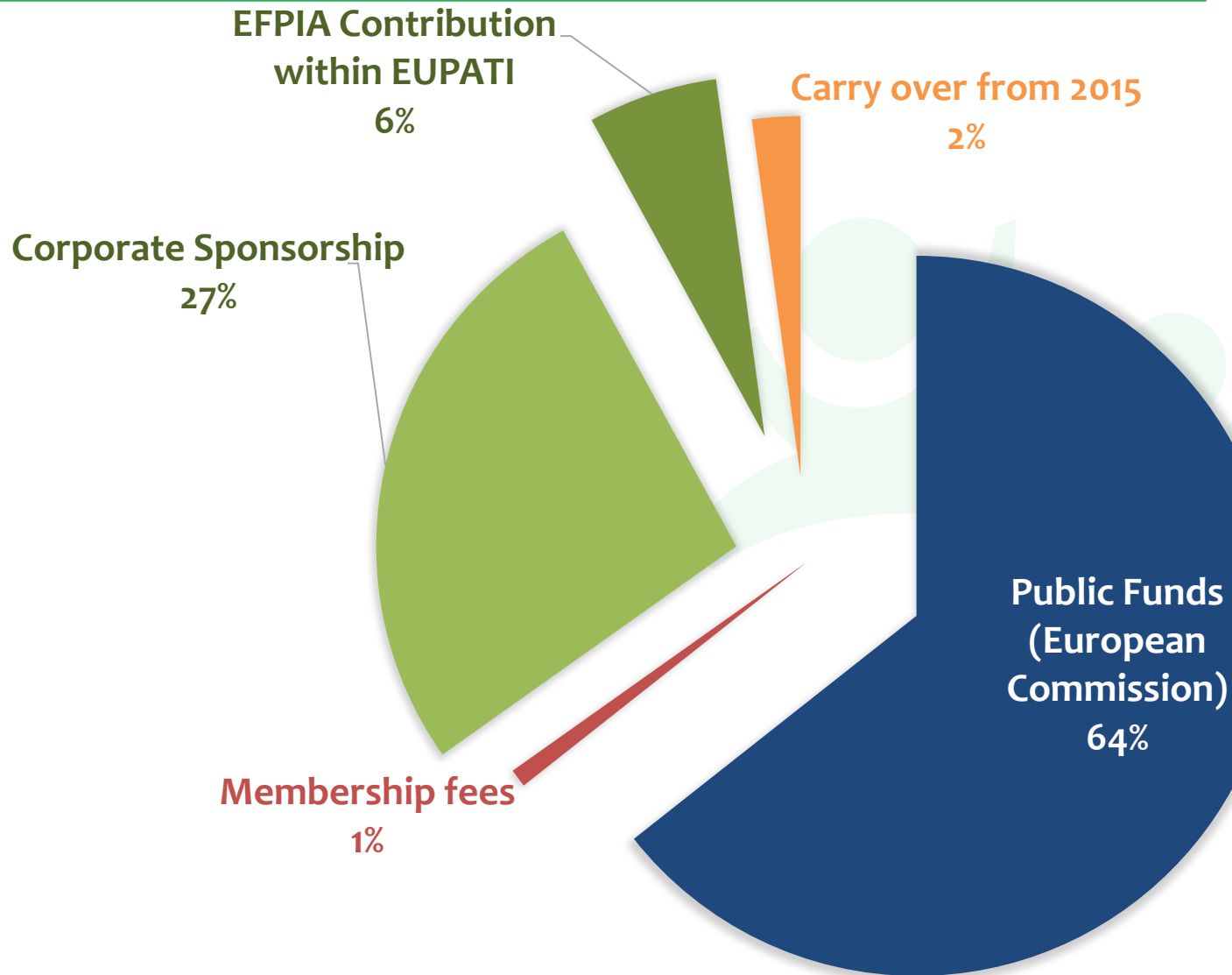
EXPENDITURES

Cost category	TOTAL	as %	Operating Grant	Capacity Building Programme	EUPATI	Other EU Funded projects	Empowerment Campaign	Access Campaign	Project Development	Other
Personnel costs	€ 962,167	52%	€ 415,541	€ 58,045	€ 271,285	€ 142,489	€ 26,998	€ 19,425	€ 28,385	
Administrative Costs	€ 209,148	11%	€ 209,148							
Mission costs of EPF Staff	€ 58,492	3%	€ 8,192	€ 6,000	€ 28,000	€ 14,200			€ 2,100	
Costs relating to operations (running of events, meetings, impelmentation of the CBP, etc)	€ 481,191	26%	€ 286,311	€ 90,000	€ 65,000	€ 9,880	€ 20,000			€ 10,000
Subcontracting	€ 101,000	6%		€ 75,000	€ 15,000	€ 11,000				
Other costs	€ 22,500	1%			€ 22,500					
TOTAL 2016	€ 1,834,498	100%	€ 919,192	€ 229,045	€ 401,785	€ 177,569	€ 46,998	€ 19,425	€ 30,485	€ 10,000
Comparison 2015	€ 1,841,232		€ 913,226	€ 141,282	€ 323,254	€ 147,985	€ 159,587	n/a	€ 53,464	€ 102,434

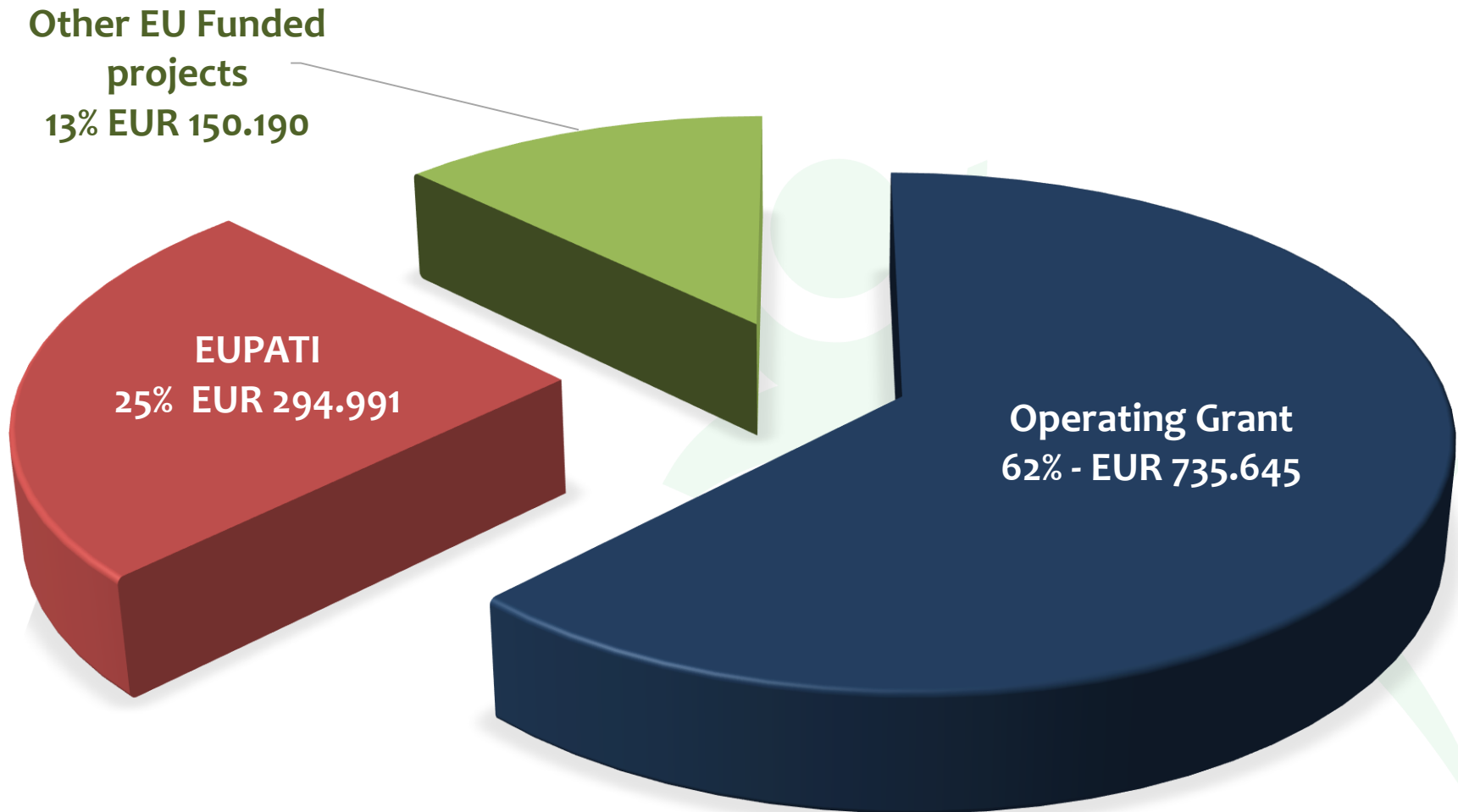
INCOME

Cost category	TOTAL	as %	Operating Grant	Capacity Building Programme	EUPATI	Other EU Funded projects	Empowerment Campaign	Access Campaign	Project Development	Other
Public Funds (European Commission)	€ 1,180,825	64%	€ 735,645		€ 294,991	€ 150,190				
Membership fees	€ 15,000	1%	€ 11,000				€ 4,000			
Corporate Sponsorship	€ 492,300	27%	€ 172,547	€ 205,315		€ 27,379	€ 32,584	€ 19,425	€ 25,049	€ 10,000
EFPIA Contribution within EUPATI	€ 106,794	6%			€ 106,794					
Carry over from 2015	€ 39,579	2%		€ 23,730			€ 10,413		€ 5,436	
TOTAL 2016	€ 1,834,498	100%	€ 919,192	€ 229,045	€ 401,785	€ 177,569	€ 46,998	€ 19,425	€ 30,485	€ 10,000
As % of total budget	100%		50.1%	12.5%	21.9%	9.7%	2.6%	1.1%	1.7%	0.5%

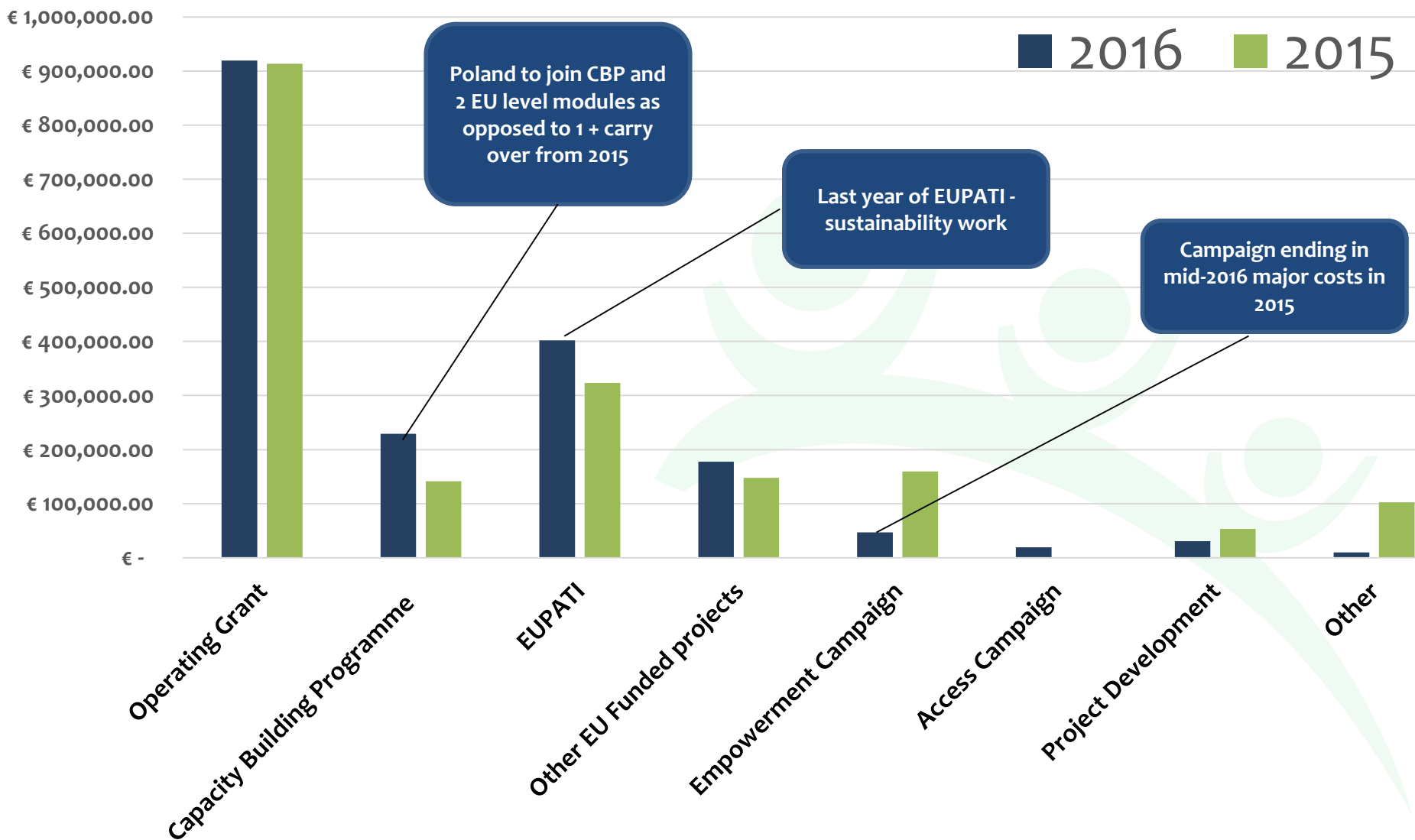
EPF Income 2016



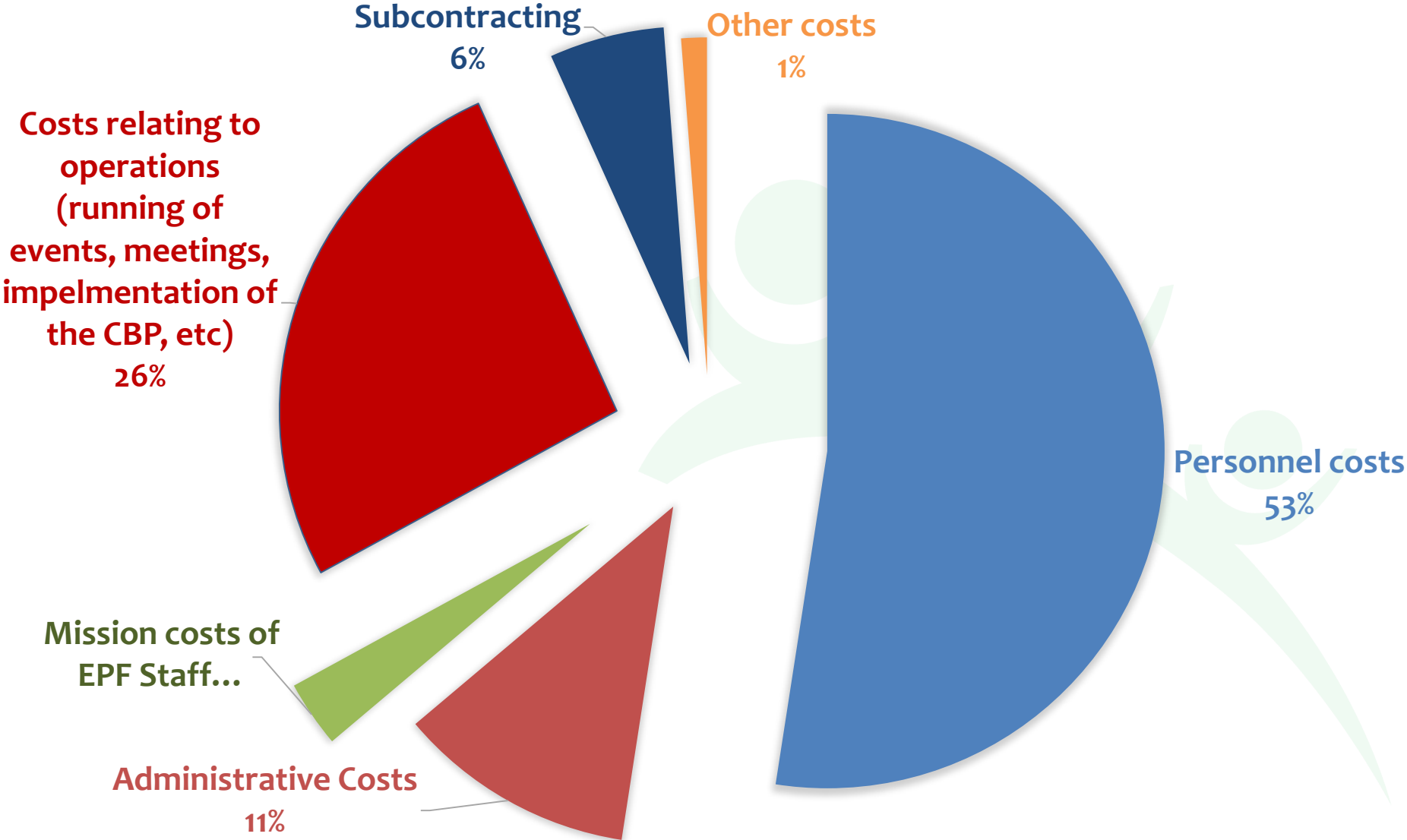
EPF Income 2016: public funds



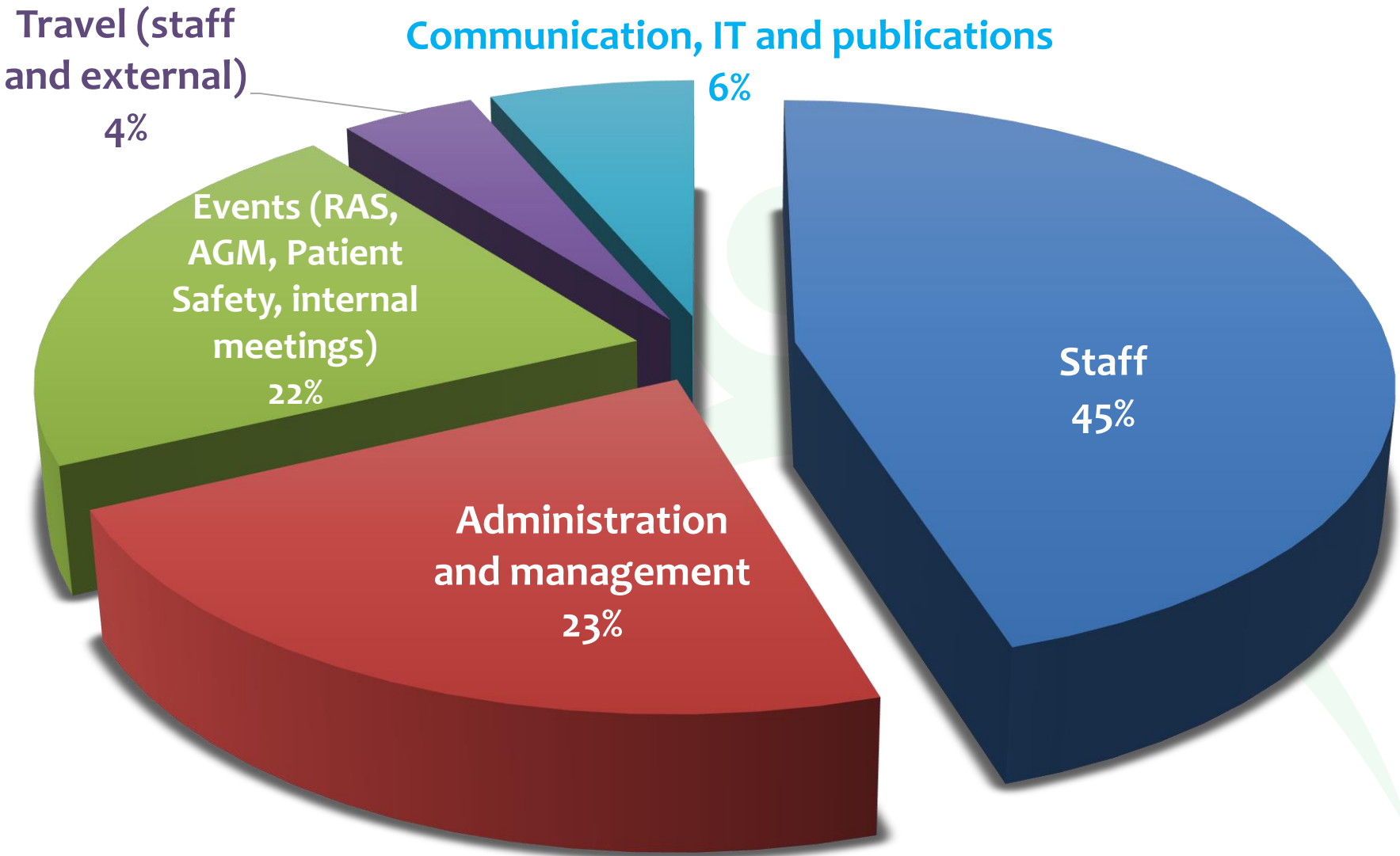
2016 Expenditures: overview



2016 Expenditures by type



Operating Grant 2016 expenditures

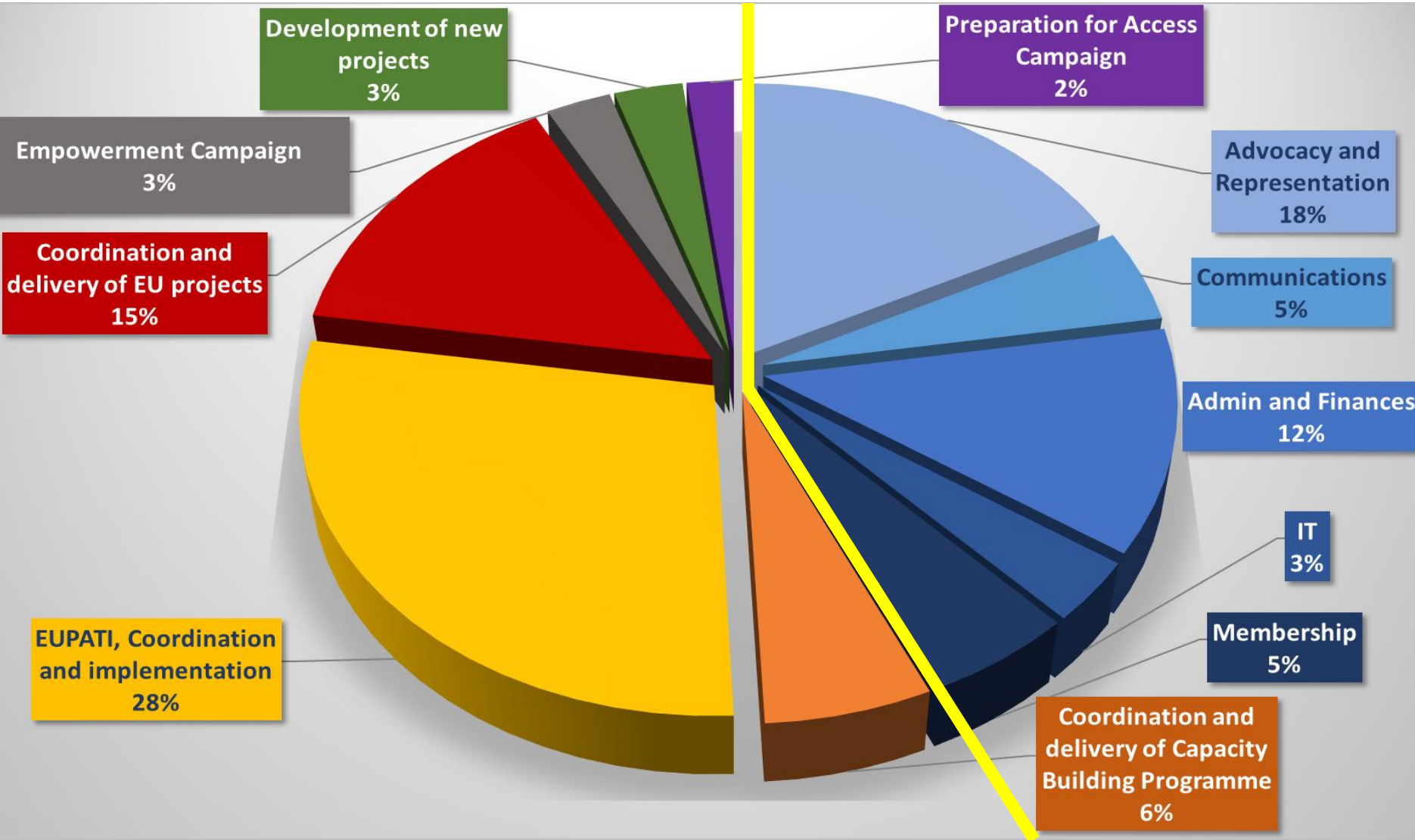


2016 Staff costs by activity



EPF

European Patients Forum



MATCHMAKING SESSION

Véronique Tarasovici, Event & Office
Manager

Brussels

22 March 2016

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

EPF Matchmaking session

Tables

- Empowerment - 2 tables
 - Access – 2 tables
 - Patient safety – 1 table
 - Discrimination – 1 table
 - Membership Engagement – 1 table
-
- **Your preferred table is indicated on your badge**



Objective

- Get to know the work of other members
- Identify synergies between your own work plans
- Start a cooperation together

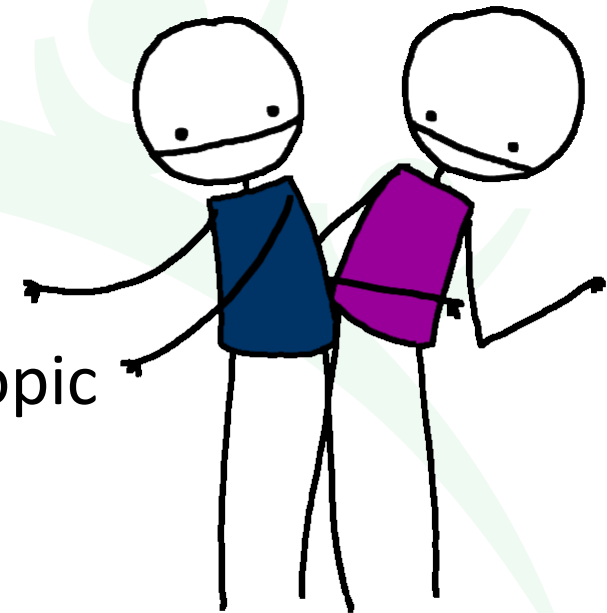
Reporting back

3

main issues/challenges on the topic

3

ideas for actions together



EUROPEAN PATIENT'S FORUM Annual General Meeting 2016

Brussels

22-23 March 2016

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