

EUROPEAN PATIENTS FORUM

Annual General Meeting

2018

14/04/18

EPF Annual General Meeting

 @eupatientsforum

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

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1. OPENING

Marco Greco
EPF President

14/04/18

EPF Annual General Meeting

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2. APOLOGIES

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3. APPROVAL OF THE MINUTES OF THE LAST AGM

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EPF President

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4. ANNUAL REPORT 2017 FROM THE BOARD AND THE SECRETARIAT

Nicola Bedlington
EPF Secretary General

14/04/18

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PATIENT ACCESS

AND

FIGHTING INEQUALITIES

EPF Campaign on Access to Healthcare

With input from **EPF's Working Group on Access**, we implemented a campaign:

- **Driven by members:** with related advocacy tools, including a toolkit for EPF members and a petition which was signed by 571 signatories.
- **With a strong political resonance:** two high-level meetings on Access to Healthcare (Commissioner Andriukaitis and the MEPs champions attended the final event).
- **Development of awareness-raising materials:** two factsheets – one on the campaign and the second illustrating a snap shot of the Roadmap.



**Universal Health Coverage
For All.
#Access2030**

Policy Dossiers & Projects

Access to Medicines



Cross-border Healthcare



Patient Safety and Quality of Care



Social Inclusion and Non-discrimination



Health Technology Assessment (HTA)



Medical Devices and In Vitro Diagnostics Regulations



**Implementing Good Practices
for Chronic Diseases**



Accelerated Development of Appropriate Patient Therapies a Sustainable, Multi-stakeholder Approach from Research to Treatment-outcomes

Patient Access Partnership - PACT

EPF is a founding member of the Patient Access Partnership (PACT), a patient-led multi-stakeholder network:

- contributed to setting up the European Parliament Interest Group on Patient Access to Healthcare;
- launched initiative with 80+ MEPs supporting statement for continued EU action in health;
- supported EPF campaign on Access to Healthcare.



2 country stakeholder meetings

Events at the European Parliament



PATIENT EMPOWERMENT

EPF and the Working Group on Patient Empowerment:

- Developed a Toolkit to support patient organisations in their advocacy on patient empowerment;
- Built on the Charter and Roadmap;
- Continued outreach and advocacy activities on patient empowerment to explore possibilities for action in areas such as patient-centred skills development.



Health Literacy and Information to Patients



Information to patients on Food and Nutrition



Digital Health, Big Data and Personalised Medicine



Clinical Trials



Pisce and PRO STEP

On self-management

prefer.
PATIENT PREFERENCES

On patient-preferences in decision making during the drug life cycle

Project: EUPATI



The 'new' EUPATI programme began under the management of EPF, continuing as a public-private partnership, with a focus on core activities including the **Patient Expert Training Course**.

The course:

- 3rd cycle launched in September, 60 trainees;
- Topics: drug discovery, non-clinical and clinical development, regulation, and HTA.
- Train the Trainer capacity-building event for 44 EUPATI alumni on how to transform the tools provided by EUPATI into training tools on a disease specific or national level.

The outreach:

- EUPATI continued to attract global attention with new partnerships with patient organisations and academia in **Brazil** to adapt the programme for their own needs.

EUPATI IN NUMBERS

60 trainees from 28
countries for 2017/2018

7 educational webinars

96 EUPATI Fellows

408,000 users on the EUPATI
website

3,300 mailing list members

2,496 Facebook fans

4,714 Twitter followers

The future:

- The **EUPATI Futures Team** will be working diligently to deliver a sustainability proposal for the future of EUPATI for the coming years.
- EUPATI will continue to maintain its mission to increase the capacity and capability of patients to understand and contribute to medicines research and development also improve the availability of objective, reliable, and patient-friendly information for the general public.



A VIBRANT
NETWORK

Mid-term review of our Strategic Plan

- **Our new Vision**

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

- **Our new Mission:**

Our mission is to be the collective, influential patient voice in European health and related policies and a driving force to advance patient empowerment and patient access in Europe.

April 2017 –
Leadership meeting
Collective reflection

June 2017 – Launch
of written consultation

September 2017 – End
of written consultation

February 2018 –
Integration of changes
Finalisation of document

Europe needs more, not less health



#EU4HEALTH campaign

What do we want?

- EU action on health that fosters **cross-country collaboration**, complements the action of Member States and supports them in addressing the unprecedented challenges the EU is facing;
- **Strong leadership for health**, and a dedicated Directorate in the European Commission;
- **Health included in the future budget** of the EU.

#EU4HEALTH AT A GLANCE

234 civil society and health-related organisations support the campaign

4 – the number of letters we sent to EU Officials (President Juncker, Vice-President Timmermans).

70% - of EU citizens want the EU to do more for health, according to a recent Eurobarometer survey.

Added Value of Patient Organisations

Patient organisations: the untapped potential of healthcare systems!

Report on the Added Value of Patient Organisations

Objective: to highlight the value of patient organisations as legitimate stakeholders in health-related policies.

The report identifies 4 main areas where patient organisations provide added value:

POLICY AND ADVOCACY

CAPACITY-BUILDING &
EDUCATION

PEER SUPPORT

RESEARCH, TECHNOLOGY
AND INNOVATION

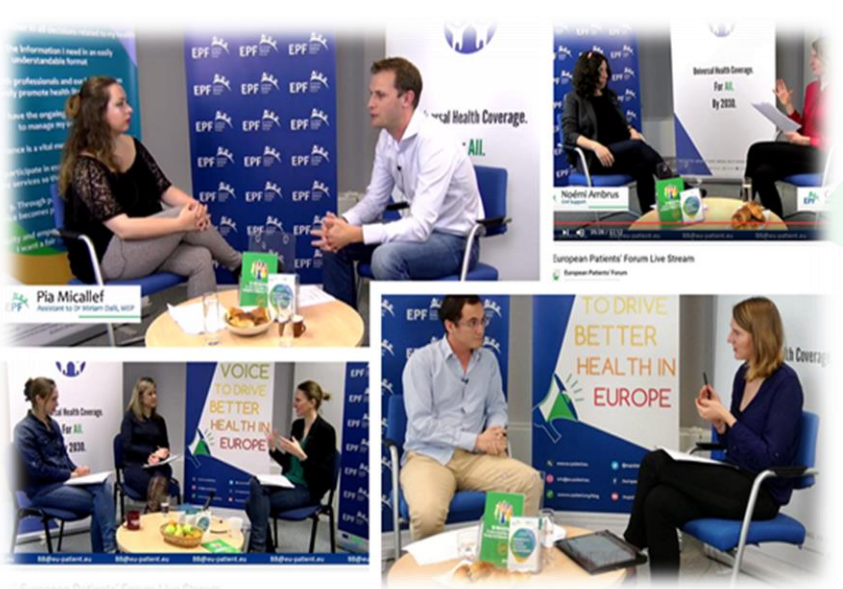


Challenges:

- Lack of resources & funding
- Credibility & alleged lack of independence;
- Professionalisation vs. representativeness;
- Overcoming the culture of tokenism;
- Lack of performance measurement – or rather lack of knowledge on how to measure the impact of patient organisations?

An innovative way of communicating with members

Video podcasts intended to help members to get the latest updates on European health policy and to receive practical advice to advance your organisation's knowledge and skills.



8 Breakfast Briefings in 2017:

- EPF campaign on Access;
- Transparency & Ethics for POs;
- Relationship with the European Parliament;
- European Solidarity Corps;
- HTA;
- Antimicrobial resistance;
- EU4Health Campaign;
- The added value of patient organisations.

National Coalitions Meeting

30 representatives from 28 countries!



The meeting focused on 3 objectives:

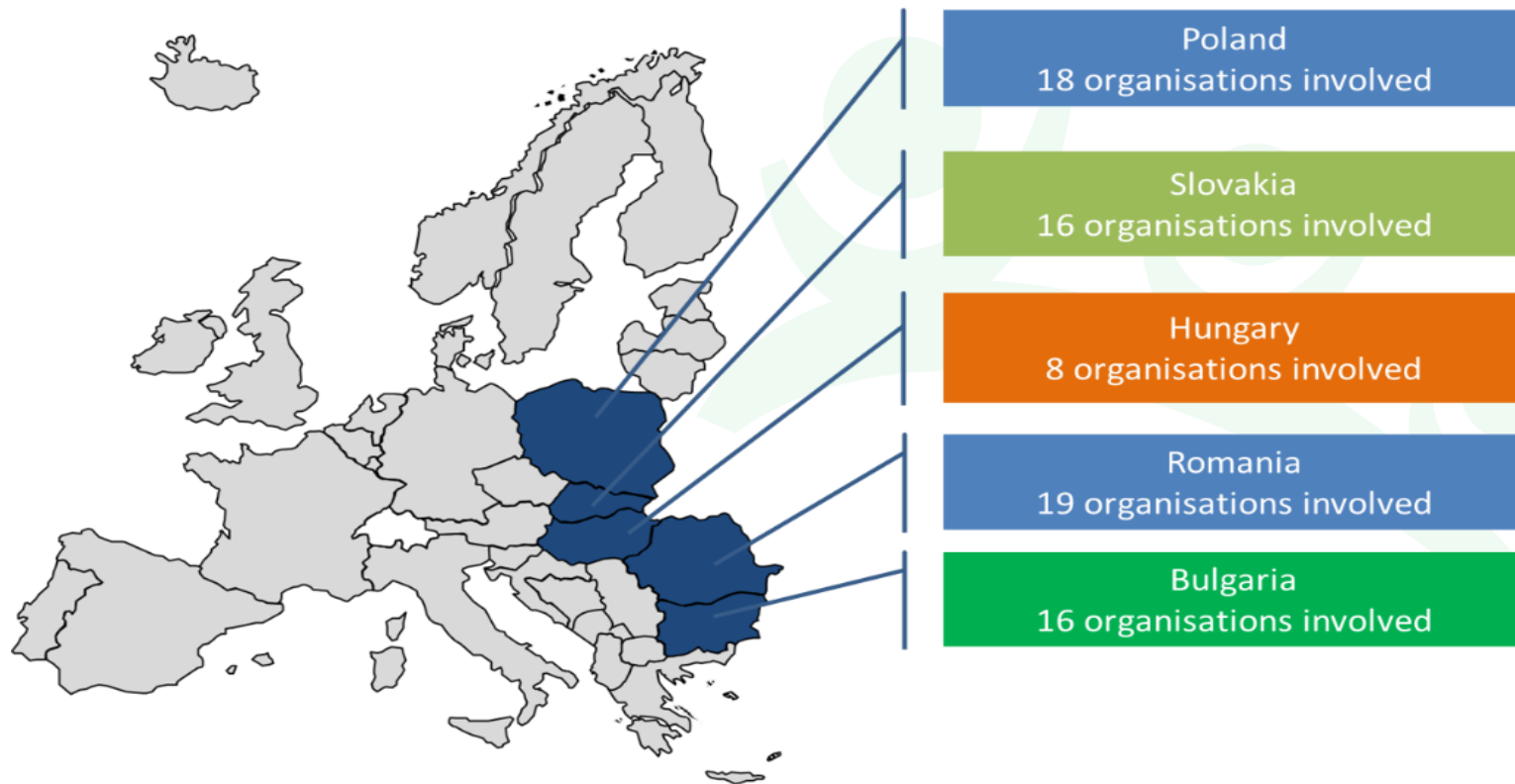
- developing the participants' knowledge of the EU;
- learning how to get involved in a European advocacy campaign;
- finding a common approach for advocacy for EPF and the national coalitions.

Participants shared **best practices in setting up and managing national coalitions** and took the floor proposing examples of the **DOs and DON'Ts in advocacy**.



EPF Capacity Building in 2017

At national level: thematic trainings



EPF Capacity Building in 2017

EPF Summer Training Course for Young Patient Advocates

The summer training:

- focused on **overcoming discrimination**;
- offered a **tailored high-quality training** to young patient advocates;
- about **advocacy** and maximising their **leadership** potential.



2017: Focus on Discrimination



- They produced a **factsheet and a video** to raise awareness of the discrimination faced by young patients with chronic conditions.
- They selected a **new Board**: Andreas Christodoulou is the new President.



- They were **speakers and panellists** at conferences, raising awareness about the special needs of young patients.

Membership

*The EPF membership counts **74 members**, strengthening the patient movement and its representativeness at the EU level!*



COMMUNICATIONS

EPF Communications in Numbers

3.500 readers of our newsletter



8.052 likes on Facebook

7.206 followers on Twitter

720 followers on LinkedIn

1.900.000 impressions on social media

45.900 unique visitors to EPF website.

3 Policy Factsheets

2 Video



5. EPF ROADMAP TO ACHIEVING UNIVERSAL HEALTH COVERAGE FOR ALL BY 2030

Katie Gallagher
Policy Adviser

14/04/18

EPF Annual General Meeting



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“How we can achieve universal health coverage for all”

2017 – Roadmap to achieve Universal Health Coverage for All by 2030

“These are our claims: we need to take action”

2017 - Campaign on Universal Health Coverage

2016- EPF Report on Access

“This is the situation we face”



“This is what Access means to us”



2015 - EPF Definition of Access: “the 5 As”

Campaign's Strategic Objective

The aim of the campaign was to contribute to making **universal access a reality for EU patients by 2030**, through **defining and promoting concrete actions, in concert with the health community**, to which decision makers need to commit, to ensure we achieve the **Health SDG by 2030**



**MISSION
ACCOMPLISHED**

Taking Action – A Roadmap to Achieving Universal Health Coverage for All by 2030

What is it about?



Leading the way to Universal Health Coverage – a reality where *everyone, everywhere* can access essential quality health care and services without facing financial hardship.

- Identifying outstanding **challenges, patients' concerns** and **unmet needs**.
- Providing **recommendations** on how to achieve UHC and what **actions** that need to be taken.
- Encouraging more **EU cooperation** and **inclusive approach** to **SDG implementation** to improve access to health.



- **Goal 3:** Ensure healthy lives and promote well-being for all at all ages.
- **Key target:** achieve **universal health coverage by 2030**, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.

“If we don’t get it right in the SDG on health, then there is a risk that the other SDGs will fail”

Nicola Bedlington



**SUSTAINABLE
DEVELOPMENT**

GOALS

Why does the Roadmap matter?


While **universal health coverage** is a well-recognised goal for all healthcare systems in the EU, this basic right is **not yet a reality** for all patients in the EU.

For this reason, such a Roadmap is needed.



Universal Health Coverage
For All.
#Access2030

- This Roadmap opens the way to achieving Universal Health Coverage for All, to ensure the rights of all patients are respected, to fight the inequalities that persist in health across the EU, and to make health a priority in all policies at national and EU levels.



*“Access to healthcare is a **basic human right** and should never be withheld in our society. Without equality in healthcare, we cannot obtain longer-term sustainable development” “Accessing quality healthcare is a problem for a large segment of the population and no longer a “minority” issue.”*

Katherine Wheeler, Vice-chair Lupus Europe

What is EPF advocating for?

- ✓ A **transparent, inclusive and collaborative** implementation of the UN SDGs;
- ✓ **Intersectoral action for health**;
- ✓ **Key elements and actions** described in the recommendations which reflect in their entirety the needs that are considered by patients to be **essential in attaining UHC**.



#Access2030



What do we want to achieve?

- *Inspire* and *motivate* decision makers and stakeholders to commit to UHC.
- *Guide* EU and MS when developing SDG implementation strategies and related policies.

Developed in dialogue with the EPF membership and wider health community



Everybody's business



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High-level Meetings

- ✓ February 2017:
Campaign Kick-off meeting

‘What are the unmet needs and barriers faced by patients?’

- ✓ December 2017:
Roadmap Launch and
Campaign Closing Meeting

‘What can be done to address these unmet needs and achieve UHC?’

OBJECTIVES



Recommendations - 5 Areas for Action



Providing access to **quality of care**



Committing to **sustainable investment** in health



Encouraging **affordability** of healthcare products and services

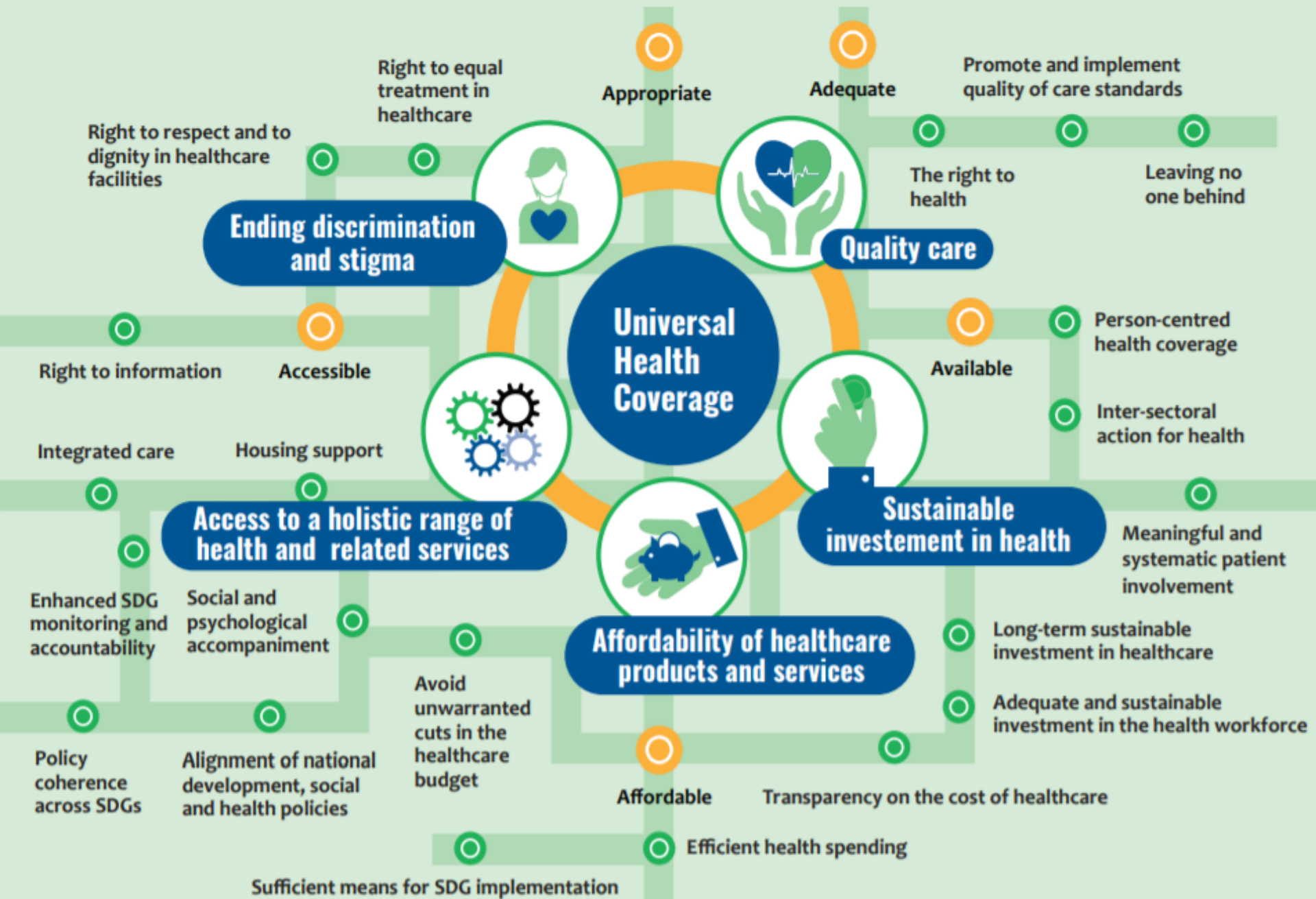


Implementing access to an **holistic** range of health and social services



Ending **discrimination** and stigma patients are facing in healthcare

The illustration below depicts 5 goals as well as complementary and interconnected key actions to accomplish in order to achieve UHC. These recommendations are described in further detail in the Roadmap.



Who is this Roadmap intended for?

- EPF will use this roadmap as a reference document for all our activities on access to health.
- EPF invites **EU and Member State decision makers** to consider this roadmap and its recommendations when developing related policies and UN SDG implementation strategies.
- EPF urges **patient organisations and civil society** to use this roadmap to engage with their governments, holding them to account for the implementation of UHC.



- EU and National SDG Implementation Strategies
- European Semester Country-Specific Recommendations
- Delivering on the EU Pillar of Social Rights

How to use this Roadmap?

How to use this Roadmap?

The roadmap serves as a guide to outstanding challenges, patients' concerns, unmet needs and recommended actions to achieve UHC for all patients.

[Y]OUR JOB



- ❖ When advocating for improved patient access to high quality health and related care to national and European policy-makers
- ❖ When engaging and holding national governments **accountable** to their commitments, as national ownership is key to achieving sustainable development
- ❖ Monitoring and reporting SDG progress
- ❖ National (parliamentary) meetings on Access – Cascade effect

- UHC Roadmap
- Factsheet: English, Bulgarian, Estonian, German, Hungarian, Latvian, Lithuanian, Maltese...
- Video


Political Opportunities

Advocacy in practice

- *Bait* (content) = **UHC Roadmap**
- *Hook* = **UN SDG framework**
- Advocacy Opportunities:



 EU and National **SDG implementation strategies, policies and plans.**

 **European Commission's mid-2018 strategy** for the implementation of the 2030 Agenda for sustainable development – June 2017 Council Conclusions on the EU response to the 2030 Agenda for Sustainable Development **EU Multi-stakeholder Platform.**

 **UN High-Level Political Forum (July):** Reviewing SDG progress / **SDG Anniversary (September).**



Political Opportunities continued

Advocacy in practice



EU Pillar of Social Rights – 20 principles and rights

Proclaimed by EP, EC and Council, November 2017

Improving enforcement + updating and complementing EU law where necessary + supporting social dialogue in the EU.

Principle 16: Health care

Everyone has the right to timely access to affordable, preventive and curative health care of good quality.

European Social Fund: support MS implementation of the Social Pillar



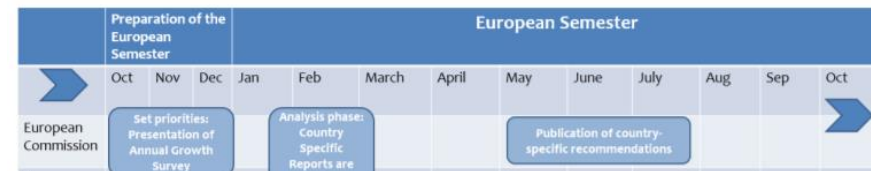
European Semester Process

Country-specific recommendations, May

Semester analysis and recs will put

emphasis on social considerations and follow-up on the Pillar

...



Next Steps

- Subsequent to our 2017 campaign, **equity of access** continues to be a **high priority** for EPF:
- New internal **working group on Universal Access to Healthcare**;
- Focus on the **implementation** of the **political steps and actions** highlighted in our Roadmap;
- Continue to raise awareness of **unmet needs and barriers** patients face in accessing healthcare;
- Support the **2030 Agenda** (SDG Watch Europe);
- While advocating for a **transparent, inclusive and collaborative implementation** of the UN SDGs and
- **Intersectoral action for health**
- **Milestones**: three events between now and 2030



‘EPF’s Roadmap Towards Achieving Universal Health Coverage for All by 2030, will feed into the Commission’s broader reflection ‘towards a sustainable Europe by 2030’.

EU Commissioner for Health Vytenis Andriukaitis

6. FINANCES

Budget 2017

Radu Ganescu
EPF Treasurer

14/04/18

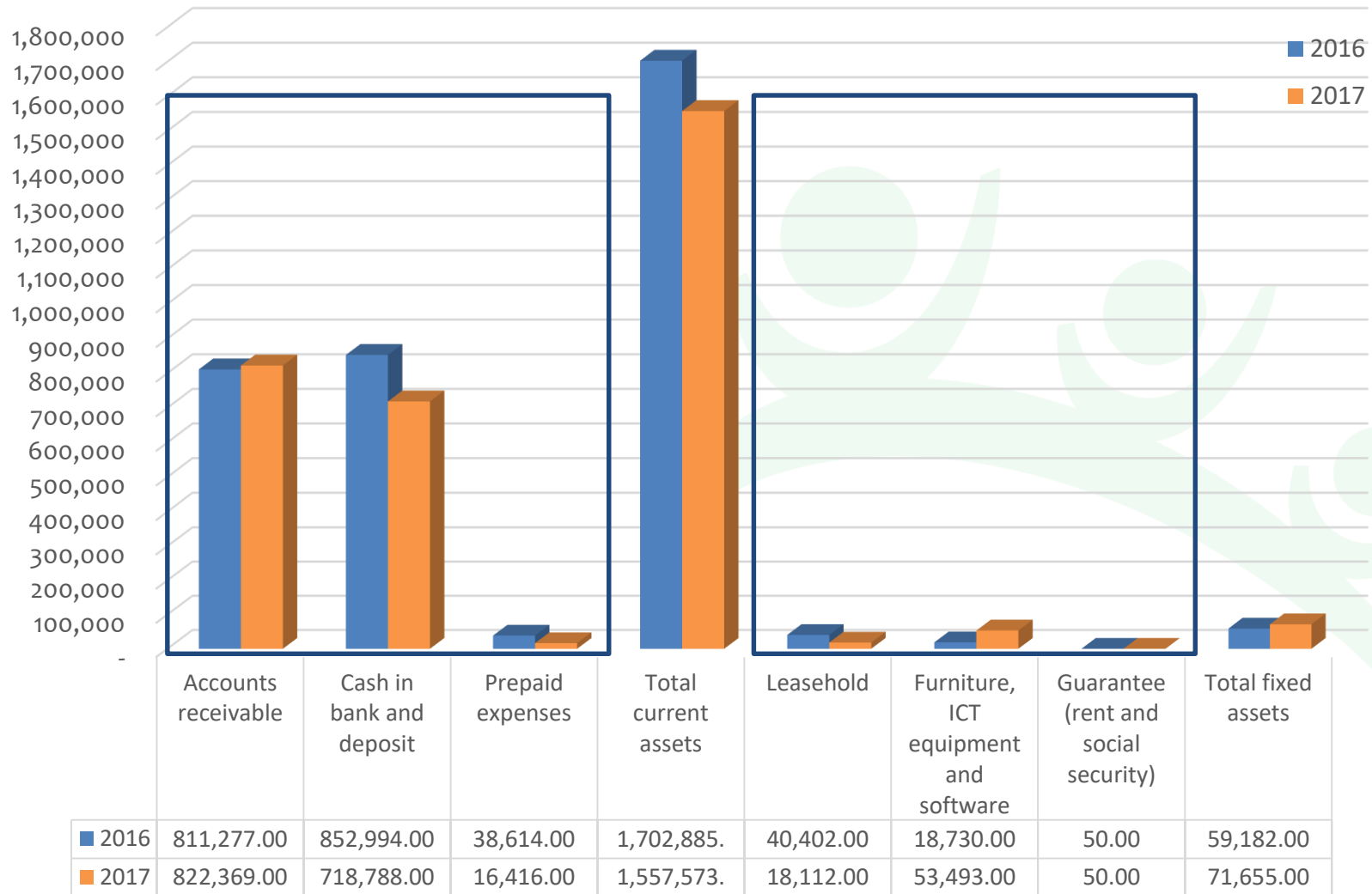
EPF Annual General Meeting

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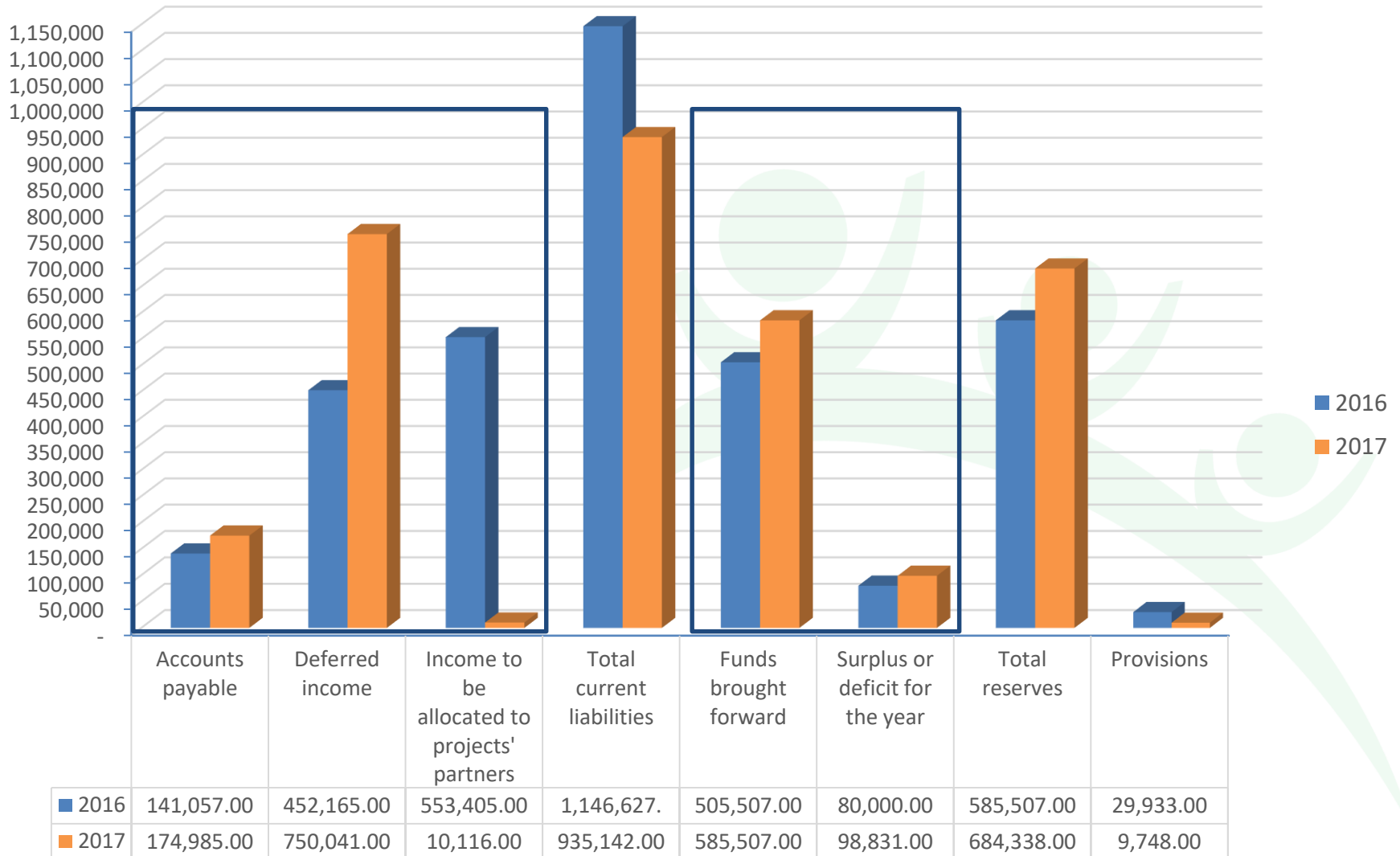
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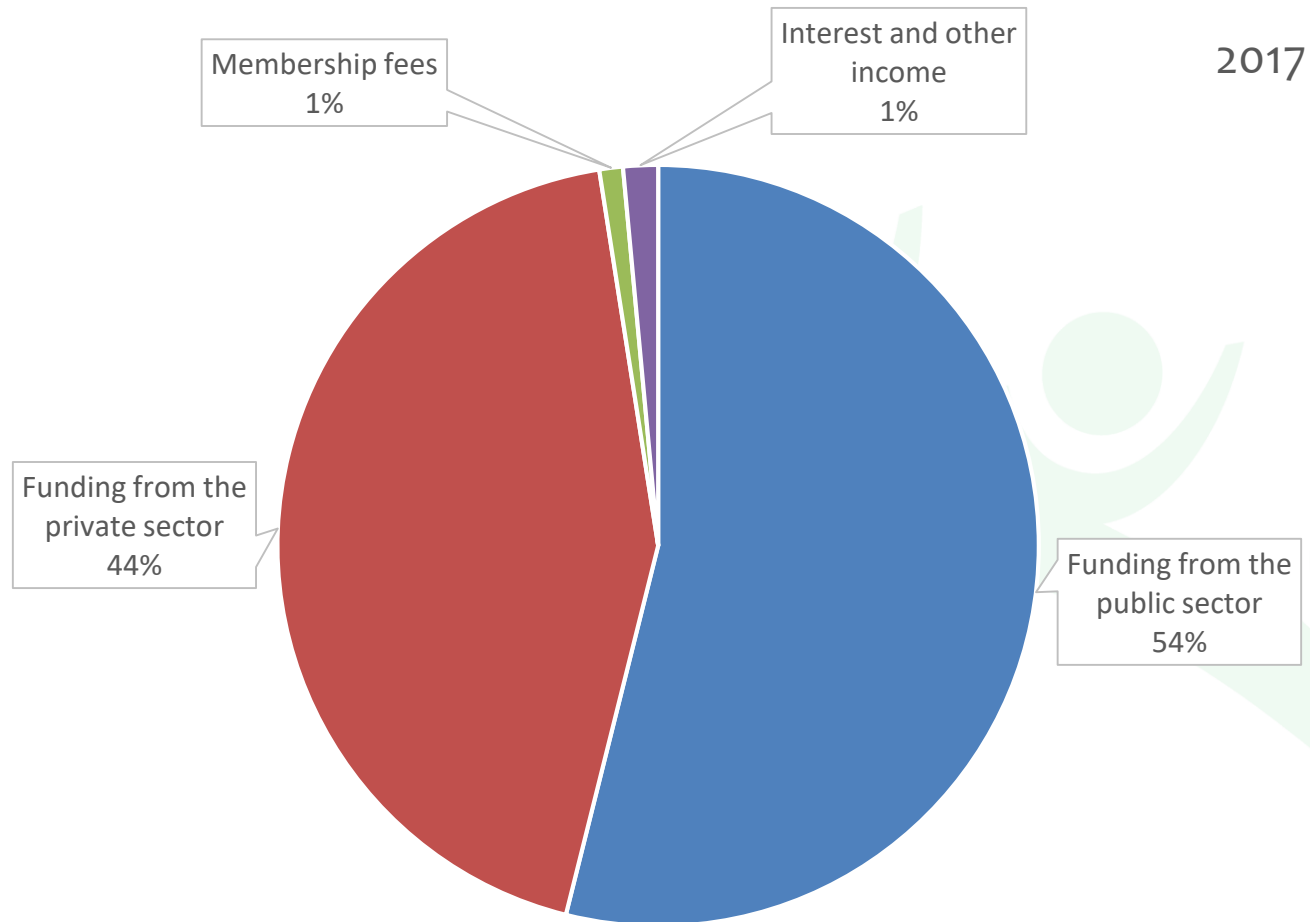
Balance Sheet - Assets



Balance Sheet - Liabilities

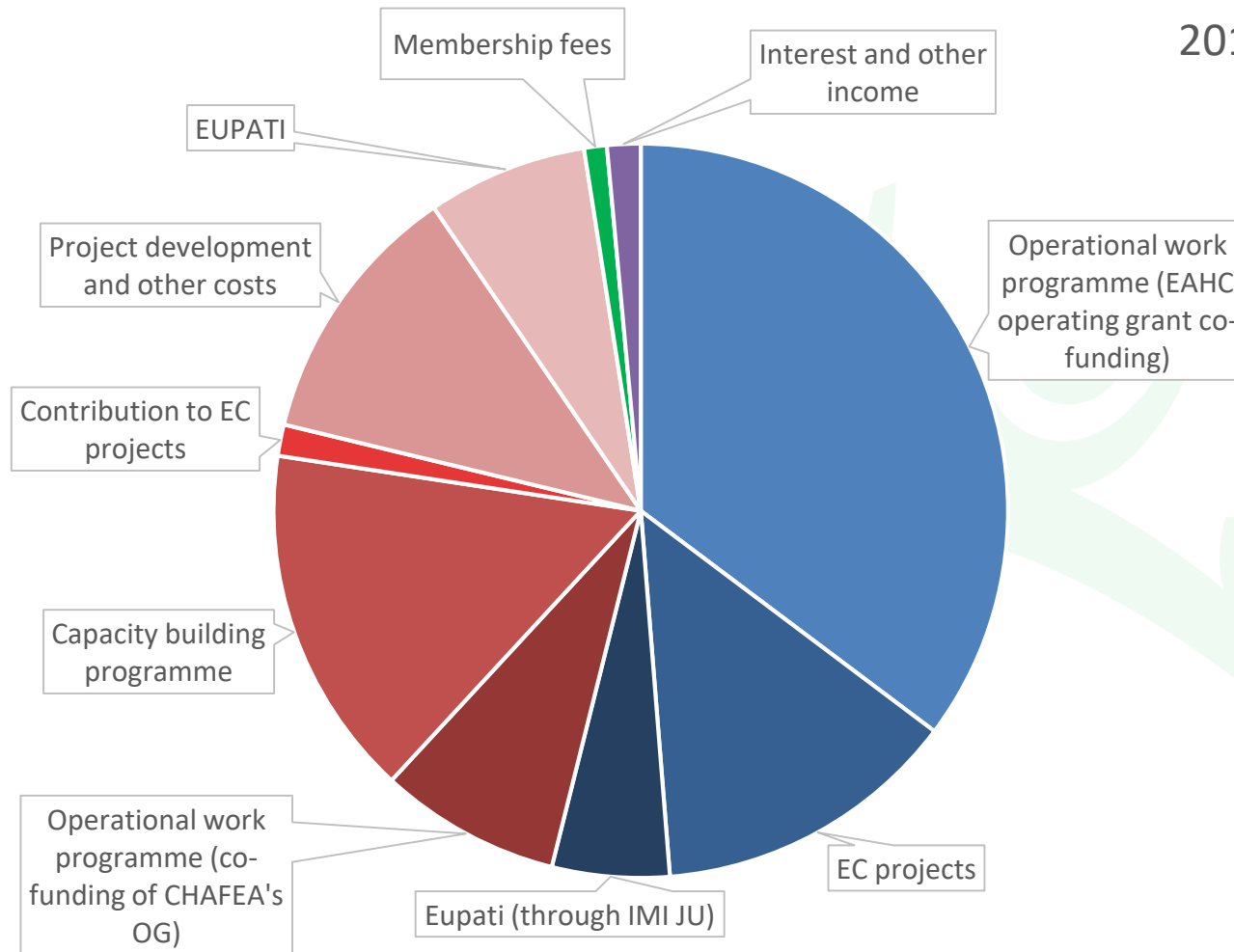


Income as at 31 December 2017

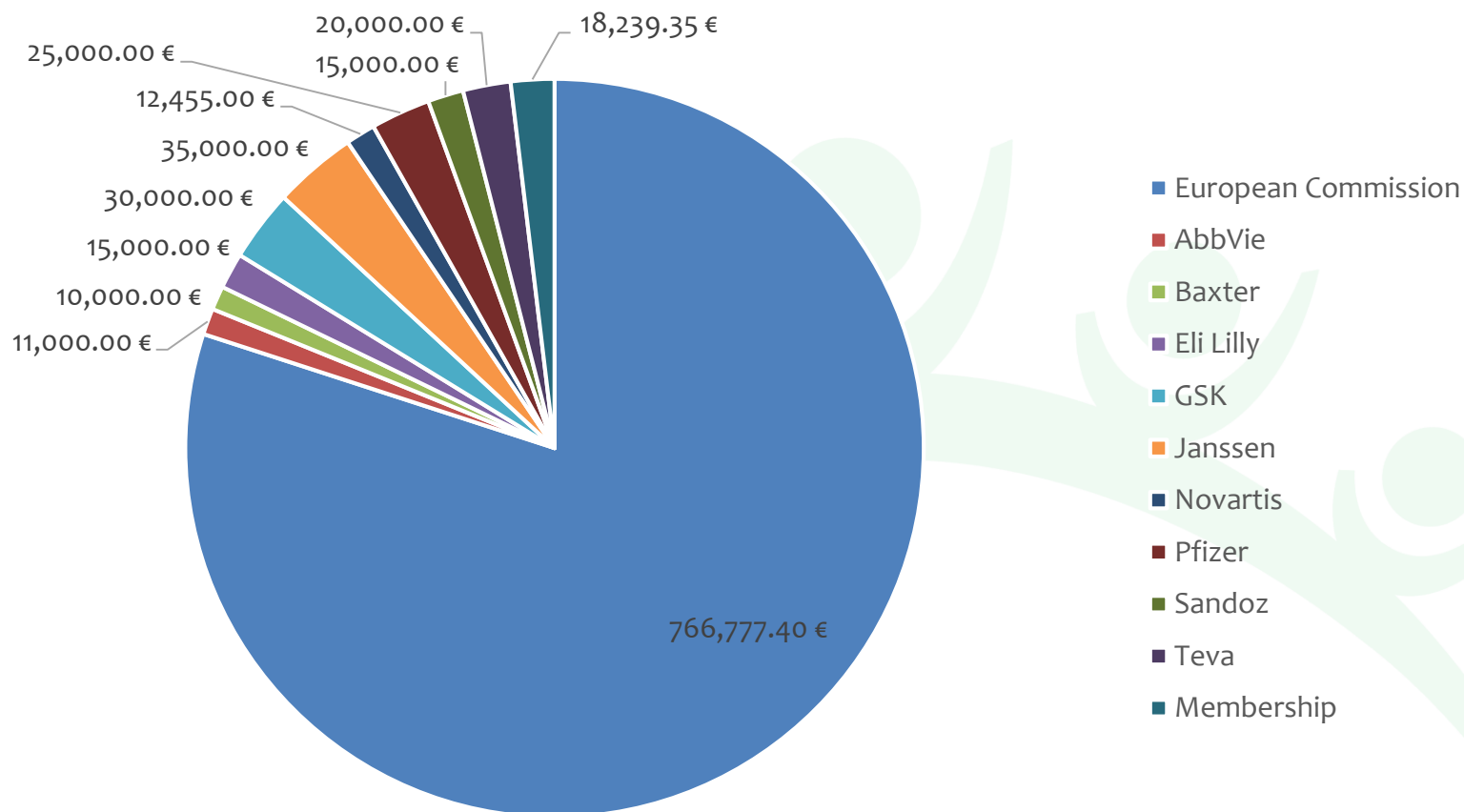


Detailed income as at 31 December 2017

2017



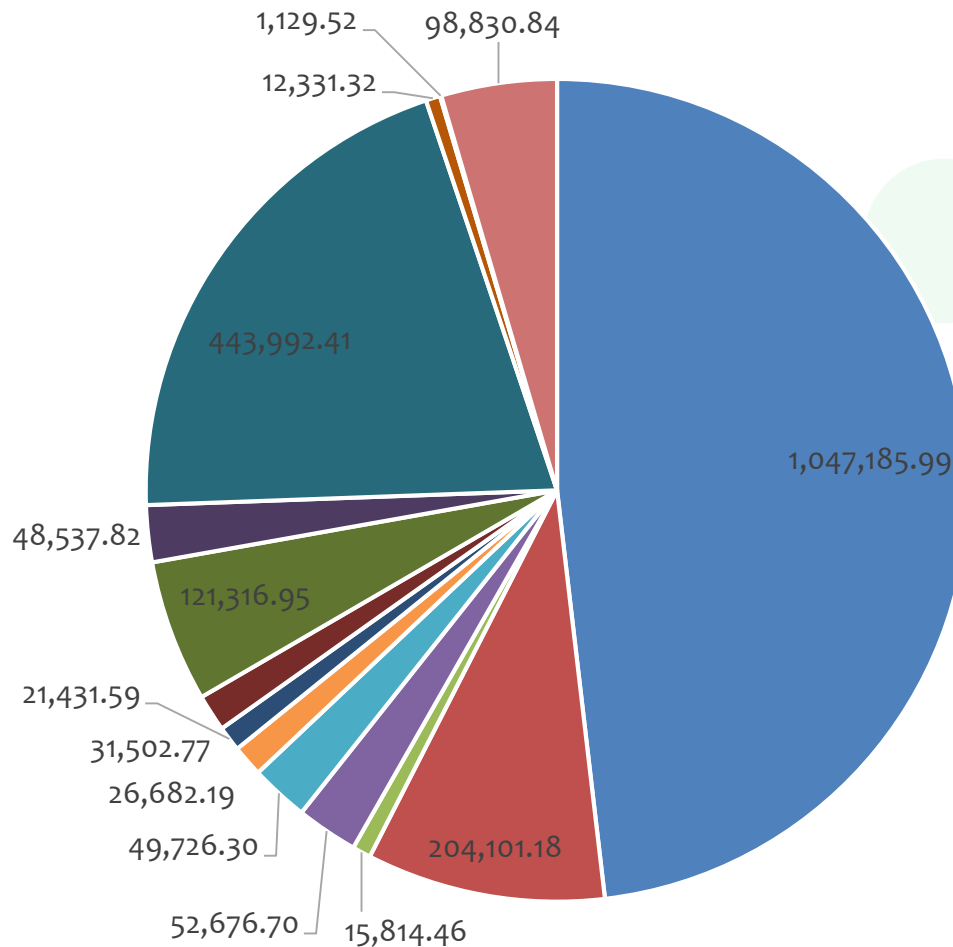
Income – Operating Grant 2017



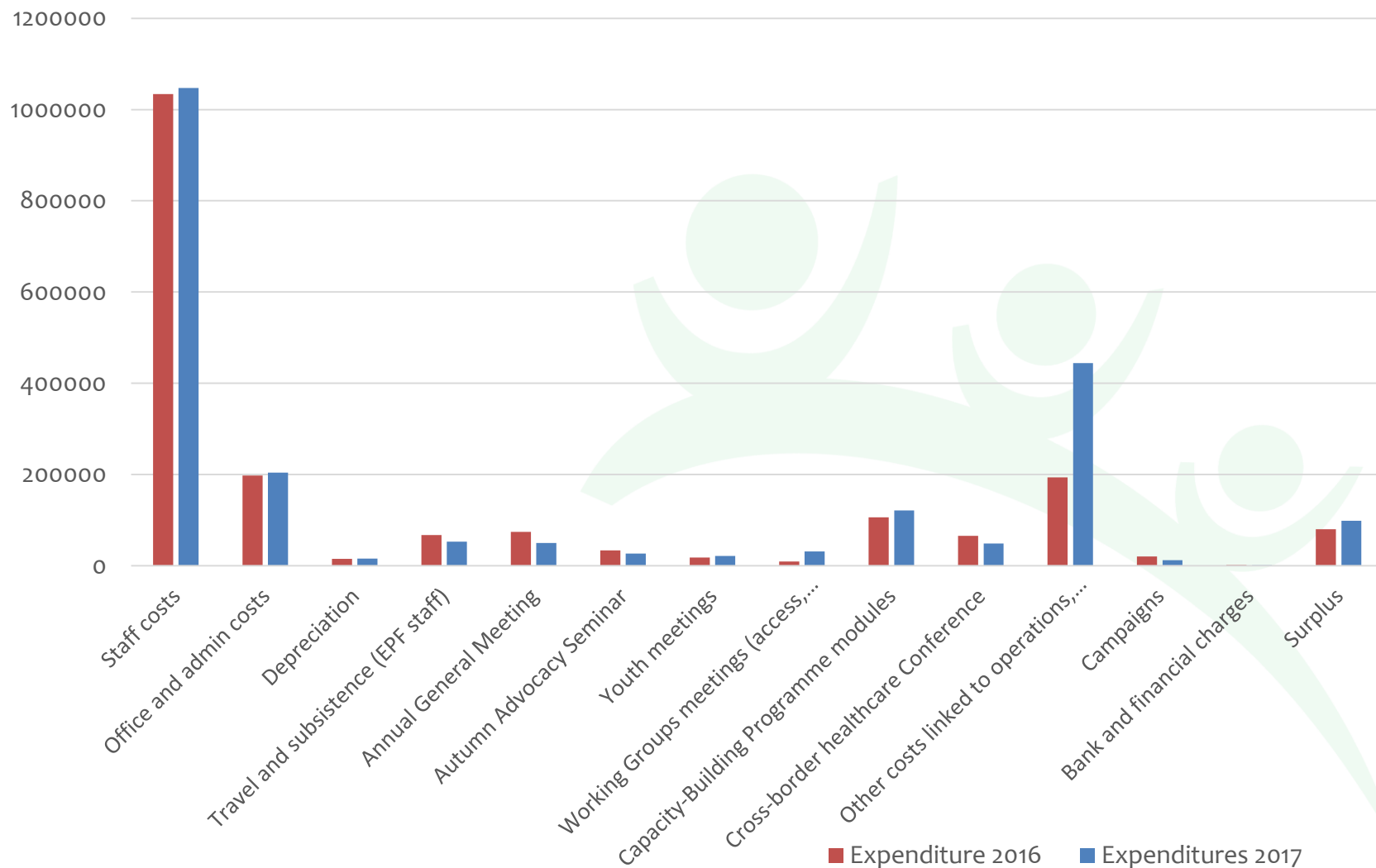
Expenditure as at 31 December 2017

Expenditures 2017

- Staff costs
- Office and admin costs
- Depreciation
- Travel and subsistence (EPF staff)
- Annual General Meeting
- Autumn Advocacy Seminar
- Youth meetings
- Working Groups meetings (access, empowerment, patient safety)
- Capacity-Building Programme modules
- Cross-border healthcare Conference
- Other costs linked to operations, project development
- Campaigns
- Bank and financial charges



Expenditure comparison 2016/2017



7. VOTE ON THE REPORTS AND DISCHARGE OF THE BOARD AND AUDITORS

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NETWORKING LUNCH

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8. EPF MEMBERSHIP

Elena Balestra

EPF Membership & Capacity Building Officer

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8.1. PRESENTATION OF CANDIDATES TO EPF MEMBERSHIP

Elena Balestra

EPF Membership & Capacity Building Officer

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Applications

➤ For Full Membership

- **Plataforma de Organizaciones de Pacientes** – Platform of Patient Organisations (Spain) 

➤ For Associate Membership

- **SAFE** – Stroke Alliance for Europe 

Plataforma de Organizaciones de Pacientes

- Applied for: Full membership
- Recommendation from the Board: Full membership



<http://www.plataformadepacientes.org/>

SAFE – Stroke Alliance for Europe



- Applied for: Associate membership
- Recommendation from the Board: Associate membership

S·A·F·E

Stroke Alliance For Europe

**THE STROKE PATIENT
VOICE IN EUROPE**



<http://www.safestroke.eu/>

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Organisations

- Membership resignation
 - **ECPP** – European Coalition of Positive People
 - **HOPA** – Hungarian Osteoporosis Patient Association
- Membership discontinuation
 - **PE.Pso.POF** – European Forum for Psoriasis Patient's Associations in Europe



European Coalition of Positive People - ECPP

- Asked for: Membership Resignation
- Recommendation from the Board: Accept their resignation

<http://www.ecpp.co.uk/>

HOPA – Hungarian Osteoporosis Patient Association



- Asked for: Membership Resignation
- Recommendation from the Board: Accept their resignation

<http://www.obme.hu/>

European Forum for Psoriasis Patient's Associations in Europe - PE.Pso.POF

- Current Status: Full Member
- Current Situation: Not active
- Recommendation from the Board: Discontinue PE.Pso.POF Membership

8.2. APPROVAL OF NEW MEMBERSHIP REQUESTS

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8.3. TRANSPARENCY GUIDELINES

Camille Bulot

EPF Director of Operations & Engagement

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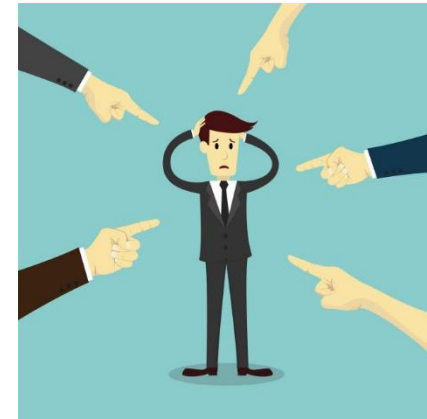
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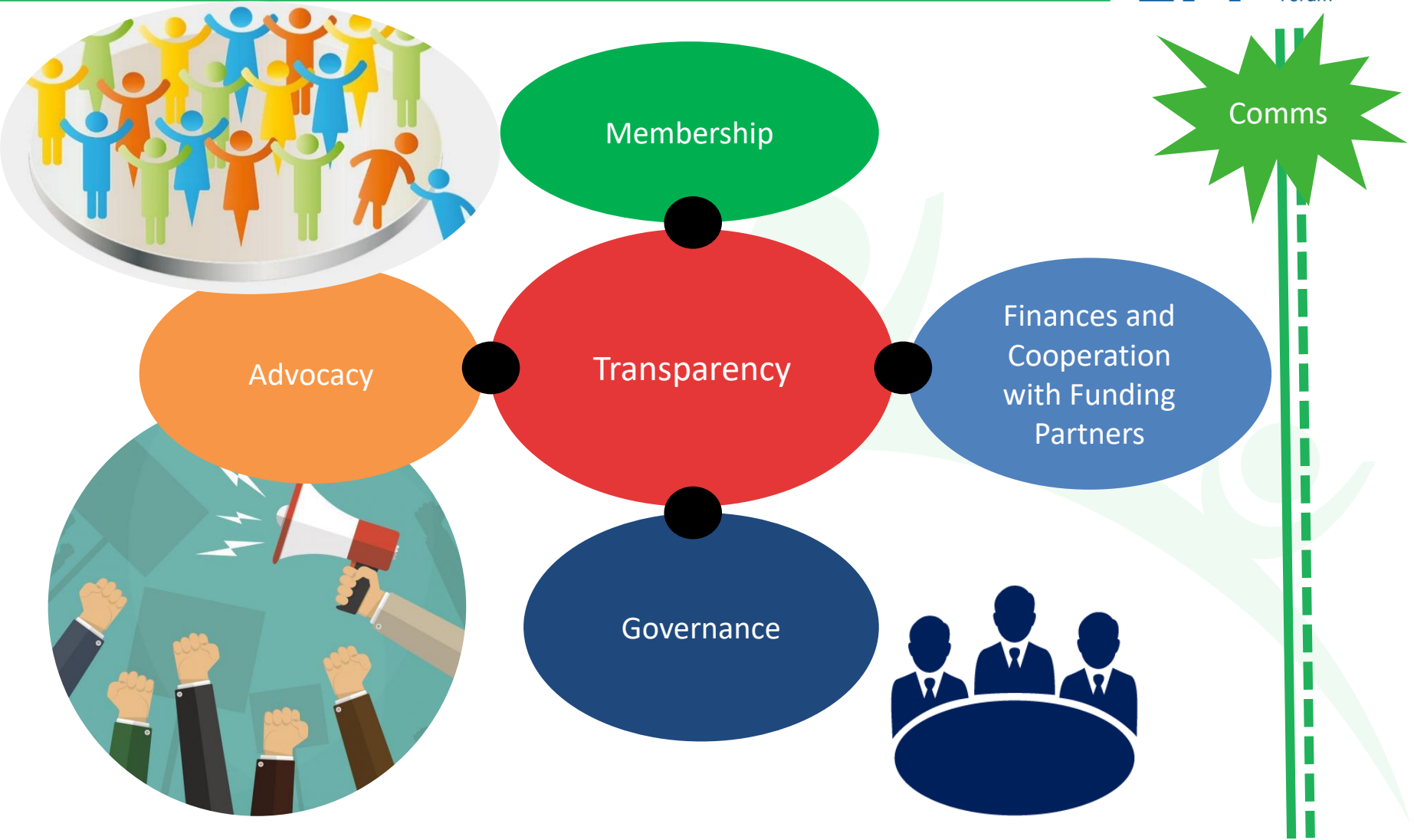
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Scope and Objectives

- Not a “blame and shame” game, but supporting and guiding patient organisation’s efforts
- Developing a common understanding of what constitutes an ethically sound patient organisation
- To reflect on the accountability of patient organisations, and how to demonstrate it
- To ensure the highest possible standards for our own network
- To increase the level of trust from other stakeholders
- A learning process for us too!



Transparency – beyond funding



Membership – the key to your legitimacy

- Who can join you? Membership criteria
- Application process
 - Who reviews the applications?
 - Objectivity, publicity, transparency, communications around the process
- Monitoring compliance over time
 - Dealing with inactive members?
- Membership consultations and involvement
 - How much involvement is enough involvement
 - The importance of providing feedback?



Positive, transparent, effective, accountable

- Your Governing bodies: a lively assembly, more than a structure on paper!
- Board (your ambassadors) – setting the example



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?



AKA the burning issue



- There is very little guidance
- Many “unspoken” rules
- A question of public perception
- Transparency of your purpose: what are you fundraising for?



- Take a minute to think of what the benefits for the funding partners are
- **It's not all about the money** – it's about the relationship, common goals, and assumed good intent
- Think creatively (it's not all about the money II)
- **Trust your worth:** you are bringing something to the table
- **Set up a framework for cooperation** (code of conduct)
- Make your finances public and intelligible!

Unrestricted funding
(no strings attached)

Independence

No single company
funding

Transparency
(publicity)



Your reputation is your currency

- We all do advocacy - Representing the interests of a patient community is advocacy
- It's about more than not giving gifts to decision-makers!



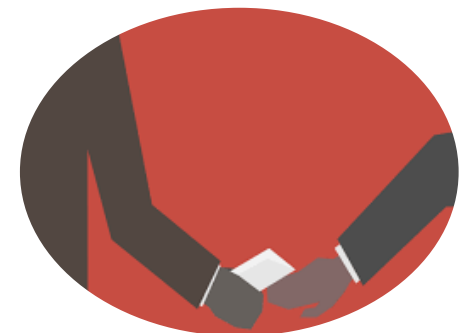
Tips:

- Develop a conflict of interest policy
- Register on the EU Transparency Register
- Say what you do (publish your position papers)
- Say whom you meet: publish your meetings



Communications

- “Making visible all of the other processes”
- “If it’s not on your website, you’re probably hiding something”
- Determine what level of publicity you need for which action;
- Communicate on figures, but also on impact!
- Choose the right tool (website, annual report, in-person meetings)...
- **Transparency is a lot about communicating what you do anyway.**



Key messages and main learnings

- Transparency is not only about funding
- Working on transparency is good for you!
 - Increased visibility, Increased credibility
 - Better governance, Reputation management
- If you don't have the answer, the answer is likely to be “consult with your membership”
- The values of your organisation are at least as important as the policies themselves



9. BOARD ELECTIONS

Elena Balestra

EPF Membership & Capacity Building Officer

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Applications

- Elisabeth Kasilingam – European Multiple Sclerosis Platform (EMSP)
- Mercedes Maderuelo Labrador – Spanish Patient Forum
- Marzena Nelken – Federation of Polish Patients (FPP)
- Cor Oosterwijk – Eurordis
- Michal Rataj – European Alliance of Muscular Disease Associations (EAMDA)
- Gabriela Tanasan - European Network of Ex-Users and Survivors of Psychiatry (ENUSP)

COFFEE BREAK

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10. PRESENTATION AND APPROVAL OF EPF WORK PLAN 2018

Kaisa Immonen
EPF Director of Policy

Valentina Strammiello
EPF Programme Manager

14/04/18

EPF Annual General Meeting



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Three thematic objectives, three pillars of work

Policy &
Advocacy

Projects:
Collecting
evidence

Capacity-
Building
Programme

Patient
involvement &
Empowerment



Sustainable
Healthcare
Systems for all



Effective
Research &
Regulatory
Framework



#1 PATIENT INVOLVEMENT & EMPOWERMENT

Strengthening the patient community

Capacity-building module on empowering leadership and positive governance

- 24 participants
- Objective: to strengthen patient organisations by enhancing their leaders' leadership skills and consequently enabling positive governance in their organisation

First face-to-face module
Bratislava, 26-27 May



Second face-to-face module
Warsaw, 6-7 October



**THE
LEADER**

Intensive
coaching

Preparing the next generation of Advocates

- **Youth Group:** joint awareness campaign on non-discrimination in access to healthcare, the work place and education
- **Second edition of the Summer Training Course for Young Patient Advocates**
 - Vienna, 1-4 July 2018
 - 40 participants
 - 23 countries
 - Focus on inclusion & non-discrimination



- 34 partners
- IMI project
- 9 million over 2,5 years
- Objectives:
 - Sustainability of patient engagement
 - Delivering tools and practices
 - Delivering metrics for impact



Focus areas

Making patient involvement a reality



PARADIGM & EUPATI – Two complementary projects

Providing the tools for patient engagement

Focus: Medicines R&D

Increasing patients' capacity to play their legitimate role



PARADIGM - providing a unique framework that enables structured, effective, meaningful, ethical, innovative, and sustainable **patient engagement (PE)**



EUPATI - education and training to increase the capacity and capability of patients to understand and contribute to medicines R&D and also improve the availability of objective, reliable, patient-friendly information for the public.

- Complementarity with #EU4HEALTH Campaign
 - #EU4HEALTH Campaign: Making sure health is a priority in the EU post-2020
 - 2019 Elections campaign: making sure patients play a role within health-related policies post-2020

Step 1 – defining our priorities



Step 2 - Collecting stories



Step 3 – Targeted advocacy

Setting the stage for EPF's patient-led Framework for Meaningful Patient Involvement

- **Mapping** the state of the art – collecting initiatives of patient involvement in different parts of healthcare
- **Patient rights** – draft paper for members' feedback

In our project portfolio:

- **COMPAR-EU**: ranking effective self-management interventions – “patient priorities” task



Health Literacy as an enabler of PE

Building Vaccines confidence in the patient community



- Pilot Project
- Objective: Understanding and countering vaccine hesitancy
- First step: EPF survey - **STILL OPEN UNTIL 16 APRIL!**
- Evidence-based, needs-oriented information tools

#2 SUSTAINABLE HEALTHCARE

FOR ALL

Universal Access to Healthcare

The Roadmap as a compass!

- Promotion of the Roadmap and awareness raising of the UN SDGs
- **New** EPF Working Group on Universal Access to Care (2 meetings)
- Cooperation with the Patient Access Partnership (PACT)
- Focus on Access to medicines and their affordability – update of EPF's paper “Pricing and Value” (2016)
- Information on generic and biosimilar medicines



Social Inclusion and Non-discrimination

Advocacy to end discrimination and stigma & promote patients' rights and inclusion of patients with chronic diseases in healthcare, employment, education and society

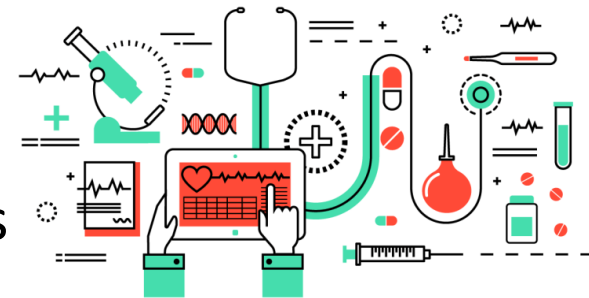
Activities

- Promotion of EPF's recommendations and materials on equal treatment and inclusion in the **workplace** (also throughout CHRODIS+)
- Cooperation with the EU Fundamental Rights Agency
- Strengthening **alliances** with NGOs representing groups vulnerable to social exclusion
- Implementation of the European Pillar of Social Rights and relevant initiatives



Patient Safety, Quality and Patient-centeredness

- Contribution to the **OECD PaRIS** initiative on indicators – PROMs and PREMs (PRIMs)
- Ensuring patient-centredness and “what matters” to patients are measured as part of healthcare quality;
- Dialogue with our members on what constitute “high/low” value care and “waste” – **policy brief**
- Engaging with WHO Europe on health systems strengthening



For patient-centred digital healthcare solutions & services

- Defining **EPF's strategy** & the patient community's vision for digital health
- **Informing you** about digital health and health data: development of info resources
- **Identifying principles** for patient-centred digital health
- **New!** Working group on digital health and health data
- EPF patient survey



#3 CONTRIBUTING TO
EFFECTIVE RESEARCH AND
REGULATORY FRAMEWORKS

Feeding the patient perspective to EU legislative proposal

Advocacy:

- Consultation with EPF membership – **until 27 April** + liaison with EU policymakers
- Cooperation with the HTA Network Stakeholder pool
- Cooperation with HTAi

In our project portfolio:

EUNetHTA Joint Action 3: focus on early dialogues, governance, re-use and national uptake of assessments



eunethta
EUROPEAN NETWORK FOR HEALTH TECHNOLOGY ASSESSMENT

Focus on information, monitoring, patient perspective

Cross-border healthcare

- Next COM report on implementation due October 2018
- Engage with patient organisations in Member States to get their perceptions

Medical devices

- Lay-friendly information

Medicines safety, pharmacovigilance, PIL...

- via engagement with EMA

Paediatric Regulation

- Watching brief on developments



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

AND ALSO...

Other challenges

- Sustainability of EPF 2019-2021
- Preparing the Constitutional reform 2019
- Cooperation with our key allies: WHO, OECD, EMA, ECDC, HCP organisations, industry partners...
- Improving our internal and external communications further



FINANCES

Budget 2018

Radu Ganescu
EPF Treasurer

14/04/18

EPF Annual General Meeting

 @eupatientsforum

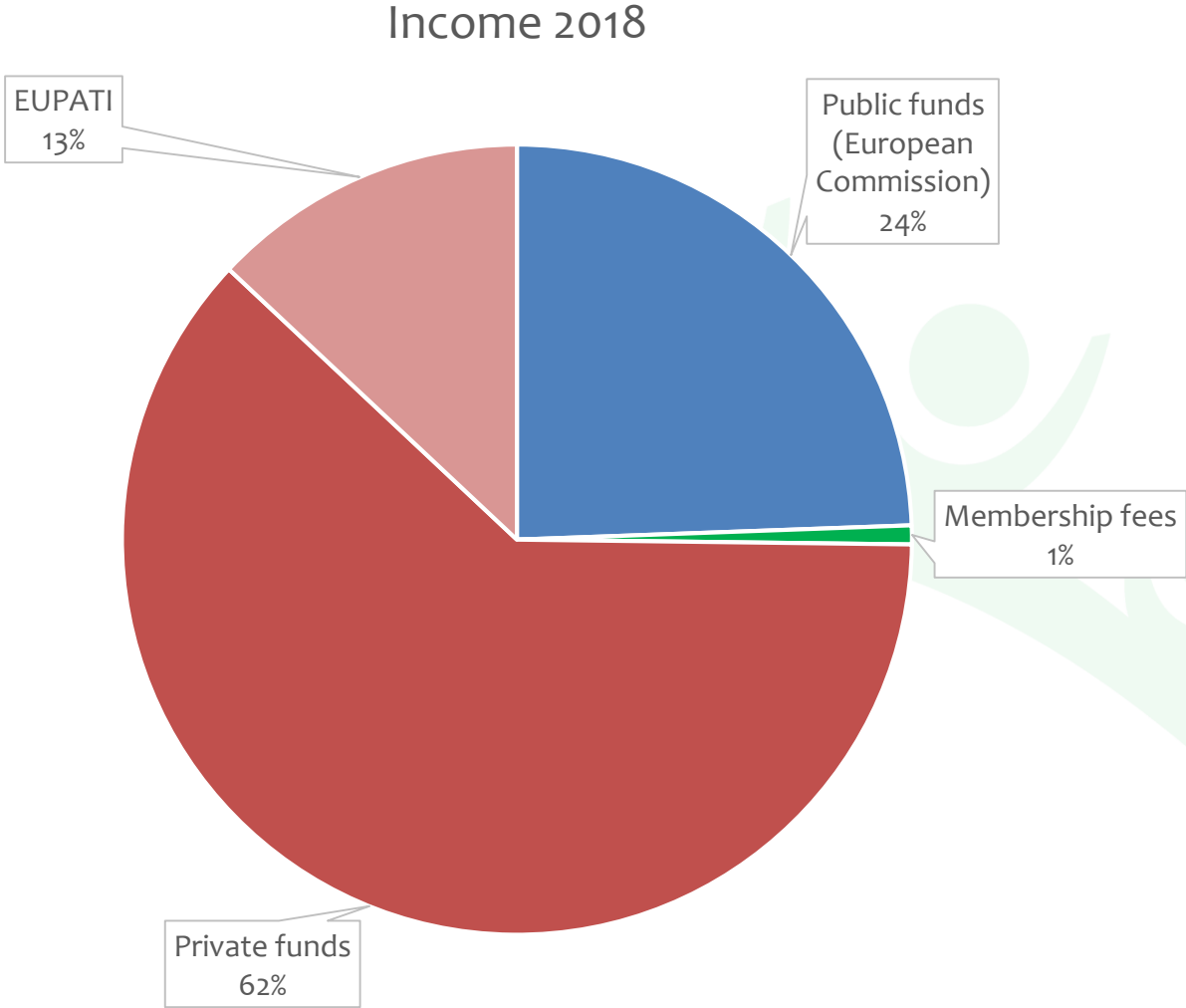
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Patients
Forum 

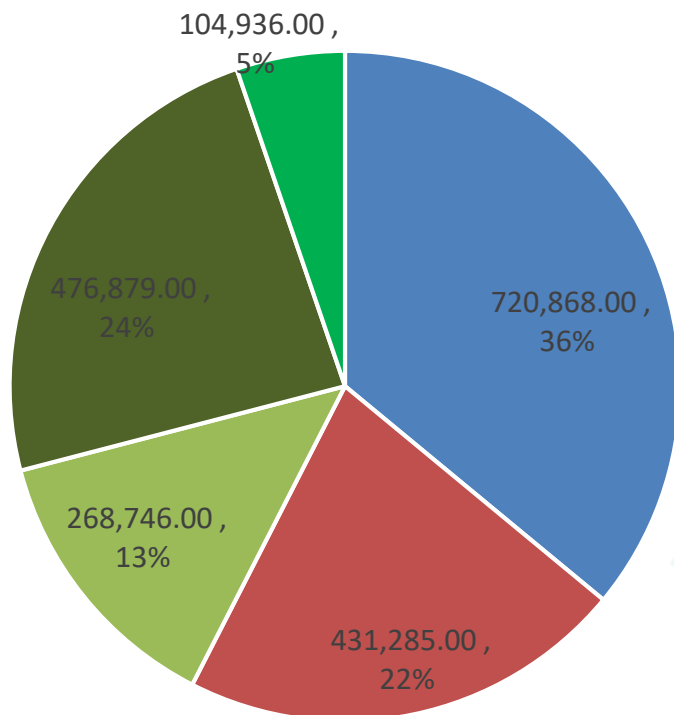
EPF Budget 2018 - Overview

EXPENDITURES							
Cost category	TOTAL	as %	Operations & Engagement	Capacity Building Programme	EUPATI Programme	Project Portfolio	Project Development
Personnel costs	€ 1,099,527	55%	€ 436,991	€ 179,870	€ 129,979	€ 274,412	€ 78,274
Administrative Costs	€ 205,231	10%	€ 52,479	€ 35,974	€ 18,255	€ 82,867	€ 15,655
Operations	€ 598,121	30%	€ 176,961	€ 189,041	€ 101,512	€ 119,600	€ 11,007
Subcontracting	€ 45,400	2%	€ -	€ 26,400	€ 19,000	€ -	€ -
Other costs	€ 9,968	0%	€ 9,968	€ -	€ -	€ -	€ -
Losses	€ -	0%	€ -	€ -	€ -	€ -	€ -
Provision for potential losses and cashflow	€ 44,468	2%	€ 44,468	€ -	€ -	€ -	€ -
Reimbursement to donors	€ -	0%	€ -	€ -	€ -	€ -	€ -
TOTAL 2018	€ 2,002,714	100%	€ 720,868	€ 431,285	€ 268,746	€ 476,879	€ 104,936
INCOME							
Cost category	TOTAL	as %	Operations & Engagement	Capacity Building Programme	EUPATI Programme	Project Portfolio	Project Development
Public funds (European Commission)	€ 474,792	24%	€ -	€ -	€ -	€ 474,792	€ -
Membership fees	€ 15,000	1%	€ 10,000	€ 5,000			
Private funds	€ 1,454,363	73%	€ 652,309	€ 426,285	€ 268,746	€ 2,087	€ 104,936
Unrestricted Sponsorship	€ 1,201,501		€ 652,309	€ 426,285	€ 15,883	€ 2,087	€ 104,936
Cash contribution EUPATI	€ 252,863		€ -	€ -	€ 252,863	€ -	€ -
Foundations	€ -	0%					
Reimbursement from third parties	€ -	0%					
Contributions from other organisations	€ -	0%					
Redistribution from other lines	€ -	0%					
Carry over from 2017	€ 58,559	3%	€ 58,559				
TOTAL 2018	€ 2,002,714	100%	€ 720,868	€ 431,285	€ 268,746	€ 476,879	€ 104,936
As % of total budget		100%	36.0%	21.5%	13.4%	23.8%	5.2%

EPF Income 2018

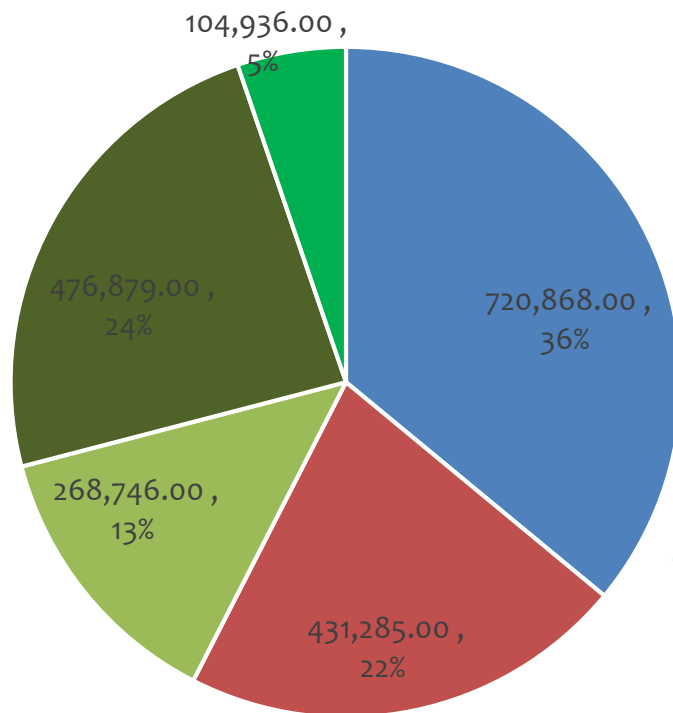


Expenditures 2018

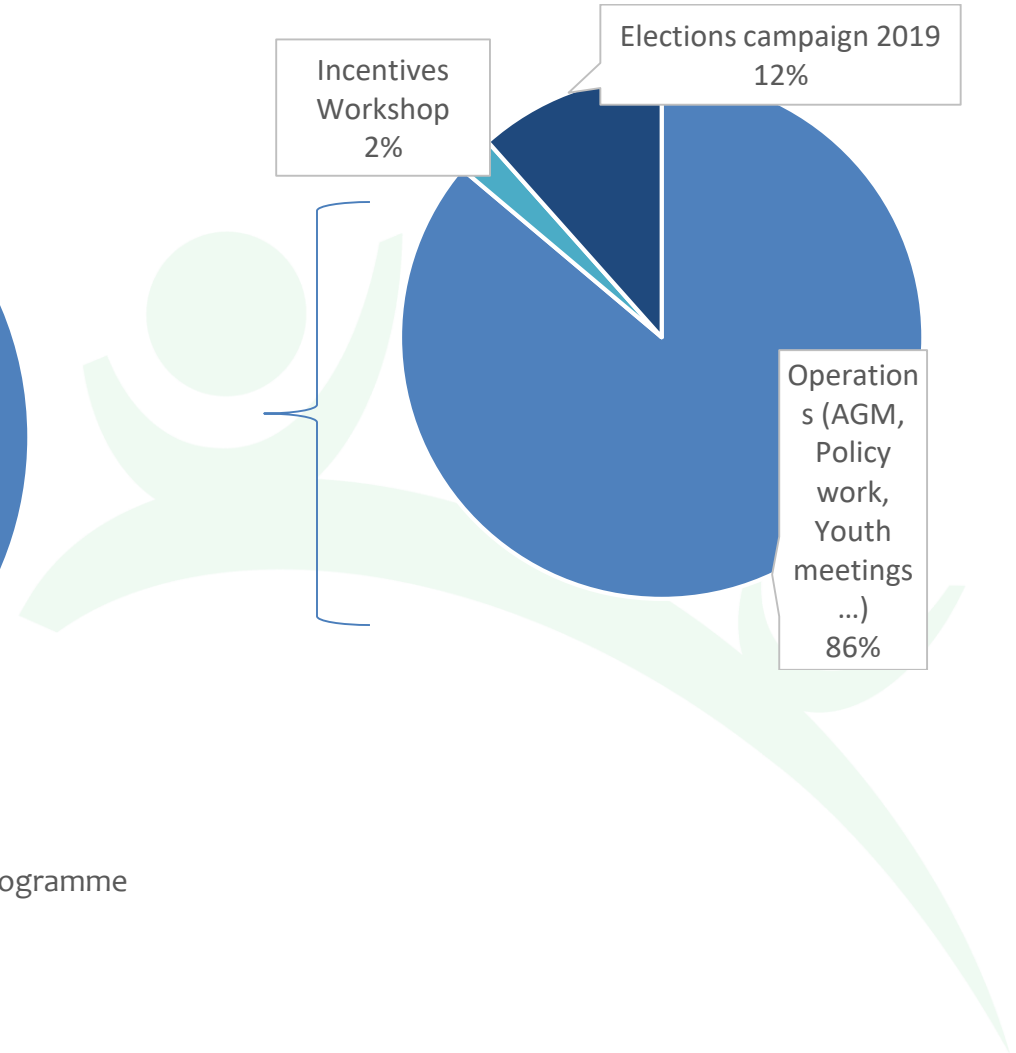


- Operations & Engagement
- Capacity-Building Programme
- EUPATI
- Projects
- Project development

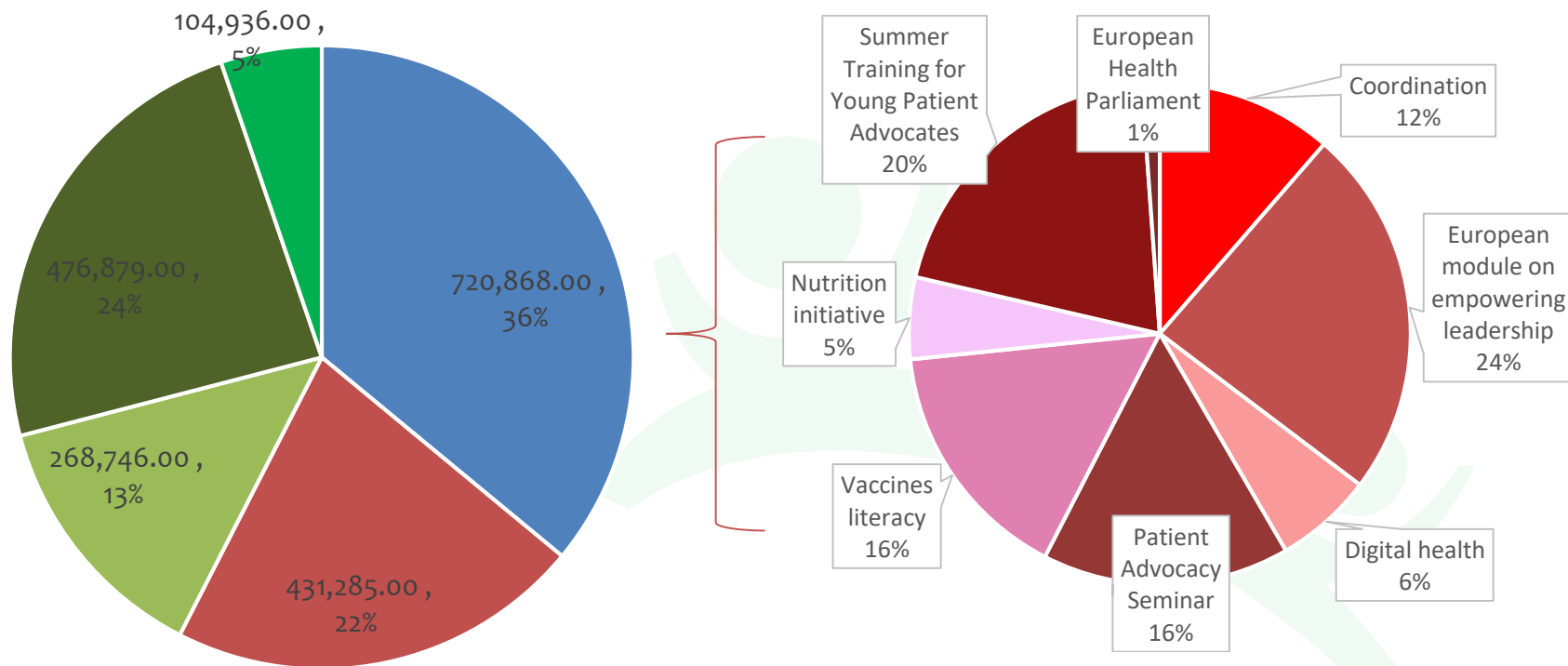
Expenditures 2018 – Core operations



- Operations & Engagement
- Capacity-Building Programme
- EUPATI
- Projects
- Project development

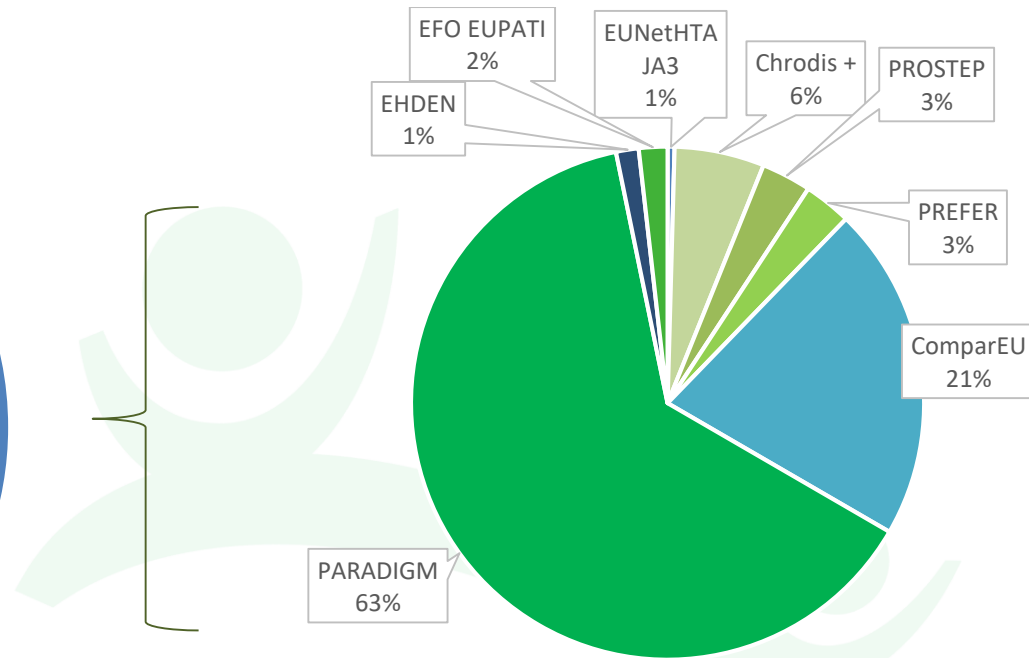
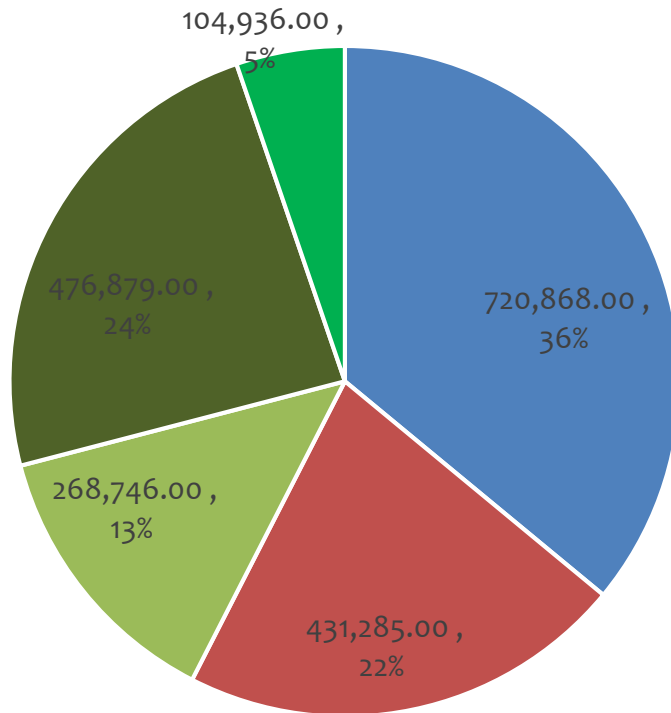


Expenditures 2018 – Capacity-building



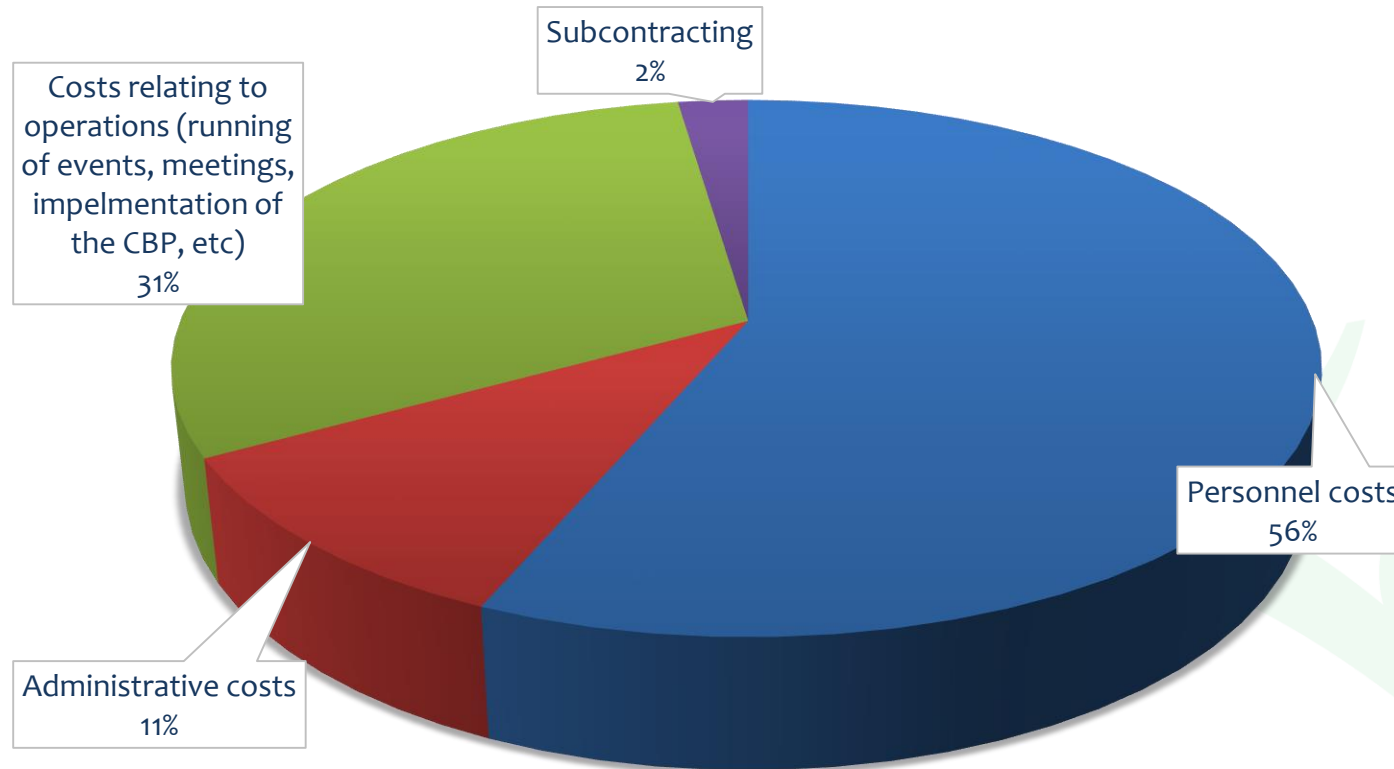
- Operations & Engagement
- EUPATI
- Project development
- Capacity-Building Programme
- Projects

Expenditures 2018 – Project portfolio



- Operations & Engagement
- Capacity-Building Programme
- EUPATI
- Projects
- Project development

2018 Expenditures by type



11. POLITICAL AND FUNDING STRATEGY TO ENSURE EPF SUSTAINABILITY

Nicola Bedlington
EPF Secretary General

Marco Greco
EPF President

14/04/18

EPF Annual General Meeting



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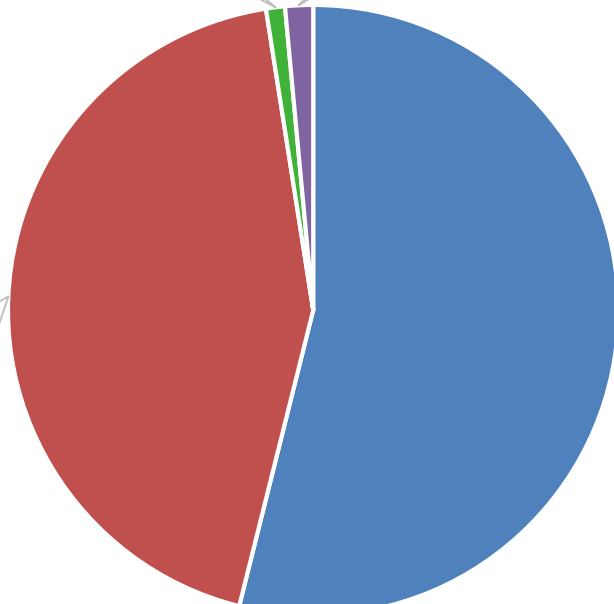


EPF Income 2017 vs 2018

Membership fees 1%

Interest and other income 1%

Funding from the private sector 44%



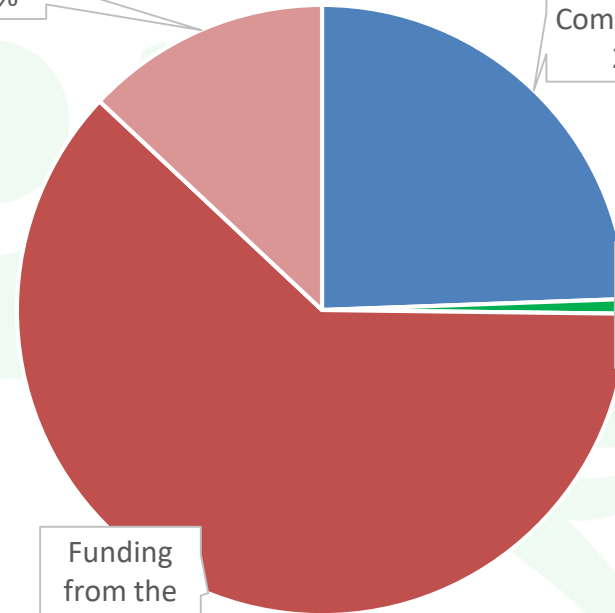
2017

EUPATI 13%

Public funds (European Commission) 24%

Membership fees 1%

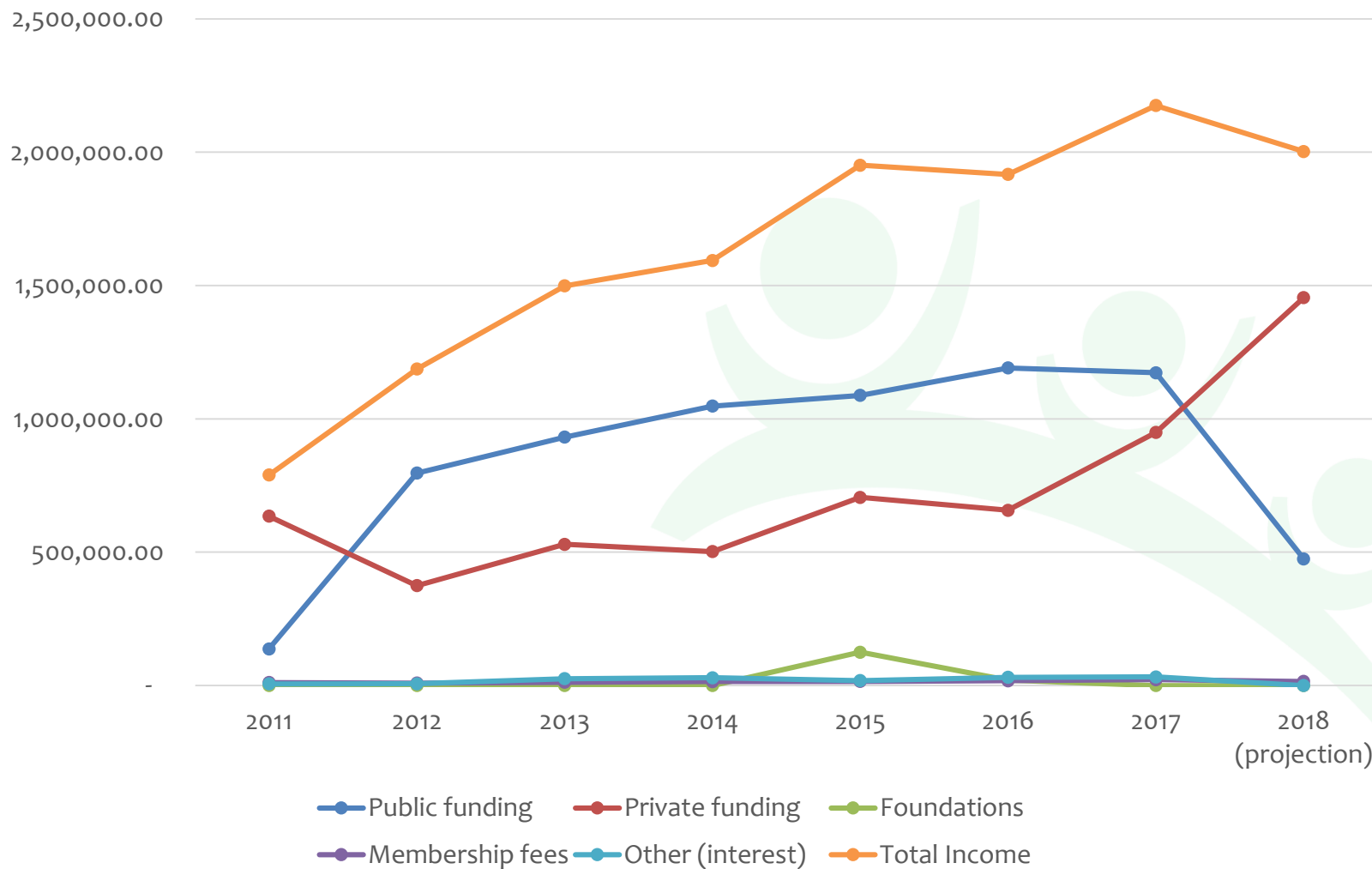
Funding from the public sector 54%



Funding from the private sector 62%

2018

Evolution of income 2011-2018



No operating Grant - Repercussions

Extremely difficult few months , but

- EPF will ‘bridge’ 2018 financially, without utilising reserves
 - Cost savings internally
 - Streamlining our work plan –delivering quality with fewer resources
 - New ventures
 - Workshop on incentives, Vaccines Project, Nutrition Initiative, etc.
 - Intense work with current and new sponsors - 35+ companies, TA
 - Overheads from major projects such as PARADIGM
 - Ongoing political work with the Commission, European Parliament to find a solution for 2019 and beyond , but NO reliance on this
- Balance between public and corporate funding no longer there

Political context – EPF yet stronger

- **Uncertainty re. future of health collaboration post-2020** – our positioning in (co)-leading the campaign, convening the players;
- Despite no core funding, **still seen as THE interlocutor** with the Commission on cross-cutting patient/ health issues;
- Increased profile as a **responsible public health NGO**, as well as the patient's voice;
- **EPF as a pan-European organisation** – new relationships with WHO Europe, sister organisations;
- New opportunities – **leading the discourse** and providing the solutions on patient involvement in health systems – creating a framework.



Discussed and agreed by EPF Board December 2017

- Industry Roundtable in June 2018;
- Additional fundraising expertise building on our existing knowledge base;
- Several prospective EU funded projects in the pipeline – link with our Strategic Plan and values;
- Own Congress 2019 – platform for visibility and income – generating;
- On-going advocacy work with the EU Institutions- also in the context of the next EU Programming Period.

12. PREPARATION FOR UPCOMING CONSTITUTIONAL CHANGE: EPF AND WIDER EUROPE

Nicola Bedlington

EPF Secretary General

Marco Greco

EPF President

14/04/18

EPF Annual General Meeting



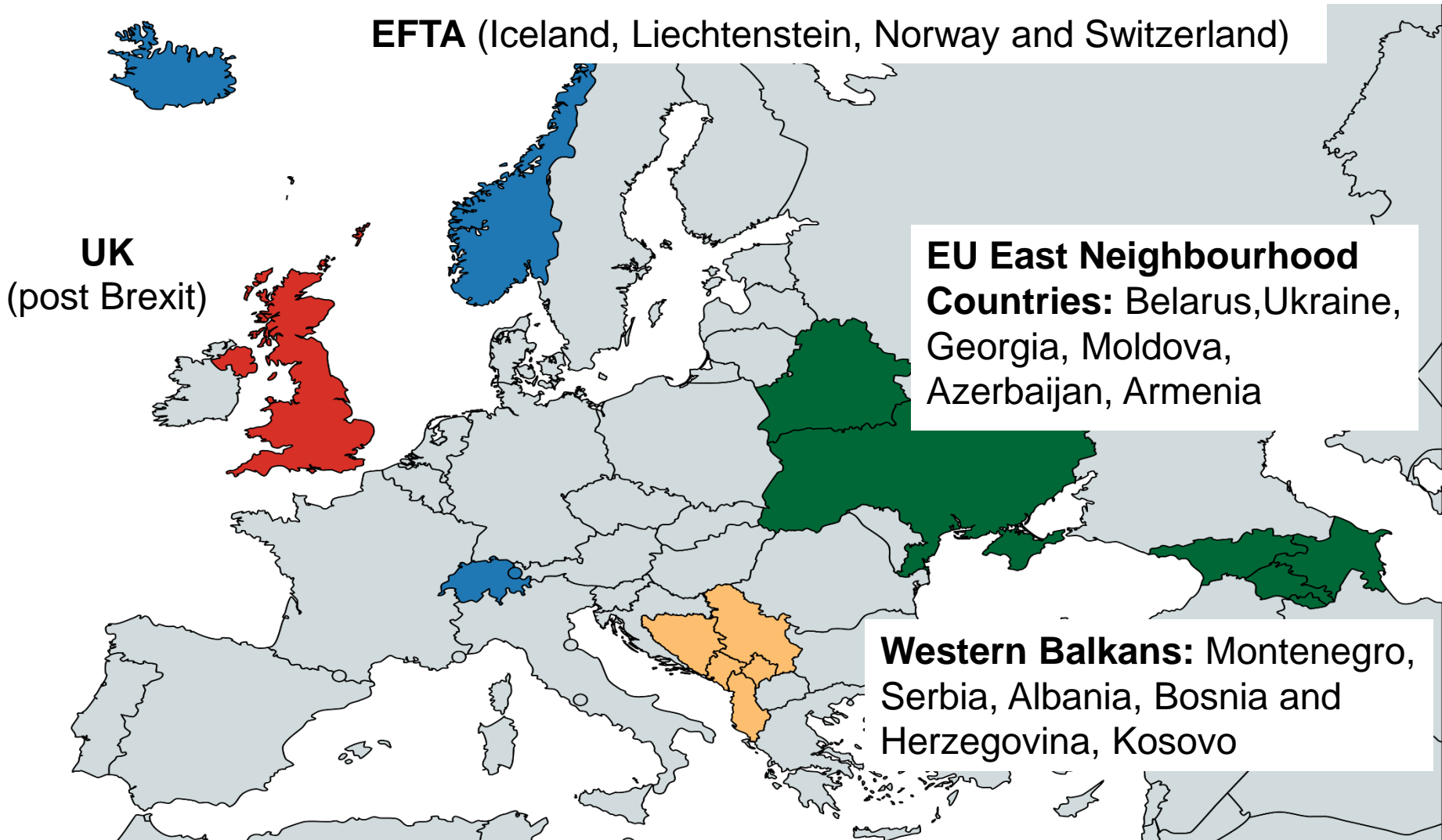
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- Mandate to examine this (AGM 2017)
- Document circulated with AGM 2018 pre-reads
 - Productive discussions with IAPO in August and agreement for EPF to work with ‘EU neighbourhood countries’
 - Confirmed interest from WHO-Europe to support process (Memorandum of Understanding, Mapping of neighbourhood countries through national WHO offices)

Geographic area



- A 'wider Europe' component in our Constitutional Reform
- A more in-depth analysis with our UK members, in context of Brexit
- Our potential 'offer' to existing national coalitions
- Formal agreement with WHO Europe, including a mapping exercise, and acquisition of NGO status
- Collaboration with our European member organisations
- Reflections in 2019 with regard to incorporating 'Wider Europe' within our next Strategic Plan, beyond 2020, and future Capacity Building Programmes.

Fit for purpose, forward-looking Constitution

- Voting seat for youth group rep on EPF Board
- Setting up an ethics committee
- Integrating EPF's enlarged geographic mandate and appropriate membership categories and definitions
- Ensuring an effective modus operandi with on-line communities, EUPATI patient alumni
- Clarity on our relationship with Institutions beyond the EU, i.e. WHO Europe, OECD
- Internal Rules that will support the governance of the organisation

a Constitutional Reform Committee

- 5 members
- to develop a revised constitution and internal rules for the EPF board -last meeting in 2018
- Revised constitution and internal rules to be agreed at the first board meeting 2019, for adoption at our AGM 2019
- The Committee :EPF President, one other board member, 3 volunteers from the EPF membership.
- Consult, as necessary, an independent, pro bono lawyer
- A complete Terms of Reference for the Committee will be drafted and agreed at its first meeting.

DINNER

From 19:00 at the restaurant

14/04/18

EPF Annual General Meeting

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