

EUROPEAN PATIENTS' FORUM

Industry Roundtable

17 June 2019

Brussels, Belgium



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



Agenda

From 12.30	A light lunch and networking
13.15-13.25	Welcome and introductions
13.25-13.45	Finance overview
13.45-14.15	Organisational matters
14.15-15.00	Twelve-month review
15.00-15.30	Coffee break
15.30-16.30	Policy discussion – ‘hot topics’
16.30-17.15	Forward look – next 12 months at EPF
17.15-17.30	Conclusions and Next Steps

FINANCE OVERVIEW



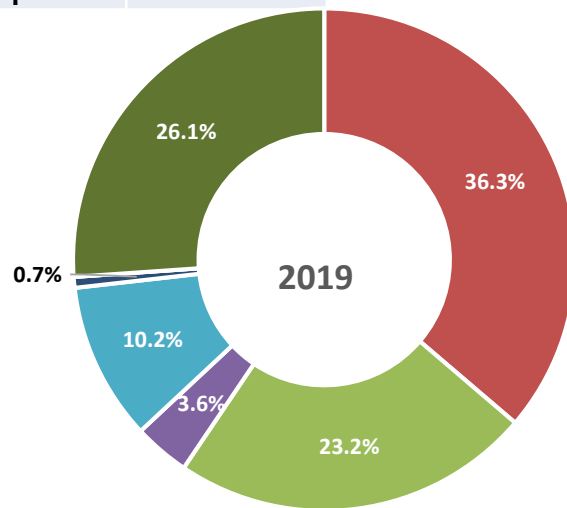
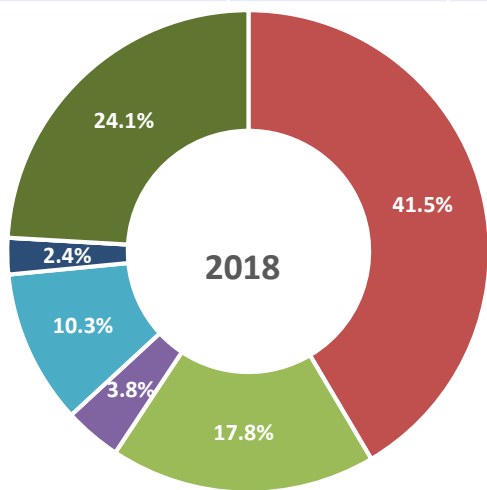
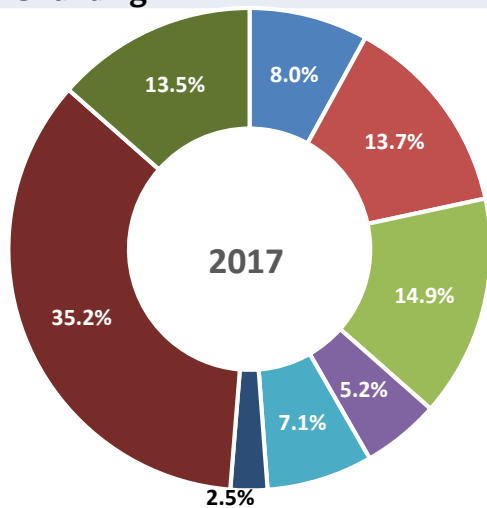
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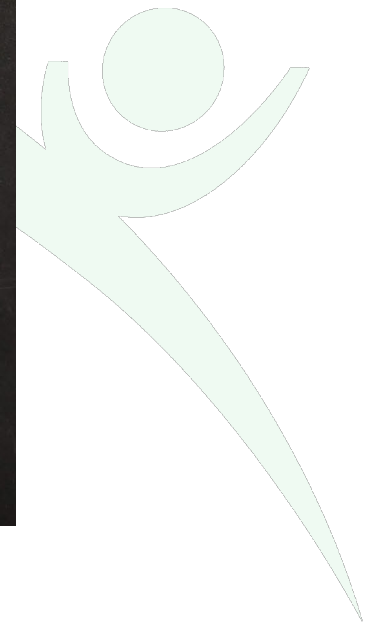


EPF Funding	2017	2018	2019
Operating Grant Contribution	8.0%		
Project Development '17 – Operation & Engagement '18+	13.7%	41.5%	36.3%
Capacity Building	14.9%	17.8%	23.2%
EC Projects Contribution	5.2%	3.8%	3.6%
EUPATI Programme	7.1%	10.3%	10.2%
Membership/ Other	2.5%	2.4%	0.7%
EC Operating Grant	35.2%	0.0%	0.0%
EC funded projects	13.5%	24.1%	26.0%
Summarised	2017	2018	2019
Industry	48.8%	73.5%	73.2%
Other	2.5%	2.4%	0.7%
EC Funding	48.7%	24.1%	26.1%

Industry
Funding







ORGANISATIONAL OVERVIEW



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Organisational Overview



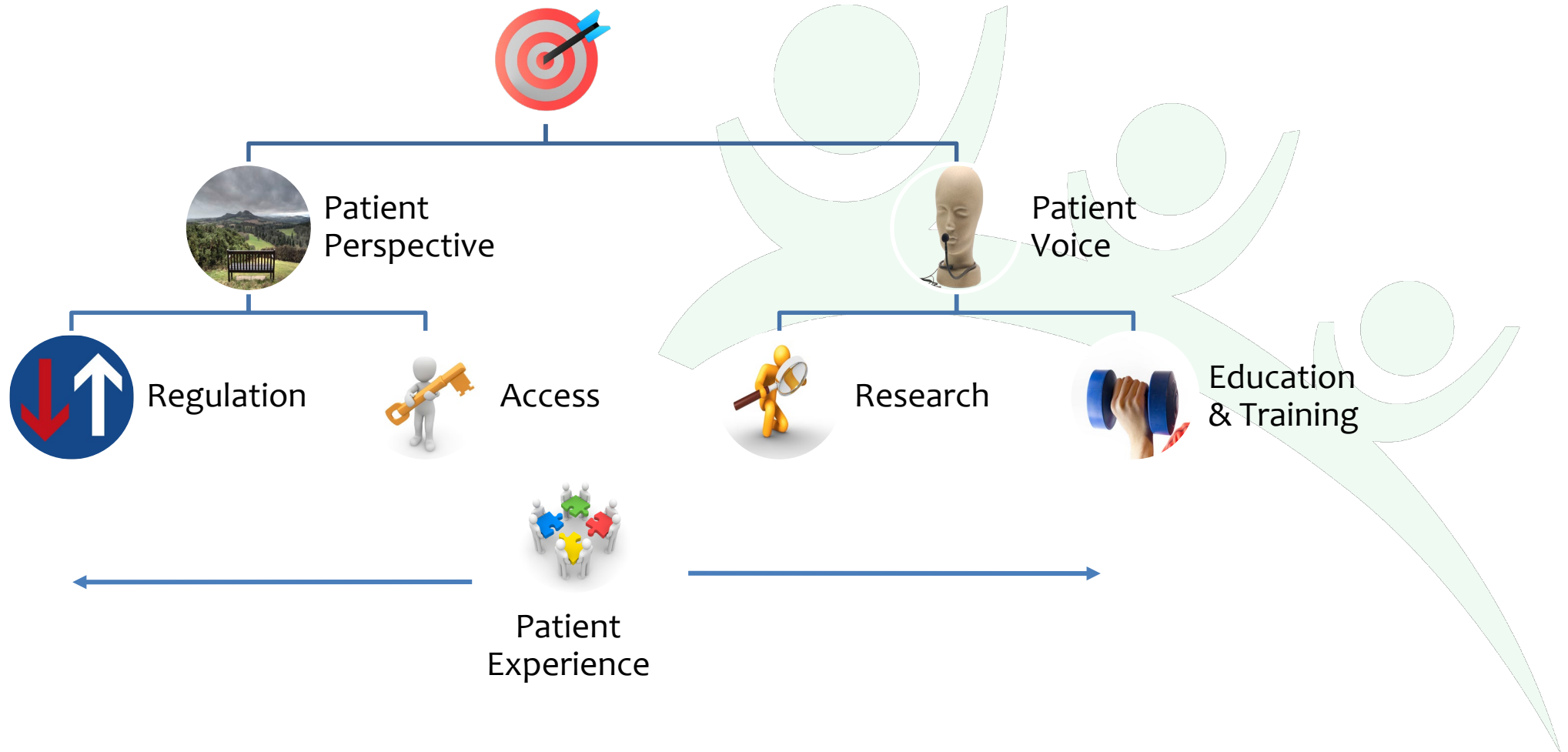
EPF Constitutional Change



New Executive Director – Initial Priorities

- Listening Exercise – Member, network and team
- Network development – augmenting from a strong starting position
- System and Management Development – priority setting and organisational development
- Systems Risk Assessment
- 2020 Operational Plan – funding, priorities
- Purpose, mission and vision – refinement and development
- Communications review – website, social media, etc
- EPF Congress 2019 – programme, audience, value
- Strategy Plan - Methodology Board and Membership Involvement

Integrating the Patient Voice



TWELVE-MONTH REVIEW



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Empowering the patient voice

Ways to incorporate the patient voice in health policy and practice through projects designed to improve patient involvement, patient experience and outcomes



PRO-STEP



PRO-STEP



Key recommendations for policy makers on the added value of **self-management in chronic diseases**.



Developing tangible solutions to **advance patient engagement in R&D for medicines development** and support a much-needed cultural change.



Identifying, comparing, and ranking **the most effective and cost-effective self-management interventions** for adults living with four high-priority chronic diseases.



Transferring valuable knowledge and capacity to the national level and ultimately **reduce the burden of chronic diseases**.

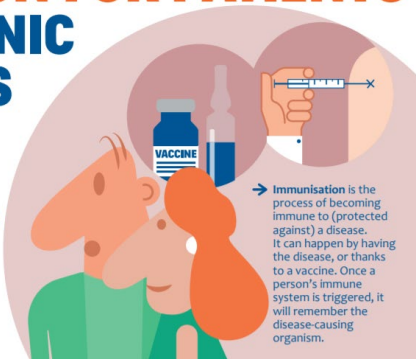
Enhancing the patient voice

Helping empower patients and patient organisations through education and training by enabling them to play a legitimate role as equal partners in the healthcare environment.

VACCINATION FOR PATIENTS WITH CHRONIC CONDITIONS

HOW DOES VACCINATION WORK?

- Vaccination is the use of vaccines to protect from infectious illnesses. The term originates in Latin (vacca = cow). The first vaccinations used a mild disease, cowpox, to produce immunity against a very serious disease, smallpox. Today, vaccines exist to prevent a great number of diseases.
- Vaccines are medicinal products that contain weakened or dead forms of the disease-causing organism, enough to get the body's defensive system to react and produce immunity, but without causing the disease.



Enhancing the patient voice



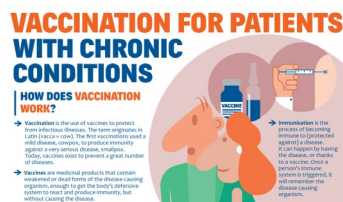
Almost 2 million users of the EUPATI Toolbox –June 2019.



Capacity Building Programme



Launch of our new Capacity Building Module on Empowering Leadership and Positive Governance. **Successful execution** of our Patients Advocates' Seminar.



First workshop organised with the patient community in Bucharest, Romania in collaboration with our member organisation COPAC.



STYPA II: 39 participants from 23 European countries.
A key, well established programme nurturing a platform where young patient advocates empower, inspire and learn from each other.



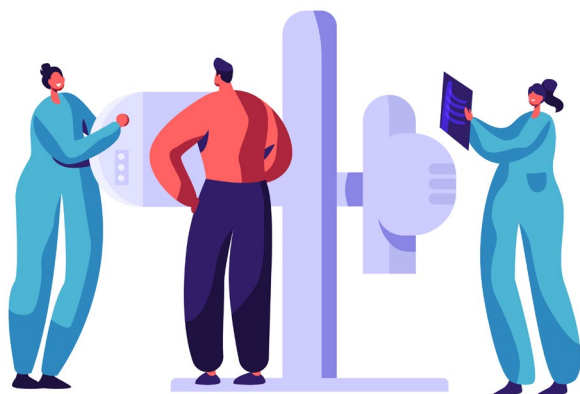
Nutrition Strategy



Improving the receptiveness and willingness of the clinical nutrition sector to involve patient. **Formal collaboration** with the European Society for Clinical Nutrition and Metabolism.

The patient perspective

Playing a key role in the European policy process, and working to ensure that the patient perspective is included and fully considered.



**Health
Technology
Assessment
(HTA)**



**patient
access
partnership**

The patient perspective

Health
Technology
Assessment
(HTA)



New initiatives in the area
of Digital Health



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

Inclusion of people with
chronic conditions



Medicines and medical devices



Working towards a patient-centred EU framework on HTA.

Digital Health Working Group, IMI project for European Health Data and Evidence Network (EHDEN) and Data Saves Lives Portal.









EPF strives to make equitable access and UHC a reality-building on our campaign and roadmap.

EPF intensified its advocacy work and supported the launch of a new MEP focus group on employment and health.

EPF contributed to the work of PACT and improved the measurement of access to healthcare in Europe.

EPF active in EMA & brought patient perspective into debates on implementation of MDR

Collaborative Initiatives on Patient Engagement

	 PATIENT FOCUSED MEDICINES DEVELOPMENT	 PARADIGM <small>Patients Active in Research and Dialogues for an Improved Generation of Medicines</small>	 EUPATI
	Global Focus	European Focus	European Focus
	Patient Engagement Guidance & Tools	Patient Engagement Guidance & Tools	Patient Capability Building
	Full Medicine Lifecycle	Time Points: Research Prioritization; Clinical Trials; Early Dialogue Regulatory & HTA Bodies	Full Medicine Lifecycle
	No Time Boundary	30 Months Duration	No Time Boundary
	http://patientfocusedmedicine.org/our-partners/	http://imi-paradigm.eu/project-partners/	https://www.eupati.eu/supporters-of-eupati/
PARADIGM advances the patient engagement agenda. Integrated approach with initiatives like EUPATI and PFMD			

Cross cutting activities

2019 **EPF**
Congress

EU4health

**EUROPEAN
HEALTH PARLIAMENT**

EUROPE'S NEXT GENERATION OF HEALTH



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COMMUNICATIONS HIGHLIGHTS



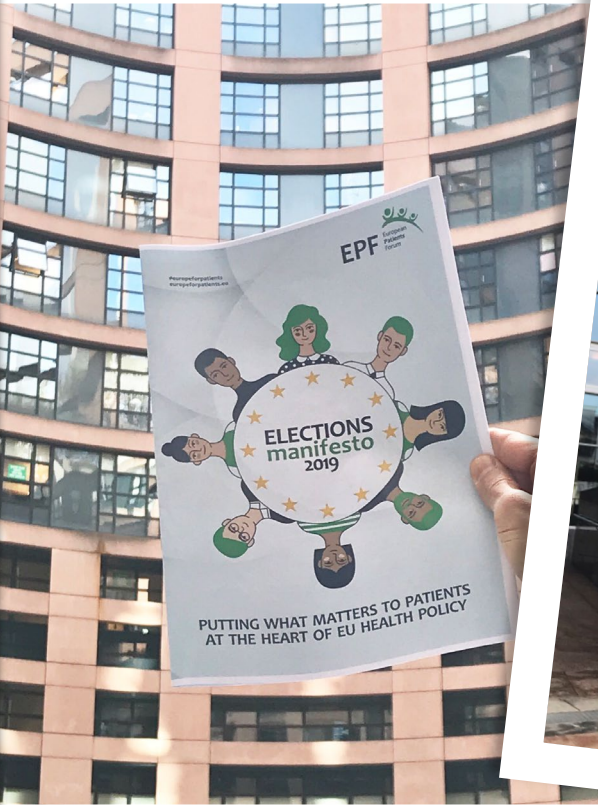
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- Sharing our work
- Engaging with our audience
- Telling the stories of patients





thistimeimvoting.eu





COFFEE BREAK



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POLICY DISCUSSION – ‘HOT TOPICS’



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“Hot topics” policy discussion

Questions received from participants

- Trend towards “individualisation” of patient advocacy – implications to EPF and its members, how EPF views itself and roles of different actors?
- EU institutional renewal – new Parliament and Commission, the place of health in the new structure
- Multiplication of initiatives in patient engagement & potential overlap or duplication as well as sustainability (if further discussion/clarification needed)
- EPF’s plans on nutrition (if further discussion/clarification needed)
- Any further questions?

FORWARD LOOK



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2019/2020 WORK PROGRAMME



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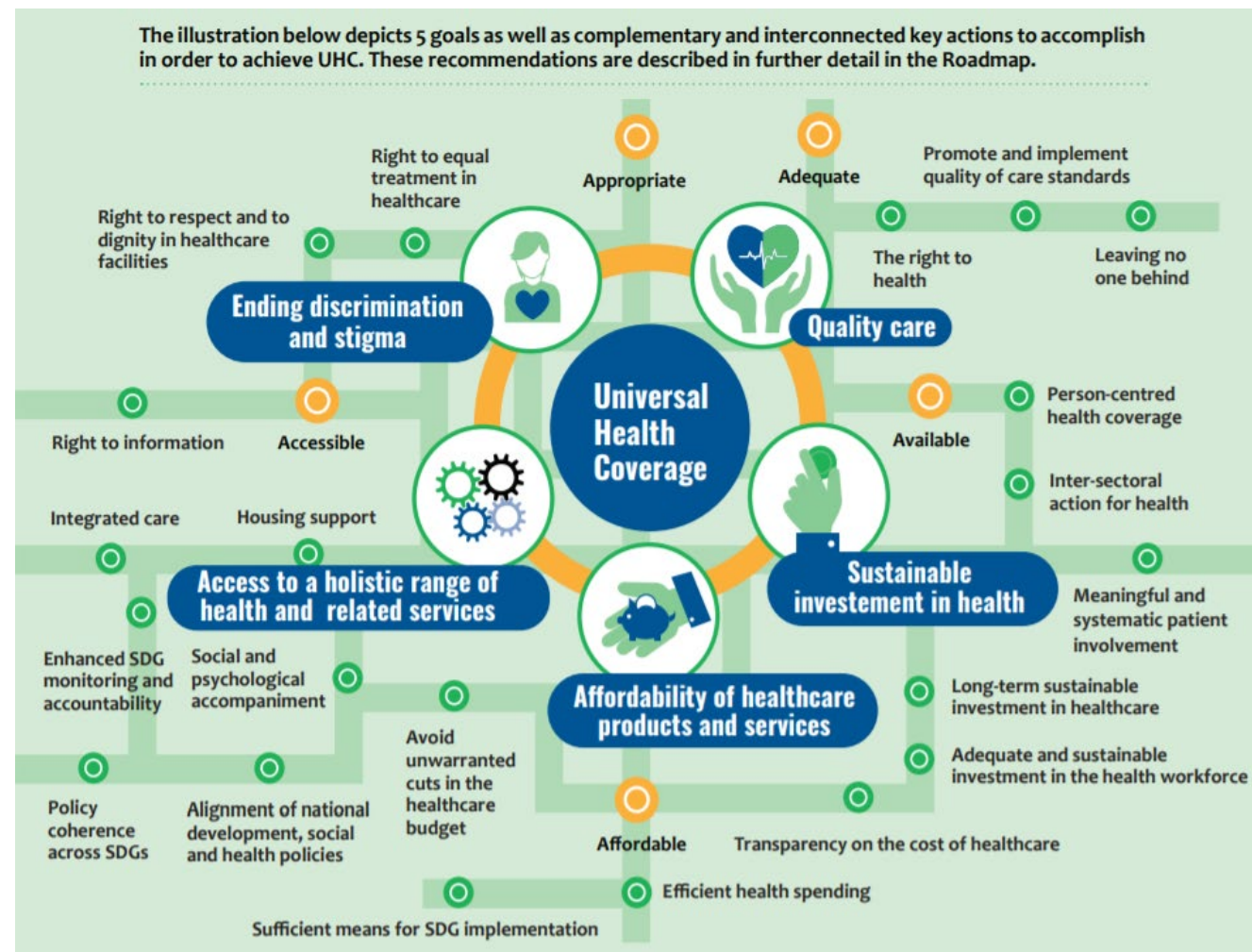


Navigating the new institutional and international environment

- Follow-up of EU elections
 - European Parliament, Commission, health collaborations
 - The Manifesto remains our guide to patients' priorities
- Strengthening collaboration and relationships with important EU and international bodies
 - EMA: continuing engagement in PCWP + representation on MB
 - OECD: standing invitation to HCQO WG + PaRIS advisory council, new PRIMs survey
 - WHO European regional office – health systems strengthening & people-centredness...
- EPF Congress – patient involvement – ensuring strong links and “actionability” of outcomes in future policy & advocacy work at different levels
 - E.g. Patient involvement in HTA – regardless of the “fate” of the policy file

Access to healthcare

- EPF UHC Roadmap = “compass” guiding our work
 - Policy brief on biosimilars & generics
 - Updated paper on value and pricing of innovative medicines
 - Internal WG on universal access
- Medical Devices
 - Regulation - implementation activities & informing patient community
- Dialogues
 - with MedTech Europe and Medicines for Europe
- Memberships and collaborations
 - SDG Watch Europe, Patient Access Partnership (PACT), ...



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Looking ahead to 2020

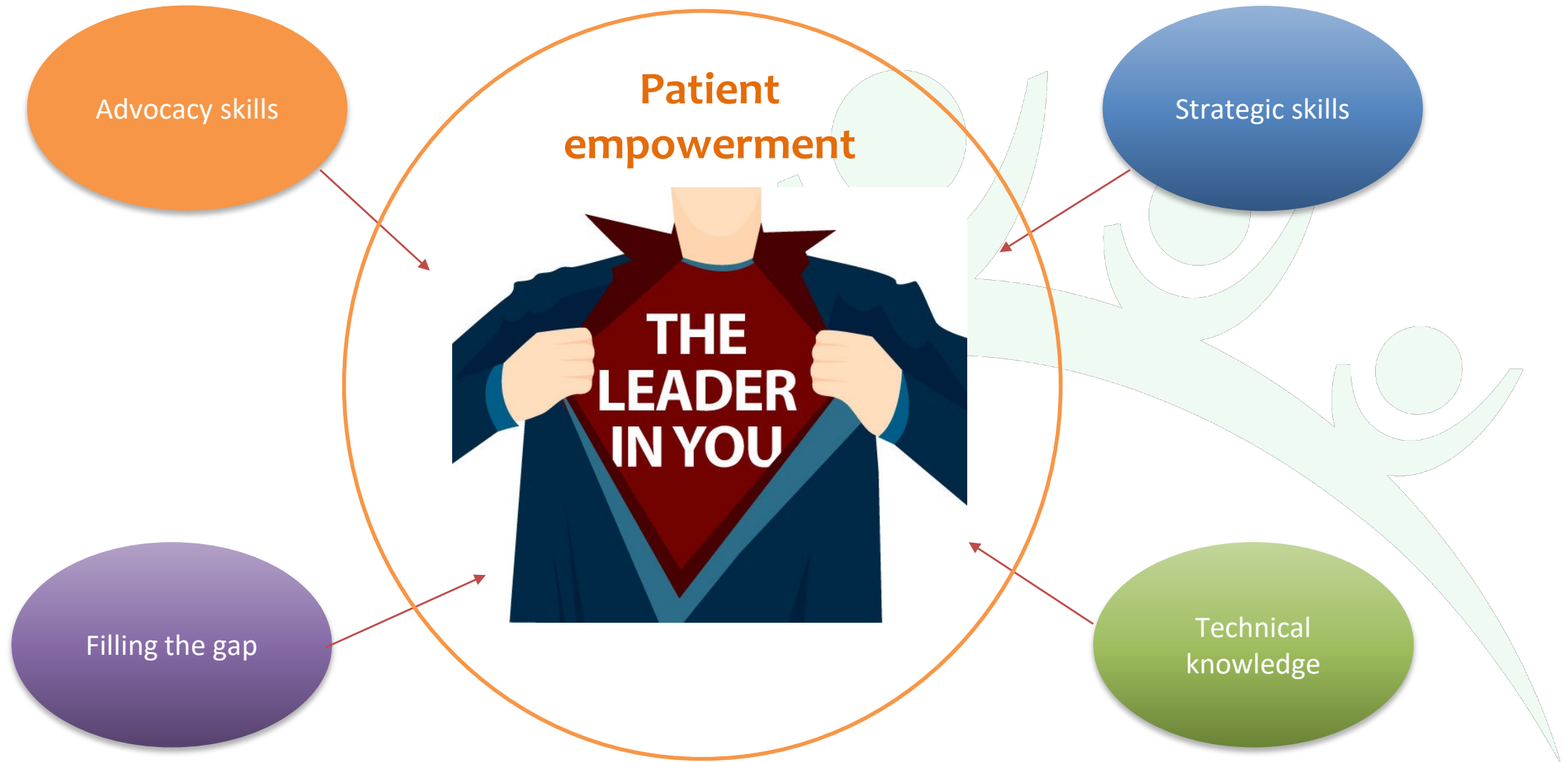


Projects

A diversified project portfolio aiming at incorporating the patient voice in health policy and practices



+5 submitted proposals
in the areas of
digital health,
patient-centered
research platforms,
education and
patient engagement



- Strengthening our capacity building activities online and offline

Leadership
Meeting

Capacity Building
Module on
Leadership and
Governance

Patient
Advocates'
Seminar

Summer Training Course
for Young Patient
Advocates

Looking ahead at the next 12 months at EPF

Areas of focus in 2020

- Operationalization of the Wider Europe strategy
- Setting up of the ethics committee and reinforce the Youth section
- Embedding in EPF post 2020 Strategy the outcomes of the EPF Congress 2019



Young patient
representatives
between 15 and
29 years old



Passionate
about change,
integration
and patient
empowerment



They all have
special needs
and expectations



The EPF Youth Group consists of 11 young patients, coming from all over Europe!

Main activities:

- WAYS project
- STYPA
- Constitutional reform! The Youth Group is now entitled to have a representative as a Board member

Future plans:

- Factsheet with key recommendations to employers and employees with chronic conditions, based on the WAYS survey results
- Video about patients' rights in the work field
- Work on a new topic - sexual health and well-being
- Youth Group Board elections coming soon

EPF CONGRESS



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A Reminder of our Starting Point

- The first ever European Congress on patient involvement driven by the patient voice
- Opportunity for dialogue and engagement with stakeholders committed to patient involvement
- Practice focus generating ideas that can make a difference
- To move forward on much-needed policy commitments in this area
- To gain a greater and genuine understanding of the wealth of expertise that patients bring to health systems' design and strengthening



**2019 EPF
Congress**

Update on Developments

- Event to be co-facilitated by a patient advocate
- Plenary speakers and panel to be announced
- Focus on developing the Day Two Seminar Sessions
- Structuring the takeaways and follow up
- Registrations in line with desire for diverse audience



2019 **EPF**
Congress

So register now to avoid disappointment!

When?

12-14 November 2019

Where?

Crowne Plaza, Place Rogier, Brussels, Belgium

Registration?

From 15 April – subscribe to our newsletter for more updates via www.epfcongress.eu



STRATEGY PLANNING

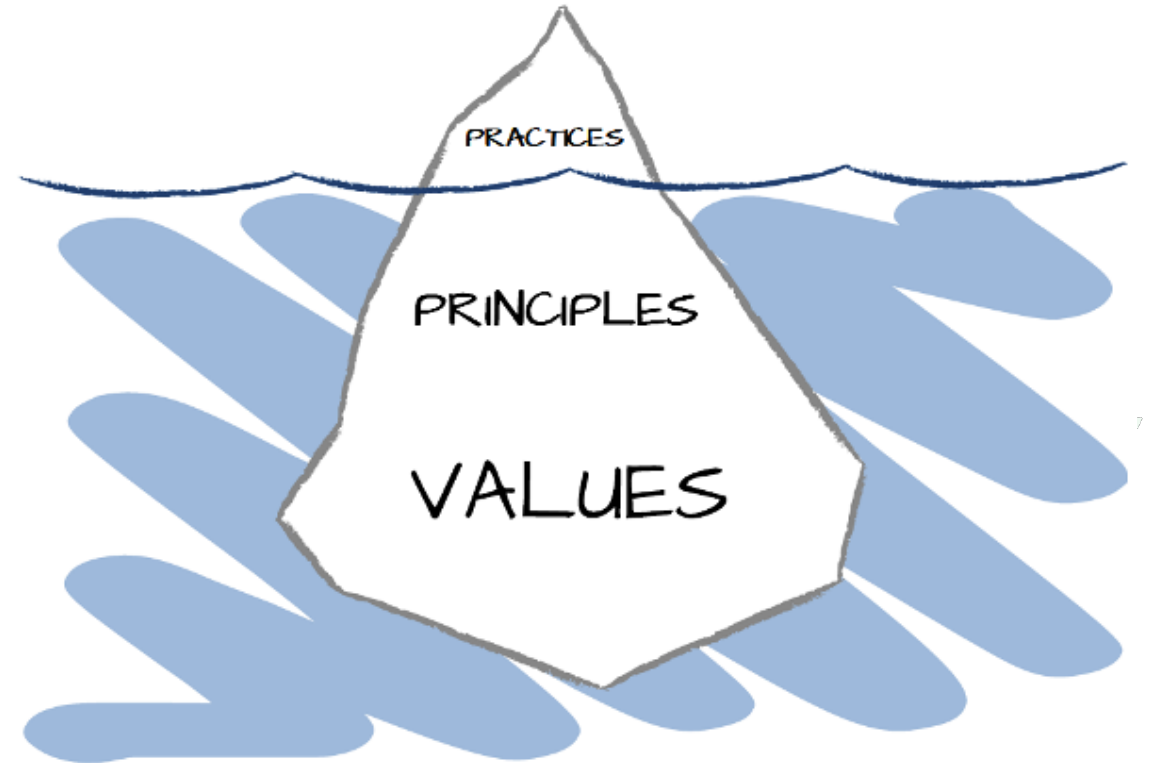


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- Focus and Value
- Standards and Excellence
- Impact and Learning
- Breadth and Depth
- Legitimacy and Independence



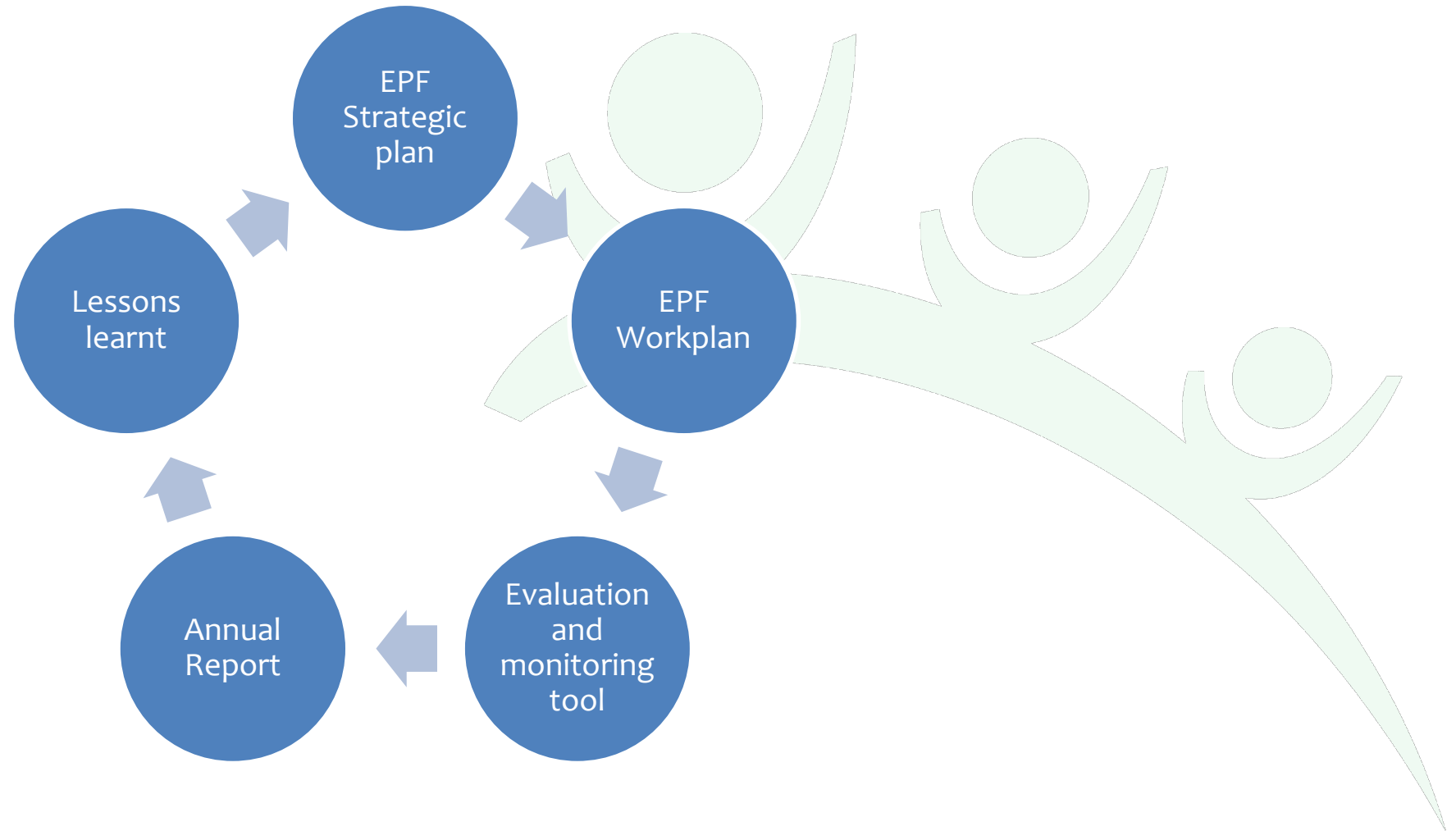
Strategy Planning Milestones

- Quarter Two
 - Bi-Laterals and Partner Engagement
 - Board Governance
 - Secretariat Project Team
- Quarter Three
 - Strategy Development Framework
- Quarter Four
 - SWOT
 - Force Field Analysis
 - Evaluation



- Quarter One
 - Stakeholder Consultation and Engagement
 - Strategic Principles Established
 - Draft Strategy Development
- Quarter Two
 - Draft Strategy Refinement
 - Presentation to AGA
- Quarter Three
 - Work Plan Development

EPF: A learning organisation



QUESTIONS & COMMENTS?



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