

# EUROPEAN PATIENTS' FORUM

## Industry Roundtable

5 June 2018

Annual Industry Roundtable



@eupatientsforum

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



# Agenda

13.30h	Financial health check of EPF
14.00h	Making the difference for Europe's patients 2017, 2018
14.30h	Priority areas in 2019
15.10h	Break
15.40h	EU – Hot topics – Exchange of views
16.40h	Brainstorm on making the funding process as efficient and as effective as possible
17.00h	Conclusions of the session and next steps

# FINANCIAL HEALTH CHECK FOR EPF

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

# 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 – circa 40 companies, Trade Associations – very high level of support and encouragement
  - 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- working on this (project portfolio)

# 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 ( ex Biosimilar event, Digital Agenda event)
- 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, World Bank, IAPO
- New opportunities – **leading the discourse** and providing some solutions on patient involvement in health systems strengthening



Discussed and agreed by EPF Board December 2017

- Earlier Industry Roundtable to share thoughts with trusted partners
- 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 showcasing, visibility and income –generating
- Strong advocacy work with the EU Institutions- also in the context of the next EU Programming Period- Health Programme



# MAKING A DIFFERENCE FOR EUROPE'S PATIENTS: HIGHLIGHTS 2017-2018

Kaisa Immonen, Director of Policy

“ A STRONG PATIENTS' VOICE TO  
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# Universal Access to Healthcare

## The Roadmap is our compass

- Promotion of the EPF Roadmap and awareness raising of the UN SDGs
- **New** EPF Working Group on Universal Access to Care (2 meetings)
- Leadership within Patient Access Partnership (PACT)
- Access to medicines – 2018 update of EPF's paper “Value and pricing”
- Information on generic and biosimilar medicines – 2018
- Engagement with European Semester





## Addressing stigma and promoting patients' rights and inclusion in society

- Promotion of our recommendations on equal treatment and inclusion in the workplace (CHRODIS+)
- Cooperation with Fundamental Rights Agency
- Strengthening **alliances** with NGOs representing groups vulnerable to social exclusion
- Monitoring the European Pillar of Social Rights and relevant initiatives
- Alignment with Youth Group activities



# Patient Empowerment 2.0

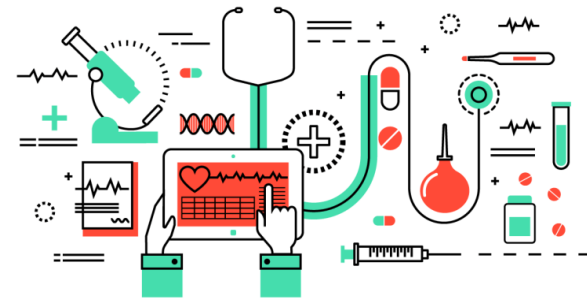
## Setting the stage for our patient-led Framework for Meaningful Patient Involvement

- EPF working group: **Toolkit** for patient organisations on patient empowerment (2017)
- **NEW** initiative on meaningful patient involvement in health systems
- Mapping – inspiring examples → Developing criteria and practical tools
- **Patients' rights** – formalisation of EPF's position in 2018



## Health systems must deliver what matters to patients

- EPF shaped the **OECD PaRIS** initiative on PROMs and PREMs
- Dialogue with our members on what constitute “high/low” value care and “waste” – **2018 policy brief**
- Engaging with WHO Europe on health systems strengthening
- **Position paper on quality of care** adopted in 2017 – identifies gaps in current concepts of quality and points to what patients value



# Patient safety – continuing priority

## Implementing our Roadmap for Action on Patient Empowerment

Theme: patient and family empowerment for better patient safety (Nov 2016)

→ Task Force 2017

→ Proposal for core competences 2017

- Work with OECD on **PRIMs** – 2017 and 2018
- Patient awareness & engagement in **AMR**
- **New** initiative on **vaccination** 2018



EPF Breakfast Briefings - Antibiotic Resistance (17 November 2017)

## Patients as partners for patient-driven digital transformation

- **New!** Working group on digital health and health data → Defining strategy & vision for digital health
- **Informing patients:** development of relevant, lay-friendly resources
- **Identifying key principles** for patient-centred digital health – engagement with COM and stakeholder initiatives
- EPF **patient survey** 2018



# MAIN PRIORITIES 2019

Nicola Bedlington

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

# Main priorities 2019

- EPF Congress
- European Parliament Election
- Wider Europe
- Constitutional Change
- Flagship projects – EUPATI and PARADIGM –critical year, and other new ventures
- Capacity Building Programme
- Policy highlights
- Strategic Planning 2020 and beyond





# EPF CONGRESS NOVEMBER 2019

“ A STRONG PATIENTS’ VOICE TO  
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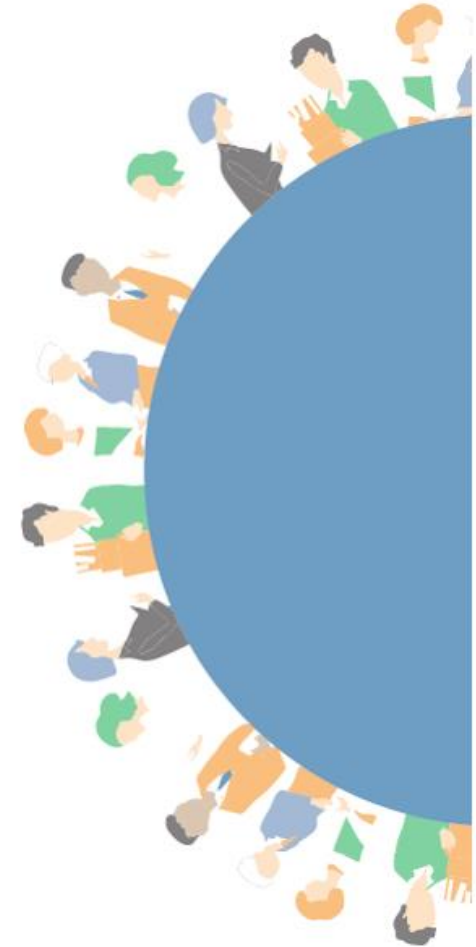
# EPF's role as an umbrella

- We channel our members' expertise
- We connect patient organisations and other stakeholders
- Aim: link innovation agenda with empowerment agenda → towards health(care) policy that is needs-driven
- EPF: parallel actions to develop patient-led frameworks on good practice in patient involvement
  - Health system: service co-design / evaluation, health research, patient-driven technology solutions
  - Patient involvement in pharmaceutical R&D – PFMD, PARADIGM, EUPATI



# Rationale for Congress

- Meaningful patient involvement - **underused resource in innovative, patient-centred healthcare design and delivery** at all levels
- EPF -a unique role as the only European-level cross-disease patient organisation, linking patient communities and European developments in health policy and practice
- A (regular) major congress on patient involvement –the opportunity to advance significantly the dialogue with a wide range of health stakeholders.



- Examine **opportunities and barriers** for meaningful patient involvement in different areas of health systems, **drawing lessons** from other areas where patient involvement is more established
  - EPF's policy and project work over the last decade
  - Link with meaningful patient engagement in the life cycle of medicines and medical technology,
- Advance on a (patient-relevant) outcomes-based approach to healthcare delivery, **from the patient perspective** ( Value based healthcare +)



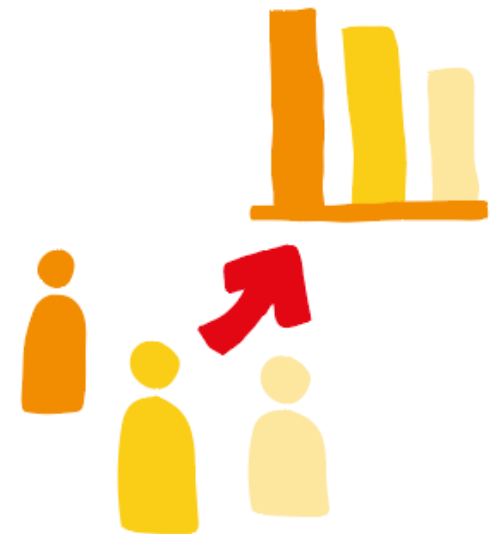
Circa 300 participants

- **Patient Representatives from throughout Europe**
- **KOL** – EU institutions , Member States, WHO, OECD, ICHOM, DIGITAL DISRUPTERS etc.
- Healthcare Industry
- Public Health Representatives
- Health Care Professionals and Managers
- Researchers
- Regulatory and HTA community
- Payers / national insurances



# ‘Feel’ of the congress

- New, fresh approach- **highly interactive**-blend of theory and practice
- **Professional** – tangible learning outcomes, akin to medical societies
- **Political** – patient –driven Congress to move the agenda on patient centred health ecosystems
- **Concrete** – contribution to EPF’s framework on patient involvement in health systems design and strengthening
- **Personal and professional development**



# Next steps – by early autumn 2018

- Feedback
  - PHARM4CHANGE, PFMD, EPF INDUSTRY ROUNDTABLE, POTENTIAL INSTITUTIONAL PARTNERS
- Creation of a steering group – composition to be discussed by EPF board 6 June
- Nail down core topics, high level speakers
- Secure seed money, venue

# EUROPEAN PARLIAMENT ELECTION CAMPAIGN

“ A STRONG PATIENTS’ VOICE TO  
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## Strategy and expected outcomes

**Objective:** patients' voice is heard by policy-makers at all levels; position of patient community reinforced

Complementarity with #EU4HEALTH Campaign

- #EU4HEALTH: ensure health is a priority in EU post-2020
- EPF Campaign: patients' role in a strong health collaboration environment

Evidence-based policy 'asks' illustrated by patient testimonials,

Launch of "What matters to patients" video campaign in September/October

**Outcome:** Secure the commitment of new and re-elected MEPs to support actively our work across EP Committees





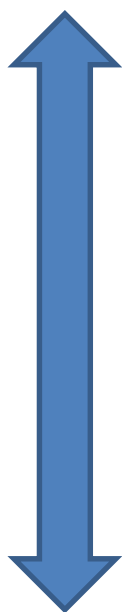


**EU  
COLLABORATION  
IN HEALTH  
MATTERS TO  
PATIENTS!**

# 5 priorities, 5 key messages

Defined together with our membership

Patients' Rights



- Participation of patient organisations in health policy
- Patient access to health/related care and non-discrimination
- Patient involvement in research
- Patient empowerment
- Patient-driven digital health

# How it works



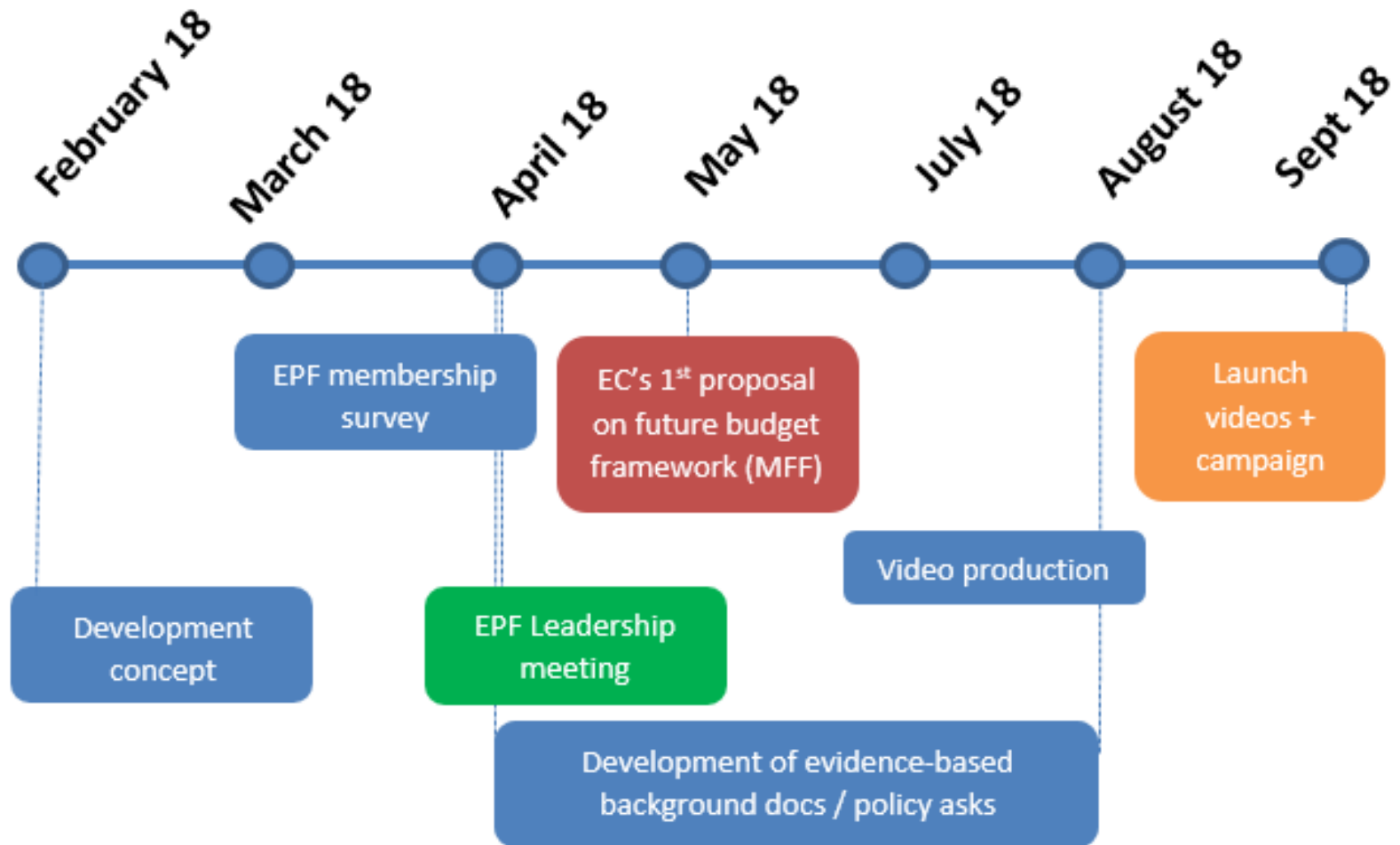
Building on the human factor.

*What matters to us and why you should support our message!*

PRIORITIES

- 1.
- 2.
- 3.

# Next steps: a timeline



# EPF AND WIDER EUROPE



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# EPF and wider Europe

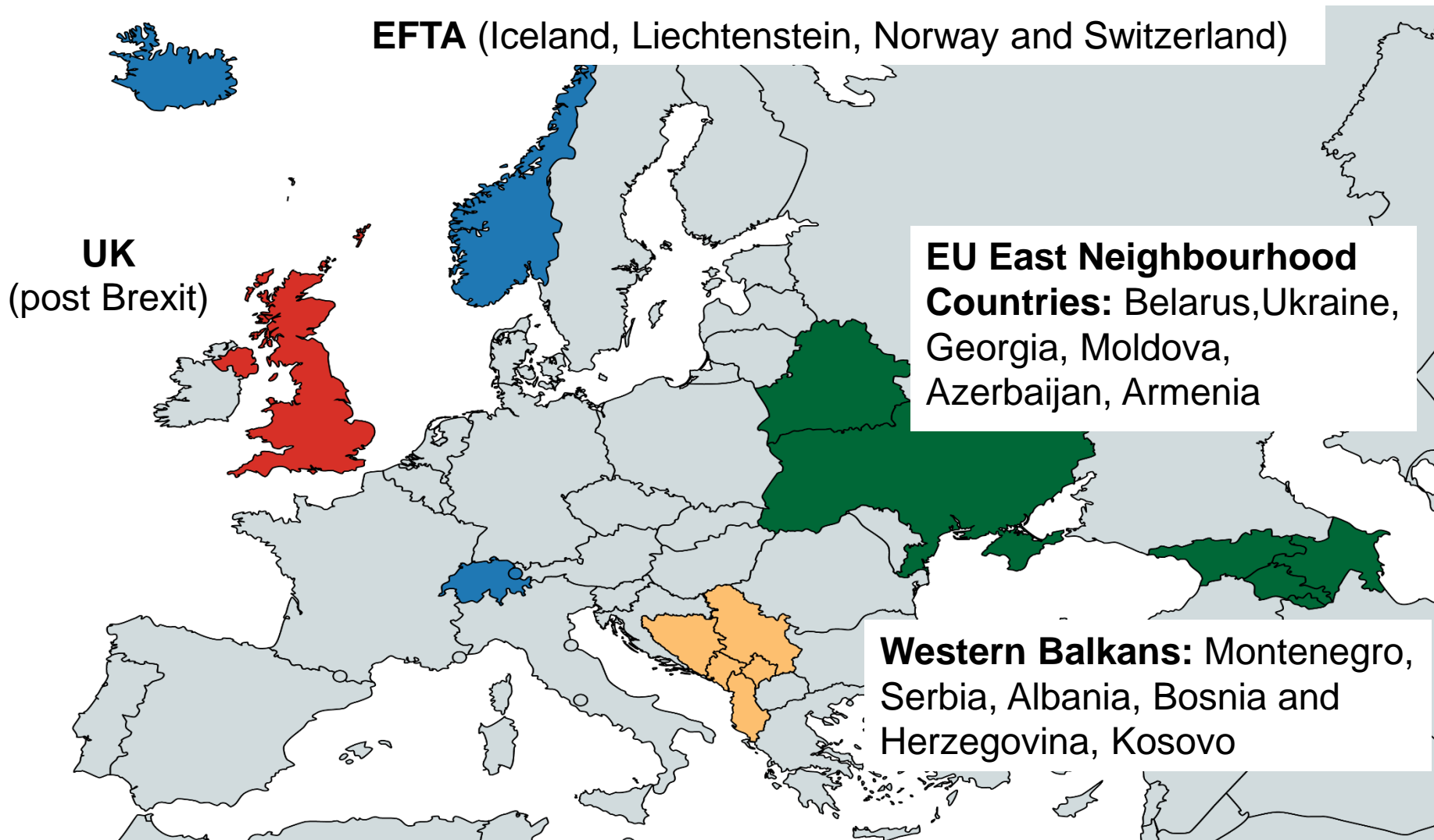
## Rationale

- All our members are Pan European
- Clarify relationship with EFTA /EEA countries
- Retain UK membership post Brexit
- Interest in EPF from Wider Europe countries
- Discussions with IAPO - agreement for EPF to work with 'EU neighbourhood' countries, and IAPO to focus on Central Asia (the 'Stan' countries)
- Confirmed interest from WHO-Europe to support process (MoU, Mapping), Upcoming meeting in Tallinn



*Note : stepwise approach over several years- manage expectations*

# Geographic area



# Next steps

- 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 in those countries
- 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 Programme.



# CONSTITUTIONAL REFORM

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## 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 etc
- Clarity on our relationship with Institutions beyond the EU, i.e. WHO Europe, OECD, World Bank
- New Internal Rules that will support the governance of the organisation
- CONSTITUTIONAL REFORM COMMITTEE – 19 June 2018



# FLAGSHIP PROJECTS



“ A STRONG PATIENTS’ VOICE TO  
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- 34 partners
- IMI project
- 9 million over 2,5 years
- Objectives:
  - Sustainability of patient engagement
  - Delivering tools and practices
  - Delivering metrics for impact



**Research and  
priority setting**



**Design of  
clinical trials**



**Early dialogues with  
regulators and HTA bodies**



**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.

# THE NEXUS BETWEEN PATIENT TRAINING AND ENGAGEMENT

The key position of EPF in the field by leading  
**EUPATI & PARADIGM**  
Founding partner of PFMD



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# PATIENT TRAINING SUPPORTS PATIENT ENGAGEMENT



## EUPATI

*European Patients' Academy on Therapeutic Innovation*

- Became a PPP Programme led and hosted by EPF after IMI-Project ended
- Bridging period to secure sustainable future
- Continuing to run Patient Expert Courses (54 trainees in Cohort 3)
- Continuing to maintain and develop Toolbox (700'000+ users 10 langs)
- Continuing to support national level platforms
- IMI Extension project 'EFOEUPATI' September 2018 – August 2020

## PARADIGM

*Patient Active in Research and Dialogues for an Improved Generation of Medicines*

- 3 main lines of work
  - *Tools and templates*
  - *Assessment of current practices*
  - *Sustainability*

## PATIENT FOCUSED MEDICINES DEVELOPMENT

Global initiative

Permanent structure



PATIENT FOCUSED  
MEDICINES DEVELOPMENT

No meaningful engagement without training.  
Training without engagement is meaningless.





## Objectives



1. Identify project topics match with our priorities and policy dossiers;
2. Meet membership requests to focus more in areas such as digital health, Electronic Health Records;
3. Expand and diversify project portfolio;
4. Improve funding balance between public and private funding.

# EHDEN- European Health Data and Engagement Network



IMI 5-year project -submitted stage 2 -BDBO

- Multi-stakeholder consortium led by Erasmus – University Medical Center Rotterdam
- EHDEN aims at developing a federated health data network based on a *quid pro quo* around data for research use;
- EPF's role – patients' readiness to share data – data security/ confidentiality/ quality/ use

H2020 project – 2 stages (successfully passed stage 1)

- Future and Emerging Technology (FET) Flagship call
- Transdisciplinary team led by Max Planck Institute
- Objective: it aims to establish a personal Digital Twin for every European citizen.
- Strong patient participation
- EPF role in WP on **Patient Engagement** to ensure patient focus and involvement in all WPs from design to implementation

# IMMUcan: Tumour Microenvironment Immuno profiling

IMI 5 year project- 2 stages (successfully passed stage I)

- Led by EORTC (European Organisation for Research and Treatment of Cancer)
- Focus on potential of personalised medicine
- EPF role:
  - Dissemination
  - Education/ communication strategy to patients and wider public about the potential, reality and limits on what personalised medicine can deliver to patients.
  - Oversight role patients perspective on informed consent and reuse of data

# InterEHR –Interconnecting EHR across Europe

- Led by EIBIR –European Institute for Biomedical Imaging Research
- Objective: harmonisation of existing local/regional/national eHealth solutions, in order to allow for interoperability of relevant EHR functionalities, using existing, and/or setting new European standards.
- EPF role:

Patient & older people's needs' assessment

Patient input in all relevant WPs

- H2020 4-year project
- Led by EATRIS (European Infrastructure for Translational Medicine)
- Objective: strengthen the capacity of the EATRIS Network

## EPF role:

- outreach and comms,
- advocacy role in the work on sustainability (HTA etc),
- Trainings (synergies with EUPATI)

# CAPACITY BUILDING PROGRAMME



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# Strengthening the patient community

## Capacity-building module on empowering leadership and positive governance

- 24 participants from 17 countries;
- Objective: to strengthen patient organisations by enhancing leadership skills and positive governance in their organisation
- Similar plans for 2019

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



**THE  
LEADER  
IN YOU**

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



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 Summer Training Course for Young Patient Advocates**
  - Vienna, 1-4 July 2018
  - 40 participants
  - 23 countries
  - Focus on inclusion, non-discrimination & societal change
- **Plans for a Third Course in 2019 – large demand from young patients**



## Legitimacy and Representativeness

- Supporting emerging national coalitions;
- Transparency and ethics guidelines;
- Informal networks and new stakeholders.



# Impactful Patient Organisations

## An Empowered and Engaged Patient Community

- Support cross-fertilization (cluster approach);
- Spark engagement and drive higher levels of participation (members' expertise database, members' participation monitoring tool).



# POLICY HIGHLIGHTS

“ A STRONG PATIENTS’ VOICE TO  
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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



# Sustainable healthcare systems for all

Universal health coverage

Access to Medicines

Position on biosimilars  
& generics

Cross-border Healthcare

Patients' report on cbhc

Patient Safety and Quality of Care

Social Inclusion and Non-  
discrimination

Inclusion of patients in the  
workplace

Health Technology Assessment (HTA)

Medical Devices and In Vitro Diagnostics Regulations

# Patient involvement & empowerment

Health Literacy and  
Information to Patients

AMR

Vaccination

PROMs and PREMs, health outcomes

Information to patients on Food and Nutrition

Digital Health, Big Data and  
Personalised Medicine

Principles on data, use and sharing

Clinical Trials

“Translating” CTR for patients

# BUILDING EPF 'S STRATEGIC PLAN 2020 +

Preliminary work

Environmental analysis- consultation  
with members, scenario building

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