

# (ACCESS TO) CARE AND PATIENT PARTICIPATION

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EFA's Annual General and Strategy Meeting  
22 May 2017

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

- Health at EU level is a **success story!** A lot has been achieved, citizens want more of it and better/more cooperation should lie ahead

On average 70% of Europeans would like the EU to act more on health than it does now

Source: EP Eurobarometer 2017

- The EU is facing common challenges: from an aging population and increased chronic disease to health inequalities and the sustainability of health systems
- We should find common solutions!

- European Patients' Forum
  - Independent & non-governmental
  - Umbrella organisation
  - Active since 2003
  - EU patients' voice
- Our members
  - 74 patients' groups
  - EU disease specific organisations &
  - National patient coalitions
- Our vision
  - All patients in the EU have equitable access to high-quality, patient-centred health and social care



# Empowerment

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

# The Patient Empowerment Campaign

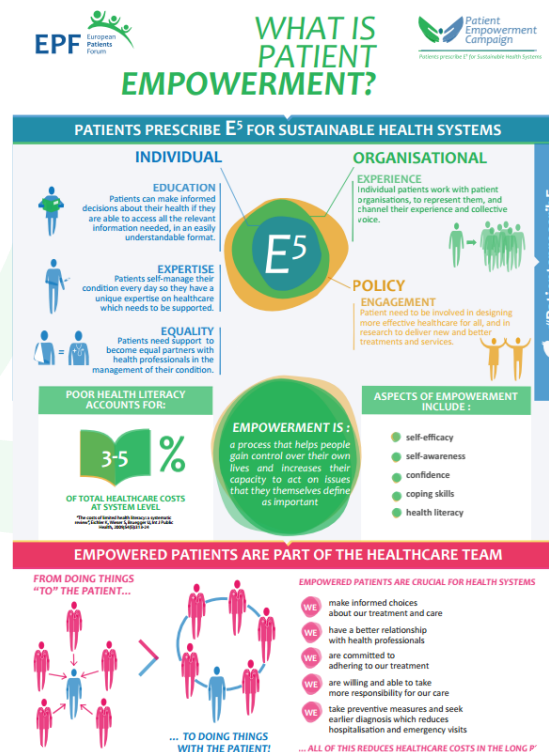


May 2015 – June 2016

EPF membership survey & Strategic Plan 2014-2020:  
Patient empowerment as key “thematic priority”,  
internal Working Group set up

Campaign:

- Promote awareness of patient empowerment to policy-makers
- What it means for patients
- Critical role of patients – the “untapped resource” for health systems
- Patients’ individual & collective participation in healthcare & policy-making



Supported by: **Robert Bosch Stiftung**  
and by unrestricted grants from GSK, Amgen and MSD.

# Campaign on Patient Empowerment

Campaign messages



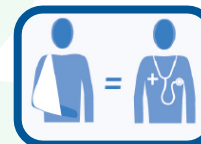
EDUCATION



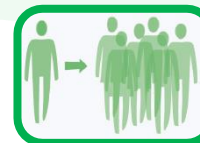
EXPERTISE



EQUALITY



EXPERIENCE



ENGAGEMENT



→ Patients prescribe **E<sup>5</sup>** for Better Health Systems!

# Outcomes & outputs

## THE CAMPAIGN IN NUMBERS

### ONLINE

2,215,708 impressions 

1,957 tweets with #PatientsprescribE 

37,108 video views 

205 pledge signatories 

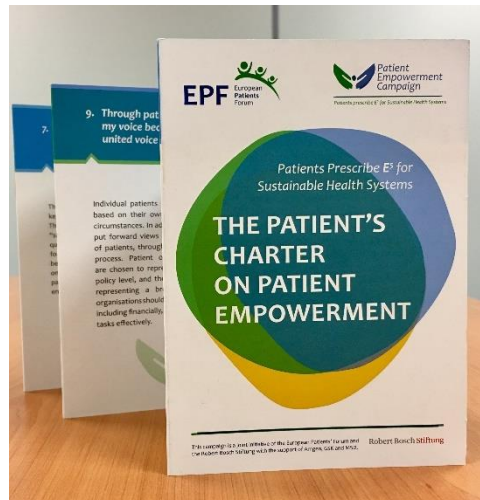
### OFFLINE

 Leaflet translated in **18** languages

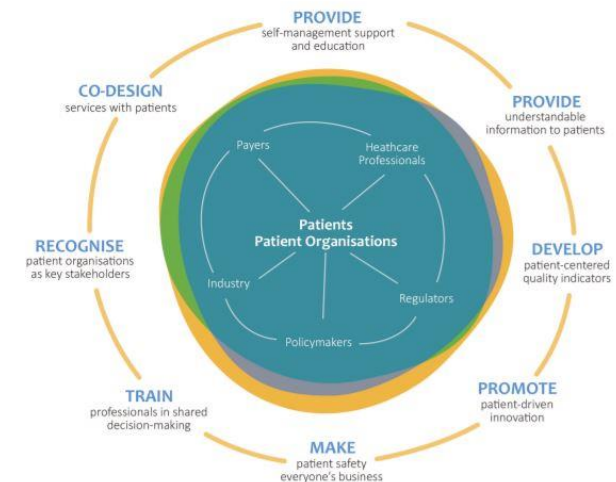
 **38** articles/publications in both national and European media.

 The campaign was presented at **22** events in **10** countries.

 Major launch conference with more than **150** stakeholders



## The Charter & The Roadmap



## Patient safety: EPF priority

- EPF active engagement: JA PaSQ, EC Expert Group...
- EU HPP on 5 December 2016: joint call for action for EU Patient Safety Policy
- Emergence of AMR and HAIs as a serious patient safety issue
- EPF takes forward patient safety linked to empowerment:
  - Conference November 2016 -> Food for thought, broad recommendations
  - Advocacy for PS as EU Health Policy priority
  - 2017: Task force -> proposal on how to address key provision of 2009 CR for patients' empowerment



- “ 2. Empower and inform citizens and patients by:
- (a) **involving** patient organisations and representatives in the development of policies and programmes on patient safety at all appropriate levels;
  - (b) disseminating **information** to patients on:
    - (i) patient safety standards which are in place;
    - (ii) risk, safety measures which are in place to reduce or prevent errors and harm, including best practices, and the right to informed consent to treatment, to facilitate patient choice and decision-making;
    - (iii) complaints procedures and available remedies and redress and the terms and conditions applicable;
  - (c) considering the possibilities of development of **core competencies** in patient safety namely, the core knowledge, attitudes and skills required to achieve safer care, for patients. ”



# Access

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

# UN SDGs - The road to universal access in the EU by 2030

- **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



However we still have some way to go... whether it is: the population covered, the type of services, or the proportion of costs that patients' pay. Many unmet needs and unequal experiences still exist.





**Campaign's strategic objective:** The EPF Access campaign will 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

# 5 Areas for Action



Providing access to **quality of care**



Committing to **sustainable investment** in health



Encouraging **affordability** of healthcare products and services



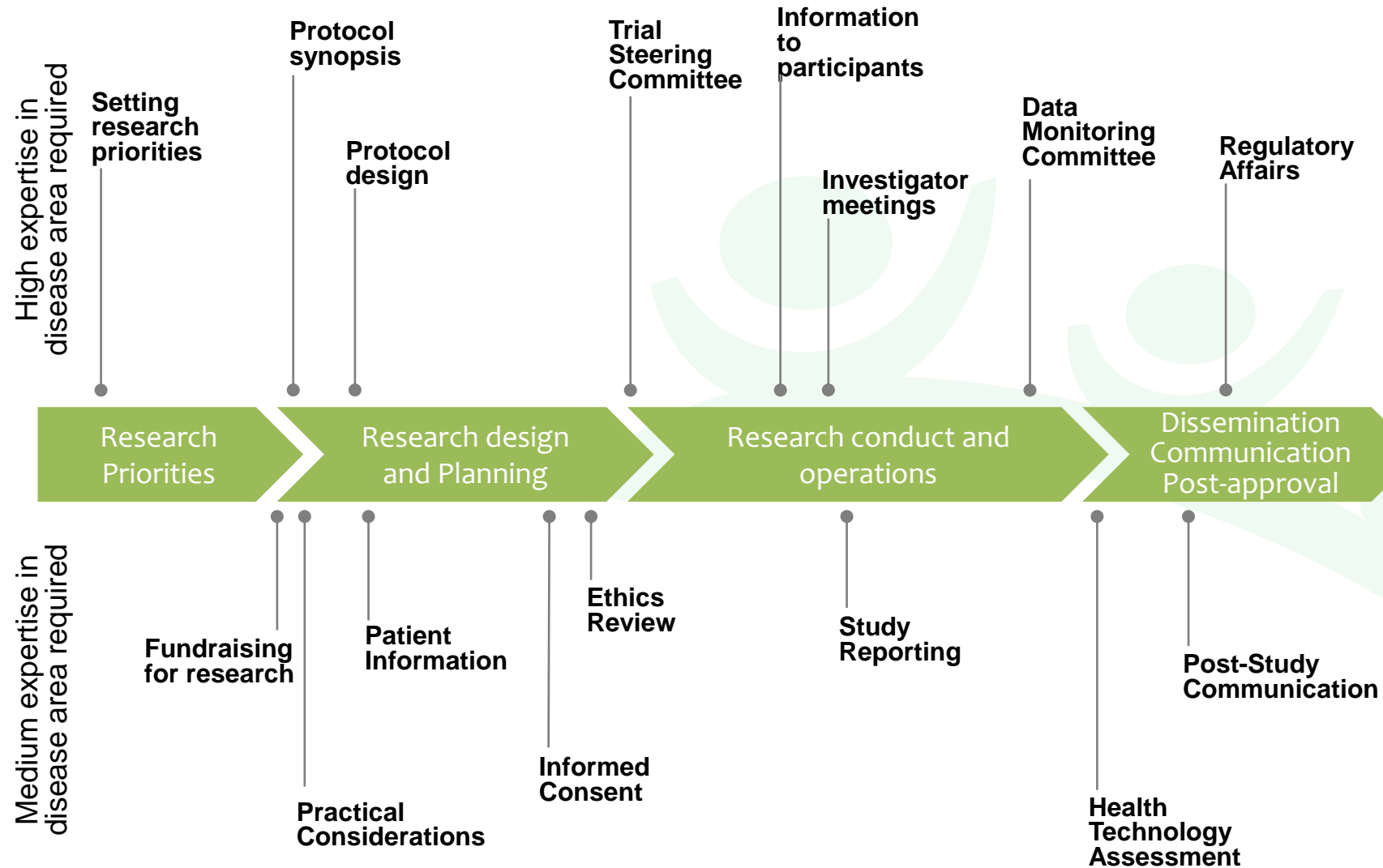
Implementing access to an **holistic** range of health and social services



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

- A comprehensive document which will identify and **propose key political steps, actions and recommendations** that EU decision makers and member states need to take in order to achieve or tend to universal health coverage for all patients in the EU.
- The EPF working group on access will have a leading role in the reflection process and drafting of the roadmap.

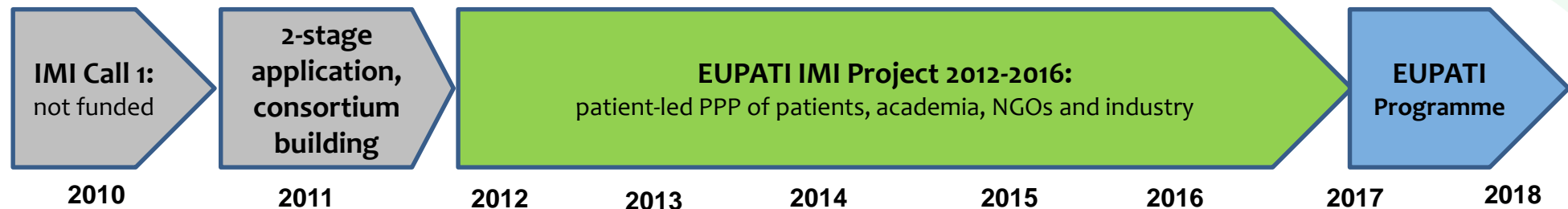
# Patient involvement in medicines R&D



# The “New” EUPATI Programme

**EPF-led, permanent programme in the PPP spirit**

- **3<sup>rd</sup> EUPATI Patient Expert Training Course**
- **EUPATI Toolbox** in all languages
- **“Mini-Course Starter Kits”** and capacity building
- **Content updates** (~10 Toolbox elements updated p.a.)
- **National Platforms**
- **Evolution!**



## a very valued cooperation

- Feeding in the perspective of people with allergy, asthma and COPD in our movement
- Long-standing member of EPF: contributed to our development
- Susanna: Vice president during EPF's formative years until 2016, Board member, represents EPF on many occasions
- Key role in advocating for the recognition of the added value of patient organisations
- Acting as critical friends



# Patient Access Partnership (PACT)



The Patient Access Partnership is a **patient-led multi-stakeholder network** bringing together patients, the medical and public health community, industry and the European and member states policy makers and institutions, in order to develop and move forward on innovative solutions **to reduce inequities in access to quality healthcare in the European Union.**



27 January

2015

2016

# Patient Access Partnership (PACT)



## Key objectives:

- To facilitate the **dialogue** between European and national health stakeholders according to the mission
- To identify key **hurdles in access** to healthcare for patients in a holistic way
- To assess **gaps in access** to quality healthcare within EU member states
- To **collaborate** with relevant EU-led or national initiatives
- To develop innovative and sustainable **solutions**



27 January

2015

2016

# Patient Access Partnership



## Health professionals

(CPME, PGEU, Hospital Pharmacists, EPHA)

## Industry

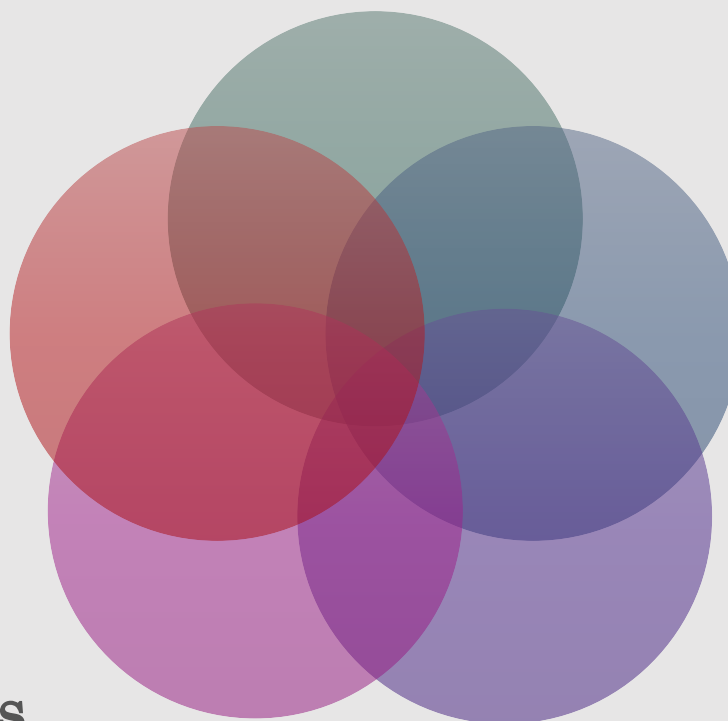
(COCIR, EFPIA, ME, MedTech Europe, EUCOPE)

## Health advocates

## Patient organizations

## Policy-makers

(MEPs, DG SANTE)



1. Improving **awareness** on available mechanisms and innovative approaches for improving access at the national level

1.1. Country round-tables

2. Explore **new approaches** for improving access across the EU-27

2.1. PACT Expert Group on universal access to healthcare

2.2. Advance the measurement tool (5As of Access)

3. Promoting the work of PACT by **applying for a Pilot Project**

3.1. Submit a tender proposal for an access measurement tool

4. Supporting the efforts in maintaining **access high on the agenda**

4.1. Support the work of the MEP Interest Group (events, etc)

A dark green circle containing the word 'ACCESS' in white, uppercase, sans-serif font. To the right of this circle is a vertical red line with four circular images connected by it, showing various meetings and events.A vertical red line with four circular images connected by it. From top to bottom: 1. A group of people sitting around a table in a meeting. 2. A group of people sitting in a large hall or conference room. 3. A group of people sitting around a table in a meeting, with a laptop open. 4. A group of people sitting around a table in a meeting, with a laptop open.



## Priority 1:

Improving **awareness** on available mechanisms for improving access



- **What?**
  - ✓ Round-table “Patient-Centred Roundtable on Working Together for Accessible Health”
- **When?**
  - ✓ June 8, Lithuanian Parliament (Vilnius)
- **Who?**
  - ✓ Lithuanian Cancer Patient Coalition (POLA) in cooperation with PACT, EPF, Committee on Health Affairs of Lithuanian Parliament, Lithuanian Patients’ Forum
- **Endorsements**
  - ✓ Under the auspices of the Lithuanian Minister of Health, Prof. Dr. Aurelijus Veryga
  - ✓ With the participation of Commissioner Dr. Vytenis Povilas Andriukaitis
- **Objectives:**
  - ✓ To increase cooperation between policy-makers and the healthcare community
  - ✓ To explore opportunities for effective engagement on healthcare policies
  - ✓ To improve access to quality healthcare for patients

## Priority 2:

Explore new approaches for improving access across the EU-27



### Objective

- To validate the PACT 5As **concept**: to improve existing access indicators or develop a new set of indicators

### Milestones

- i) Extensive **literature review** of the existing measures assessing access,
- ii) Development of comprehensive **tool** for measuring healthcare access
- iii) **Pilot-test** of the new tool to each group of stakeholders
- iv) **Validation** study in Greece, Bulgaria and Cyprus
- v) **Comparison of the current situation in healthcare access** between the three European countries.

## Priority 3:

Promoting the work of PACT by **applying for a Pilot Project**

**Pilot Project** “Towards a fairer and more effective **measurement of access** to healthcare across the EU in order to enhance cooperation and know-how transfer”

### **PACT's application**

#### Objectives

- Addresses the need for **comparable and timely data on access** in EU through
  - improvement of existing indicators
  - piloting of a new set of measurements
- Affirms the importance of a **credible and comparable tool for measuring access**

## Priority 4:

Supporting the efforts in maintaining access high on the agenda

www.eupatientaccess.eu  
twitter: @PACT\_eu

patient  
access  
partnership

Interest Group on Access to Healthcare

[ Better Access, Better Outcomes -  
Shared Vision, Shared Responsibility ]

29 June 2016 16:30 - 18:30 room ASP 3E2 European Parliament

**Opening remarks**  
Co-Chairs of the MEP Interest Group on Patient Access to Healthcare

**EU action on improving access to medicines - state of play and way forward. What the EU can do**  
**Andrzej Rys**,  
Director for Health Systems, Medical Products and Innovation,  
DG SANTE, European Commission

**Christian Siebert**,  
Head of Unit, Biotechnology and Food Supply Chain, DG GROW,  
European Commission

**Insights into Presidency-related activities**  
**Marcel van Raaij**,  
Director, Ministry of Health, Welfare and Sports, The Netherlands

**EU options for improving access to medicines**  
**Soledad Cabezón Ruiz**,  
Rapporteur in the ENVI Committee

**Stakeholder debate**

Access to the EP Building from the Spinelli entrance  
Registration for the event: andrey.kovatchev-office@ep.europa.eu

patient  
access  
partnership

Interest Group on  
Access to Healthcare

State of Health in the EU - Health at a Glance: Europe 2016  
28 November 2016, 17:00 - 19:00, room JAN 6Q.1, European Parliament

Hosted by  
the Co-Chairs  
of the Interest Group  
on Patient Access to Healthcare  
**Biljana Borzan, Cristian Silviu Buşoi,  
Karin Kadenbach, Kateřina Konečná,  
Andrey Kovatchev and Lieve Wierinck**

The revamped Health at a Glance: Europe report is the first deliverable of the two-year "State of Health in the EU" cycle. The new publication is more closely aligned with the European Commission Communication adopted in 2014, which defined 'increasing accessibility to health care' as one of the three pillars for an EU agenda for health systems.

The main findings of the "Health at a Glance: Europe 2016" report will be presented by **Gaetan LAFORTUNE** (Senior Economist in the OECD Health Division). Deputy Director-General of DG SANTE **Martin SEYCHELL** will elaborate on the objectives of the "State of Health in the EU" cycle, its subsequent deliverables, as well as the broader effort of the European Commission to strengthen country knowledge and boost analytical capacity.

The presentations will be followed by a debate with decision-makers and stakeholders on the contribution of the exercise to identifying policy measures to address barriers to access.

Access to the EP building from the JAN entrance  
Registration for the event:  
andrey.kovatchev@ep.europa.eu

## The Value of EU Cooperation in Healthcare

- **Robert Madelin**, Senior Adviser for Innovation, European Political Strategy Centre
- **DG SANTE**
- **Dr Clemens-Martin Auer**, Director-General, Austrian Federal Ministry of Health (tbc)
- **Sandra Garcia-Armesto**, Executive Director, Institute of Health Sciences in Aragon
- **Yann le Cam**, Chief Executive Officer, EURORDIS (tbc)
- **Stanimir Hasardzhiev**, Patient Access Partnership

Jun 29  
2016

Nov 28  
2016

Jun 27  
2017



## PACT provides:

- A unique multi-stakeholder platform with **all** concerned stakeholders on various issues
- An opportunity to engage with **high-level actions** (*MEP Interest Group*)
- A platform for **local-level activities** (e.g. *PACT Regional Conference*)
- **Valuable input** in line with EPF's efforts to expand access (e.g. *EPF WG on Access*)
- An opportunity for collaboration on **specific projects** (e.g. *EPF Access Campaign*)
- Support for **patient advocacy** activities (e.g. *5As' modeling for disease-specific areas*)

THANK YOU!