



## **Patient Access Partnership**

Work Plan 2017

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## ABOUT 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.

### Vision

The patient access partnership enables different health stakeholders to join forces to develop, drive and propose to the EC and the Member States sustainable solutions to ensure equitable patient access to quality healthcare in the EU. Stakeholders will actively participate in delivering these solutions.

### Mission

The activities of the patient access partnership are patient-focused. Information and knowledge transfer are a key requirement to identify gaps in and measure access to quality healthcare between and within member states. The Partnership will develop a tool to monitor and measure equity of access in member states on an on-going basis. Through holistic collaboration with relevant EU-led or national initiatives, the Partnership will provide a much-needed space for creativity, coherence and collaboration and propose sustainable solutions.

### Strategic goals:

- Introducing EU mechanisms for accelerating access throughout Europe and support the member states
- Support EU legislation on standards for increasing quality of healthcare and access
- Identify barriers and gaps in access across EU – develop a tool to measure access in EU28
- Explore innovative approaches to increasing access in Europe – e.g. fare pricing system to improve access to innovation and enhance competitive environment

### 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

## OVERVIEW

Work Plan 2017 is developed on the ground of the conclusions, feedback and outstanding questions that emerged from a number of activities that we conducted in 2016. More specifically, we will seek to integrate the conclusions of the PACT Regional Conference (2016), the proposals put forward by participants in the three Workstreams, the discussions of the Steering Committee of PACT as well as considerations of the socio-political developments both at EU and the national levels.

Two complementary ideas will broadly define our work in 2017 – continuity and aspiration. More specifically, Work Plan 2017 outlines the necessity to advance the activities undertaken in 2015 / 2016 in order to meet the challenges of the dynamic socio-political and economic developments in the European Union.

A fundamental milestone that will have an impact on the final Work Plan 2017 is the announcement of 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”, adopted by the EU Parliament in 2015. Developed in close cooperation with PACT, the Pilot Project addresses the need for comparable and timely information on access in EU through the improvement of existing indicators and the piloting of a new set of measurements. It also reflects the key findings of the Opinion on Access to Health Services in the European Union by the Expert Panel on Effective Ways of Investing in Health, in which the importance of a credible and comparable tool was stressed.

The activities will be carried out in the framework of the following **key priorities**:

1. Improving awareness on available mechanisms and innovative approaches for improving access and healthcare provision at the national level
  - 1.1. Country round-tables
2. Elaborating on the work conducted in the previous years to explore new approaches for improving access across EU Member States
  - 2.1. PACT expert group on universal access to health care
  - 2.2. Advance into the next phases of the measurement tool of access
3. Promoting and expanding the work of PACT by applying for a Pilot Project
  - 3.1. Submit a tender proposal for Pilot Project on access
4. Supporting the efforts and providing input, where possible, to maintain the issue of equitable access high on the EU political / legislative agenda
  - 4.1. Support the organisation of high-level events of the MEP Interest Group

## CORE ACTIVITIES

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

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#### *\*In the framework of Workstream “Ensuring Access is high on the Agenda”*

One of the main conclusions coming from the discussions between various stakeholders from Central and Eastern Europe during PACT Regional Conference 2016 was that the European Semester process should better reflect the country-level situation. An emphasis was put on the need to allow for broader stakeholder involvement and input with respect to the Country Specific Recommendations (CSRs).

During the conference, DG SANTE (European Commission) expressed interest in considering a proposal on a structured process to select stakeholders at the country level to provide recommendations and local experience with respect to the CSRs.

#### **Activities:**

##### **1.1. Country round-tables**

In view of the aforementioned, it is important to extend the EU policy agenda to practical implementation possibilities at the Member State level. In this context, PACT is taking the initiative to increase cooperation between policy-makers and stakeholders within the countries from the region by holding a small-scale country round-tables in cooperation with the European Commission representatives, country-level EU Semester officers and PACT local partners and stakeholders.

The purpose of these meetings is to:

- Follow-up on the conclusions of the PACT Regional Conference and encourage multi-stakeholder collaboration models and best-practice exchange to improve the frequency, quality and scope of communication of the national actors in the healthcare field. The goal is to establish trust, transparency and mutual understanding among the concerned parties on issues related to access to healthcare.
- Seek and promote the need for involvement of national stakeholders in the discussions over the CSRs in preparation of the Annual Growth Survey in the framework of the European Semester

The round-table objectives will be:

- To discuss opportunities for more formal stakeholder cooperation at local level
- To discuss possibilities for structured stakeholder input to the EU Semester consultations

Countries to be considered (subject to discussions) are:

- Malta
- Estonia
- Bulgaria
- Romania

#### **Deliverables:**

1. A consultation meeting
2. Four country country-tables
3. Four meeting reports with recommendations

## 2. *Elaborating on the work conducted in the previous years to explore new approaches for improving access across EU Member States*

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### *\*In the framework of Workstream “Measurement Tool”*

#### **Activities:**

#### **2.1. PACT expert group on universal access to health care**

During the PACT Partners’ Assembly, held on December 11<sup>th</sup> 2015, it was suggested that part of the work conducted in the forthcoming year should be focused on defining constitution of an accessible healthcare system and an oversight of the key components of an “access package”, a package based on evidence-based good practices to be available to all in the EU. In line with the recommendations emerging from the [Expert Panel’s Preliminary Opinion](#)<sup>1</sup>, the project will further inform the work of the Workstream “Measurement Tool”.

Following an Open Call among the Partners, a small Ad-hoc Expert Working Group was formed and invited to attend a meeting in Brussels on 19 January 2016 to assess this initiative’s need. As a result of a couple of follow-up meetings and consultations, the Ad-hoc WG developed a concept for a project entitled **“Request for an expert opinion: Universal access to health care in the context of the European Union”**.

The proposal envisages drawing on the richness of PACT partners’ insights to develop a framework that can serve as a critical input into efforts to measure health systems, by gathering together a representative subset of individuals (“Experts”) from within the Partnership (or from among those specifically designated by Partners) to consolidate stakeholders’ expertise and perspectives to identify, with respect of each of the 5 As – availability, adequacy, accessibility, affordability and appropriateness – what are the critical elements of universal health care. In particular, Experts would represent the perspectives and expertise of the variety of stakeholders. It is proposed that external experts from other institutions also be invited to participate in some capacity in the Group of PACT Experts.

The work will be carried out in the following provisional (to be confirmed) order of activities:

- i. Open call to all PACT Partners to nominate a representative from their own organisation, or from another organisation or institution, to participate in the expert group.
- ii. Initial meeting of the PACT expert group to refine its terms of reference and designate one or more rapporteurs to lead the writing of the group’s outcome report. (1/2 day)
- iii. Second meeting of the PACT expert group to elaborate its outcome report. (1.5 day)
- iv. Rapporteur(s) present(s) outcome report to the Partners’ Assembly

#### **Deliverables:**

1. An outcome report

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<sup>1</sup> Available at: [http://ec.europa.eu/health/expert\\_panel/consultations/access\\_healthcare\\_en](http://ec.europa.eu/health/expert_panel/consultations/access_healthcare_en)

*\*In the framework of Workstream “Mapping Access”***Activities:****2.2. Advance into the next phases of the measurement tool of access**

In 2015, PACT undertook the first of a number of ambitious steps in conducting a survey to assess the extent to which national healthcare systems meet the 5As criteria for access as defined by PACT: *availability, adequacy, accessibility, affordability and appropriateness*. The survey was conducted among a wide range of stakeholders to avoid bias through reflection of variety of perspectives on the issue at stake.

In 2016, PACT presented the initial results and key conclusions of the survey in a publication in the Public Health Genomics Journal, entitled “**A Conceptual Framework of Mapping Access to Health Care across EU Countries: The Patient Access Initiative**”.

Yet, the preliminary study conducted in EU-28 showed that the questionnaire needs to be revised in order to ensure that it is a reliable and valid instrument to assess access in Europe. For this purpose, a validation study will be carried out (countries to be confirmed later) with a different version developed for each group of stakeholders (e.g. patients, patient organizations, public health representatives, physicians, policy makers and the industry), in alignment with the one already established by PACT.

The main objectives of the project are:

- i. Extensive literature review of the existing measures assessing access
- ii. Development of comprehensive tool for measuring healthcare access (based on the “PACT-5As Indicator” and existing measures)
- iii. Pilot-test of the new tool to each group of stakeholders
- iv. Validation study
- v. Comparison and contrast of the current situation towards healthcare access between the selected countries

To develop further the idea for the critical elements of universal healthcare, we shall request input from the partners to map existing initiatives of access across the EU.

The purpose of this exercise is to:

- Avoid overlap in initiatives and projects that address issues of access to healthcare;
- Provide the opportunity to obtain more comprehensive understanding on access to healthcare in the EU;
- Supplement the work of WS Measurement Tool on the project “Request for an expert opinion: Universal access to health care in the context of the European Union” and the work on the validation of the measurement tool of access

**Deliverables:**

1. Literature review
2. Measurement tool
3. Pilot test
4. Validation study
5. Report

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

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Another element of Work Plan 2017 is the *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*<sup>2</sup> which aims to “enable the development of policies that address health inequalities and barriers to access on the basis of objective and comparable information and help improve the sustainability and performance of healthcare systems in Member States.”

The Pilot Project will develop and pilot a new set of healthcare access measurements and/or the improvement of existing measurements, in order to address the different needs of various healthcare stakeholders and propose a framework for measuring access to healthcare in the EU and a strategy and a roadmap for scale-up and implementation of that framework. The expected outcomes are:

1. Review of existing measurements and indicators as well as the different aspects of access across the EU;
2. Development, through consultation with key stakeholders, of possible new indicators and/or improvement of existing indicators, to ensure that groups vulnerable to exclusion are reached and a ‘total picture’ of access to healthcare in countries and regions is thus acquired;
3. Exploration and possible validation of a new set of indicators and/or of existing indicators improved upon with the relevant European and international organisations;
4. Strategy and roadmap for possible scale-up and implementation, focusing on priority areas

The overall budgetary allocation reserved for procurement contracts in 2016 amounts to EUR 250.000. Deadline for submission of proposal: 24 February 2017.

#### ***Activities:***

##### ***3.1. Submit a tender proposal for Pilot Project on access***

It is vital that PACT seizes the opportunity to submit an application. The Steering Committee discussed and confirmed that a wiser approach in view of current operational and capacity framework of PACT would be to combine the proposals put forward by WS Measurement Tool and WS Mapping Access and use them as the basis of the Pilot Project proposal of PACT. This will ensure coherence with respect to the activities carried out by the three Workstreams.

PACT has approached consultants who have put forward a proposal, analysis and a timeline for action and potential partners as per the Terms of Reference. PACT will seek to form a consortium.

Due to the administrative burden related to the application process, management capacity and financial history, PACT will pass the project leadership to EPF. Yet, PACT will maintain its fundamental and key role in the project management and direction of activities.

If unsuccessful, PACT will need to consider an alternative plan for action with respect to its activities in 2017, i.e. execute Work Plan 2017 as per the initially planned activities. It is possible that Work Plan 2017 undergoes minor amendments in order to optimize the use of human and financial capacity available for the execution of the proposed activities.

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<sup>2</sup> Available at: <http://ted.europa.eu/udl?uri=TED:NOTICE:465522-2016:TEXT:EN:HTML&src=0>

#### **4. Supporting the efforts and providing input, where possible, to maintain the issue of equitable access high on the EU political / legislative agenda**

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During 2015, the MEP Interest Group on Access to Healthcare has made a significant progress in raising awareness among key policy actors about the challenges to access that patients across the EU28 face.

Among other activities, two major successful events marked this year's remarkable contribution of the MEP Interest Group to the issues of access in the EU:

1. **"Better access, better outcomes - Shared vision, shared responsibility" (Jun 29)** provided an opportunity for all interested stakeholders to discuss policy responses at EU level to improve patients' access to medicines and close the current gap on health inequalities;
2. **"State of Health in the EU - Health at a Glance: Europe 2016" (Nov 29)** which gave the floor to the recent joint Commission/OECD report entitled 'Health at a Glance: Europe 2016' which is part of the Commission's current efforts to build a solid knowledge base as a resource for Member States in addressing challenges to their health systems.

A recognition for the work of the MEP Interest Group was the fact that it grew larger as Ms. Lieve Wierinck MEP joined. With her arrival as a new co-chair of the Interest Group, another major political group is represented in the team of co-chairs.

##### **Activities:**

#### **4.1. Support the organisation of high-level events of the MEP Interest Group**

PACT will continue to support the MEP Interest Group in their efforts in favour of supporting EU legislation on standards for increasing quality of healthcare and access. Whilst the significant efforts invested in searching for ways to establishing a dialogue with other EU institutions, there is still more to be done to ensure that equal access is widely recognised as a major issue that needs to be tackled. More specifically, EU countries remain to a large extent reluctant to discuss broader measures for action that go beyond the Member States' legacy. The MEP IG events are in this respect, extremely valuable opportunities to address relevant issues.

The topics of the MEP events are set in accordance with the most pertinent issues related to access. PACT is grateful that the MEP Interest Group welcomes the proposals put forward by PACT partners in the framework of Workstream Ensuring Access is High on the Agenda.

The first for 2017 MEP event will explore the possibilities for cooperation and deeper connection to ensure stronger patient organisations in Europe. The purpose of the event is to bring together national and EU patient organisations to discuss key issues and exchange knowledge and understanding of the common challenges that patients across the EU face.

The topic of the second MEP event will be confirmed later. However, a possible proposal to be taken into consideration is the European Semester as a topic. Having European Semester and the stakeholders involvement discussed at the national level (in the context of the country round-tables) and within the frame of the MEP Interest Group (including EU stakeholders) at the EU level, would allow for a greater bridge of national – EU dialogue.

##### **Deliverables:**

1. Two events of the MEP Interest Group on Access, organised with the support of PACT
2. Two reports
3. Two press-releases

## COMMUNICATION & DISSEMINATION

### ***1. Develop further the internal procedural and structural working mechanisms to optimise the achievements by taking advantage of the human and expert potential of the Partners***

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#### ***Activities:***

- Agree upon working procedures for collecting input and receiving timely feedback from the Partners
- Explore the possibility to integrate internal channels for dissemination of key information materials to ensure timely interventions at the EU and national levels
- Integrate and stimulate the use of mechanisms for best-practice exchange between the Partners

### ***2. Maintain the existing dissemination channels and explore new tools for increasing awareness and visibility***

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#### ***Activities:***

- Create infographics on challenges to access
- Create video messages of Partners on relevant issues related to access
- Publish regular press releases
- Publish position papers on key issues at stake
- Elaborate the contents/design of the existing newsletter
- Actively use the available communication channels but also explore new ones to successfully convey key messages:
  - Twitter
  - Facebook
  - Website
  - YouTube
  - Thunderclap

## BUDGET

## Budget 2017 (est.): Core Activities



ITEM	BUDGET '17 (Est.)
<b>MEETINGS</b>	
Workstream "Mapping Exercise" x 2 meetings (venue, equipment, catering, T&A)	3 000 €
Workstream "Measurement Tool" x 2 meetings (venue, equipment, catering, T&A)	3 000 €
Workstream "Ensuring Access on the Agenda" x 2 meetings (venue, equipment, catering, T&A)	3 000 €
Steering group meetings x 4 (venue, equipment, catering, T&A)	5 000 €
Meetings at EP (Interest Group) x 2 (venue, equipment, catering, speakers, materials, reports, T&A)	6 000 €
Partnership Assembly Meeting (venue, equipment, catering, speakers, materials, T&A)	7 000 €
<b>Subtotal</b>	<b>27 000 €</b>
<b>ADMINISTRATIVE COSTS</b>	
Staff support costs	26 000 €
Office sublet (incl. telephone, equipment)	13 000 €
Representation (travel and accommodation)	15 000 €
Consultancy services (Pilot Project)	12 000 €
<b>Subtotal</b>	<b>66 000 €</b>
<b>COMMUNICATIONS</b>	
Website / social media (contents development, website monthly maintenance fee, printouts, etc)	2 000 €
<b>Subtotal</b>	<b>2 000 €</b>
<b>Contingency</b>	<b>5 000 €</b>
<b>TOTAL</b>	<b>100 000 €</b>

Balance 2016  
Income 2017

## Budget 2017 (est.): Project Activities



PROJECTS	BUDGET '17 (Est.)
<b>COUNTRY ROUND-TABLES</b>	
4 country meetings (venue, equipment, catering, logistics)	20 000 €
Representation (travel & accommodation)	10 000 €
4 reports (drafting, editing and design)	8 000 €
Interpretation services	4 000 €
Contingency	2 000 €
<b>Subtotal</b>	<b>44 000 €</b>
<b>PACT EXPERT GROUP ON UNIVERSAL ACCESS</b>	
2 meetings (venue, equipment, catering, logistics)	10 000 €
Representation (travel & accommodation)	4 000 €
Remuneration (10 experts & 2 rapporteurs)	5 000 €
Final (extensive) report (drafting, editing and design)	5 000 €
Printing and dissemination of report	3 000 €
Contingency	2 000 €
<b>Subtotal</b>	<b>29 000 €</b>
<b>NEXT PHASE OF MEASUREMENT TOOL OF ACCESS</b>	
Preparation (modifications and finalisation of questionnaire - phase 1, literature review)	1 000 €
Approval (preparation and communication of questionnaire - phase 2)	2 000 €
Validation (on-line platform, monitoring, data analysis, presentation of results, modifications, final data analysis)	17 000 €
Follow-up (paper publication, presentation of results)	5 000 €
Contingency	2 000 €
<b>Subtotal</b>	<b>27 000 €</b>
<b>MAPPING ACCESS EXERCISE</b>	
2 meetings: launch and follow-up (venue, equipment, catering, logistics)	10 000 €
Representation (travel & accommodation)	2 000 €
Final report (drafting, editing and design)	2 000 €
Contingency	2 000 €
<b>Subtotal</b>	<b>16 000 €</b>
<b>TOTAL</b>	<b>116 000 €</b>

PACT Regional  
Conference  
leftover

Pilot Project  
Procurement