

This document outlines the objectives, agenda, agenda committee roles, speakers overview and potential outputs for the event: **“Patient-Centred Roundtable on Working Together for Accessible Health”**.

BRIEFING NOTE

“PATIENT-CENTRED ROUNDTABLE ON WORKING TOGETHER FOR ACCESSIBLE HEALTH”, PORTUGAL, 2019

Organised by the Patient Access Partnership (PACT) in partnership with GAT – Grupo de Ativistas em Tratamentos, the collaborative initiative MAIS PARTICIPAÇÃO Melhor saúde that GAT promotes and with the institutional support of the Health Parliamentary Commission (Portuguese Parliament) and the Ministry of Health of Portugal

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1) “Patient-Centred Roundtable on Working Together for Accessible Health in Portugal”

In 2017, the [Patient Access Partnership \(PACT\)](#) committed to sustain a long-term initiative to increase cooperation in the field of healthcare between policy-makers and healthcare stakeholders within the EU countries by holding small-scale country stakeholder meetings. These meetings aim to raise awareness on the challenges and opportunities for improving access to healthcare in the countries. They also offer an opportunity to increase cooperation between healthcare stakeholders, national authorities and EU institutions for the purpose of improving access to prevention, diagnosis and treatment.

The first PACT country stakeholder meeting was held in [Lithuania](#) (June 2017 at the Lithuanian Parliament) while the second meeting took place in [Romania](#) (November, 2017) under the auspices of the Minister of Health in each country respectively.

Against this background, Portugal has been selected to be the country of the third strategic meeting that PACT will organise in partnership with [GAT – Grupo de Ativistas em Tratamentos](#), the collaborative initiative [Mais participação Melhor saúde](#) that GAT promotes and with the institutional support of the Health Parliamentary Commission (Portuguese Parliament) and the Ministry of Health of Portugal.

The purpose of this meeting will be to discuss the opportunities to improve health promotion and prevention and ensure quality healthcare for patients in Portugal through meaningful public dialogue and engagement.

The meeting is to be held on **February the 25th, 2019 at the Parliament of the Republic of Portugal.**

The meeting will provide a platform for an open and cooperative discussion between key stakeholders, the national institutions and the European Commission on health promotion and prevention policies, use of available EU mechanisms to support national actions and potential areas for future collaboration in the field of health.

The list of invitees will include representatives from the European Commission (DG SANTE), country-level EU Semester officers, national institutions and experts, and various national stakeholders (patient associations, healthcare professionals, public health NGOs and experts, academics and umbrella trade associations).

2) Agenda

“Patient-Centred Roundtable on Working Together for Accessible Health in Portugal”

10:00 – 10:45	Registration & coffee	
10:45 – 11:20	Welcoming remarks	Co-chaired by Mr. Daniel Simões , Policy officer, GAT
	<ul style="list-style-type: none"> <i>The added-value of cooperation for improving access to healthcare in Portugal: the state of affairs, challenges and opportunities</i> <i>The event as an opportunity to reflect on: Equity in access to healthcare and inclusion to vulnerable populations; Sustainability of the national healthcare system; Health promotion and prevention</i> 	<ul style="list-style-type: none"> Mr. Stanimir Hasardzhiev, Secretary General, PACT Ms. Isabel Aldir, Director for Viral Hepatitis and HIV / AIDS and Tuberculosis Priority Program
11:20 – 13:00	Session I. Overview of existing initiatives to bring EU issues to Portuguese level	Co-chaired by Mr. Stanimir Hasardzhiev , Secretary General, PACT
	<ul style="list-style-type: none"> <i>Overview of EU Country Specific Recommendations 2017 - 2018</i> <i>Existing initiatives to bring EU issues to Portuguese level and the main challenges, potential solutions and implementation strategies</i> 	<ul style="list-style-type: none"> Mr. Carl Larsson Lindqvist, DG SANTE , European Commission Mr. Elsa Frazão Mateus, EUPATI fellow, Portugal Mr. Paolo Gorgoni, Community representative, Fast Track Cities Lisbon
13:00 – 14:00	Lunch	
14:00 – 15:00	Session II. Panel discussion: How to improve the current model of cooperation in Portugal?	Co-chaired by Mr. Gilles Dussault , Institute of Hygiene and Tropical Medicine (IHMT), New University of Lisbon
	<ul style="list-style-type: none"> <i>The added-value of cooperation in health and strategies to improve the current model of cooperation in Portugal.</i> 	<ul style="list-style-type: none"> Mr. Alexandre Lourenço, President of the Association of Hospital Administrators

	<ul style="list-style-type: none"> • <i>How can such strategies improve:</i> <ul style="list-style-type: none"> ○ <i>Equity in access to healthcare and inclusiveness for vulnerable populations</i> ○ <i>Sustainability of the national healthcare system, availability and efficiency of existing resources</i> ○ <i>Health promotion and prevention</i> 	<ul style="list-style-type: none"> • Mr. Américo Nave, Executive Director, Crescer • Ms. Isabel Aldir, Director for Viral Hepatitis and HIV / AIDS and Tuberculosis Priority Program • Mr. António Vaz Carneiro, Director of the Institute of Preventive Medicine and Public Health, University of Lisbon • Mr. João Madeira, President of APOGEN • Ms. Sofia Crisóstomo, MAIS PARTICIPAÇÃO Melhor Saúde
15:00 – 16:30	Session III. Open discussion: how to work together on strategic matters for the Portuguese health system?	Co-chaired by Mr. Henrique Barros , President of the National Health Council and Mr. Daniel Simões , Policy officer, GAT
	<i>Discussion with <u>all participants</u> to identify 3 key areas where stakeholders can work together in the future</i>	
16:30 – 17:00	Session IV. Next steps: from solutions into action	
	<i>Presentation of key conclusions, outcomes of the meeting and next steps</i>	<ul style="list-style-type: none"> • Mr. Stanimir Hasardzhiev, Secretary General, PACT • Mr. Luís Mendão, President, GAT
17:00 – 17:30	Networking / tea time	

3) The Agenda Committee

To ensure a multi-stakeholder inclusive process in developing the agenda, the PACT Steering Committee decided to form an Agenda Committee for the forthcoming Stakeholder meeting in Portugal which role will be to shape the agenda format and suggest speakers and participants.

The Agenda Committee consists of representatives of organisations in the following broad categories: patient organisations, healthcare professionals, umbrella trade associations, public health NGOs and experts and academia.

4) The Agenda Committee Members

Name	Organisation	Position	Category
Ana Rita Cavaco	Ordem dos Enfermeiros	President	Healthcare Professionals
Ana Valente	APOGEN	Executive Director	Umbrella trade associations (pharmaceuticals)
Antonieta Lucas	APORMED	President	Umbrella trade associations (medical devices)
Beatriz Padilla	University Institute of Lisbon	Researcher	Academia
Bruno Gago	University of Aveiro	Assistant Professor	Academia
Daniel Simões	GAT	Policy Officer	Patient Organisations
Andre Biscaia	USF-AN		Healthcare Professionals
José Miguel Ribeiro de Castro Guimarães	Ordem dos Médicos	President	Healthcare Professionals
Isabel Loureiro	National Health Council	Vice-President	Public Health NGOs and Experts
Sofia Crisóstomo / Margarida Santos	Mais Participação, Melhor Saúde	Coordinator	Patient Organisations / Public Health NGOs and Experts

5) The Role of the Agenda Committee

The Agenda Committee will be expected to provide input during 2 teleconference calls and a brief consultation process via e-mail on:

- Potential speakers / topics to be included in the agenda outline
- Questions to be addressed during the presentation sessions and discussion panel
- Expected outcomes and strategy for follow-up actions
- Participant list suggestions in addition to the identified potential invitees

6) Overarching themes of the event

Considering the added-value of cooperation in health and the strategies that may improve the current model of cooperation in Portugal, a survey was distributed among the members of the Agenda Committee to determine the most relevant topics for the Portugal healthcare system. During the corresponding discussions in both Teleconferences, the following themes were defined as the backbone for the conversations of the event:

- Equity in access to healthcare, including accessibility to care for vulnerable populations
- The sustainability of the national healthcare system in terms of both availability and efficiency of resources. This includes as well an effective and efficient organizational structure that supports sufficient, motivated and well trained health workers.
- Health promotion and prevention

7) Speakers



Mr. Américo Nave is a Clinical Psychologist, who works with vulnerable populations – people who use drugs, homeless people, asylum seekers, refugees and migrants. Has 18 years of professional experience in implementing and coordinating harm reduction projects with multidisciplinary teams, such as a drop-in centre, Housing First programs, outreach teams, a low-threshold methadone program and, in the treatment field, worked in a therapeutic community. Currently, coordinates the project É UMA CASA, Lisboa Housing First, targeted to long term homeless people with psychoactive substance use, and other harm reduction projects, all of them developed by CRESCER, of which he is Executive Director and founding member.

Dr. António Vaz Carneiro is the Director of the Faculty of Medicine of the University of Lisbon since 2017, Cochrane Portugal since 2014, and Center for Evidence-Based Medicine Studies at the Faculty of Medicine of Lisbon University since 1999. With a PhD in Medicine from the Faculdade de Medicina de Lisboa (1994) and a Master's Degree in Medical Education, Faculdade de Medicina de Lisboa (2000), Author of more than 400 articles, chapters of scientific books



Mr. Carl Larsson Lindqvist is a trained economist and joined the Directorate-General for Health and Food Safety (European Commission) in 2014 and is currently working as policy officer in the unit of Performance of National Health Systems, where he follows Portugal and Czech Republic in relation to the European Semester. He has previously worked as policy officer on Health Technology Assessment and Health Systems Performance Assessment.

Mr. Daniel Simões currently holds a doctoral fellowship in Global Public Health at the Institute of Public Health of the University of Porto, is a member of the Board of the GAT and a Clinical Psychologist with a Masters in Community Psychology. He works in the third sector since 2006, and in the response to HIV, Viral Hepatitis and Tuberculosis since 2011, as project coordinator and later in the area of advocacy. Member of the European AIDS Treatment Group and the policy group of this organization, is also a co-chair of EUROTEST, and one of the representatives of Portugal at the Civil Society Forum on HIV, Hepatitis and Tuberculosis in the European Union. He is a member of the Advisory Group for monitoring the Dublin Declaration in Europe with the European Centre for Disease Control and has recently joined the European Laboratory Initiative of the European Delegation of the World Health Organization





Dr. Elsa Frazão Mateus holds a PhD in Anthropology (specialization Anthropology of Health) from the Institute of Social Sciences of the University of Lisbon. Diagnosed with juvenile idiopathic arthritis in 1977, she is currently Chairman of the Portuguese League against Rheumatic Diseases and Chair-elect of the Standing Committee of People with Arthritis/Rheumatism in Europe in EULAR (European League against Rheumatism). As a representative of the League, she is a member of the Board of Directors of the Health Platform in Dialogue and is also president of the association EUPATI Portugal.

Prof. Gilles Dussault is a retired Professor from the Institute of Hygiene and Tropical Medicine (IHMT) Lisbon, Portugal. Before joining IHMT in August 2006, he worked as Senior Health Specialist at the World Bank Institute (Washington D.C). He was responsible for the “Health Sector Reform and Sustainable Financing” Program in French, Portuguese and Spanish-speaking countries. Between 1985 and 2000, he was Professor and Director of the Department of Health Administration, Faculty of Medicine, at the University of Montreal, Canada. He has been teaching in numerous countries, including one-year as invited lecturer at the National School of Public Health in Brazil, and has been involved in cooperation projects in Africa, Europe, Latin America and Asia. His main research interest is the formulation and implementation of health workforce policies. Since 1986, he has been member of several working and advisory groups of international professional and multilateral organizations



Dr. Isabel Aldir is a Hospital Assistant Graduate in Infectious Diseases at the Hospital Egas Moniz. Medical Director of the Hospital Egas Moniz since 2008. Invited Assistant Professor of Illness at the Faculty of Medical Sciences of Lisbon. Postgraduate in Management of Health Units at the Faculdade de Ciências Económicas e Empresariais da Universidade Católica Portuguesa; Program of High Management of Health Institutions (PADIS) of the Association of Higher Studies of Company (AESE). Director of the National Program for HIV and AIDS Infection, DGS. Director of the National Program for Viral Hepatitis and Tuberculosis Priority Program, DGS.

Mr. Luís Mendão concluded his studies in biochemistry in 1983 at the University Pierre et Marie Curie, in Paris. He is currently Chair of the Board of GAT –Treatment Activist Group, an NGO founded in 2001 and working in prevention, early diagnosis, treatment and care of HIV/AIDS, viral hepatitis and tuberculosis focus on key populations. He is also the founder and on the Board of Directors of the Anti-Prohibitionist Association (SOMA-APA). Current co-chair of the Civil Society Forum on HIV/AIDS at the European Commission and he’s Chair of the European AIDS Treatment Group (EATG). He also integrates to the Steering Committee of the HIVPORTUGAL initiative. In the last ten years, he has been a community consultant of the Regional Office of the World Health Organization Europe (WHO Europe), EMCDDA and ECDC. Luís Mendão was diagnosed with HIV and HCV in 1996



Ms. Sofia Crisóstomo is a member of GAT - Treatment Activist Group, APC - Portuguese Celiac Association and EPI - Portuguese Association of Relatives, Friends and People with Epilepsy. Co-coordinator of the collaborative project "MORE PARTICIPATION, better health" since 2015. Pharmacist and MSc in Development, Local Diversity and Global Challenges, with a dissertation on the involvement of people living with HIV/AIDS in public health policies. PhD candidate in Public Policy, with a special interest on pharmaceutical financing and public participation policies. Member of the National Health Council, as GAT representative, and member of the Commission for the Revision of the Basic Health Law. Consultant to the Portuguese Pharmaceutical Society for citizens' involvement.

Ms. Paolo Gorgoni, currently living and working in Portugal, is in the direction of Plus - Onlus, LGBT network of people living with HIV in Italy since 2013, and is currently a member of European AIDS Treatment Group, GAT Portugal and a member of the deliberative commission of the project Lisboa Cidade sem SIDA- Fast Track Cities. He is also incorporating his activism into his research in performing arts with the stage name of Paula Lovely.”



Dr. Stanimir Hasardzhiev is the Chairperson of the Bulgarian National Patients’ Organization (NPO) – the biggest patients’ umbrella organization in Bulgaria. He has devoted himself to the work in the patients’ advocacy sector and in defense of patients’ rights. As of May 2013, he is a board member of the European Patients’ Forum as well as a member of several regional and international organizations and networks, e.g. World Hepatitis Alliance, European Community Advisory Board, International Capacity Building Alliance and others. He is one of the founders and the Secretary General of the joint initiative of the European Patients’ Forum and the Bulgarian National Patients’ Organization – the Patient Access Partnership (PACT) – a multi stakeholder platform for finding innovative solutions to reduce inequities in access to healthcare in Europe. Dr. Hasardzhiev is also leading a Think Tank group on patient access focusing on the CEE region which brings together patient representatives, health professionals and pharmacoeconomists to work together to identify regional challenges in healthcare and propose sustainable solutions to national governments.

8) The background

In recent years, access to quality healthcare has increasingly attracted the attention of national policy-makers and European Union institutions. There has been a shift in thinking about public health: healthcare is no more simply a sectoral policy but is more often referred to as a component of economic sustainability and social well-being with healthcare and long-term care sectors accounting for 8% of the total European work force and for 10% of GDP in the European Union.

The need to build effective, accessible and resilient health systems is often recalled. In 2016, the European Commission launched a consultation on the European Pillar of Social Rights where the right to healthcare was affirmed as a fundamental value. Only recently, the Council Conclusions (Nov 2016) also addressed the importance of improving the cost-effectiveness of health systems. Another initiative - the State of Health in the EU – draws on the existing expertise to strengthen country health systems and boost evidence-based analysis of existing challenges. A repeatedly mandated Expert Panel on effective ways of investing in health has produced a number of recommendations on ways of improving access to healthcare across the EU. Yet, as emphasized by the European Commission in the latest Communication on the Country Reports, “further policy action will be needed enabling the individual to stay healthy for longer, while making health systems more effective, accessible and resilient.”

The strive for improving access to healthcare of the EU is complemented by the call of the United Nations for universal access for all as emphasized in Goal 3 of the Sustainable Development Goals (SDGs). Every human being, without exception, is entitled to receive high quality healthcare by virtue of it being an intrinsic human right.

Despite these efforts, much more needs to be done to improve access at the Member State level. Inequality in access to prevention, treatment and care is a reality with patients experiencing severe difficulties in accessing healthcare due to legal, administrative, financial and logistical reasons. What is thus urgently needed is to bridge the gap between EU policies and national implementation strategies. With consideration of the patient experience with respect to access, decision-makers should take concrete measures to make access to healthcare a reality for all as health cannot be the privilege of some.

In line with these efforts, the Patient Access Partnership held the first [PACT Regional Conference “Cooperation within the Region: A Way to Improve Access to Quality Healthcare in CEE”](#) (Sept 2016, Bulgaria) to explore common challenges and possible solutions as identified by a variety of stakeholders from 15 countries from Central and Eastern Europe. One of the main conclusions of the meeting was the need to raise awareness on the opportunities for stakeholders to influence the EU and national policy agendas, namely by actively engaging (and advocating engagement) within the framework of the European Semester. In due consideration of these suggestions, the EU Commission expressed interest in considering a proposal on a structured process to identify stakeholders at the country level and to facilitate their involvement in providing recommendations and sharing local experience with respect to the Country Specific Recommendations (CSRs).

The discussions among the participants at the PACT Regional Conference clearly outlined the need for cooperation – cross-sectoral collaboration between health, social and financial authorities; multi stakeholder partnership within countries, and multi-level coherence – between EU institutions and national level authorities.

Additionally, the European Patients’ Forum (EPF) has recently launched a year-long flagship campaign on access to healthcare. Under the tagline ‘Universal Health Coverage for All’, the campaign raises awareness about the barriers patients face in accessing healthcare, and will build on current political momentum – including the UN Sustainable Development Goals for health – to foster more EU cooperation on access to healthcare. It will contribute to make universal access a reality for EU patients by 2030, through defining and promoting concrete actions which decision makers need to commit to in order to achieve the Health SDGs by 2030. In the context of our 2017 Campaign on Access to Healthcare, EPF has developed a roadmap entitled [Taking Action – A Roadmap to Achieving Universal Health Coverage for All by 2030](#).

In view of the aforementioned, PACT took the initiative to increase cooperation between policy-makers and stakeholders within the countries from the region by holding a small-scale country stakeholder events. PACT is engaging the European Commission representatives, country-level EU Semester officers, national authorities and the PACT local partners and stakeholders.

As a result, in 2017, PACT held two country stakeholder meetings entitled “Patient-Centred Roundtable on Working Together for Accessible Health” under the auspices of the respective Ministries of Health – the first one in Lithuania (8 June), together with the Lithuanian Cancer Patient Coalition (POLA) and the second one in Romania (20 November) with the Coalition of Organisations of Patients with Chronic Diseases in Romania (COPAC), a member of EPF.

The meetings aimed to gather policy-makers and the healthcare community for increasing cooperation between them to improve access to quality healthcare for patients. The country stakeholder meetings were initiated by PACT as follow-up events to the PACT Regional Conference (2016, Sofia) where 150 stakeholders from Central and Eastern Europe agreed that the European Semester process should better reflect the country-level situation. One way to achieve this is to allow patients and health stakeholders to participate in consultations for the Country Specific Recommendations (CSRs).

9) Contacts

Should you have any concerns, please contact:

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