

Patient-Centered Roundtable on Working Together for Accessible Health:

Portugal



February 25, 2019
Lisbon, Portugal

CONTENTS

Executive Summary

2

Key messages

3

Welcoming remarks

4

Session I. Overview of existing initiatives to bring EU issues to Portuguese level

5

Session II. Panel discussion: How to improve the current model of cooperation in Portugal?

8

Session III. Open discussion: How to work together on strategic matters for the Portuguese health system?

11

Closing remarks

14

EXECUTIVE SUMMARY

On February 25, the Patient Access Partnership (PACT) in collaboration with Grupo de Ativistas em Tratamentos (GAT) and the collaborative initiative MAIS PARTICIPAÇÃO melhor saúde, held a meeting at the Portuguese Parliament, entitled “Patient-Centered Roundtable on Working Together for Accessible Health”, to discuss opportunities for improving cooperation between Portuguese health stakeholders for better access to quality healthcare in the country. The event was organized with the institutional support of the Health Parliamentary Commission and the Ministry of Health of Portugal.

During active discussions and constructive dialogue, the participants highlighted many of the positive developments in Portugal with regards to public and patient involvement in Health Policy design and implementation, but remarked that more coordination and efficiency is needed for a truly inclusive, user-friendly healthcare system. Matters, such as health promotion and disease prevention, health literacy, coordination between EU and local efforts, performance indicators that include wellbeing, quality of life, and quality of services determined by the end-user, and inclusion of all members of society under the national health service umbrella were pivot during the meeting.

All the stakeholders present, representatives of a broad range of healthcare stakeholders, were invited to take action in their respective fields and to advocate for the messages and priorities collectively agreed upon.

KEY MESSAGES

- The healthcare system must be patient/user friendly and centered
 - Adequate, accessible and clear information is central to the process of patient/user involvement
 - Patients must be involved actively across a broad range of actions including health policy design and implementation, as well as clinical trials and research
 - Quality of services should be determined by the end-user and quality of life should be included as an important indicator
- Patient/user reported outcomes/indicators should be used to improve services
 - Health promotion and disease prevention, as well as health literacy, must be a priority
 - Actions prior rather than after-the-fact are not only most cost-effective, but also the most inclusive strategy – the system should be pro-active not reactive
 - Situations of vulnerability should be comprehensively approached with the goal to achieve a universal healthcare coverage
- The EU can contribute to local improvement by supporting challenges related to accessibility, effectiveness and sustainability of healthcare systems. Member state/ stakeholders knowledge of available resources is often limited, for example tools such as [State of Health in the EU](#) cycle
 - The linkage between the MS and EU institutions has great potential and is highly needed, however there is still room for better communication and coordination
 - The EU has a great role to play, in terms of coordination and setting quality standards and information- sharing
 - The existence of a “one-stop-shop” where patient perspectives and information is gathered and coordinated can facilitate actions and communication with the EU institutions
- Equity of access to services and care is essential for all groups of society, including the most vulnerable populations
 - Solutions and policies must be tailored to the real and particular needs of the users, with distinction to vulnerabilities as appropriate
 - Digitization of health and access to big data are a valuable resource that can support equity to access to care and services
- e-health is essential for sharing good practices within and across MS
 - The digitalization process should be patient centered and user friendly
 - Integrated care and strengthening of Primary care services along with take-home technologies
- The actions to advance health must be in accordance with the fact that health is a constitutional right and Portugal as well as Europe, have committed to the UN Sustainable Development Goals by the year 2030
 - There is an urgent need for better coordination and dialogue among the different political sectors within the country as well as the different stakeholder in health – including civil society, academia, healthcare professionals, policy makers, the industry, patient organizations etc.
 - Optimization of existing resources is essential in order to avoid duplication of efforts

WELCOMING REMARKS

Welcoming the participants, **Luís Mendão (president of GAT)**¹ highlighted the importance of health systems that are both patient and prevention centered. With gratitude for the meeting and the presence of the participants, he remarked the importance of the Patient Access Partnership (PACT)² as an organization and the need of assuring better cooperation and coordination between the European and local institutions. Mr. Mendão took the opportunity to remind the participants of the common commitment to the Sustainable Development (SDG) agenda by the year 2030 and the importance of health in all goals.



Stanimir Hasardzhiev (Secretary General, PACT) underlined the importance of the meeting, not only because of the challenge of the format but also because of its goal. He introduced himself and related to his experience and work between Bulgaria and Belgium, he remarked how often reality seems different between what he called the “Brussels bubble” and the Member States (MS) - the later seem disconnected from the EU-based perspectives. This is not surprising given that dialogue is often difficult even within the same country however, we must aspire for improvement and hope to find common synergies in favor of all patients. Mr. Hasardzhiev went on to present PACT as a multi-stakeholder, pan-European platform that aims to improve this issue by bringing health stakeholders together hoping to find common solutions.

Isabel Aldir (Director for Viral Hepatitis and HIV / AIDS and Tuberculosis Priority Program), began her contribution by re-stating the commitment of the National health plan to all citizens. It is a basic health plan aligned with the SDGs, constantly hoping to improve health services, access to care and outcomes in terms of communicable and non-communicable diseases. Every stakeholder has a part in assuring access. The system is built based on 4 basic pillars among which health is central and in which citizens remain the main actors. However, to assure that citizens’ participation is adequate and influential, they need to be empowered and properly informed. Knowledge and health literacy are central to the improvement of the system. Initiatives such as MAIS PARTICIPAÇÃO melhor Saúde³ were born to tackle this need. Moreover, it is important to actively involve a wide range of different stakeholders in health policy as well as better inter-sectorial cooperation.

¹ [Grupo de Ativistas em Tratamentos \(GAT\)](#)

² [The Patient Access Partnership \(PACT\)](#)

³ [MAIS PARTICIPAÇÃO melhor Saúde](#)

Ricardo Baptista Leite (Member of Portuguese Parliament, PPD/PSD) underlined that health needs to be accessible to all citizens however, health information is a prerequisite for such access. Patients need to be aware of what their rights, needs, and responsibilities are. In this regard, GAT has had a major role to play. Not only by informing and actively involving patients, but also by bringing a variety of stakeholders together. Health as a constitutional right (universal, widely accessible and free) is a principle accepted by all political parties in Portugal and actions must be consistent with this fact. For this reason, Mr. Leite decided to join UNITE,⁴ a global platform that actively contributes toward keeping HIV/AIDS, Viral Hepatitis and other Infectious Diseases high on the political and media agendas consistent with the United Nations SDG agenda. UNITE hopes to support patients' involvement in all health discussions, so their concerns as users are heard - The system should be patient-centered.

SESSION I. OVERVIEW OF EXISTING INITIATIVES TO BRING EU ISSUES TO PORTUGUESE LEVEL

Moderating the session, Mr. Hasardzhiev, asked the participants to do a tour-de-table introducing themselves and their organizations. He then moved on to present the 3 priorities defined by the Multi-stakeholder Agenda Committee (AC) during the preparatory meetings of the event:

1. Equity in access to healthcare, including vulnerable populations
2. 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.
3. Health promotion and prevention

These priorities will be re-visited throughout the meeting and participants, were asked to consider their own priorities as they can express them by the end of the event. Introducing the next speaker, Mr. Hasardzhiev stated that often, citizens are not aware of the tools and possibilities the European Commission offer and that is common to find that Europeans do not know what the Semester, or what the country-specific recommendations are. Patient Organizations must find a way to come together as a united voice to report to the Commission more efficiently –a one-stop-shop that connects all local patient organizations is needed.

⁴ [UNITE Network](#)



Carl Larsson Lindqvist (DG SANTE, European Commission) began his intervention by briefly presenting the priorities of the European Semester:

- Ensuring sound public finances
- Preventing excessive macroeconomic imbalances in the EU
- Supporting structural reforms, to create more jobs and growth
- Boosting investment

The Commission acknowledges the great importance of assessing and supporting healthcare systems of all MS given that health represents a great part of their GDP expenditure, it is a key economic sector contributing to research, development (R&D) and innovation, trade jobs and growth; and it is a key sector of social protection as well as a key determinant of inequality and exclusion.

The European Pillar of social rights was created to promote the sustainable development of Europe based on balanced economic growth while considering social progress. Health is included as principle number 16 establishing that everyone has the right to timely access to affordable, preventive and curative health.

In terms of country-specific recommendations for Portugal, the Commission has focused on fiscal sustainability and cost-effectiveness of the health system. In particular to the fact that projected health spending poses a high risk to the long-term sustainability of public finances in the country. In terms of health indicators, the overall health status of the country remains above the EU average with a rapid increase in life expectancy and low amenable mortality. However, inequalities remain in terms of gender, income and location (urban vs. rural) and cardiovascular diseases and cancer remain the highest contributors to mortality. The prevalence of diabetes and respiratory diseases remains high in comparison with other MS.

In relation to the Multiannual Financial Framework (MFF) there is an initiative to strengthen the existing links between EU funding and the semester. The semester recommendations alongside European Structural and Investment Funds (ESIF) have proven to be an effective strategy. Other initiatives, such as the launch of the pilot project entitled “Towards a fairer and more effective measurement of access to healthcare across the EU” were mentioned.

Mr. Larsson Lindqvist underlined the importance of EU cooperation in health and mentioned three current examples of actions at EU level that benefit access to health:

- EU cooperation on HTA: HTA Network, EUnetHTA
- E-Health: e-Health network, eHAction (Portugal lead)
- European Reference Networks: virtual networks involving healthcare providers across Europe

Following Mr. Larson’s contribution, the participants discussed the importance of an adequate consultation process, inclusive of all health stakeholders in the context of the Semester recommendations – the involvement of civil society and patients should be predominant. Additionally, the stakeholders discussed the burden of out-of-pocket payments (OOP) from the perspective of the patients should remain a priority in all EU health recommendations and policies.

Mr. Hasardzhiev invited the participants to foster and engage in a continued inter-sectoral dialogue to assure that EU level recommendations, policies, and actions remain relevant and truly patient-centered.

Elsa Frazão Mateus (EUPATI fellow, Portugal) introduced EUPATI as a pan European level consortium. It was launched in 2012 as a public-private partnership involving the pharmaceutical industry, academia, not-for-profit, and patient organizations. The Academy was started, developed and implemented as a flagship project of the Innovative Medicines Initiative, and continues to be led by EPF. EUPATI exists because patients need up-to-date, credible and understandable information about treatment innovation and in reality, patients lack the knowledge about clinical trials, research, personalized medicine, drug-economics, etc. and their essential role in these processes. Some of the educational tools open for patients and patient advocates include the patient’s expert training course, the educational toolbox and the EUPATI internet library. These tools inform the recipients of matters ranging from drug development, pre-clinical and clinical, clinical Trials, regulatory affairs, drug safety, pharmacovigilance and Health Technology Assessment (HTA). EUPATI in Portugal was created in 2017 with the goals to prevent diseases, promote and protect health by sharing good practices, increase health literacy and patient engagement in medicines research and development.

Paolo Gorgoni (Community representative, Fast Track Cities Lisbon) introduced the Lisbon without AIDS initiative as a working platform that hopes to boost existing and share innovative solutions about HIV. Solutions that involve the institutions but that are primarily patient and community-centered. It raises awareness of the needs of patients and existing vulnerabilities. Its main goal is to create an Action plan aimed at sharing good practices, increasing literacy and the effectiveness of existing solutions – by showcasing available resources and optimizing them, as well as boosting the utilization of services. Ensuring that these tools work for citizens and that they are tailored for the users is one of the central principles of the initiative.

Fast Track Cities Lisbon has been focusing efforts on communication. These campaigns focus on raising awareness of pre (PREP) and post-exposure prophylactics (PEPs) – many users are not aware of their existence, availability and safety, screening and use of viral suppressors (so the virus is not transmitted). These informative initiatives focus also on fighting stigma with empowering, real-life messages. Access to care is still limited, especially in terms of screening and misconceptions regarding contracting the virus – consultations and advice should be available to all members of the population and not only among vulnerable communities.

DISCUSSION AMONG PARTICIPANTS:



The local competences and possibilities of the healthcare system, as well as the role of the EU as a central organ that assures that information and resources are widely available to all MS were discussed. Civil Society has a great role to play and while raising awareness is important, the tools available must have adequate quality standards. There is a need for more cooperation with other non-health stakeholders given that health is an essential pre-requisite for the achievement of all other societal aspects (finances, education, environment, etc.) and all other Sustainable Development Goals by 2030 – a commitment, which Europe has undersigned to.

National platforms often have a different aim and utility than the centralized ones leading to uncertainty and lack of clarity. From the perspective of the industry, recognition and transparency are essential without the need for very large resources, rather a more efficient system. In terms of the public healthcare system, there is fragmentation of information across the different services and duplication of efforts. Information platforms should be citizen-friendly, properly coordinated and widely available. Strengthening primary healthcare can increase proximity to the citizens and multidisciplinary professional teams can greatly help.

SESSION II. PANEL DISCUSSION: HOW TO IMPROVE THE CURRENT MODEL OF COOPERATION IN PORTUGAL?

The co-chair of the session, **Gilles Dussault, (Institute of Hygiene and Tropical Medicine (IHMT), New University of Lisbon)** invited the participants to consider the importance of better cooperation among stakeholders within Portugal as well with the organs of the European Union and other MS that can offer valuable practices and experiences.

Miguel Lopes (Secretary General of the Association of Hospital Administrators) emphasized the importance of citizen's involvement in all health policies, however the biggest challenge remains to change the current, outdated culture that does not facilitate things for patients – it is not patient/user-

centered and it does not promote integration. This paradigm change must happen across all levels including the training of healthcare providers - patient awareness and literacy are not at the center of the current education model. Building a partnership between health infrastructures as well as with the patients (including the user's perspectives) is beneficial to everyone – policies and decisions are better informed and evidence-based which can avoid unnecessary, obsolete investments. More coordination and efficiency can substantially decrease the financial load of the National Health Service.

In addition, greater investments in new technologies such as e-health and communication technologies for the benefit of sharing good practices can help. In terms of health literacy, a pertinent, universal one-stop-shop is needed to coordinate the enormous amount of information available to assure user-friendly access.

Américo Nave (Executive Director, Crescer), introduced Crescer as an organization that works for the benefit of vulnerable populations. These populations are faced with inequalities and stigma from the point of entry where a specific kind of practitioner is assigned to them - the system is the factor limiting their access rather than facilitating it. The system pushes vulnerable users and homeless people further into poverty and exclusion rather than supporting an improvement. The National Health System cannot properly monitor the needs of these populations, therefore it cannot guarantee access. Structures such as the Mobile Health Units should implement actions that increase contact with populations in need and specific tools such as Hepatitis or HIV screening should be strengthened. Bureaucracy and the lack of appropriate human resources hinder the process. He explained that medical practitioners do not focus on the larger perspective of the situation of vulnerability that led the patient to a medical problem. He underlined the importance of prevention and actions before users reaching out to the system rather than after the fact - this would be the most cost-effective and inclusive strategy.

Isabel Aldir (Director for Viral Hepatitis and HIV / AIDS and Tuberculosis Priority Program), stated there is a need to broaden the concept of a “vulnerable population”. At times, solutions are different according to the condition and what may work for one group may not for another. For instance, patients with rare diseases, are very vulnerable and are often not considered as such, moreover, their needs may be quite different from those of an illegal immigrant.

In 2007, the European Parliament passed a resolution encouraging MS to develop discussion fora and Portugal was one of the first countries to follow this recommendation. The added value of the forum has been immense – it is a consultative organ that has helped define strategies to adjust the solutions to the real needs of the patients, avoiding a paternalistic perspective and rather embracing different points of view. This has also proven effective when designing effective prevention campaigns.

António Vaz Carneiro, (Director of the Institute of Preventive Medicine and Public Health, University of Lisbon) introduced the “Patient-Reported Outcomes”, a series of indicators and experiences from the patient’s perspectives designed to improve health services. The clinical research occurring in this field is cutting edge and innovative hoping to understand, not only the physiopathology of diseases, but also understand its impact on the patients’ lives and their experiences at a national and European level. For instance, patients with Rheumatoid Arthritis highlight proper sleep as an indicator of wellbeing, but when further investigated, no clinical research had investigated the impact of sleep in patients’ everyday lives. In fact, most factors considered important by patients differed from the priorities established by most medical researchers. Mr. Vaz Carneiro underlined the importance of investing in hospitals based on performance from the patient’s perspective hence encouraging better, more inclusive practices while stimulating competition.



proper sleep as an indicator of wellbeing, but when further investigated, no clinical research had investigated the impact of sleep in patients’ everyday lives. In fact, most factors considered important by patients differed from the priorities established by most medical researchers. Mr. Vaz Carneiro underlined the importance of investing in hospitals based on performance from the patient’s perspective hence encouraging better, more inclusive practices while stimulating competition.

João Madeira (President of APOGEN), presented APOGEN as an organization that encourages the dissemination of biosimilar and generics in a sustainable and inclusive market and moved on to highlight some main points mentioned so far. First, quality of life and the patient’s perspective is not properly addressed however, change is happening and patients are becoming more involved in innovation and research. Another matter is the sustainability of the healthcare system since the current model relies on increasing GDP and should focus more on using the existing resources more efficiently. Digitalization as a tool to support the progress of the system and to facilitate access to big data (from a patient-centered perspective) should be a priority. As mentioned before by Mr. Vaz Carneiro, researchers are still unable to understand some of the most relevant issues from the patient’s perspective - big data so far has not supported this process.

Cooperation in health is imperative since the patient is the user and they should remain at the very center of all efforts. Presenting an example of strategic partnerships that benefit both research and the patient whilst keeping the user at the center, Mr. Madeira mentioned that for instance, while keeping the particular needs of homeless people in mind, the industry could develop a medication that could perhaps be taken without water. The state, as the administrator of funds, should acknowledge the efforts done by the different parties, including the industry, in terms of better treatments, and better access. Quality of health services and outcomes should be defined by the end-user – the patient, in terms of their experience and their perceived benefits.

Sofia Crisóstomo (MAIS PARTICIPAÇÃO melhor Saúde), introduced her organization and some of the partners, including GAT, with whom they share the commitment to promote patient’s involvement in the development of health policy. In a survey conducted among 618 people (including multiple health stakeholders), over 95% of the respondents indicated that patients should be actively involved in health

polymaking. Collaboration in the European context can greatly support this process as evidenced in many existing efforts.

Ms. Crisostomo moved on to present some of the lessons learned from the past years. First, she remarked that a bottom-up participatory approach to decision-making is feasible – patients can truly have a meaningful impact on the status quo. This approach has been very helpful for HIV and should be further developed for other diseases. To legitimize the input by patients in the decision-making process, all parties should be seen as equals, regardless of their level of literacy/experience which frequently varies greatly. Specific resources, not only monetary, should be allocated to support the patient’s participation in the process. To assure that those involved see the positive results of their involvement, transparency and feedback are essential - participation has to have a visible effect.

Regarding the consultation process of the European Commission and the European Semester, Ms. Crisostomo underlined the importance of transparency during the process - citizens should be informed about how the process is done and with whom.

DISCUSSION AMONG PARTICIPANTS:

Finishing the session, the participants discussed the matter of redistribution of power and financial resources in a holistic manner that emphasizes prevention rather than solely treatment – the system should not be reactive, it should be proactive. The importance of information and easy access to it was remarked – health literacy can have a great impact on the sustainability and stability of the health system.

In terms of future priorities, innovative and digital devices can support the sustainability of the healthcare system benefiting the patient as well. Examples of integrated care (take home-devices) in the areas of cardiology and orthopedics can evidence the added value in terms of access to health for patients.

SESSION III. OPEN DISCUSSION: HOW TO WORK TOGETHER ON STRATEGIC MATTERS FOR THE PORTUGUESE HEALTH SYSTEM?



The participants engaged in a lively exchange of concluding remarks around the key areas where stakeholders can work together in the future to assure better and more inclusive healthcare in Portugal. See below the most recurrent and relevant conclusions:

HOW TO IMPROVE THE STATE OF AFFAIRS?

- Assuring patient-centered care is of outmost importance – one that is not paternalistic, but rather responsible; one where the information is shared with the users to empower them as well as to share the responsibilities implied.
- Performance indicators must be smarter and holistic, including quality of life – with the awareness that such concepts can be subjective and vary greatly depending on the point of view.
- In terms of indicators, for the assessment and metrics to translate into real change, they should include a proper assessment of health results. A cost-benefit analysis of the impact of implementing vs. not implementing our proposed policies – this should be done by a designated body.
- There cannot be taxation without representation hence patients should be at the center of health policy and decision making.
- The distribution of power is very important, the patient should also be held accountable for his/her health.
- In terms of practice and from a primary care perspective, promotion of citizen participation (assessment models, financing models) as an indicator could have a real impact and can facilitate inclusion to the political agenda. The creation of indicators has an impact on the results.
- Customer satisfaction and quality of healthcare should be part of the indicators that evaluate the system – this would empower and include the user and would support the change to a more patient-centered system.
- Collaboration and dialogue between sectors, including civil society, between Member States and between States and EU Institutions must always remain active to address some of the most serious health challenges for all of Europe. There must be clear and concrete objectives with proactive action.
- More active collaboration between the different sectors is needed – the results should not be left only to the Ministry of Health and health should be discussed at all high political levels and sectors - proposal for the creation of an inter-ministerial committee or team.
- The EU offers real added value in terms of guiding principles and guidelines and this brings to the table the subject of data and data standardization (including sharing of best practices) among MS and regions.
- Active stakeholder involvement with proper knowledge and literacy is the best way to counteract the growing populist wave in Europe.
- Lack of truly inclusive information and health literacy – healthy eating habits are available to only those who can afford them.
- Prevention including education for citizens in terms of eating habits (mentioned the “Change for Life” educational campaign in the UK).
- Prevention is a very broad subject and should include a variety of factors including living conditions and housing.

- Poverty and the lack of support are the causes of many other issues such as drug use; homelessness, for instance, is a common cause of health issues.
- Access to therapies, not only pharmacotherapy and involving a range of actions including prevention and healthy nutrition.
- Authorization of generics and biosimilar products can have great potential for the sustainability of therapies.
- Digital services that support the proximity of services and information to the population and providers.
- Effective use of big data and how we manage information.
- An electronic platform that allows citizens to give suggestions on how to improve the system.
- Patients' needs vary greatly, hence we need to go beyond information and frame it appropriately according to each patients' needs.
- Discussions by policymakers should be more active to lead to real change and an investment in education (including healthcare professionals) from the earliest stages could have an amplified impact.

CLOSING REMARKS



Dialogue among different stakeholders is very important however, these discussions should serve as a basis for real change in concrete practice. The participants are invited to act as representatives and “broadcasters” of these messages and work pro-actively to bring them about in daily practice.

Mr. Hasardzhiev (PACT) presented the closing remarks by encouraging participants to continue active cooperation and dialogue. The several examples presented during the meeting are evidence that initiatives that underline collaboration are possible, have successful outcomes and could be implemented across all disease areas to assure more patient and stakeholder inclusion in the policymaking process. The topic of patient involvement was very active throughout the meeting and this is essential because more active inclusion offers added value to the system, health policies, and actions. Referring to the EU and international cooperation, Mr. Hasardzhiev remarked that coherence of information is needed and that the EU has a crucial role in determining standards, guidelines, platforms and resources. He invited all health stakeholders to act within their respective fields and to encourage more active dialogue and cooperation to assure that change is brought about.

Thanking all the participants of the event, Mr. Mendão (GAT) invited all the patient organizations in Portugal to work together and to collaborate with the hope to create a one-stop-shop that links Portuguese patient’s perspectives to larger European umbrellas and institutions. Moreover, patient-centered organizations need to work together with Europe to raise awareness of the relevance of health and health promotion, with inclusive innovation and research that does not leave anyone behind. In Europe, access to health and technologies need to have equity at the core.