





REPORT

HEALTH INEQUALITIES IN THE NEW EU MEMBER STATES AND CANDIDATE COUNTRIES. EQUITY OF ACCESS TO QUALITY HEALTHCARE



CONTENTS

Introduction	2	
Agenda	4	
Welcome Remarks	6	
Session 1: Data	7	
Session 2: Possible Solutions	12	
Session 3: Discussion	16	
Next Steps	18	
Acknowledgement	19	
Appendix		

INTRODUCTION

Article 2(1) of the Treaty of Lisbon proclaims that "the Union's aim is to promote peace, its values and the well-being of its peoples"ⁱ. 'Well-being' pre-supposes access to high quality healthcare, yet across Europe, we witness the profound impact of barriers to access and health inequalities, 'lived' by patients on a daily basis.

The economic crisis and austerity measures introduced by governments in Europe put at risk access to the healthcare they need for some patients, and lead to growing inequities in access to treatment in countries like Greece, Romania, Cyprus, Bulgaria and other EU Member States. In some parts of Europe, citizens' fundamental right of access to healthcare as stipulated in the Charter of Fundamental Rights of the European Union – a legally binding part of the Treaty of Lisbon – is being violated.

It has become evident that the strict budgetary discipline and budget cuts, without accompanying reforms and indicators reflecting human capital development, cannot revive the European economy and growth.

To raise and address these issues, the National Patients' Organisation of Bulgaria (NPO) in collaboration with the European Patients' Forum (EPF) and under the auspice of the Minister of Health of Bulgaria and Dr. Andrey Kovatchev, MEP, convened a conference on health inequalities with a particular emphasis on the new EU Member States, entitled "Policy Makers and Patients – creating the change" which took place in Sofia, Bulgaria on 20-21 September 2012.

The first conference concluded with the adoption of a Resolution by the participants – European and national policy makers as well as patients' organisations from 15 EU countries alongside three EU candidate countriesⁱⁱ. The Resolution addresses the burden of health inequalities and health austerity measures in the south-eastern region, and reflects the will to look at the discrepancies among the EU Members States with regards to access to healthcare and the quality of care, calling for recognition of "cultural differences in different regions of Europe and their impact on health inequalities".

As a follow-up to the conference, the National Patients' Organisation and the European Patients' Forum undertook the initiative to conduct an in-depth survey among patients' organisations to ensure up-to-date and concrete data on the direct impact of inequalities on patients' well-being.

In recognition of the urgency to tackle these issues, we gathered in Brussels to discuss possible solutions such as establishing a European partnership for equity of access to quality healthcare as a platform to combine the efforts of patient leaders, authorities, stakeholders and industry to identify possible new mechanisms for ensuring that patients have access to affordable and quality healthcare. The debate was intended to mirror the governments' discussion in the Council Working Party under the Reflection process "Towards Modern, responsive and sustainable health systems" (launched by the Hungarian Presidency) and underline citizens' fundamental rights to healthcare.

AGENDA

JUNE 26, 2013

HEALTH INEQUALITIES IN THE NEW EU MEMBER STATES AND CANDIDATE COUNTRIES.

EQUITY OF ACCESS TO QUALITY HEALTHCARE

VENUE: European Parliament; Rue Wiertz 60, 1047, City of Brussels ROOM: József Antall Building 6Q1

- 11:30 12:30 REGISTRATION/ BUFFET LUNCH
- 12:30 12:40 Welcome Remarks
 - Dr. Andrey Kovatchev, MEP; European Parliament
 - Mr. Tomasz Szelagowski; Federation of Polish Patients (FPP), Poland

SESSION 1: DATA

Participants discuss the First Conference on Health Inequalities in the New EU Member States which took place in Sofia, Bulgaria, on the 20–21 September and the related in-depth survey among patients' organizations in the new EU Member States and candidate countries. The session also includes case studies on access to quality healthcare in hepatitis and oncology.

Moderator: Mrs. Nicola Bedlington, European Patients' Forum (EPF), Belgium

- 12:40 12:50 "Outcomes of the First Conference on Health Inequalities in the new EU Member States"
 - Dr. Stanimir Hasardzhiev; National Patients' Organization (NPO), Bulgaria
- 12:50 13:00 "Access to healthcare: results of survey amongst patients' organizations in the new EU Member States and candidate countries"
 - Ms. Emily Peasgood; INCITE, UK
- 13:00 13:10 "Access to quality healthcare of hepatitis patients: case study"
 - Mr. Achim Kautz; Policy Director, The European Liver Patients' Association (ELPA)
- 13:10 13:20 "Access to quality healthcare of oncology patients: case study"
 - Mr. Erik Briers; Secretary, Europa Uomo (European Prostate Cancer Coalition)

SESSION 2: POSSIBLE SOLUTIONS

This session explores the ways to create equity access to treatment and care in the EU Member States. Panelists will share their insights on the possible solutions for expanding the access to quality healthcare throughout Europe.

• <u>Moderator:</u> Dr. Andrey Kovatchev, MEP

13:20 - 13:30	"Collaboration and best practice sharing between the EU Member States"
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- Ms. Dessislava Dimitrova; Chair of the Standing Committee of the Regional Committee, WHO
- 13:30 13:50 "Sustainable pricing system and how to expand access to medicines in Europe?"
 - Mr. Johan De Cock; General Administrator at National Institute of Health & Disability Insurance (RIZIV), Belgium
- 13:50 14:00 "What does the EU do to reduce health inequalities in the new EU Member States"
 - Ms. Nathalie Chaze; Head of Unit, DG SANCO, European Commission

14:00 - 14:30 DISCUSSION PANEL

Panelists will discuss key objectives and approaches (EP resolution, EC initiative, European partnership for equity of access to healthcare) to help shape EU policies 2020, in particular with regard to restoring equity and expanding access to quality healthcare for citizens in the EU Member States and candidate countries.

• <u>Moderator:</u> Mr. Nikos Dedes, "Positive Voice", Greece

14:30 – 14:40 WRAP UP OF THE CONFERENCE

HEALTH INEQUALITIES IN THE NEW EU MEMBER STATES

EQUITY OF ACCESS TO QUALITY HEALTHCARE

I. WELCOME REMARKS



Dr. Andrey KOVATCHEV, MEP

The host of the conference at the European Parliament, Dr Andrey Kovatchev, MEP, welcomed the participants and introduced the topic at stake – reducing health inequalities across Europe and ensuring equity of access to quality healthcare. In light of the current economic and financial crisis, the EU institutions need to decide how to use the EU

integration and core values such as solidarity to the benefit of all EU citizens. Dr Kovatchev suggested that among the key priorities for the European Union ahead should be building health infrastructure.

Dr. Kovatchev expressed his belief that the conference will lay the basis for a fruitful future collaboration between all concerned – institutions, stakeholders, professional and patients' organizations, for the purpose of identifying the most effective measures to be introduced at the EU policy level to fight health inequalities and improve access to healthcare across the European Union. To contribute to this process, Dr Kovatchev provided a platform to hear the voice of all involved parties.

Mr. Tomas SZELAGOWSKI, EPF, Belgium

Mr. Tomas Szelagowski delivered a welcome address to the guests in his capacity as a Treasurer of the European Patients' Forum (EPF). The European Patients' Forum aims to address the most urgent challenges that patients face by conducting advocacy activity at the EU institutional level. Most importantly, however, it observes that these policies are effectively implemented at the national level.



Mr. Tomas Szelagowski emphasized the importance of the issue of health inequalities. At a moment when the European Union family grows with another member – Croatia, it is important to recall the responsibility we have as EU citizens to contribute to the well-being of others. Mr. Szelagowski urged the participants to join forces and fight inequalities in a spirit of solidarity.

II. SESSION I: DATA

Moderated by Mrs. Nicola Bedlington, Executive Director of the European Patients' Forum, panelists discussed the First Conference on Health Inequalities in the New EU Member States which took place in Sofia, Bulgaria, on the 20–21 September and the related indepth survey among patients' organizations in the new EU Member States and candidate countries. The session also included case studies on access to quality healthcare in hepatitis and oncology.

Moderator: Mrs. Nicola Bedlington, European Patients' Forum (EPF), Belgium

- "Outcomes of the First Conference on Health Inequalities in the new EU Member States", Dr. Stanimir Hasardzhiev, National Patients' Organization (NPO), Bulgaria
- "Access to healthcare: results of survey amongst patients' organizations in the new EU Member States and candidate countries",
 - Ms. Emily Peasgood, INCITE, UK
- "Access to quality healthcare of hepatitis patients: case study", Mr. Achim Kautz, Policy Director, European Liver Patients' Association (ELPA)
- "Access to quality healthcare of oncology patients: case study", Mr. Erik Briers, Secretary, Europa Uomo (European Prostate Cancer Coalition)

OUTCOMES OF THE FIRST CONFERENCE ON HEALTH INEQUALITIES IN THE NEW EU MEMBER STATES

Dr. Stanimir Hasardzhiev, National Patients' Organization (NPO), Bulgaria



Dr. Stanimir Hasardzhiev provided an overview of two realities – local which he faces as the Chairperson of the Bulgarian National Patients' Organization where being a patient, doctor or a policy-maker is a challenge and a daily battle and an international, in the halls of the European institutions where policy over healthcare issues is shaped, which he experiences as the Executive Director of the European Liver Patients' Association (ELPA) and a Board member of the European Patients Forum.

Dr. Hasardzhiev emphasized that patients across the European Union face similar problems. Due to this fact, there is an overall recognition of the necessity to unite and undertake a common initiative to fight health inequalities. In light of these concerns, the European Patients' Forum and the National Patients' Organization – Bulgaria undertook the ambitious task to raise the issue of health inequalities at the conference titled "Health Inequalities in the 'New' EU Member States and Candidate Countries. Policy Makers and Patients – Creating the Change" which took place in Sofia, Bulgaria on 20-21 September 2012. Dr. Hasardzhiev presented a summary of the event and the outcomes in a video format.

The conference, which concluded with a Resolution, addresses the challenge of health inequalities and access to healthcare and the quality of care. The event fostered a deeper collaboration and led to a follow-up survey among patient leaders to receive their opinion as to what are the most urgent healthcare issues that need to be resolved. Based on the results, Dr. Hasardzhiev explained, EPF and NPO brought forward the initiative to face these urgent challenges at the conference in the European Parliament.

ACCESS TO HEALTHCARE: RESULTS OF SURVEY AMONGST PATIENTS' ORGANIZATIONS IN THE NEW EU MEMBER STATES AND CANDIDATE COUNTRIES

Ms. Emily Peasgood, INCITE, UK



Ms. Peasgood presented the patients' survey, initiated by the National Patients' Organization and the European Patients' Forum, which reflects the concerns of patient advocates across the European Union. The survey was conducted for a period of 3 months during which 286 patients with chronic diseases and their carers across 15 EU countries responded.

The results demonstrated that the most pressing issue that patients identify is access to quality healthcare where access implies consideration of waiting time for and availability of products and services, access to quality hospitals, equipment, treatment screening and prevention policies as well as access to medical specialists.

Patients feel that the economic crisis has had an impact on the access to healthcare. A clear indicator in this direction is the decrease in budget expenses for healthcare. Half of the patients feel that waiting time for treatment (medicines, treatment and services) has worsened. According to patient advocates, there are fewer new medicines available on the market.

The most urgent issues that patients identify concern the need for ensuring sustainable funding of the healthcare system, improving waiting time for treatment, developing effective screening and prevention policies, making treatment more available, improving the health infrastructure as well as improving access to innovative therapies.

Ms. Peasgood explained that patients believe that changes need to be implemented. The survey provided possible case scenarios to give the chance to patients to assess to what extent such measures will improve the situation in their country. Among the key solutions, as identified by patient leaders, was introducing the right of patients to be treated abroad, implementing affordable pricing as well as introducing specially tailored programmes to meet the needs of patients in their home country.

As the results clearly suggest, access to healthcare (hospitals, doctors, infrastructure, medicines etc) is the main challenge to be addressed. Ms. Peasgood concluded that new approaches need to be explored to optimize the sustainability of the healthcare such as for example, exchange of best practice, quality standards and sustainable pricing.

ACCESS TO QUALITY HEALTHCARE OF HEPATITIS PATIENTS: CASE STUDY

Mr. Achim Kautz, Policy Director, European Liver Patients' Association (ELPA)



The main focus of the European Liver Patients Association (ELPA), an umbrella organization which represents the rights of patients with liver diseases from 24 countries, is viral hepatitis. A disease which shows no symptoms, hepatitis is the main risk factor for liver cancer and cirrhosis but it can also be the cause for cardiovascular disease or diabetes. Mr. Kautz explained that there are approximately 500 million carriers of hepatitis

across the world. However, the detection rate is very low – less than 10%. Mr. Kautz emphasized that the effects of the disease can be reversed if detected on time.

It is for these reasons, Mr. Kautz noted, why it is important to implement early diagnosis, however, in consideration of the present economic and financial situation in Europe. Thanks to the tireless advocacy activity of all stakeholders, a number of hepatitis plans across Europe have been either implemented (France and Scotland) or follows to be implemented shortly (Bulgaria, Croatia, Germany, Ireland, Italy, Greece and Romania).

Mr. Kautz summarized the development of treatment options since 1991 when only 7% of the patients were cured with mono-interferon therapies with huge side effects while in 2011 approximately 50% reached sustained viral response (SVR) with the Pegylated Interferon and Ribavirin duo therapy. Predictions envision treatment chances to increase to 95% from next year onwards with the innovative therapies. Paradoxically, Mr. Kautz explained, although short successful treatment with few side effects is available, it is unaffordable as only in 5 EU countries, patients enjoy unlimited access to the newest components. Furthermore, although the greatest challenge is experienced by Eastern European countries due to socio-economic factors, some advanced countries, such as Spain and Portugal, also refuse to introduce the treatment die to the high costs involved.

In such complex circumstances, Mr. Kautz suggested that new solutions need to be explored to allow for a voluntary agreement between Member States and industry over treatment prices which reflect the ability and willingness of governments to pay for treatment. According to Mr. Kautz, what is needed is a new pricing mechanism to ensure treatment for patients. All relevant institutions (DG SANCO, DG ENTERPRISE and the Internal Market) need to collaborate and form a task force with the support of the Presidential Troika and the European Parliament for the purpose of exploring the optimal solutions to health inequalities and the unequal access to treatment.

ACCESS TO QUALITY HEALTHCARE OF ONCOLOGY PATIENTS: CASE STUDY

Mr. Erik Briers, Secretary, Europa Uomo (European Prostate Cancer Coalition)



Mr. Briers explained that like in hepatitis, early detection is crucial to the treatment of liver cancer. To address health inequalities in healthcare across the European Union is crucial to provide adequate education to patients with respect to the need for diagnostics.

Apart from education, Mr. Briers noted, it is crucial to ensure equal access to modern equipment for diagnostics and treatment as well as to medicines. Mr.

Briers added that scientific advancement has identified another challenge in light of the different types of one disease which imposes the necessity for taking into consideration the case for personalized medicines it aims to create specially tailored medical treatment to meet the individual needs of patients according to the specific disease characteristics.

In Mr. Briers' view, the inequalities are ingrained in the disease process. To take an example, palliative care in cancer is not available equally throughout Europe. Mr. Briers reinforced the notion that early diagnostics is far more cost effective in the long run and in this respect, expressed severe disappointment with the fact that in some countries, the cheapest initial detection tests are no longer reimbursed and therefore, only patients in advanced stage of the disease are detected.

Mr. Briers suggested that it is vital to establish centers of excellence across Europe where patients from all over the EU can be treated to ensure that patients who will be transferred to the respective center will be treated by dedicated experts with specialized equipment.

III. SESSION II: POSSIBLE SOLUTIONS

This session explored the ways to create equity access to treatment and care in the EU Member States. Panelists shared their insights on the possible solutions to expanding access to quality healthcare throughout Europe.

Moderator: Dr. Andrey Kovatchev, MEP

- "Collaboration and best practice sharing between the EU Member States", Ms. Dessislava Dimitrova, Chair of the Standing Committee of the Regional Committee, WHO
- "Sustainable pricing system and how to expand access to medicines in Europe?"

Mr. Johan De Cock, General Administrator at National Institute of Health & Disability Insurance (RIZIV), Belgium

"What does the EU do to reduce health inequalities in the new EU Member States",

Ms. Nathalie Chaze, Head of Unit, DG SANCO, European Commission

COLLABORATION AND BEST PRACTICE SHARING BETWEEN THE EU MEMBER STATES

Ms. Dessislava Dimitrova, Chair of the Standing Committee of the Regional Committee, WHO



Ms. Dimitrova began her presentation by briefly comparing the European strategy for health and well-being *Europe 2020* and the strategy that the World Health Organization developed for Europe as a whole - *Health 2020*.

The need for the latter occurred as a result of the fact that despite the improvement in life expectancy in the last 5 years, health inequalities still remain a major issue across and within countries. *Health 2020* endorses the reduction of health inequalities and improvement of leadership and

participatory governance as strategic goals. The four priority interventions are investing in life through a life-course approach, tackling Europe's major challenges, strengthening public health systems and creating resilient communities. Ms. Dimitrova explained that the goal is to expand the scope of the strategy to the global level.

Ms. Dimitrova stressed on the need to develop new sustainable development goals following the path of the current Millennium Development Goals, which conclude in 2015. She pointed to the fact that there is tension over this issue between the European stakeholders who advocate for setting a single goal such as universal health coverage and other stakeholders who believe that this goal is only the means to the greater end - improving life expectancy.

A crucial component of *Health 2020* is the monitoring mechanism which includes indicators to measure the level of implementation. The purpose was to use the available data and group it in appropriate manner to avoid creating new requirements which will require the collection of more data. The framework is intended to effectively address the most pressuring issues in the healthcare sphere.

Ms. Dimitrova shared her excitement regarding the pre-conference dinner with key stakeholders where it was affirmed that health inequality and access to healthcare need to be tackled through the united efforts of multiple stakeholders. She reinforced the need to outline a concrete agenda for action with clear definition of the conceptual scope of 'access' and a surveillance system to assess the progress and success of the undertaken measures.

SUSTAINABLE PRICING SYSTEM AND HOW TO EXPAND ACCESS TO MEDICINES IN EUROPE

Mr. Johan de Cock, General Administrator at National Institute of Health & Disability Insurance (RIZIV), Belgium



To view the presentation of Mr. Jo de Cock please click $\underline{here}.$

WHAT DOES THE EU DO TO REDUCE HEALTH INEQUALITIES IN THE NEW EU MEMBER STATES

Ms. Nathalie Chaze, Head of Unit, DG SANCO, European Commission



Ms. Chaze noted that health inequalities remain substantial across the European Union but emphasized that they can be addressed, as they are not inevitable. Ms. Chaze compared the EU as a whole with Bulgaria and Romania in terms of life expectancy, infant mortality and percent of GDP for health expenditure to demonstrate the gaps between the EU Members States. She insisted that a minimum level of investment in health is also a key factor in tackling inequalities, together with action on social determinants.

The Commission is supporting Member States in reducing health inequalities, including through identifying gaps and best practices. In the context of the European semester, the European Commission encourages improvement in the EU Member States health system, at the country-specific level. The country recommendations are adopted by the European Council and give guidance on how to tackle the structural problems in each country. Ms. Chaze took Bulgaria as an example where she noted the most urgent needs concern the inequalities in access (urban vs. rural but also for economic reasons), financing of the system, capacity and organisation of the hospital sector, human resources strategy and referral from GP to specialist. To apply the recommendations, Ms. Chaze advised Member States to use the available structural funds. Looking at health inequalities from a more horizontal angle, the Commission should soon publish a report on health inequalities.

Ms. Chaze also emphasised the need to ensure equal access to high quality healthcare; however at the moment, she continued, there is no clear shared understanding of quality of healthcare. Member States are at very different level of development of their strategies and there is not even clear and transparent information on quality of healthcare. This is preventing mutual learning. A recent Eurobarometer has shown that patients are not fully confident in the safety and quality of the care they receive. Therefore, it is crucial in any further work to involve patients.

Reacting to the previous speaker's intervention, Ms. Chaze also believes that currently, there is inadequate transparency on pricing of pharmaceutical products. She suggested that, although Member States are sovereign in their pricing policies, their decision at home affect the situation in other Member States, including on access to medicines. Enhanced transparency and cooperation could help achieving better access of citizens to medicines.

The evolving role of the Commission is to help individual Member States with specific recommendations and not only to address health inequalities from a cross-regional outlook. In that context, it is necessary to look at health inequalities through different angles: organisation and functioning of the health systems as well as social determinants for health. Ms. Chaze welcomed the idea for a broader partnership approach for equity of access to quality healthcare.

IV. SESSION III: DISCUSSION

Moderated by Mr. Nikos Dedes, panelists highlighted some key objectives and approaches (EP resolution, EC initiative, European partnership for equity of access to healthcare) to help shape EU policies 2020, in particular with regard to restoring equity and expanding access to quality healthcare for citizens in the EU Member States and candidate countries.

Mr. Achim KAUTZ, ELPA

Mr. Kautz suggested that it is crucial to develop an instrument to assess the cost and re-allocate money effectively to achieve the right goals. In similar lines, the European Liver Patients' Association undertook the task to collect the best practices in healthcare policies across the world on hepatitis and calculate the current expenditure of governments for the purpose of preparing country-

specific recommendations as to how to optimize the invested funds to achieve effectiveness and efficacy in treatment of patients with hepatitis.

Mr. Alojz PETERLE, MEP

Mr. Peterle underlined the need for integrating knowledge, science and research in any approach for improving access to healthcare. Based on better coordination and collaboration, the concerned stakeholders should allocate funds for clearly defined goals. Patients are interested in the results achieved through competent decision-making. Mr. Peterle, who himself was diagnosed



with cancer, believes that it is important to set a personal example in fighting for equality in access. He concluded that being such an important issue, health inequalities ought to be tackled at the EU level in a comprehensive and sustainable manner.



Dr. Andrey KOVATCHEV, MEP

Dr. Kovatchev made a commitment to lead the process of setting an informal group of Members of the European Parliament to discuss and address the issue of health inequalities and equity of access in healthcare across Europe. His intention is to engage the European Commission to increase the visibility on the subject

and raise awareness among the concerned institutions on the scale and scope of the issue. Dr. Kovatchev emphasized that this is the appropriate time to consider and act upon the matter, especially in light of the upcoming election at the European Parliament. **Dr. Antonyia PARVANOVA, MEP** Dr. Parvanova expressed delight that the topic of health inequalities and equity of access to healthcare is being addressed. According to Dr. Parvanova, to achieve results there needs to be an ambitious goal such as amending the Treaty of Lisbon to include health as a priority and empower the EU institutions to



address the issue in a decisive manner. Dr. Parvanova was skeptical of the capacity of states to ensure equity of access to healthcare. One instrument could be to set up a pressure group at the EU level to advocate the goals and pursue their implementation. Dr. Parvanova endorsed the proposal for the establishment of an informal MEP group and committed to active contribution. She further suggested that the first step should be to prepare an action plan which includes evidence, demands, an advocacy strategy and allocated responsibilities.



Mr. Petru Constantin LUHAN, MEP

Mr. Luhan reinforced the notion that what is vital is to gather all stakeholders at the discussion table to evaluate the implication of any particular approach from all possible aspects – scientific, technical, financial, legislative. Mr. Luhan also expressed willingness to actively participate in a newly formed pressure group.

CONCLUSION AND NEXT STEPS

MEPs - champions for patients' rights and equity in healthcare launched an informal MEP interest group during the discussion. The informal group will hold its first meeting after the conference to discuss strategic actions and future activities.

Following the conference, EPF will initiate consultation process with the EU and health stakeholders to establish a European partnership for equity of access to quality healthcare.

NPO and EPF will further lead the initiative to set up a Steering Committee to lead the organization of a following conference focusing on equity of access in healthcare. The conference is intended to be held in Athens during the next 2014 EU Presidency.



ACKNOWLEDGEMENTS

The National Patients' Organization and the European Patients' Forum would like to thank all participants for taking part in the **conference "Health Inequalities in the New EU Member States and Candidate Countries. Equity of Access to Quality Healthcare"**. Your dedication, support and invaluable insights contributed to raising awareness and encouraging future action to curb health inequalities.

Together, we shall work to ensure quality and accessible healthcare in Europe!

The National Patients' Organization, Bulgaria The European Patients' Forum

APPENDIX

LIST OF PARTICIPANTS

Mr.	Achim Kautz	European Liver Patients' Association	Vice President	kautz@elpa-info.org
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ⁱTitle 1, article 2(1) of the Treaty of Lisbon ⁱⁱRepublic of Macedonia and Republic of Serbia (candidate countries); Croatia (acceding state)