



## **“The challenges of chronic diseases and patients’ rights in the framework of EU healthcare sustainability”**

### **9<sup>th</sup> European Patients’ Rights Day**

#### ***Opening Remarks and keynote Presentations***

Good morning and welcome to the European celebration of the Ninth Edition of the European Patients’ Rights Day.

As Director of Active Citizenship Network, the promoter of this event since 2007, I would like to thank each one of you for being here.

First of all, I would like to thank the European and national Institutions, and of course a special thanks to the Members of the European Parliament David Borrelli, Co-Chair of the Europe of Freedom and Direct Democracy Group, and Gianni Pittella, Chair of the Group of the Progressive Alliance of Socialists and Democrats in the European Parliament, for having accepted to host this initiative.

Secondly, a great thanks to Hans Martens for having agreed to the uncomfortable role as Chair of the conference. I am sure your great experience as Associate Professor and past Chief Executive of the European Policy Centre will be beneficial for the topic and to respect the agenda.

A warm welcome to leaders of civic and patient organizations from 22 Countries<sup>1</sup>, representative and leaders of 20 networks at EU level, experts, professionals, companies and stakeholders.

This year we have decided to face the sustainability of healthcare systems focusing on what concerns chronic diseases.

The context is quite well known:

- Chronic diseases represent the major share of the burden in Europe and are responsible for 86% of all deaths. They affect more than 80% of people aged over 65 and represent a major challenge for health and social systems.
- An estimated € 700 billion euro per year are spent on chronic diseases in the European Union (which is 70 to 80% of the overall EU health care budgets).
- The economic crisis has a direct impact on healthcare access, especially for the vulnerable population, which are exposed to social exclusion, increased private costs or giving up altogether medical care.

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<sup>1</sup> Austria, Belgium, Bulgaria, Cyprus, Croatia, Denmark, Estonia, France, Germany, Hungary, Iceland, Italy, Kosovo, Lithuania, Macedonia, Malta, Netherlands, Poland, Slovakia, Slovenia, Spain, Ukraine.



- The Commission noted back in 2012 that patient safety was being undermined by austerity measures entailing across-the-board cuts in health services and directly affecting the quality of care. As written in the ENVI Report on safer healthcare in Europe (whose Rapporteur is MEP Piernicola Pedicini whom I thank for his presence here today), such a situation is truly intolerable.
- Moreover, we need to keep in mind the increasing demands for expensive medical technology that are made by a society that is ageing rapidly. Usually, there is a general concern about the increased healthcare costs due to patient associations with chronic diseases pressuring health institutions, as the latter's main objective should be increased access and better reimbursement of new and expensive treatments and medicines. But, at the same time, we perfectly know they play a decisive role in the development of a modern patient-centred health systems, as debated last year in the VIII Edition of the European Patients' Rights Day.

With this scenario, the sustainability of our health and social systems is at stake. It is crucial to find new ways of investing in sustainable healthcare systems, moving beyond limiting expenditure to addressing the demand for health and social services, much of which is related to chronic diseases.

The problem is that if the context is quite well known there are less solutions to be found.

If we were to move towards this direction, we have to take into consideration at least two different but complementary aspects, on the one hand the responsibility of different actors involved in sustainable healthcare systems, and on the other hand the role of prevention and innovation.

I would like to thank in advance the panelists for having accepted to speak at the conference and provide us their expertise on different aspects of the topic.

Let me do a brief introduction of the two panels.

The first panel will debate about the responsibility of different actors in the sustainability of healthcare systems, in a context where there is a high risk that indirect costs for patients becomes unsustainable. As a consequence, the treatment and dignity for chronic patients are no longer a right, but a privilege for a few lucky ones. All of these considerations cannot be done at a national dimension anymore, but should be expanded at the European level, as chronic patients may suffer the same issues and face the same challenges even if they do not live in the same place.

The second panel will debate about the role of prevention and innovation in the framework of the sustainable healthcare systems. What we need to look for, are more effective and smarter approaches to the prevention and treatment of chronic diseases



and the preservation of “life with dignity” for patients. To find new approaches and change what is wrong, it is fundamental to reflect on how and to what extent the right to quality standards can be respected, especially during financial restrictions.

This also leads us to another aspect that has been a key concern of the informal meeting of the 28 European Health Ministers held last on 22nd and 23rd September 2014, during the Italian Presidency of the Council of the European Union: if there is a real danger that quality healthcare cannot be guaranteed to patients, what could be the “innovative approaches” to make healthcare more sustainable? This concern was also highlighted in the 2015 European Commission's Annual Growth Survey.

It is true that many EU countries already have recommendations to reform their health systems to make them more efficient and more sustainable, but this is not enough.

A country's health status is not determined by how much money it spends but the way the money is spent. This is in line with what the Health Commissioner Andriukaitis said in the concluding remarks of the Council of Ministers of Health on December 1<sup>st</sup> 2014 in Brussels. According to him the “*health sector is a contributor to growth*” and “*innovation is crucial to guarantee patient safety and quality of care*”.

So, the goal of the conference is to increase awareness on the topic and facilitate the exchange of different points of view, with the aim to try to identify concrete strategies and actions to strengthen citizens' participation to create efficient, sustainable and equitable European health systems.

Over the years, Active Citizenship Network has developed several civic assessments<sup>2</sup> in order to produce information on the implementation of patients' rights at EU level. In 20 countries, the level of awareness regarding the 14 rights mentioned in the European Charter of Patients' Rights (you have received a copy of it), is generally unacceptable. This negative evaluation was also confirmed last year<sup>3</sup> with the assessment regarding the “Right to avoid unnecessary suffering and pain” (one of the rights in the European Charter of Patients' Rights), realized to make it visible the condition of patients suffering with chronic disease and chronic pain, and to put this topic for the first time in the European agenda.

These negative results send a precise signal to the civic world and to the European institutions about the work that still needs to be done: it is a difficult challenge which needs to be faced as a joint effort.

I believe and I hope that we all agree that the healthcare systems – and its sustainability - are a common good to be safeguarded, thus a common challenge for different actors: Institutions at EU and national level, professionals, companies, providers, citizens and patients.

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<sup>2</sup> [www.activecitizenship.net/files/patients\\_rights/civic\\_assessment/european\\_patients\\_rights\\_day\\_report\\_light.pdf](http://www.activecitizenship.net/files/patients_rights/civic_assessment/european_patients_rights_day_report_light.pdf);  
[www.activecitizenship.net/images/patientsrights/abstract\\_eu\\_charter\\_patient\\_rights\\_civ\\_ass.pdf](http://www.activecitizenship.net/images/patientsrights/abstract_eu_charter_patient_rights_civ_ass.pdf)

<sup>3</sup> [www.activecitizenship.net/patients-rights/109-pain-report-on-respect-of-patients-rights-among-the-europe.html](http://www.activecitizenship.net/patients-rights/109-pain-report-on-respect-of-patients-rights-among-the-europe.html)



All around Europe, civic and patient organizations, are worried about how to reach this goal: the risk of not involving citizens, patients and their associations, will lead patients' rights and its protection not being taken into consideration. Or just stated in law and affirmed in theory but not denied in practice.

Faced with this scenario, our commitment and proposal is to encourage the Members of the European Parliament towards the establishment of the new Interest Group "European patients' rights and cross-border healthcare".

We believe that it could represent an effective message of the European Institutions' commitment that any action towards a sustainable healthcare system should be done by putting patients' rights at the forefront.

The proposal to create a new informal Interest Group focused on patients' rights is linked to the widespread request of at least 80 civic and patient organizations from all around Europe, which are calling to the EU Parliament to recognize officially the European Charter of Patients' Rights based on the Charter of Fundamental Rights of the European Union and the European Patients' Rights Day.

The Group should focus on the following issues, among others:

1. Make the European Parliament acknowledge the European Patients' Rights Day in order to officially recognize and institutionalize it.
2. Actively support the celebrations of the European Patients' Rights Day and collaborate with civic and patient associations at the national and European level.
3. Strengthen the protection of patients' rights in the European legislation, starting from the adoption of the European Charter of Patients' Rights, 14 patients' rights that together aim to guarantee a "high level of human health protection" (Article 35 of the Charter of fundamental rights of the European Union) and to assure the high quality of services provided by the various national health services in Europe.
4. Establish the European Year of Patients' Rights during its mandate.
5. Promote initiatives that encourage among EU countries the respect of the primary and secondary European legislation and Recommendations focused on patients' safety and the protection of their rights. It could be done with the involvement of civic and patient associations, starting from the Directive 2011/24/EU on patients' rights in cross-border healthcare and the most recent "Draft Report on safer healthcare in Europe: improving patient safety and fighting antimicrobial resistance (2014/2207(INI))", approved unanimously on 16th April 2015 by the ENVI Committee on the Environment, Public Health and Food Safety. A document that we appreciate a lot for the recommendation to "actively and formally involve patients' organizations", for the invite to introduce collective redress and promote information campaigns, in order to guarantee patients rights such as the right to information, to free choice, to safety, to innovation, to complain and to compensation. In this document, ENVI Committee underlines that treatment should centre on patients; health services should not be subjected to unwarranted cuts ostensibly dictated by austerity. And



last but not least, in this document ENVI Committee recognizes the value of citizens' initiatives, such as the European Charter of Patients' Rights based on the Charter of Fundamental Rights of the European Union, and the European Patients' Rights Day, and invites the Commission and the Member States to support the European Patients' Rights Day at local, national and EU level.

In order to increase awareness about it, first we will launch an online petition open to citizens and patients across Europe, asking to support the request to make the European Patients' Rights Day officially. Secondly, in order to celebrate its 10th anniversary next year, we will hold a civic mobilization in partnership with civic and patient associations in at least 20 countries.

The reinforcement of patients' rights will become effective only with the cooperation and commitment of all healthcare stakeholders in every EU country, where patients must be considered as partners in the health policy, sharing - with the Institutions and professionals - the responsibility of finding the balance between patients' interests and the sustainability of healthcare systems.

It is thus essential to increase awareness regarding the importance of patients' rights and everyone's responsibilities in guaranteeing their respect. And we hope that this European Parliament and this European Commission will be remembered for their commitment on patients' rights.

Thank you again for wishing a useful and interesting conference.

Mariano Votta