



## “European citizens’ rights: Patients’ Involvement and Cross Border Care” *7th European Patients’ Rights Day*

European Economic and Social Committee  
16<sup>th</sup> May 2013 – Brussels  
Room VM3 (2nd floor, Van Maerlant Building, 2 rue Van Maerlant)

### Introduction

In occasion of the **7th European Patients’ Rights Day** (EPRD), Active Citizenship Network (ACN) has decided to emphasize the final principle of the European Charter of Patients’ Rights<sup>1</sup>, i.e. the “**Right to participate in policy making in the area of health**”.

2013 is indeed very significant for civic participation for two main reasons :

- The 2013 **European Year of Citizens** aims at raising citizens' awareness of their rights and at stimulating their active participation in the European policy-making;
- The official deadline for the transposition of the directive 2011/24/EU on the application of patients’ rights in cross-border healthcare is **25 October 2013**. This directive, which recognizes most of the European Charter patients' rights, is planned to be implemented by Member States in consultation with patient organisations.

The structure of the conference will therefore reflect these two priorities.

### *The Directive on Patients’ Rights in Cross Border Care*

The **Directive on Patients’ Rights in Cross Border Care** creates a clarified legal framework for patients’ entitlement to seek healthcare in another Member State and to get reimbursed. But first and foremost, it is an innovative text which formally states for the first time the existence of EU patients’ rights such as free choice, right to information, to quality of care, etc.

The conference is part of a process aimed at supporting the involvement of civic organisations in the transposition of the Directive in every Member State, **for a citizen-centered and successful implementation**. This strategy, which will be officially launched by ACN in occasion of the conference, will bring to the **celebration of the 25 October all over the EU**. It will be an occasion for all patient and civic organisations to inform European citizens on what has been done and on what still has to be done to make the rights sanctioned in the Directive come true.

### *Patients’ involvement and citizens’ participation*

**Citizens and Patients’ involvement** should become a core strategy of European Health systems. However, despite the large agreement about the necessity to engage citizens, there is no systematic commitment on this issue, neither at EU nor at national levels.

The conference will be an occasion to present an overview of the situation in Europe (laws, experiences, obstacles, good practices) regarding the main fields of patients’ participation (agenda setting, decision making, implementation, assessment, etc.), with a focus on participative policies in cancer care, in which the access to innovation and personalized treatments is especially crucial.

---

<sup>1</sup> [http://www.activecitizenship.net/images/patientsrights/poster\\_england.pdf](http://www.activecitizenship.net/images/patientsrights/poster_england.pdf)



## **“European citizens’ rights: Patients’ Involvement and Cross Border Care”** *7th European Patients’ Rights Day*

### **Draft program**

#### **Morning session: Towards a citizen-centered implementation of the Directive on patients’ rights in cross-border healthcare?**

##### **10:00 - 10:10 Opening remarks**

- Renate Heinisch, Representative of the European Economic and Social Committee
- Antonio Gaudio, General Secretary of Cittadinanzattiva

##### **10:10 - 10:30 Keynote speeches**

- Paola Testori-Coggi, European Commission - Director General of DG Health and Consumers
- Antonyia Parvanova, Member of the European Parliament

##### **10:30 - 11:45 PANEL 1: Participation of patients’ organisations in the transposition process**

The first panel will consist in a discussion on the state of the art of the Directive transposition in the Member States, with a specific attention to the involvement of patients’ organisations in the implementation process and in the definition of the future national contact points. (Qs of the Moderator – 45 min; Qs of the public – 30 min)

*Moderated by: Charlotte Roffiaen, Consultant in European Affairs*

- Nathalie Chaze, DG Health and Consumers, Head of the Healthcare Systems Unit
- Elvira Foteva, Chief Expert of the Medical Activity Directorate, Ministry of Health, Bulgaria
- Gertrude Buttigieg, Secretary General of Malta Health Network, Malta
- Liene Sulce Revele, Chair of the board of Pacientu Ombuds, Latvia
- Dula Rusinovic-Sunara, President, Croatian Association for Patients' Rights, Croatia
- Michael Prunbauer, Staff member, Austrian Patient Advocacies, Austria
- Wolfram-Arnim Candidus, President, DGVP e.V. für Gesundheit, Germany

##### **11:45- 13.00 PANEL 2: Implementation of the right to “informed choice”**

The second panel will focus on the challenging implementation of the right to informed choice in cross border healthcare and on how different stakeholders could/should collaborate to guarantee citizens’ friendly information on treatment options, availability, quality, safety and prices of healthcare. (Qs of the Moderator – 45 min; Qs of the public – 30 min)

*Moderated by: Charlotte Roffiaen, Consultant in European Affairs*

- Luigi Bertinato, Medical Director of the Health Care Authority n.22 of the Veneto Region, Italy
- Paul Garassus, Representative of the European Union of Private Hospitals
- Chiara Marinacci, Directorate General for Health Planning, Ministry of Health, Italy
- Francesca Moccia, Vice-Secretary General of Cittadinanzattiva, Italy
- Collectif Interassociatif Sur la Santé, France

## **Lunch 13:00 –14:00**

### **Afternoon session: Patients' involvement in health policies in Europe**

The afternoon session will be dedicated to the state of the art and perspectives of citizens and patients' involvement in health policies in Europe, taking into account the EU, the national and the regional levels. It will include case studies on Health Technology Assessment and on Cancer Policies, as the involvement of stakeholders is a constituent part of HTA approach and the participation of patients is especially developed in the cancer field.

### **14:00– 14:30 Presentation of the report “The patients’ involvement in health policies in Europe”**

Antonio Gaudioso, General Secretary of Cittadinanzattiva

### **14:30 -15:45 Panel**

The members of the panel will discuss the results of the ACN report, based on their concrete experience in patients' involvement.

*Moderated by: Erik Briers, Executive Director of European Cancer Patient Coalition (ECPC)*

Geoffrey Henning, Director of Policy, Europacolon

Joop van Griesven, President of the Board, Pain Alliance Europe

Giovanna Marsico, Member of the Steering Committee, Cancercontribution.fr

Sascha Marschang, Policy Coordinator for Health Systems, European Public Health Alliance

Teresa Petrangolini, Member of the Steering Committee, HTAi Interest Group on Patient & Citizen Involvement in HTA

Thomas Sannié, President of the Regional health and autonomy conference, Ile de France Region, France

### **15:45 – 16:00 CLOSING REMARKS**

#### **\* to be confirmed**

This event has been made possible also thanks to an unrestricted educational grant from Abbvie, Bayer, Celgene, Hoffmann-La Roche, Lilly, Pfizer, Sanofi.