



2013 European Year of Citizens

16th May 2013 – Brussels

Room VM3 (2nd floor, Van Maerlant Building, 2 rue Van Maerlant)

7th European Patients' Rights Day

“European citizens’ rights: patients’ involvement and Cross Border Care”

An occasion to share and debate on the state of Patients’ rights

Active Citizenship Network (ACN) together with a group of European citizens organisations in 2002 drafted the European Charter of Patients’ Rights, which states 14 patients’ rights 3 rights of active citizenship, which recognize the role of patients as actors of Health policies¹. They allow individuals and groups of organized citizens to promote and verify the implementation of patients’ rights and as such, they are the necessary corollary of the Charter.

The reinforcement of these rights will become effective only with the cooperation and commitment of all healthcare stakeholders in every EU country. It is thus essential to increase awareness regarding the importance of patients’ rights and everyone’s responsibilities in guaranteeing their implementation. Celebrating a **European Patients’ Rights Day** every year in all the EU Member States shall greatly contribute to this goal. It is a unique occasion to inform, discuss and take commitments to improve patients’ rights in Europe.

The framework of the “European Year of Citizens”

The EU has decided to dedicate 2013 to European citizens and their rights. The Commission's goal is to raise citizens' awareness of their new rights resulting from the EU policies, as well as to stimulate their active participation in the Union policy-making. This is the reason why ACN has decided to focus the **7th European Patients’ Rights Day** on directive 2011/24/EU on the application of patients’ rights in cross-border healthcare, which shall be transposed by 25 October 2013, and on patients’ involvement, as a form of citizens’ participation in Health policy.

The conference

The **7th European Patients’ Rights Day** will be celebrated with an international conference organized on **16 May 2013 in Brussels** and national events taking place on 18th April all over Europe.

¹ Right to perform general interest activities; Right to perform advocacy activities; Right to participate in policy-making in the area of health.

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. It also provides a legal basis for enhanced European cooperation in key areas of healthcare – including quality, safety, HTA, eHealth and rare diseases. This 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.

We would thus like, first to raise the awareness of the patient communities on the provisions of the new legislation and second, to support patient organisations' involvement in their implementation in every Member State.

The patients' involvement

The patients' **involvement** and citizen participation should become a core strategy of European Health systems. The lack of financial resources and the economic crisis which have raised important sustainability concerns, and the increasing request of innovative treatments and personalized care, do both require new models of governance. 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 (planning, decision making, implementation, assessment, etc.) with a focus on participative policies in Cancer Care, an area in which the access to innovation and personalized treatments is especially crucial.

The main target of this multistakeholder conference will be citizens and patients' organisations, together with health professionals (physicians, nurses, pharmacists) and national/regional health authorities.

The expected participation is about 160 people.

See the draft program below.



Draft program

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The morning session

Will be dedicated to a brief presentation of new patients’ rights in the Directive on Cross Border Care and their implementation and to a discussion on citizens’ participation in the Directive implementation. The session, lead by ACN Director, will be organized as a round table and the discussion will be animated by the citizens’ organizations invited.

10:00 – 10:15 Opening remarks:

- European Economic and Social Committee
- Antonio Gaudio, Active Citizenship Network

10:15 –11:45 KEYNOTE PRESENTATIONS

- Paola Testori-Coggi, European Commission - Director General of DG SANCO

Setting the scene on the Directive on Cross Border Care implementation:

- **The state of the art:** Nathalie Chaze, DG SANCO, Health Systems Unit

10:45 11:45 ROUNDTABLE

Concrete experiences:

-Quality and safety standards for healthcare providers: Paul Garassus, European Union of Private Hospital –UEPH

European Hospital and Healthcare Federation – HOPE

-Patients’ information for an informed choice (national infopoint):

Ministry of Health, Italy

1 representatives from another national Ministry of Health in charge of the Directive implementation

- Patient organisations’ engagement for a successful implementation

Malta Health Network

Pacientu Ombuds, Latvia

EURORDIS, Rare Disease Europe

European Patients Forum

11:45 - 12:30 – OPEN QUESTIONS/DISCUSSION

Interventions from the audience

Lunch 12:30 –13:15

The afternoon session

Will be dedicated to the presentation and discussion of ACN Report on patients' involvement in Health policies. Patients' organizations and other stakeholders will present their experience in patient involvement, with a particular attention to Cancer Care.

13:15– 13:35 KEYNOTE PRESENTATION

-[The report](#), Alessio Terzi Cittadinanzattiva – ACN

13:35 14:45 ROUNDTABLE

-[Concrete experiences on patient involvement](#):

Teresa Petrangolini, specialist in health technology assessment (HTA)

Joop van Griesven, Pain Alliance Europe

Giovanna Marsico, Cancercontribution.fr Platform

Nickie Colson, European Cancer Patients Coalition ECPC

Geoffrey Henning, Europacolon

Nadia Ceratto, Valuable Ideas Association

14:45 – 15:15 OPEN QUESTIONS/DISCUSSION

Interventions from the audience

15:15 – 15:30 CLOSING REMARKS