



## **MEPs Interest Group “European Patients’ Rights & Cross- Border Healthcare” Launch Event**

### **MEETING MINUTES**

**Theme:** Patients’ Rights and Cross-Border Healthcare in the European Agenda and in the Stakeholder perspective

**Date:** December 2<sup>nd</sup> 2015

**Conference Organizers:** Cittadinanzattiva Onlus - Active Citizenship Network

**Host:** MEP David Borelli (Co-Chair of Europe of Freedom and Direct Democracy Group)

**Venue:** room ASP A7H1 - European Parliament, Brussels

### **OPENING KEYNOTE**

#### **Antonio Gaudioso – Secretary General of Cittadinanzattiva Onlus**

The meeting is opened by Antonio Gaudioso, who thanks everybody for being there.

He introduces the initiative thanking the MEPs 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, because they were the first MEPs that decided to support the Interest Group.

He explains that the meeting will be divided into two panels: the first one dedicated to “Patients’ Rights and Cross-Border Healthcare in the European Agenda” and the second one dedicated to “Patients’ Rights in the Stakeholder perspective”.

#### **David Borrelli MEP – Co- Chair EFDD Group & Co-Founder of the Interest Group**

He explains that the event marks a journey begun with Active Citizenship Network, and he hopes it will continue actively with those who belong to the civil society and the Institutions to ensure that there will always be communication and cooperation between them.

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For, even though we are in a single market, the sense of European citizenship has yet to be fully implemented.

The abolition of borders for those affected by diseases is a strong sign of progress in this regard, provided it is implemented effectively and efficiently.

He concludes saying that he will always be on the front line in the joint efforts to address the many issues related to the implementation of legislation.

### **Mariano Votta – Director of Active Citizenship Network**

He explains that the aims of the Interest Group go in the same direction of the latest decisions of the European Commission, who has recently introduced the right of cross-border healthcare.

There are several reasons that pushed Active Citizenship Network to found this Interest Group and, among those, “Patient centricity” and “health in all policies” were the two major drivers.

All the citizens suffering from different diseases have the same rights to be informed, to promptly access to the most appropriate care, to freedom of choice, to avoid unnecessary pain, to innovation in favour of patients, etc.

Having carried out many activities with the purpose of describing the interest of the Institutions and the stakeholders but also the level of awareness of citizens and patients in relation to their rights. A satisfactory situation is still far, in terms of both formal acceptance and recognition of patients’ rights by national and European laws and the effective respect and exercise of these rights.

The Interest Group aims at drawing and maintaining the highest level of attention on the topic, because a strengthened protection of rights all over Europe may consequently contribute to reinforce a sense of belonging to a European citizenship that we desperately need to build.

### **1<sup>st</sup> panel: Patients’ Rights and Cross-Border Healthcare in the European Agenda**

#### **Therese Comodini Cachia, MEP – PPE**

In her opinion, there are four main challenges to face about cross-border healthcare :

- At national level, the first challenge concerns an efficient implementation of the Directive in the Member States, which must come up with measures to ensure a fair implementation of the legislation.
- It is not possible to achieve this goal without the contribution of patients and every Member State has to act responsibly, ensuring that patients are aware of their rights, by providing correct information and facilitating their access to such information.

- The third challenge is related to the differences of the quality of information that can be collected in the Member States (How effective are the National Contact Points? They should ensure the highest quality).
- The last challenge is to find ways to provide real benefits. We need greater collaboration between patient organizations present in the different Member States thanks to a more cohesive network, giving them the opportunity to verify the responsibilities of Member States through a concrete implementation of the Directive. In this case, we must also consider the role of another stakeholder: the European Commission, that represent the watchdog able to request an assumption of responsibility by the Member States in order to proceed with the full and correct implementation of the Directive.

#### **Piernicola Pedicini, MEP – EFDD Group, Member of the ENVI Committee**

He confirms that the current implementation of the Directive is an opportunity to show that citizens' organizations are not involved in the right way and that, from his point of view, the National Contact Points have not worked as they should have done because of a lack of transparency and clarity.

He also points out that does not exist any insurance for the patients to have reimbursement for incurred expenses for cross-border treatments or to have the recognition of their own doctor's prescription with the consequence of an inadequate access to medicines and care.

However, he is currently dealing with all these issues and he believes it is crucial to solve them with urgency just to better meet the needs of the actors involved as well as citizens.

#### **Annika Nowak - Member of the Cabinet of Dr. V. Andriukaitis, Commissioner for Health and Food Safety**

She refers to information about what has been done, is being done and will be done by the Commission, specifying that the Commission wants to make sure that there is a full implementation of legislation eventually, and so that patients can actually benefit of their rights.

It is not just the issue of cross-border care, but also that of the improvement of the whole system in all Member States, in order to ensure that the patients can receive the care they need even in in their own country. The transposition of this Directive is the first, very complex, step: the Commission has decided to assist each Member State in the transposition process to be sure that it is correct, considering all the existing differences between every national health service.

She mentions how the Commission has communicated with the Ministers of Health of each Member State to ensure that the transposition happens in the proper way.

Despite these controls and these moments of discussion, violations for incomplete and inadequate transposition have been found in 26 States.

Many Member States were surprised by the seriousness adopted by the Commission to judge them, but the Commission has an obligation and all the legal procedures must be followed thoroughly, they cannot be ignored.

She explains that the implementation is now almost complete, the Commission has completed all the procedures and all the Member States have set up their National Contact Points.

Now, the Commission must check what the result is, given that currently only a limited number of countries has implemented the Directive (in some cases it is a problem of privatization of the structures, in other cases the citizens' lack of awareness of their rights).

The Member States must do more to inform their citizens through their National Contact Points.

The Commission has alerted the Member States to remove barriers and improve information.

In September 2015, the Commission has also launched the compliance check and they are ready to take the necessary action in the future. The next report is scheduled in three years and this will be related to compliance checks to ensure that all arrangements are properly implemented by all Member States.

As Commission, they are really doing all they can, but they certainly need to work together with all the stakeholders, who need to push the Member States to do more.

#### **Mariano Votta – Director of Active Citizenship Network**

He believes the Directive has a positive structure, even if there are current concerns. Among the others:

- The transposition process has been slow and almost "in the dark";
- The involvement of citizens' organizations is yet to be considered a priority;
- Information to patients on their rights under the Directive is currently lacking;

However, Member States are often aware about what is still missing and so, from his perspective, what should be done at EU level. Three are the main ongoing issues:

- 1) Accessible and comparable information among healthcare structures and among countries
- 2) Better knowledge of the data of the phenomenon
- 3) An integration of different European policies

#### **Alceste Santuari – Professor (Ph. D. Law – Cantab) European Association of Health Law**

He thanks for the invitation and refers that he has followed the phases of the first versions of the Directive.

He says that Member States are free on how to implement the Directive inside of their systems and they are responsible for that. The implementation of the Directive is often complicated and maybe sometimes there is a need to resort to the European judicial systems (the Court of Justice).

In his opinion, the question of prior authorization is very controversial and it must be well discussed.

The implementation of this Directive should allow the overcoming of the purely economic issues and focus more on welfare.

### **2<sup>nd</sup> panel: Patients' Rights in the Stakeholder perspectives**

#### **Elena Gentile, MEP – S&D Group, Member of the ENVI Committee**

The real big issue in her opinion is the democracy of the 'access to healthcare, in a political relevant context between rights and security systems.

The Directive has still not been implemented, probably because of the patient's "loneliness". It is appropriate to initiate a reflection with respect to the declination of the Directive, by identifying the most critical points with the final goal of simplification.

Moreover, the issue of costs is cumbersome compared to the initiative of the Directive, in a period when healthcare is also subject to cuts, inconsistent with the aim of protecting the right to health, which instead should prevail on the idea of the cost.

In fact, spending on health should not be seen as a cost but as an investment, and this must be a common goal to reach as a cultural leverage for sustainable development that contributes to welfare.

#### **Birgit Beger – Secretary General of the Standing Committee of European Doctors (CPME)**

According to her, it is important to put the patient at the centre. Many patients have a medical need to move, so the Directive actually puts together all the patient's rights. Privacy and confidentiality are the essential elements.

On December 18th 2015, a conference on the issue of continuing education of physicians and patient representatives will be organised in Luxembourg and she will participate.

This is an important issue and she suggests thinking about how to use the tools and information systems for the common goal.



**Paul De Raeve – Secretary General of the European Federation of Nurses Association (EFN)**

He starts by thanking and reminding everyone the importance of voters.

In his opinion, there is a need to simplify the language. Citizenship has a crucial role and must be able to express their views. The information should be conveyed with simple words.

**Paolo Giordano - Secretary General of the European Union of Private Hospitals (UEHP)**

He points out that this version represents a problem for the 'acceptance with the Member States: to ensure that all Member States could accept the Directive text was a bit ' diluted.

He continues saying he believes that the keyword is information: patients should be informed of the 'existence of a service, the quality of the service and the cost of the same.

The National Contact Points are not working properly and he concludes with the proposal to this Interest Group to start collecting data from the National Information Points to understand how they are operating.

**Giovanna Marsico – Director of Cancer Contribution**

She sums up keywords of the discussion as democracy and education.

In her opinion, other important issues to be discussed are:

- the passage of the therapies at home (which is a progress because on one hand reduces costs and improves patients' lives, but from the other hand it cannot be done without a continuous care);
- the topic of a less expensive doctor: the increase in the price of treatments calls into question everything and there is the need of new models.

**DEBATE**

**Marju Lauristin, MEP – vice-president S&D Group**

She intervenes by explaining that before Christmas a work on a new regulation about data protection will be completed. There is a great attention to healthcare topics in it, also thanks to the collaboration with many patient and doctors organizations in order to make it adequate for the needs of patients, researchers and all actors involved in the delicate context of the health system.



She guaranteed to be extremely interested to cooperate and to discuss these issues: they are all of paramount importance.

**Thomas Kanga-tona (Burson-Marsteller)**

He asks if there is the intention to work with other interest groups on related topics, because maybe a wider cooperation could bring more results.

**Paul Laffin (British Medical Association)**

He supports what the Commission has said: the level of information must undoubtedly be improved and everybody must put pressure on his own government.

**Alberto De Santis (ECHO- Anaste)**

He thanks Borelli because he has worked a lot on this initiative and he hopes for the creation of a single Parliamentary Group.

**Silvia Bottaro (HOPE – European Hospital and Healthcare Federation)**

She introduces her organization and announces that since 2012 they have been involved in a project promoted by the 'European Union. They have collected over the time many useful ideas that could help to improve services and might be illustrated in a subsequent meeting.

**Annette Dumas (ASDM Consulting)**

She emphasizes the importance of patient organizations to disclose information in a widespread manner, in collaboration with health professionals.

**Paul De Raeve – Secretary General of the European Federation of Nurses Association**

He highlights the importance to discuss the gender issue and to propose solutions to protect women who take care of patients at home.

## **Final Remarks**

### **Mariano Votta – Director of Active Citizenship Network**

He thanks everybody and hopes for future cooperation among all the stakeholders.

He suggests some proposals and anticipates that next May, on the 10th anniversary of the EU Patients' Rights Day, it will launch a communication campaign in 15 countries, entitled "Patients' rights have no borders", promoted by Active Citizenship Network.

## **KEY POINTS**

- Lack of clarity;
- inefficiency of national contact points are inefficient;
- lack of accessibility and exchange of information between healthcare structures and the member countries;
- lack of information to patients on their rights under the Directive;
- spending on health is still seen as a cost and not as an investment;
- lack of concrete cooperation between stakeholders.

## **PROPOSALS FOR SOLUTIONS**

- To find a common solution in order to make more clear and accessible the information contained in the Directive and make citizens and patients aware of their rights;
- to make the National Contact Points more efficient, capable of transmitting information and documents clearly to be a real support for citizens;
- to spread the culture of health and improving the exchange and collaboration between healthcare structures and the Member States;
- to inform patients about how the Directive can help their access to the best possible therapies;
- to strengthen the network of communication and cooperation between patient organizations and other stakeholders, in order to work better together to achieve common goals;
- to keep a policy debate alive and constant, also through and thanks to this Interest Group;
- to encourage events and campaigns on the theme.