

EU day of patient rights

By Mariano Votta

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Good morning everyone and thank you on behalf of Active Citizenship Network for the invitation in this forum for dialogue and exchange.

I am very proud and happy to stay here in the 7th health conference concerning patient rights in the Euregion Meuse-Rhine, a day before our fix appointment: the European Patients Rights Days. Tomorrow, in Italy, my organization organize open events in the square of hundreds of towns, to underline the relevance to guarantee the protection of patients rights.

I really appreciate a lot that you have deliberately organized this conference on the 17th of April thinking on the European Patients Rights Day, thanks a lot.

As you know, this year the main celebration of the European Patients Rights Day it will be in May, 12 and 13 in Brussels, with the European Commission, DG Sanco. And I invite all you to join us, and I hope the promoter of this event can accept my invitation to be my host in Brussels to attend the event: there will be more of 40 patient and civic association and, for first time, also speakers coming from America and Asia.

But now, before to try to answer your main question: what about the EU view on patient rights, let me please introduce with a brief presentation my organization.

ACN presentation

Active Citizenship Network is one of the widespread open and flexible network of civic and patients organizations at European level. Created in 2001, it's coordinated by Cittadinanzattiva, the Italian non-profit & consumer organization founded in 1978 and independent from political parties, trade unions, private companies, public institutions.

Cittadinanzattiva main objectives are the promotion of civic participation and the protection of citizens' rights. It considers citizens a fundamental resource for democracy who play an active role in society and should have the opportunity to participate in everyday policy-making. Our headquarters, located in Rome, support the activities in Italy and abroad.

We work to encourage active participation of citizens in European policy-making in order to promote the construction of a European citizenship as an "active citizenship", meaning the exercise of powers and responsibilities of citizens in public policies. This includes:

- recognizing the primary role of citizens and civic organizations in the care of common goods;
- supporting their participation in policy making at local, national and EU level;
- involving them in the defence of their fundamental rights as citizens, patients, consumers, passengers, users, savers, etc.

Our Network

Ever since its founding, the partnership within the network has been created by the constant activities of partners in common projects, discussions and participation in common initiatives, allowing strong co-operation basis.

This is our add value. With its EU partners, ACN works in very different fields, even if the health care is a main topic.

Over the past 10 years, ACN has promoted political activities and carried out 30 EU projects together with partners coming from 27 EU Countries, and from 2009 we started to work in South of America too, in Colombia, where we have opened 3 Citizen Advisory Center on Public Services and Health and drafted the First Charter of Patients' Rights in that Country, involving, of course, civic and patients local associations.

Milestones of ACN activities

2002: drafted the European Charter of Patients Rights which has become a reference for EU citizens' rights in the healthcare field.

2005-2006: in collaboration with FONDACA, drafted the European Charter of Active Citizenship to bridge the gap existing in the EU rules about the rights, duties, powers and responsibilities of civic organisations acting in the public policies cycle.

2007: launched the European Patients Rights Day, a fix appointment celebrated every year on 18th April through local, national and EU events organized all over Europe.

2007: received the Civil Society Award of the European Economic and Social Committee for its work on citizens' rights.

ACN is official member of "EU Health Policy Forum", led by DG Health & Consumers, EU platform dealing with health and patient's rights, and "Active citizenship Structured Dialogue Group", led by DG Education and Culture, EU platform dealing with the civic participation.

Protection of patients' rights: EU overview

Well, trying to address the topic and to see what must be done in the upcoming years, to be honest, in the Euregion Meuse-Rhine I do not what is the situation, I stay here to listen. I know in general the situation at European level, and then I'll try to introduce to you some activities that we can carry out together.

As you know, my organization join with 15 patients associations coming from several EU Countries drafted years ago the European Charter of Patients Rights. The objectives of the Charters of Rights regarding health care are the proclamation of a "set of rights" which are clarifications and specifications necessary to give substance to the more general right to health. Widely used in health care, the citizens' Charter of Rights is a tool to understand and interpret the more general constitutional rights towards health.

Drawn up in 2002, it is based on the experience of the Tribunal for Patients' Rights and in particular on previous national, regional and local Italian Charters for Patients' Rights and on the Charter of Fundamental Rights of the European Union.

The European Charter brings together the inalienable rights of the patient which each EU country should protect and guarantee.

All of the following rights under the Charter of Fundamental Rights of the European Union are fundamental for European citizens and health services, even if they are at risk, among other things, due to the global financial crisis of the national welfare system:

1 Right to Preventive Measures

Every individual has the right to a proper service in order to prevent illnesses.

2 Right of Access

Every individual has the right of access to the health services that his or her health needs require. The health services must guarantee equal access to everyone, without discriminating on the basis of financial resources, place of residence, kind of illness or time of access to services.

3 Right to Information

Every individual has the right to access all information regarding his/her state of health, the health services

and how to use them, and all the scientific research and technological innovation available.

4 Right to Consent

Every individual has the right of access to all information that might enable him/her to actively participate in the decisions regarding his/her health; this information is a prerequisite for any procedure and treatment, including the participation in scientific research.

5 Right to Free Choice

Each individual has the right to freely choose among different treatment procedures and providers on the basis of adequate information.

6 Right to Privacy and Confidentiality

Every individual has the right to the confidentiality of personal information, including that regarding his/her state of health and potential diagnostic or therapeutic procedures, as well as the protection of his/her privacy during the performance of diagnostic exams, specialist visits, and medical/surgical treatment in general.

7 Right to Respect of Patients' Time

Each individual has the right to receive necessary treatment within a swift and predetermined period of time. This right applies at each phase of the treatment.

8 Right to the Observance of Quality Standards

Each individual has the right of access to high quality health services on the basis of the specification and observance of precise standards.

9 Right to Safety

Each individual has the right to be free from harm caused by the poor functioning of health services, medical malpractice and errors, and the right of access to health services and treatments that meet high safety standards.

10 Right to Innovation

Each individual has the right of access to innovative procedures, including diagnostic procedures, according to international standards and independently of economic or financial considerations.

11 Right to Avoid Unnecessary Suffering and Pain

Each individual has the right to avoid as much suffering and pain as possible, in each phase of his/her illness.

12 Right to Personalized Treatment

Each individual has the right to diagnostic or therapeutic programmes tailored as much as possible to his/her personal needs.

13 Right to Complain

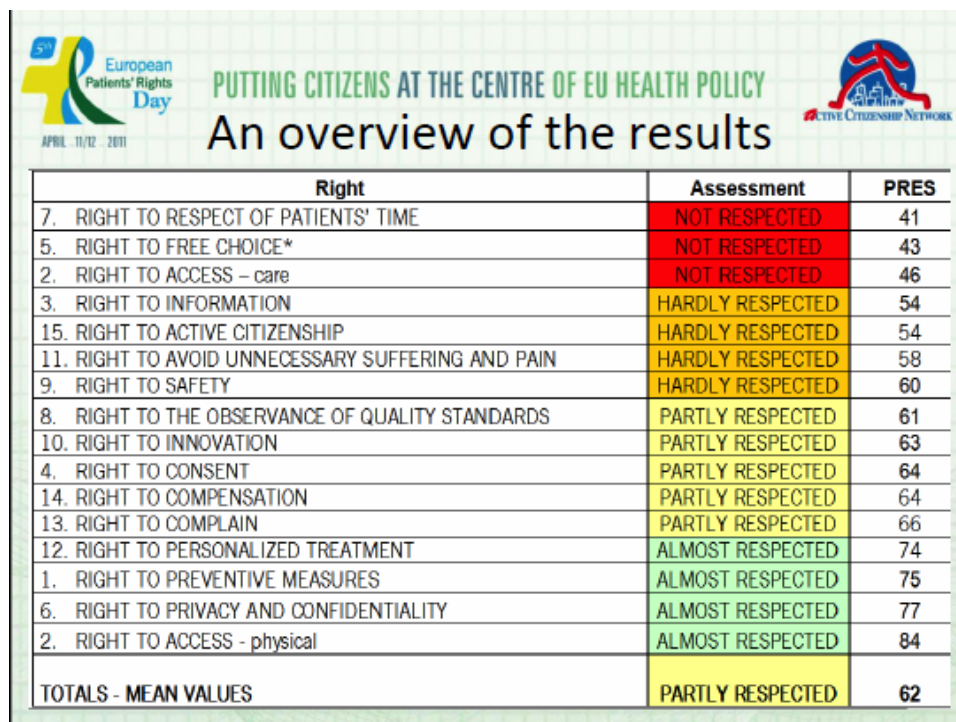
Each individual has the right to complain whenever he/she has suffered harmful treatment and the right to receive a response or other feedback.

14 Right to Compensation

Each individual has the right to receive sufficient compensation within a reasonably short time whenever he/she has suffered physical or moral and psychological harm caused by a health service treatment.

In the past years, ACN have developed two European Assessment programmes on the Patients' Rights Charter according to data collected in 20 European countries. The aim was to put citizens at the centre of health policies, transforming their role from mere targets and users of health services to active citizens participating in health care policymaking and, at the same time, to produce information on the actual implementation of patients' rights at EU level.

The overview of the Report shows the following results:



Right	Assessment	PRES
7. RIGHT TO RESPECT OF PATIENTS' TIME	NOT RESPECTED	41
5. RIGHT TO FREE CHOICE*	NOT RESPECTED	43
2. RIGHT TO ACCESS - care	NOT RESPECTED	46
3. RIGHT TO INFORMATION	HARDLY RESPECTED	54
15. RIGHT TO ACTIVE CITIZENSHIP	HARDLY RESPECTED	54
11. RIGHT TO AVOID UNNECESSARY SUFFERING AND PAIN	HARDLY RESPECTED	58
9. RIGHT TO SAFETY	HARDLY RESPECTED	60
8. RIGHT TO THE OBSERVANCE OF QUALITY STANDARDS	PARTLY RESPECTED	61
10. RIGHT TO INNOVATION	PARTLY RESPECTED	63
4. RIGHT TO CONSENT	PARTLY RESPECTED	64
14. RIGHT TO COMPENSATION	PARTLY RESPECTED	64
13. RIGHT TO COMPLAIN	PARTLY RESPECTED	66
12. RIGHT TO PERSONALIZED TREATMENT	ALMOST RESPECTED	74
1. RIGHT TO PREVENTIVE MEASURES	ALMOST RESPECTED	75
6. RIGHT TO PRIVACY AND CONFIDENTIALITY	ALMOST RESPECTED	77
2. RIGHT TO ACCESS - physical	ALMOST RESPECTED	84
TOTALS - MEAN VALUES	PARTLY RESPECTED	62

As it's possible to observe, several rights have a very low score. That means a missed respect of this right. For example, the very negative result regarding the respect for the rights to avoid unnecessary suffering and pain is clearly of fundamental relevance in the assessment carried out by and with patient organizations committed to reducing unnecessary pain. It sends a precise signal to the civic world and European institutions about the work still to be done: it is a difficult challenge which needs to be faced as a joint effort. For this reason, actually we are working at EU level to draft Civic

Recommendation in the field on pain and compassionate care, in which the role of patients' organizations is fundamental. And actually we have involved 4 patient associations from Nederland in order to collect data and information at national level: Stichting Pijn Platform Nederland, Foundation Pain-Hope - Pain Hope, Fibromyalgie en Samenleving F.E.S., Stichting Pijn-Hoop.

Due to the waiting list, the right to respect the patient time is not respected at all.

What can we do to improve the respect of our right as patients?

Proposals

- 1) To continue in the assessment on the condition of the patients, the respect of their rights, but at the same time, to share and disseminate the good practices.
- 2) Ask the New European Parliament to involve in the EU Treaty the rights expressed on the European Charter of Patients' Rights and to officially recognize the European Patients' Rights Day. For example, at the end of the next European Patients' Rights Day, we'll send to EU candidates a Manifesto on chronic disease, in order to better understand what will do their commitment on this topic.
- 3) To monitor the effective implementation of the EU Directive on patient rights to cross-border healthcare in the national legislations. About it, both citizens and patients associations waited quite a lot for this Directive, which makes easier moving "in the fullness of rights" across the EU member states in order to obtain the health care services needed.

This is the reason to the high expectation and our great attention for its transposition, a unique occasion to enhance the collaboration between national institutions and representatives of patients and users to agree on implementation measures as much adapted as possible to the needs of citizens in each country.

In fact, recognizing certain rights and eliminating barriers, the Directive obliges each Country to do its best to ensure standards of quality and full rights in their own territory in order to avoid excessive spending and borrowing.

One year ago, in occasion of the 7th European Patients' Rights Day, Active Citizenship Network created a **European coordination of patient associations and other stakeholders** interested in working together on the implementation of the Directive, in sharing information, as well as good and bad practices, and drafted the "Manifesto for the implementation of the Right of European Patients to make an informed choice", because we believe that the implementation of this principle, contained in the Directive (art. 4 § 1.b), shall allow all patients to access services better adapted to their personal requirements, both abroad and in their own country/region.

Patients' right to "make an informed choice" officially recognizes the "**right to free choice**"¹ and the "**right to information**"² included in the European Charter of Patients' Rights drafted – as you know - in 2002 by 15 associations partner of Active Citizenship Network.

¹ "Everyone has the right freely to choose among different treatments and suppliers on the basis of adequate information."

² "Everyone has the right to access all information regarding their health status, health services and their use and all that scientific research and technological innovation provides".

The Manifesto has been subscribed by 30 associations coming from 13 Countries and 2 EU Networks, Pain Alliance Europe, and the European Union of Private Hospitals.

After the Manifesto, we have started to collect data presented, last 23rd October to DGSANCO, in the Report "The right to information and free choice in a European perspective. Patients' Rights Have No Borders", in which you can find information related the transposition of the Directive in 12 Countries: Austria, Croatia, Estonia, Finland, France, Germany, Italy, Latvia, Malta, Norway, Portugal, Romania.

We believe the Directive has a positive structure, and the principles contained in it can become a tool not only to move abroad to get the medical care, but to claim that in every place of care, in every state, region or local health services, there is the possibility to have equal rights to access to care, to information, to freedom of choice, innovation, quality and safety of care, to the complaint, intended as listening and protection of legitimate expectations of the citizens. It is therefore a challenge for everyone.

Civic and patients associations want clearly shown that the innovative potential expressed by the Directive is strong and thus they are committed to work for its implementation. And I hope we can collaborate together on it.

Thanks for your attention

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