The Experience of the European Charter of Patients' Rights

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Esteemed Institutions, dear guests and colleagues,

it is a privilege and an honour, for me personally and for the association I represent, to be here with you today. I would like to congratulate the Polish Institutions on the political value of their decision to include the topic of patients' rights in the Programme of the Polish Presidency of the Council of the European Union - thus putting it at the centre of the European political agenda. As outlined in the recently published White Paper "Healthcare Policy Recommendations", the willingness to implement concrete measures aimed at the official adoption of the European Charter of

Patients' Rights marks a key step. And if we are here today, it is to confirm our support for this very important goal to be achieved.

To be honest, yours was a decision that was not taken for granted, in some ways even unexpected, if we think not only of the unstable global situation we are experiencing, but also of the recent European elections where, with some exceptions of course, the subject of the health conditions of European citizens was the great absent in the pre-electoral debate. Coupled with the complete absence of new health initiatives in the State of the Union Address delivered by the President of the European Commission in September last year.

Above all, this is a very timely and necessary decision: firstly, because we firmly believe in the key role of the European Institutions for the well-being of all of us, and this decision goes in the right direction of strengthening the trust between the Institutions and the European citizens; secondly, because the political will expressed by you gives a response to the request of the civic and patients‘ associations - and more generally of the informal and growing movement born around the European Charter of Patients’ Rights - who have been waiting for a concrete signal on this issue for more than a quarter of a century; thirdly, because - let us say it now and clearly - without a common and standardised framework of patients' rights at the European level, the European Health Union will never be complete, as it will always lack the “rights leg”.

From the importance that will be given to health issues in this European political framework, we will understand whether the need to create a stronger European Health Union, as emphasised by the President of the European Commission Ursula von der Leyen, is just a claim or the actual direction taken by the European institutions and the key point by which we will evaluate their work.

We appreciate the fact that you, esteemed Institutions, value the pioneering role of my organisation Cittadinanzattiva-Active Citizenship Network in developing standards for the protection of patients' rights in Europe. The European Charter of Patients‘ Rights has become a milestone in the development of patients’ rights and has gained not only wide public recognition but also the attention of the main European Institutions.
That is why we immediately accepted your kind invitation to work together under the Polish Presidency of the Council of the European Union to institutionalise the principles of patients' rights at the European level and incorporate them into the *acquis communautaire*.

My association Cittadinanzattiva has over 40 years of experience in protecting citizens‘ rights in the health sector, and I have been invited to focus my presentation on the experience and value of the European Charter of Patients’ Rights.
First of all, what is a ‘Charter of Rights’ and what is it for?

A Charter of Rights is a document containing a set of rights that express ways of protecting the more general right to health. These rights, although recognised by laws (national and international), are often unknown or violated.

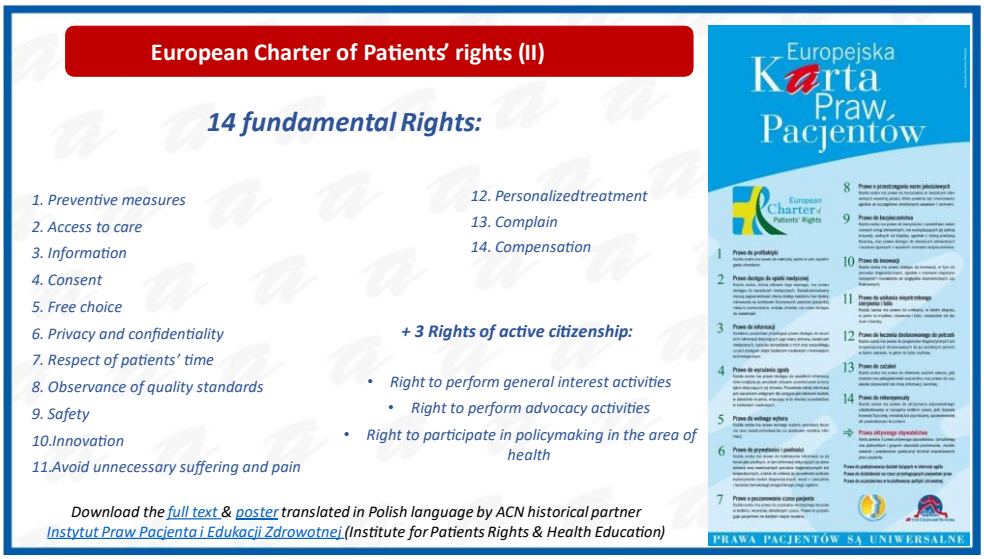
What makes a Charter of Rights different?

- A charter is **based on civic participation and advocacy**.
- It is not legal or technical, but **stems from citizens' reports and complaints** about violations or inefficiencies in local, national and international systems.
- It is a **bottom-up initiative**, which means - again - that it must come from citizens.
- It **allows rights to be enforced** concretely with specific actions and interventions.

As you know, the European Charter of Patients‘ Rights, which we developed in 2002 together with civil society and patients’ organisations from several Member States (as my colleague and friend Stephen McMahon, director of the Irish Patients‘ Association, one of the co-authors of the Charter here with us today, can testify) and then presented in Brussels on 15 November 2002, is a fundamental social document in the field of patients’ rights.

It lists fourteen patients' rights that every EU country must protect and guarantee. The fourteen rights apply to all individuals and, together, aim to guarantee a ‘high level of human health protection’, as stipulated in Article 35 of the Charter of Fundamental Rights of the European Union, and to ensure the high quality of services provided by the various national health services in Europe.

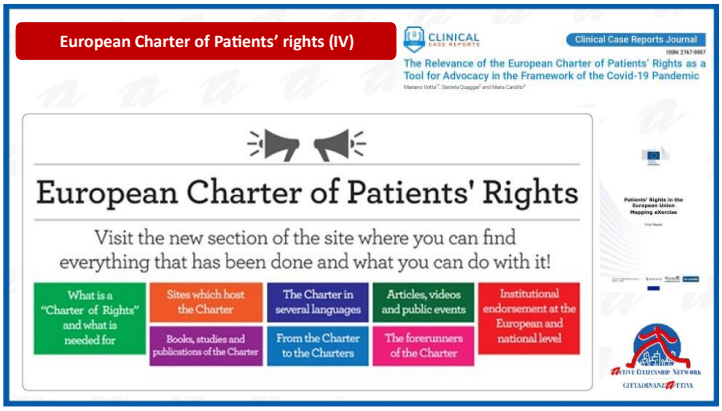
It has become a benchmark for EU citizens' rights in healthcare and a milestone for those advocating for public health.



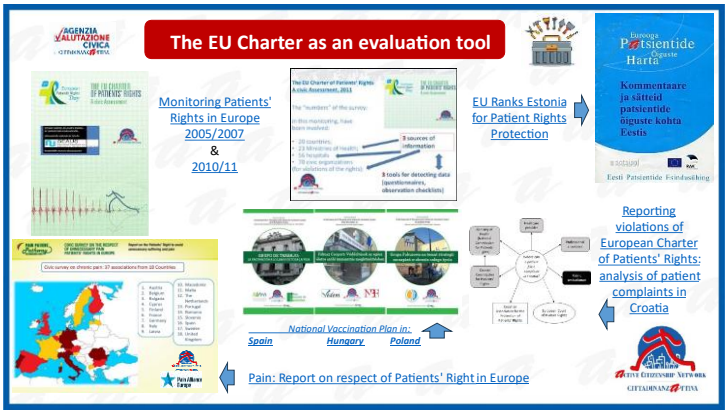
Being an expression of the fundamental rights of the EU, these rights must be recognised and respected in every country. They are related to duties and responsibilities that both citizens and health professionals must assume, and they are: the right to preventive measures, the right of access, the right to information, the right to consent, the right to free choice, the right to privacy and confidentiality, the right to respect patients' time, the right to comply with quality standards, the right to safety, the right to innovation, the right to avoid unnecessary suffering and pain, the right to personalised treatment, the right to complain, the right to compensation.

Over the years, beyond the constituency of Active Citizenship Network, the so-called 'European Patients' Rights Movement' has sprung up

spontaneously. Translated into at least 21 languages - also outside the EU - the Charter has become a common European heritage, disseminated, explained and used by many PAGs, as can be seen from the logos of the patient associations displayed alongside ours.



Especially on the occasion of the Covid-19 pandemic, the need to implement the European Charter of Patients' Rights has become more topical than ever. For this reason, we have collected all the numerous achievements, information, documents, activities and publications, which have been realised over the years thanks to the European Charter of Patients' Rights, in an online repository accessible to all.



In concrete terms, the Charter acts as an empowerment, informative, evaluation, monitoring and legal tool.

- As an evaluation and participation tool, it is used as a common basis for evaluating and monitoring health services from the perspective of citizens and patients.
- As an empowerment and information tool, on the one hand the Charter can be used to educate citizens and patients. On the other hand, health providers and practitioners can make specific commitments to its implementation, developing activities to better protect the condition of their patients.
- As a legal and advocacy tool, the Charter can inspire institutions in drafting official acts and laws on patients' rights. Here are some concrete examples of endorsements:

- Most of the 14 rights are contained in the '**Council Conclusions** on Common values and principles in European Union Health Systems', adopted in June 2006.
- The **European Economic and Social Committee** endorsed an Opinion on patients' rights citing ACN and the Charter, recalling the European Commission's commitment to ensure effective access to health services for all European citizens based on the principle of solidarity.

- the **Directive 2011/24/EU** on the application of patients' rights in cross-border healthcare officially recognises the "right to free choice" and the "right to information" included in the European Charter of Patients' Rights.

- **Two resolutions** of the European Parliament called for the adoption of the European Charter of Patients' Rights, as you can see in the slide.

We do not have time to also highlight the approval at national level, but later on I will give a relevant example from my country, Italy.

Over the years, the European Charter of Patients' Rights has become a milestone and a premise for the creation of tailor-made Charters of Rights, not only at the European level. Even though it was written more than 20

years ago, the multitude of charters referring to the rights of the European Charter demonstrates the relevance of the Charter as an advocacy tool even today. However, how can its relevance be further enhanced? How can the Charter act as a stronger advocacy tool?

ACN has already worked on several initiatives to improve the European Charter of Patients' Rights as an up-to-date and more effective advocacy tool.

Since 2007, in order to reinforce the principles set out in the European Charter of Patients' Rights, Cittadinanzattiva-Active Citizenship Network has taken the initiative to launch the European Patients' Rights Day, an annual event celebrated throughout Europe as a common occasion to inform, discuss and make commitments to improve patients' rights in Europe and in each Member State.

European Patients' Rights Day celebrations are always organised by Active Citizenship Network with the involvement and support of the European institutions, with the traditional format of a large multi-stakeholder conference focusing on the role played by key actors in decision-making on health priorities.

This regular appointment, on 18 April, is very common here in Poland but also throughout Europe, as you can see and as many colleagues here can confirm. Dear institution, why not take the opportunity to institutionalise it at European level?

Also because, over the years, the European institutions have shown great attention and support for the European Patients' Rights Day, whose European celebration organised by Cittadinanzattiva/Active Citizenship Network has always been hosted in Brussels by the European Economic and Social Committee or the European Parliament. For its part, the European Commission has never failed to participate, often with the Commissioner for Health.

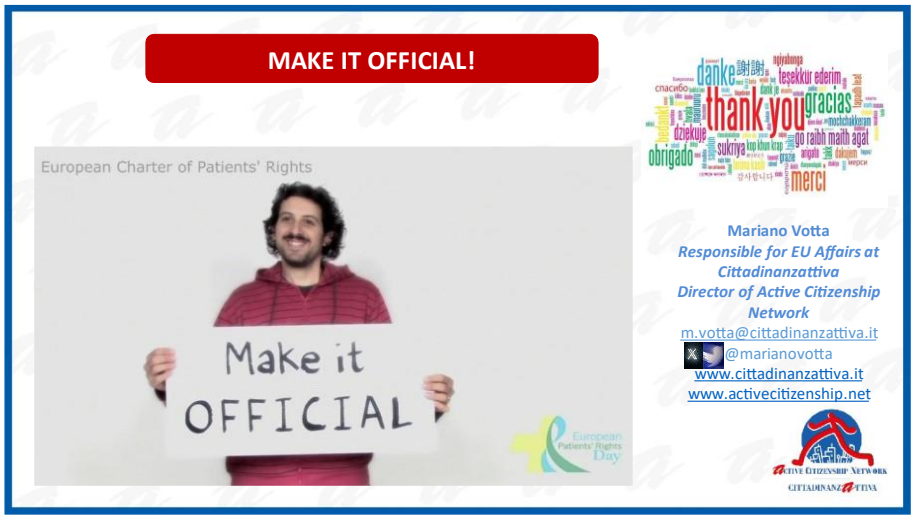
Within the European Parliament, ACN encouraged the ~~idea of an informal~~ interest group of MEPs focused on patients‘ rights to officially recognise the value of citizens’ initiatives, such as the European Charter of Patients‘ Rights and the European Patients’ Rights Day. The request was launched and then approved in May 2015 by the European Parliament during the 9th European Patients' Rights Day. This is another step towards greater recognition of the Charter as a valuable advocacy tool.

Well, even ~~Although~~ several principles outlined in the European Charter of Patients' Rights have been incorporated into the national legislation of some Member States - and the Charter itself has received the support of the European Parliament and has been widely discussed in EU fora - it has never been officially adopted.

We strongly believe that, after the Covid-19 pandemic, the Charter should be implemented more than ever as a useful tool to reduce health inequalities, improve the high quality of health services and a high level of human health protection.

Each of the national health systems in EU countries has different realities with regard to patients‘ rights. The adoption of the European Charter of Patients’ Rights, suitably adapted and updated, would represent significant progress in health policy throughout the EU, strengthening the degree of protection of citizens' rights in health-related matters.

Now we are called upon to reflect on how to adapt it to the present day, which is appropriate, but let us always remember to treat patients' rights, and therefore the Charter that sets them out, with the utmost care, respect and attention, because behind every word, every principle enunciated, there is always an experience, often of suffering, sometimes of injustice.
Dear Institutions, we don't need to be motivated to defend the protection of patients‘ rights and to take care of the most vulnerable groups of the EU population, we ask you to facilitate our role, moving towards the harmonisation of patients’ rights in the European Union. It's your turn and you can count on us to make it official!



Thank you for your attention, and I invite you to watch a short video.