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PUBTEXTO

Towards a Standardised Framework of Patients' Rights across Europe

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Abstract

We - patient's associations, patients' advocacy groups and civil society organizations committed on public health - applaud the Polish institutions for the political value of including the topic of patients' rights in the programme of the 2025 Polish presidency of the Council of the European Union [1] - thus placing it at the centre of the European political agenda. As outlined in the published White Paper "Healthcare Policy Recommendations" [2], the willingness to implement concrete measures aimed at officially adopting the European Charter of Patients' Rights [3] marks a key step that has been awaited for years.

Key Words: EU health technology assessment

Introduction

A decision that was not taken for granted and, in some ways, even unexpected. Not only must we consider the unstable global situation we are experiencing but also of the 2024 European elections, where the health of European citizens was largely absent from the pre-electoral debate, with some exceptions of course. This was coupled with the complete absence of new health initiatives in the State of the Union Address delivered by the President of the European Commission before the EU elections [4].

Above all, this is a timely and necessary decision. Firstly, because we firmly believe in the key role of the European institutions in ensuring our well-being, and this decision strengthens the trust between the institutions and European citizens. Secondly, because the political will expressed by the Polish Presidency of the Council of the European Union responds to the request of civic and patient associations, and more broadly, to the informal and growing movement [5] born around the European Charter of Patients' Rights, who have been waiting for a concrete signal on this issue for over 25 years. Thirdly, because without a common, standardised framework of patients' rights at European level, the European Health Union will never be complete as it will always lack the 'rights leg'

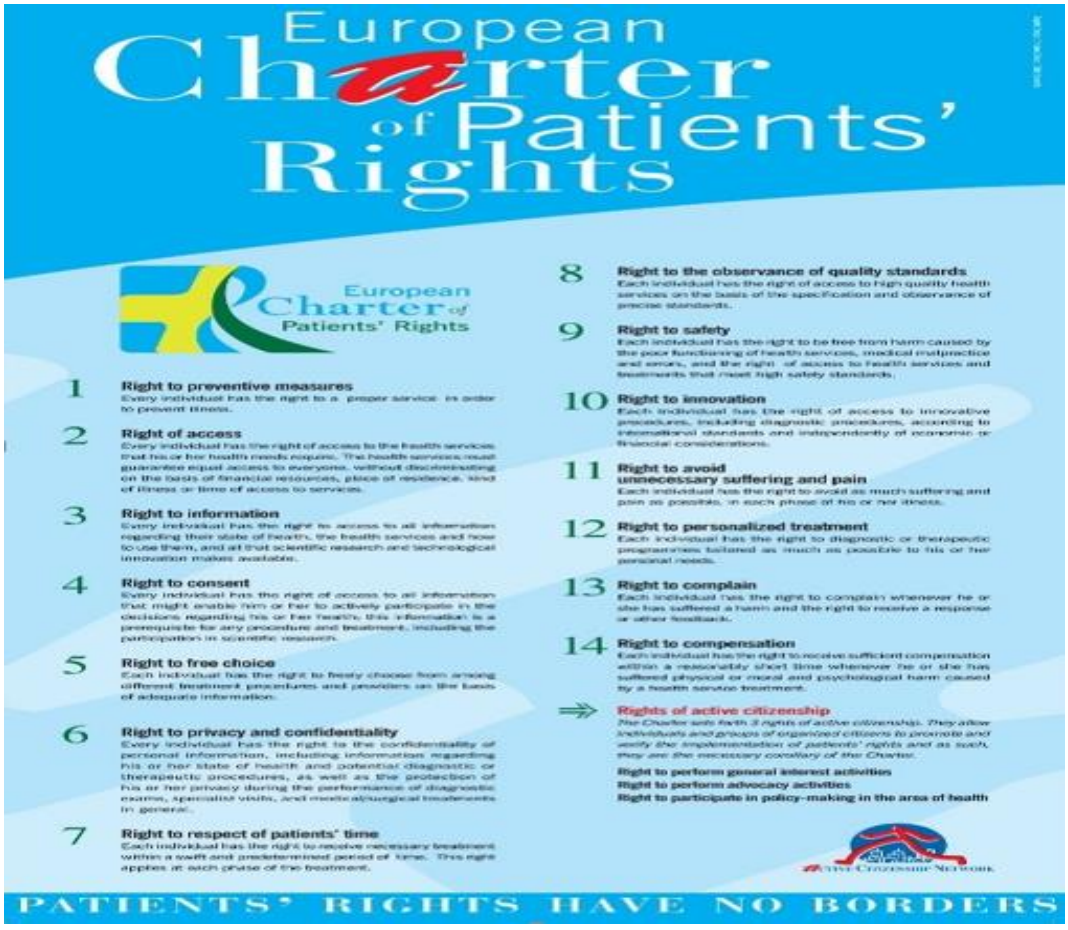

Figure 1: *The European Charter of Patients' Rights.*

The successful story of the European Charter of Patients' Rights

The European Charter of Patients'Rights [6] was drafted in 2002 by Active Citizenship Network [7], the European branch of the Italian NGO Cittadinanzattiva [8], together with civil society and patients' organisations from several Member States, beginning with the Irish Patients Association [9]. It was then presented in Brussels on 15 November 2002.

It is a fundamental social document in the field of patients' rights, which sets a benchmark for their protection. It has quickly become a milestone in the development of patients' rights, gaining wide public recognition and the support of the main European institutions.

It sets out fourteen fundamental patients' rights that every EU country must protect and guarantee. These rights apply to all individuals and together aim to ensure a 'high level of human health protection', as set out in Article 35 of the Charter of Fundamental Rights of the European Union [10], and guarantee the high quality of services provided by national health services across Europe. It has become a benchmark for EU citizens' healthcare rights and a milestone for those campaigning for public health.

As they are an expression of the fundamental rights of the EU, these rights must be recognised and respected in every country. They are associated with the duties and responsibilities of both citizens and health professionals, which are: the right to preventive measures [11], the right of access [12], the right to information [13], the right to consent [14], the right to free choice [15], the right to privacy and confidentiality [16], the right to respect patients' time [17], the right to comply with quality standards [18], the right to safety [19], the right to innovation [20], the right to avoid unnecessary suffering and pain [21], the right to personalised treatment [22], the right to complain [23], the right to compensation [24].

Over the years, the so-called "European Patients' Rights Movement" has spontaneously emerged beyond the constituency of Active Citizenship Network. Translated into at least 21 languages, also outside the EU [25], the Charter has become a common European heritage. Disseminated, explained and used by many Patient's Associations (PA), Patients' Advocacy Groups (PAGs) and Civil Society Organizations (CSOs), it is now part of the European landscape.

Figure 2: *The European Charter of Patients' Rights, Translated in Different Languages.*

The European Charter of Patients' Rights has also become a milestone and premise for creating tailor-made Charters of Rights, not only at the European level [26]. Despite being written over 20 years ago, the numerous charters that refer to the rights set out in the European Charter demonstrate its continued relevance as an advocacy tool.

How the Charter acts

A Charter of Rights is a document that outlines a set of fundamental rights and freedoms considered essential for citizens – in this case, the more general right to health [27]. Although these rights are recognised by national and international laws, they 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 rather stems from citizens' reports and complaints about violations or inefficiencies in local, national and international systems.
- It is a bottom-up initiative, meaning it must come from citizens.
- It allows rights to be enforced concretely with specific actions and interventions.
- In practice, the European Charter of Patients' Rights serves as a tool for empowerment, information, evaluation, monitoring and legal support.
- As an evaluation and participation tool, the Charter provides a common basis for evaluating and monitoring health services from the perspective of citizens and patients.
- As an empowerment and information tool, the Charter can be used to educate citizens and patients. On the other hand, health professionals and practitioners can commit to implementing it, developing activities to better protect their patients' rights.
- As a legal and advocacy tool, the Charter can inspire institutions to draft official acts and laws on patients' rights. Here are some concrete examples of endorsements:

✓ Most of the 14 rights are included in the "Council conclusions on common values and principles in European Union health systems", which were adopted in June 2006 [28].

✓ The European Economic and Social Committee endorsed an Opinion on patients' rights, citing ACN and the Charter, recalling the European Commission's commitment to ensuring effective access to health services for all European citizens, based on the principle of solidarity [29].

✓ 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 [30].

✓ Two resolutions of the European Parliament called for the adoption of the European Charter of Patients' Rights [31,32].

Although several principles outlined in the European Charter of Patients' Rights have been incorporated into the national legislation of some Member States [33] - and the Charter itself has received the support from the European Parliament and been widely discussed in EU fora - it has never been officially adopted.

We strongly believe that, following the Covid-19 pandemic, the Charter should be implemented more than ever as a useful tool to reduce health inequalities, improve the quality of health services, and ensure a high level of health protection [34].

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

Patient organisations call for the harmonisation of patients' rights across the European Union

Much has undoubtedly changed since 2002, and advances in patient advocacy have been hard won. Today, patient advocacy has evolved into a robust movement grounded in the language of rights and supported by comprehensive European Union and international laws, such as the aforementioned European Cross-Border Healthcare Directive and the General Data Protection Regulation (GDPR) [35], as well as AI protections [36]. 2025 also started with two promising developments for patients: the EU Health Technology Assessment (HTA) Regulation came into force in January 2025 after a three-year transition period that began in January 2022, placing great importance on patient input [37]; and the EU Health Data Space Regulation entered into force in March, marking the start of the transition phase towards full implementation [38].

Patient associations, Patient Advocacy Groups and all Civil Society Organizations that recognize public health as a common good to be safeguarded do not need to be motivated to defend patients' rights and care for the most vulnerable groups in the EU population. All we ask of national and European institutions is to facilitate our role by moving towards the harmonisation of patients' rights in the European Union. We are proud that, after almost 25 years, work is finally underway to formally recognise the principles set out in the European Charter of Patients' Rights in the acquis communautaire. It is now up to the institutions to make it official!

Figure 3: *Communication Campaign on the European Charter of Patients' Rights [39].*

To reiterate our full support in achieving this goal, leaders and representatives of PA, PAGs and CSOs have drafted and signed an official "Call for action" to harmonize patient protections within the EU. Patients are at the heart of healthcare. The time has come for the European Union to formally recognize and uphold their rights by establishing a framework that guarantees equality, dignity and protection in all healthcare settings. European citizens with different health conditions deserve a common set of rights that are recognized, agreed upon and implemented at the EU level.

This is crucial for ensuring that European citizens with different health conditions are treated fairly and equitably across the EU.

Within the framework of the Polish Presidency of the EU Council, the Polish Commissioner for Patient Rights and the Minister of Health coordinated the "Call from Patient Organisations for the Harmonisation of Patient Rights in the European Union", with the support of Cittadinanzattiva – Active Citizenship Network.

On 13 March 2025, the document was discussed at the international conference '10th Health Challenges Congress' in Katowice [40], where it was officially endorsed by the following 21 organization leaders from 15 Member States:

"Bulgarian Association for Patients' Defence", Bulgaria
"Croatian Association for Patients' Rights", Croatia
"National Association of Patient Organizations", Czech Republic
"Finnish Pain Association", Finland
"The Finnish Spinal Health Association", Finland
"Greek Patients' Association", Greece
"Youth Cancer Europe", Hungary
"Irish Patients Association", Ireland
"Cittadinanzattiva-Active Citizenship Network", Italy
"Lithuanian Heart Failure Association", Lithuania
"Malta Health Network", Malta
"EPECS-European Patients Empowerment for Customized Solutions", Netherlands
"Alivia Cancer Foundation, Polish Cancer Federation", Poland
"Institute for Patient Rights and Health Education", Poland
"We Patients Foundation", Poland
"Too Early Association", Poland
"National Forum for Rare Disease Therapy 'Orphan'", Poland
"Association of Chronic Pain Patients of the Azores", Portugal
"MOG Association - Gynaecological Oncology Movement", Portugal
"Coalition of Patients Organization with Chronic Disease from Romania", Romania
"FOKUS Patient", Sweden

Figure 4: *Participants In the "Patients' Rights in Europe: Shared Experiences and Challenges" Event. Consultation between the Patient Ombudsman, the Ministry Of Health, and Patient Organisations from Poland and the EU, Organised By the Polish EU Presidency [41].*

The importance given to health issues in this European political framework will indicate whether the need for a stronger European Health Union, as emphasised by the President of the European

Commission, Ursula von der Leyen [42], is merely a claim or an actual direction taken by European institutions. This will be the key point by which we will evaluate their work.

Declarations

Each of the authors confirms that this manuscript has not been previously published by another international peer-review journal and is not under consideration by any other peer-review journal. Additionally, all of the authors have approved the contents of this paper and have agreed to the submission policies of the journal.

Authors' contribution

Each named author has substantially contributed in managing the described initiative and drafting this manuscript.

Conflict of interest

To the best of our knowledge, the named authors listed on the first page declare that they do not have any conflict of interest, financial or otherwise.

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The Commissioner for Patients' Rights is a central authority of government administration in Poland, established by the Act on the Protection of Patients' Rights. Each year, it receives approximately 100,000 submissions, investigates violations of patients' rights, provides compensation for medical incidents through the Medical Event Compensation Fund, and works towards systemic patient safety.

The author and all co-authors thank the Polish institutions for having been invited to the special session of the Patient Ombudsman and the Polish Ministry of Health within the framework of the Polish EU Presidency, titled "Patients' Rights in Europe – Shared Experiences and Challenges," held on 13 March 2025. The event took place as part of the 10th Health Challenges Congress (HCC), which was held on 13–14 March 2025 at the International Congress Centre in Katowice, Poland.

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