



Patients' Rights In Europe: *an active citizenship approach*

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Active Citizenship Network

PATIENTS' RIGHTS HAVE NO BORDERS



Active Citizenship Network

- European network started in 2001.
- Promotes the participation of citizens' organizations in European and national public policies.
- Over 90 partner organizations from 30 European countries.
- Set up and promoted by a national Italian organisation Cittadinanzattiva.

Patients' Rights an EU issue or not

- Health services and thus Patients' Rights are normally considered only of national competence based on the principle of subsidiarity.
- European Court of Justice Ruling: ruled on patient getting treatment in other countries based on right of free movement of people and services (30 and 49–50 of the EC Treaty).
- Article 35 of the Charter of Fundamental Rights of the EU and guarantee a “high level of human health protection”.
- European Council: Convention on Human Rights and Biomedicine and Rec.(2000)5 citizen and patient participation.
- WHO Declaration on the Promotion of Patients' Rights in Europe.

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European Active Citizenship

1. European Charter of Patients' Rights
2. Patients' Rights as a standards for assessing healthcare
3. European Patients' Rights Day

EU Active Citizenship Approach

1. **Rights based:** rights are transnational though health care systems are organised nationally.
2. **Elements:**
 - Bottom-up
 - Alliance building
 - Multistakeholder
 - Citizen participation
 - National \Leftrightarrow EU

European Charter of Patients' Rights

- **Bottom-up policy initiative** (from a national citizens' view constructing a European vision). Drafted in 2002.
- Despite differences in healthcare systems the **same rights are at risk** in all EU countries
- **Not only rights of patients but rather of all citizens** (including users, family members, vulnerable population and all individuals residing in the EU) with respect to healthcare.
- Make **concrete art.35 EU Charter** of Fundamental Rights high level health protection.

14 Patients' Rights

1. Preventive measures
2. Access to care
3. Information
4. Consent
5. Free choice
6. Privacy and confidentiality
7. Respect of patients' time
8. Observance of quality standards
9. Safety
10. Innovation
11. Avoid unnecessary suffering and pain
12. Personalized treatment
13. Complain
14. Compensation

3 Active Citizenship Rights

- Participate in policy making



EU Council Common Values and Principles in EU Health Systems

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11 of the 14 patients' rights

Values: Universality, Access to quality care , equity and solidarity. (prevention)

Operative Principles:

1. Quality (standards, innovation)
2. Safety
3. Care based on evidence and ethics
4. Patient involvement (choice, information, consent)
5. Redress (complain and compensation)
6. Privacy and confidentiality

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European Charter of Patients' Rights

- Building a European Identity
- Instrument for awareness building, facilitating dialogue among different stakeholders and for setting standards.
- Used in national situations or on specific disease.
- 17 languages



Patients' Rights: a standard for healthcare

- Monitoring the 14 Patient Rights in 15 EU countries by citizens organisation: **174 indicators**, Patients' Rights Matrix.
- To produce new information on the actual implementation of patients' rights at the EU level.
- To transform the traditional role of citizens from mere targets and users of health services to active citizens participating in the healthcare assessment.
- Existing data and information on health care at European level would be enriched with patients' rights-focused one. (standards)
- Financing of health structures conditioned to the respect of patients' rights.

Patients' Rights: a standard for healthcare

High	Complain	29,25
	Privacy	29,25
	Information	28
	Physical access	26,4
	Personalized treatm.	25,15
	Safety	24,75
	Quality	24,5
Low	Prevention	20,5
	Compensation	19,75
	Avoid pain	19,65
	Consent	19,5
	Innovation	19,25
	Free choice	18,9
	Access to care	17,7
Respect for time	12,9	

European Patients' Rights Day

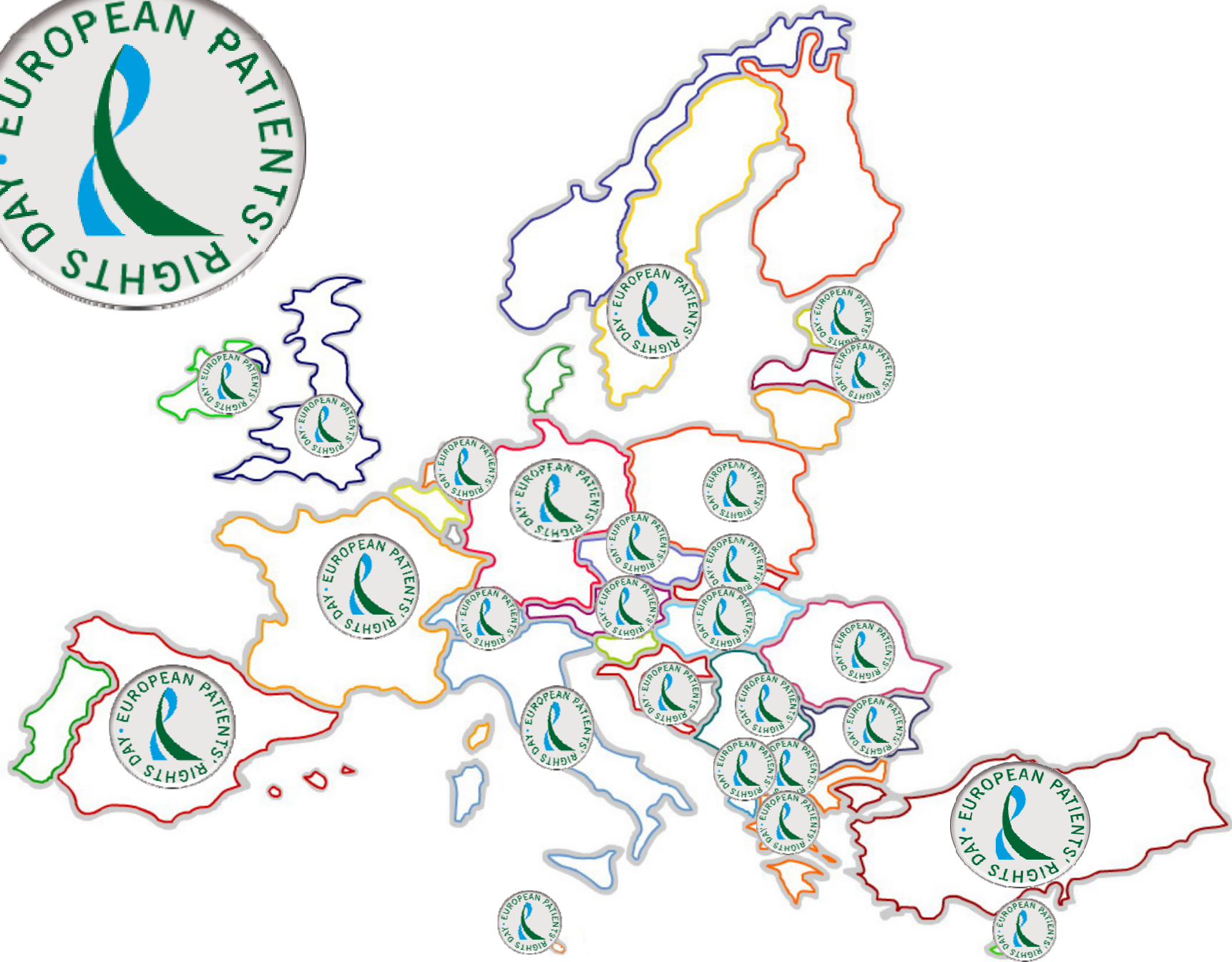
- To promote an official day to talk about patients rights in Europe.
- To raise awareness of Members States on the implementation of patients' rights.
- To present and assess the respect of these rights each year.
- To make commitment for concrete actions.

1^o European Patients' Rights Day 2007



2^o European Patients' Rights Day 2008





2° European Patients' Right Day

1. **80 events in 26 European countries (22 EU MS):**
 - Seminars, conferences, Handing out information in hospitals, clinics, pharmacies, medical schools, Press Conferences, Meetings with national officials
 - Education-communication campaign “***Patients’ Rights-my rights***” (Poland)
2. Charter translated in **17 languages** (available on our website)
3. European Conference in Gorizia, Italy “*European Patients’ Rights: a European and a national Challenge*”
4. Patronage of the European Parliament, European Commissioner of Health, EESC,

European Parliament

2 resolutions in 2007 called for the

- *“adoption of a European charter of patients' rights into the framework in order to ensure that such rights are exercised in the practice of cross border and*
- *on the basis of existing charters in the Member States and of the **work carried out by non-governmental organisations.***

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Recognition by EESC

Opinion on Patient's rights that

- *“Welcomes and acknowledges the European Charter of Patients' Rights, promoted by Active Citizenship Network*
- *Calls on the European Commission to establish a European Patients' Rights Day. “*

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Points to Reflect on

“In discussing future strategies, our shared concern should be to protect the values and principles that underpin the health systems of the EU.”

Health Ministers June 2006.

Points to Reflect on

1. Adopting a European Charter of Patients' Rights to reinforce the common Values and principles stated by Health Ministers and provide clarity for all citizens.
2. Including information (indicators-standards) regarding patients' rights in EU and guaranteeing the active participation of citizens and patients in assessing and evaluating health care systems.
3. Using patients' rights-based approach in dealing with new scenarios such as: information on drugs, use of biotechnologies.

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Let's Make it Official!!

3. Recommendation to

Institutionalize 18^o of April as the European Patients' Rights Day to promote greater awareness and discuss regarding patients' rights in Europe and at the national level.

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ACTIVE CITIZENSHIP NETWORK

**Join us in celebrating the
3^o European Patients'
Rights Day:
18 April 2009**

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