

The evolution of patients' rights - the role of civic and patients organizations.

Advocacy activities at national & EU level

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Cittadinanzattiva is a non-profit organization founded in Italy in 1978

It is independent from political parties, trade unions, private companies and public Institutions

Its main objectives are:

- the promotion of **civic participation**
- the protection of **citizens' rights**

Citizens: a fundamental resource for democracy { active role in the society
opportunity to participate in
everyday policy-making

It has +30 years experience in the protection of citizens' rights in the health sector:

- Since 1980: Tribunal for Patients' Rights (**TDM**) - more than 200 local points and 10.000 volunteers
- 84 Citizen Advisory Centres (**PIT**) providing guidance, information and protection for free
- Since 1996: National Coalition of Associations for Patients suffering Chronic Diseases (**CnAMC**)



Active Citizenship Network (ACN), established in 2001, is our European branch

A **flexible network** of more than **100 EU civic and patient organizations**



Member of:

- [EU Health Policy Platform](#) (DG Sante)
- [Active Citizenship Structured Dialogue Group](#) (DG Home)
- [European Consultative Consumer Group](#) (DG Justice and Consumers)

Our commitment at EU level:

- **European Charter of Patients' Rights** (2002): 14 rights, among which the right to avoid suffering and unnecessary pain
- **European Patients' Rights Day** (since 2007) celebrated every year on 18th April with local, national and EU events across Europe
- [MEPs Interest Group "European Patients' Rights and Cross-border Healthcare"](#) (2015)



The evolution of Patients Rights in Italy:

The idea of a Tribunal for Patients' Rights ...dates back to the '80s (I)

Situation extremely critical:

- beds were thrown from the windows of the hospitals by patients as protest for their conditions;
 - hospital canteens were managed by the army because of the strikes of health workers;
 - children were tied to beds as hospitals were short-staffed;
 - money were extorted for services due;
 - patients were abandoned;
 - there were strict restrictions of any connection with outside;
 - harassment, offenses and violence;
 - constant violation of confidentiality and of decency;
 - dirty hospitals;
 - patients used to be among excrements;
 - there was lack of medicines, gauze, etc.

CA to decide to launch on 1 January 1980 the Tribunal for Patients' Rights



The Tribunal for Patients' Rights dates back to the '80s (II)

The message of the Tribunal for Patients' Rights spread quickly among people involving thousands and thousands of citizens, who **started to collect reports** and send them to us. Among the first reports we remember that of Maria Grazia Carbone, who reported the inhuman care his late daughter received at the Policlinico Umberto I in Rome. Maria Grazia was sharing her experience so, she said, that **“the same must not happen anymore”**.

Our first instrument

The foundation of the charter of 33 patients' rights

The charter established the centrality of the patient, who owns specific rights and the assumption of responsibility of citizens.

Our first battles / Our first achievements

Right to dignity: wider time visits, presence of family for children, hygiene

Right to comfort: transforming large rooms with 6/10 people without bathrooms or privacy in more comfortable places

Simplification: against bureaucratic harassment

Right to avoid suffering: appropriate care to relieve pain at any stage of the disease

Right to information: collaboration in the drafting of the law on charters of services

Right to safety: after the collapse of the hyperbaric chamber we helped draft the charter of safe medical practice, and the creation of tools to monitor errors in hospitals

Right to informed consent: lawsuits won because of lack of informed consent, hospital infections, bedsores etc.

Infected blood: pressures to obtain a law on the recognition of compensation for harmed people through pilot actions

And much more...

Coming back to the present... How do we work in Italy?

Over the years Cittadinanzattiva has invested in the technology of citizen protection creating “[PiT](#)” (integrated project of citizen protection).

PiT provides free **guidance, information and citizen protection** to citizens who have experienced inadequate services within the **healthcare service** and/or other **public services**:

- It has a front line and a back office;
- 84 local Citizen Advisory Centres (the majority of them inside public hospitals)
- It involved more than 10.000 volunteers;
- Each year we collect an average of **25.000** among complaints and requests of information in health service
- Each year we produce an **Annual Report “PIT SALUTE”** (XIX Edition in 2016) presented to the Institutions and relevant stakeholders: a picture of the daily relationship between citizens/patients and the National Health System & healthcare providers. What you can find there: benchmark over the years, emerging trends & problems, possible solutions, good practices, case histories.
- **PiT offers more than a simple system of protection: it is a way to promote our political actions starting from real cases.**



**In 2007 we have been awarded a gold medal
for our commitment to improving the public health system in Italy**

How we achieve concrete results

Some characteristics at national & EU level of our advocacy strategy:

- We do not focus on the patient's disease or disorder, but on the **violation of patient's rights**;
- **Production of citizens' information** i.e. information *directly produced by citizens*, based on their point of view. Starting from those data we work to change the current state of things and to improve effectively the protection of citizens' rights and achieve conditions for effective protection through follow-ups, enquiries and citizens' audits;
- We encourage the **direct involvement of citizens themselves** to participate actively to their own protection;
- We adopt an **inclusive approach & never work alone**: we promote alliances and **multi stakeholder partnerships** with public & private sectors, professionals, experts, organisations, etc.;
- We denounce what does not work but we also appreciate what is good: **promotion a policy on good practice**

Good practice: the policy of Cittadinanzattiva: [click here to know more](#)

Our work on Patients Rights in Europe

The European Charter of Patients' rights

In 2002, ACN, together with organizations from 15 EU countries, established the European Charter of Patients' Rights. It lists 14 fundamental patients' rights, which each EU country must protect and guarantee. Drafted in 17 languages, it has become a reference for EU citizens' rights in healthcare and a milestone for other EU Charters.

Why?

- To bring together the inalienable patients' rights which each EU Member State should protect and guarantee
- To help building a European identity
- To facilitate dialogue among different stakeholders and for setting standards.

We used it

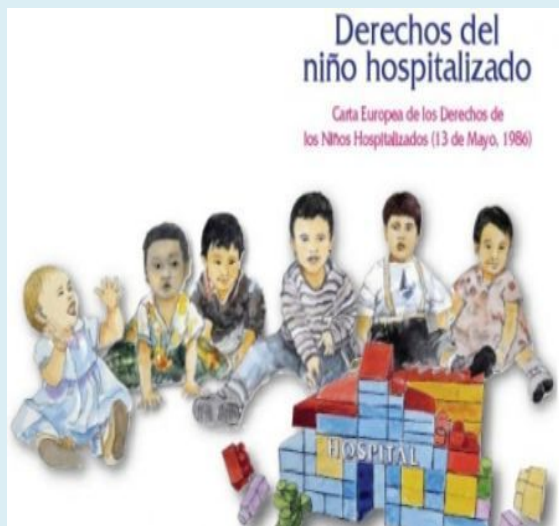
As tool of action for the implementation of patients' rights and their protection:

- Empowerment tool (know your rights!)
- Evaluation / participation instrument (are these rights respected in my hospital, country etc..?)
- Legal instrument (basis for national or EU laws on patients' rights)



Our work on Patients Rights in Europe The European Charter of Patients' rights

It has become a milestone and has inspired many other Charters of rights in Europe!



The European Charter of Patients' rights

Endorsement at EU level

- The majority of those 14 rights are embodied within the Council conclusions on Common values and principles in EU Health Systems adopted in June 2006.
- Two Resolutions from the European Parliament have called for the adoption of the European Charter of Patients' Rights that the European Patients' Rights Day promotes (cfr. European Parliament's Resolution, March 15th 2007. P6_TA(2007)0073 & European Parliament resolution, May 23, 2007 ([2006/2275\(INI\)](#)))
- The European Economic Social Committee approved an Opinion on Patient's rights citing ACN and the Charter (cfr. Opinion of the EESC on 'Patients' rights' (2008/C 10/18))
- The EU Directive 2011/24/EU on the application of patients' rights in cross-border healthcare officially recognizes the "right to free choice" and the "right to information" included in the European Charter of Patients' Rights.
- Article 6 § 1 of the Directive establishes that "Member States shall ensure that the national contact points consult with patient associations, healthcare providers and health insurance agencies", recognizing and enhancing also the ultimate principle of the European Charter of Patients' Rights, namely the "right to participate in policymaking in the health field".

From the EU Charter of Patients' Rights to the new MEP Interest Group



European Patients' Rights Day

Since 2007, Active Citizenship Network, together with citizens' and patients' organizations across Europe, has been taking the initiative to organise every year, on the same day, a [European Patients' Rights Day](#) in all the EU Member States + a European Conference in Brussels.



It has become a fixed appointment in European political agenda to inform, discuss and take commitments to improve patients' rights in Europe and in each Member State.



European Patients' Rights Day



EUROPEAN PATIENTS' RIGHTS DAY: 10 benefits the EU brings to patients

A high level of health protection, the right to benefit from medical treatment; access to healthcare - preventive, diagnostic and curative treatment regardless of financial means, gender or nationality. These principles are enshrined in the European Union's Treaty and its

Charter of Fundamental Rights and the EU institutions are bound to them in their actions. On European Patients' Rights Day, let's take a look at some of the benefits of being a patient in the European Union. As an EU citizen, you can expect

ENT SAFETY -semina

nki, Finland

: patient's rights and patient

MEP Interest Group on Patients' Rights

The idea to encourage a MEPs informal Interest Group focused on patients' rights follows the widespread request of more than [100 civic and patient organizations](#) sent to the EU Parliament to recognize officially the value of citizens' initiatives, such as the European Charter of Patients' Rights and the European Patients' Rights Day.

It is the only Interest Group whose co-founders are the Presidents of two parliamentary groups, who decided to support it because they strongly believe that the European Parliament has today the opportunity to play an active role in improving the protection of patients' rights in the European framework.



The MEP Interest Group was officially launched on 2 December 2015

A concrete example of the evolution of patients rights in Italy and Europe:

One of the most violated rights is the patient's right to avoid pain

The commitment of Cittadinanzattiva - ACN in the fight against useless pain

The commitment of Cittadinanzattiva in the fight against useless pain

Strategic actions over the last 15 years:

Daily protection against violations of rights

Collection and dissemination of best practices

Patient advocacy

Promotion of cultural changes

Citizens awareness raising

Partnership promotion

Some of the projects carried out

in Italy

&

in Europe

- [Let us abolish forced pain](#) campaign (2001). To dispel false myths on the tolerability and incurability of pain
- [Charter of Rights against Unnecessary Pain](#) (2005) to declare and protect 8 fundamental rights often violated and obtain treatment in order to remedy
- [We are not born to suffer](#) (2008) campaign. Creation of 40 local info-points to facilitate dialogue between physicians and patients
- [Civil Recommendation on Non-oncologic Chronic Pain](#) (2008) is the result of the dialogue between citizens and experts about pain treatment
- [In-dolore](#) (*painless*) (2012-2014) an information campaign & a monitoring project carried out inside the Italian hospitals
- [European Charter of Patients' Rights](#) (2002) 14 patients' rights that aim to guarantee a "high level of human health protection". Among them the "right to avoid suffering and unnecessary pain"
- [Pain Patient Pathway Recommendations](#) (2012-2014) a 3 years multi-stakeholder project to promote a EU policy on chronic pain and reduce its impact on all areas of the European society
- [Chronic pain: making the invisible visible](#) (2014) a EU civic research
- ["European Civic Prize on Chronic Pain - Collecting Good Practices"](#) (2015)
- Involvement in the ["Societal Impact of Pain" \(SIP\)](#) as cooperation partner since 2015

Main goals achieved at national level

1. Italian Law 38/2010, a benchmark at European level

- At the article 1 is stated the patients' right to access to palliative care and pain therapy.

2. Our direct **involvement & contribution** with data in drafting the National Report written by the Ministry of Health to the Parliament on the **state of implementation of the Italian Law 38/2010**, that assures the citizens' right to have access to palliative care and to antalgic centers in case of either oncologic or non-oncologic pain.

- Download the Annual report [2010](#) and [2011](#) (IT language).

3. Since 2015, Cittadinanzattiva represents the citizens' associations in the **Technical Committee for Palliative Care and Pain Therapy of the Italian Ministry of Health** dedicated to the implementation of Law 38/2010 on palliative care and pain management.

- On 7th of June 2016, Cittadinanzattiva presented a document stating the patients' point of view about the implementation of the Law 38/2010 on chronic pain. The presentation took place during a hearing of the Technical Committee for Palliative Care and Pain Therapy of the Italian Ministry of Health. [Read the document](#) (IT language).



Main goal achieved at European level

1. 2014: Pain therapy and palliative care in the European political agenda

- Pain therapy and palliative care in many official political documents provided by Italian Government before and during the Italian Semester, and then by EU Institutions and official statements.
- High concentration of events and media coverage during the same period.

Achievements by the Italian Presidency:

- Ministers from the 28 EU Member States reached a common position on the need to **create a European network** ensuring training of professionals in the sector and exchange of information on the effectiveness of therapies for the weakest population groups.
- The European Union health ministers pledged to **further promote the use of palliative care and pain therapy** in the EU Member States
- **Non-profit associations and volunteer organisations have also played a key role** in promoting palliative care in the country

2. **Strengthening of the “chronic pain voice” across Europe**

- Increased accreditation of civic and patient associations dealing with pain therapy and palliative care to the Institutions and stakeholders.
- Less auto-referential approach by the stakeholders and increased autonomous initiatives co-promoted together with medical/patient/advocacy groups, private sector, Institutions: SIP, SINE DOLORE WORLD PARK, etc.

Charter of rights against UNNECESSARY PAIN

1 Right not to suffer unnecessarily

Every individual has the right to have its pain alleviated as efficiently and rapidly as possible.

2 Right to acknowledgement of pain

Every individual has the right to be listened to and believed when reporting personal pain.

3 Right to access pain therapy

Every individual has the right to access the treatment needed to alleviate its pain.

4 Right to qualified assistance

Every individual has the right to receive pain assistance, in observance of the latest, approved quality standards.

5 Right to continued assistance

Every person has the right to have its pain alleviated continuously and assiduously throughout all phases of illness.

6 Right to a free, informed choice

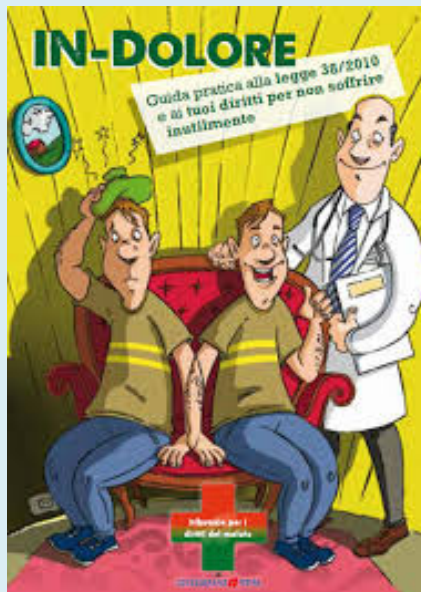
Every person has the right to actively participate in the decisions made regarding its pain management.

7 Right of children, the elderly and those "without a voice"

Children, the elderly and "sensitive" subjects have the same right not to suffer unnecessary pain; special consideration should be given to their particular status.

8 Right not to suffer pain during invasive and non-invasive diagnostic tests

Anyone having to undergo diagnostic tests, especially those which are invasive, must be treated in such a manner as to prevent episodes of pain.



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