

Addressing the patients' right to avoid pain: Advocacy activities at national & EU level

Mariano Votta
Director Active Citizenship Network
Responsible EU Affairs at Cittadinanzattiva



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 voters
- 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)



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 (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.**



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

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**, in order to enforce and increase the “constituency on pain” relief with the larger “patients’ rights constituencies”;
- We **never work alone**: we promote alliances and **multi stakeholder partnerships** with public & private sectors, experts, organisations, etc.;
- **Multi-level activities**: Institutional bodies, raise awareness campaign, researcher and experts, 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](#)

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).



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.
- Increased the PAE role and its membership, also thanks to our commitment and our approach.

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.



PAIN PATIENT Pathway RECOMMENDATIONS



Logos: Pain Alliance Europe, Active Citizenship Network, GRIJNTHAL



First edition
Collecting Good Practices
European Civic Prize on Chronic Pain
ACTIVE CITIZENSHIP NETWORK

BE COMMUNICATION
CORPORATE SOCIAL RESPONSIBILITY
NETWORK OF PUBLIC ADVOCACY SERVICES
CTIVISM
CONSUMERISM

Chronic pain: making the invisible visible.
European collection of good practices

Without the following preliminary conditions, all the activities mentioned would not have been effective:

- No one-shot initiatives, but multiyear activities on the topic and continuity of action;
- Ability to work together, and to be independent from private sector and public bodies;
- Institutional accreditation at National level;
- Commitment on the topic at national and EU level.

Widespread approach for future activities:

- Humanization of care, palliative care and not only pain therapy.
- Emerging issues: for instance, pain management & cross-border healthcare.
- Collecting good practices on chronic pain: from the EU Civic Prize to the Pain Euro-Mediterranean Coalition, an agora of operators of good practices on pain to ensure longer life to the good practices and to identify conditions to replicate or implement them in other contexts. An initiative promoted together with the Spanish Foundation “Sine Dolore” and hosted in the framework of [the “Sine Dolore World Park”](#).

Our contacts

Mariano Votta

Director Active Citizenship Network
Responsible EU Affair at Cittadinanzattiva

m.votta@cittadinanzattiva.it
m.votta@activecitizenship.net

CITTADINANZATTIVA ONLUS
ACTIVE CITIZENSHIP NETWORK (ACN)

HEADQUARTERS
Via Cereate, 6
00183 Rome – Italy
www.cittadinanzattiva.it

REPRESENTATIVE OFFICE TO THE EU
Rue Philippe Le Bon, 46
1000 Brussels - Belgium
www.activecitizenship.net