

Collecting good practices on chronic pain: from the EU Civic Prize to the Pain Euro-Mediterranean Coalition

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 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)



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

Why a collection on good practices?

- The role of any advocacy group is not only to identify emerging problems but also possible solutions;
- Our daily relationship with citizen allows us to collect not only complains and request of information, but also to be aware about good examples;
- To denounce what works bad but also to appreciate what is good;
- To balance criticism with the active role of professionals, users, citizens, public bodies as well private actors involved in public policies;
- A policy and not only a project, in line with the aims of EU Institutions that in each field of action stimulate the collection of good practices.



Our logo for all the good practices collections

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

Led by Cittadinanzattiva in Italy:

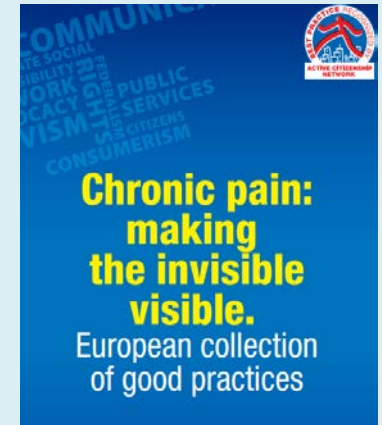
- the “Andrea Alesini Award for the humanization of care” (since 1997) in which pain management is an important issue;
- the “National Prize on Chronic Pain Nottola - Mario Luzi” (since 1997) organized by Cittadinanzattiva-Tuscany.

Other examples of awards related to pain are:

- In **Italy**, Journalist Award “38 VOLTE BASTA!” promoted by Antea Onlus;
- Premio Giornalistico “Vivere senza dolore” promoted by the patient association “Vivere senza dolore”;
- National award “Un ospedale con più Sollievo” promoted by the Fondazione Ghirotti;
- “Gerbera d'oro 2014” awarded by the Conferenza delle Regioni and by the Fondazione Ghirotti to healthcare structures which are in the front line in fighting unnecessary pain;
- “Isico Award”, promoted by Isico (Istituto Scientifico Italiano Colonna Vertebrale) to award research and studies in localized pain per (headache, cervical pain);
- In **Spain**, “Premio ALGOS” to help raise awareness of pain in children, promoted by ALGOS a research group dedicated to the study and treatment of pain.

A civic research-project at European level with the aim to:

- highlight the **existing good practices** regarding the fight against pain
- raise **awareness** on the topic
- increase the **evidence** of positive experiences and successes
- strengthen the **commitment** in this issue



This research gave continuity to the work started in 2012 by Active Citizenship Network in cooperation with Pain Alliance Europe

3 main topics for the collection of good practices:

- **Policies** - with a particular attention to campaigns and educational initiatives
- **Innovation** - apps & tools for chronic pain management, focusing the attention on the real added value they produce
- **Age** - solutions for the young, the elderly, etc.

11 countries involved

46 good practices collected



Most of them are related to: fibromyalgia, back pain/low back pain, neuropathic pain/localized neuropathic pain (LNP); dementia, arthritis and rheumatoid arthritis, osteoarthritis, pelvic pain, facial pain, cephalalgia, cervical pain, Machado-Joseph disease and diabetes.

Active Citizenship Network and HC experts have selected some of the best **healthcare apps** which stand out in terms of **innovation and enhanced patient care**, which can be used to improve wellness, prevention or **treatment regimens**:



iHeadache: Headache & Migraine Diary App



My Pain Diary: Chronic Pain & Symptom Tracker



myIBD - By The Hospital for Sick Children affected by Inflammatory Bowel Disease



A research-project with the aim to **give evidence on existing good practices** in terms of struggle against pain by:

- raising awareness among the institutions about the need to **identify chronic pain as a priority** in health policies and programs at EU and national levels
 - encouraging the **exchange of experiences** between professionals and patient associations
 - creating a body of evidence that can be used to support the **expansion of tailored programmes** dedicated to the care and treatment of chronic pain patients
 - sharing **technological advances and their impact** on the care and treatment of chronic pain as the improvement of chronic pain patients' lives
- It was a recognition of ongoing excellences and, after a lot of important national experiences, the **FIRST EUROPEAN new award**: “EU Civic Prize on Chronic Pain”.
 - The research allowed us **to give continuity** - expanding it with some specificities – to the investigation for good practices in the struggle against pain started by ACN at EU level in 2014.

This project has been made possible thanks to the support of the pharmaceutical companies Pfizer and Grunenthal

The Jury



Jury composed by international experts in chronic pain from academia, HC professionals and providers organisations, civic and patient associations, etc...



Categories:

The following categories are based on the main output of the previous EU project [Pain Patient Pathway Recommendations](#) developed and subscribed by 21 civic and patients organizations dealing with chronic pain. The types of good practice to be identified will be classified as follows:

- Patients' empowerment
- Innovation (legislative and technological)
- Clinical practices
- Professionals education

Criteria to be taken into account when selecting the good Practices:

- **Reproducibility** – The possibility of transferring and implementing the identified practices in situations and places different from the ones where they were observed.
- **Innovativeness** – The capacity of producing new solutions.
- **Added Value** – The capacity of the identified practices to produce a greater impact on the situation.
- **Appropriateness** – A practice enabling an efficient and effective management of an issue.

4 categories

- Patients' empowerment
- Innovation (legislative and technological)
- Professional education
- Clinical practices

11 different countries

Malta, Great Britain, Spain, Portugal, Ireland, Italy, Germany, Denmark, Finland, Netherlands, Russia

Most of the **30** good practices collected are related to **patients' empowerment** and about half of them are related to **innovation** and **professional education**. Only few are related to **clinical practice**.
4 of them are related to headache disorders

Awards ceremony
in **Malta** on **June 8th**

the recognition of
ongoing excellences

Field of action

Collection of Good practices and experiences on chronic pain, cancer & no cancer-related

The key role of the networking

The Good practices collected involved the networks and contacts of ACN in Europe

This coalition aims to be:

- The first **civic Hub-incubator** of best practices against pain across Europe
- An **open multi-stakeholder platform** mainly addressed to the constituency dealing with pain relief at **local and national level** across Europe, rather than to EU umbrella organizations
- The missing piece necessary to **integrate the scientific research** on pain **with the “civic information” approach**
- The agora of operators of good practices on pain, encouraging the **exchange of experiences** among health professionals, healthcare providers, Institutions, civic associations and Patient Advocacy Groups
- **A bridge** on pain built in the Mediterranean area but **intended to overcome EU borders and reach non-EU countries** as well
- The **fusion of experiences** coming from pain and patients’ rights constituencies
- The **facilitator for advocacy and policy actions** on chronic pain at local, national and European level

promoted by



Official launch on May 2017 in Menorca
during the XII Mediterranean
Multidisciplinary Pain Forum

Institutional support

The institutional support is provided by the MEPs Interest Group “[European Patients’ Rights & Cross-border Healthcare](#)”.



Scientific support

The scientific support is provided by the European Multidisciplinary Network in Pain, Research and Education ([Efhre International University](#)).

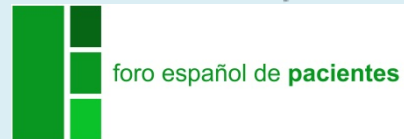
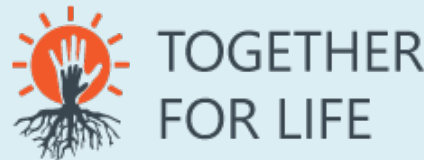
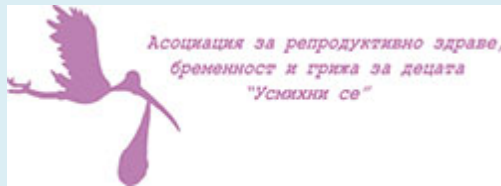
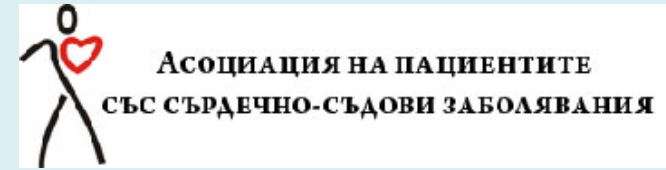
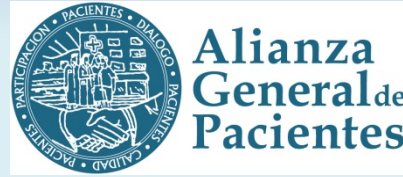


Location & Geographical impact

- In order to exploit the geographical impact on chronic pain management, the idea behind this Coalition is to join the forces among the countries within the Mediterranean area.
- The Coalition will meet yearly in Minorca during the SINE DOLORE WORLD PARK



Pain Euro-Mediterranean Coalition: constituency (ongoing activity)



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