

The evolution of patients' rights in Italy - the role of civic and patients organizations: the case of Cittadinanzattiva- Tribunale for Patients' Rights

In those years, the situation was 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.

The difficulties and the demand for justice of citizens who experienced health services in those years led CA to decide to launch on 1 January 1980 the Tribunal for Patients' Rights

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. She said Maria Grazia was sharing her experience so that **“the same must not happen anymore”**.

The foundation of the **charter of 33 patients' rights**

The charter establishes the centrality of the patient, who owns specific rights and the assumption of responsibility of citizens. Indeed, the latter exercise powers, rights and responsibilities to promote the general interest.

- 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 sufferance: 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.....

From citizens' experiences...

Violations

Injustices

- Protection against violations of human rights reported by citizens
- Collection and dissemination of good practices
- Awareness and informative campaigns addressed to citizens
- Actions designed to promote cultural change
- Institutional dialogue
- Production of civic information and civic evaluation
- Charter of Rights
- Collaborations
- Symbolic actions

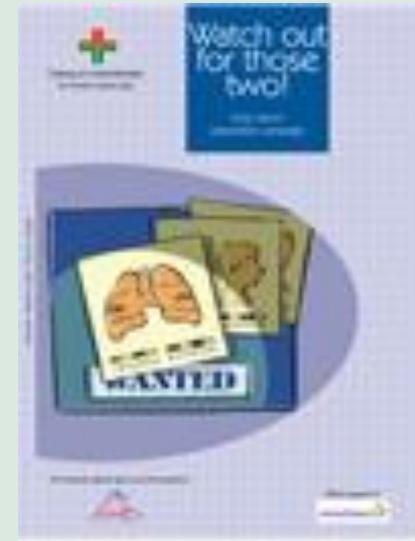
- 3 annual reports on health: citizens and nhs Rapporto PiT Salute, Osservatorio Civico sul federalismo in sanità, Rapporto sulle politiche delle cronicità
- Civic recommendations (e.g. pain, e-health, hospital infections, etc.)
- Audits and service evaluations: emergency rooms, waiting lists, closing of small hospitals, etc.
- Informative campaigns and empowerment on safety, prevention of cerebro-cardiovascular diseases and pain relief, generic drugs, etc.



Smartphone app for generic drugs



8 rights against unnecessary pain



Prevention of lung cancer



Disability protection



Subsidiarity involves "doing" not just "saying"

It is not only about participating to discussions and decisions on some issues, but it is also the solution of the problems themselves.

1. Input: reports – breaking news

1. Analysis of reports :

Is it a recurring fact? Is it a sentinel event? In what reality?

What generates it?

What effect has on citizens? What about the system?

Who benefits? Who loses?

Who is potentially interested to a change?

3. Planning an intervention

What actions could «rock» the situation?

3. Build an intervention

What kind of value does it own?

Whom should I contact?

Which means do I use? Do I need more than one?

Find allies

4. Assess the effectiveness

What results has produced my intervention ?

Has it produced changes? Which one?

5. Making public the results achieved

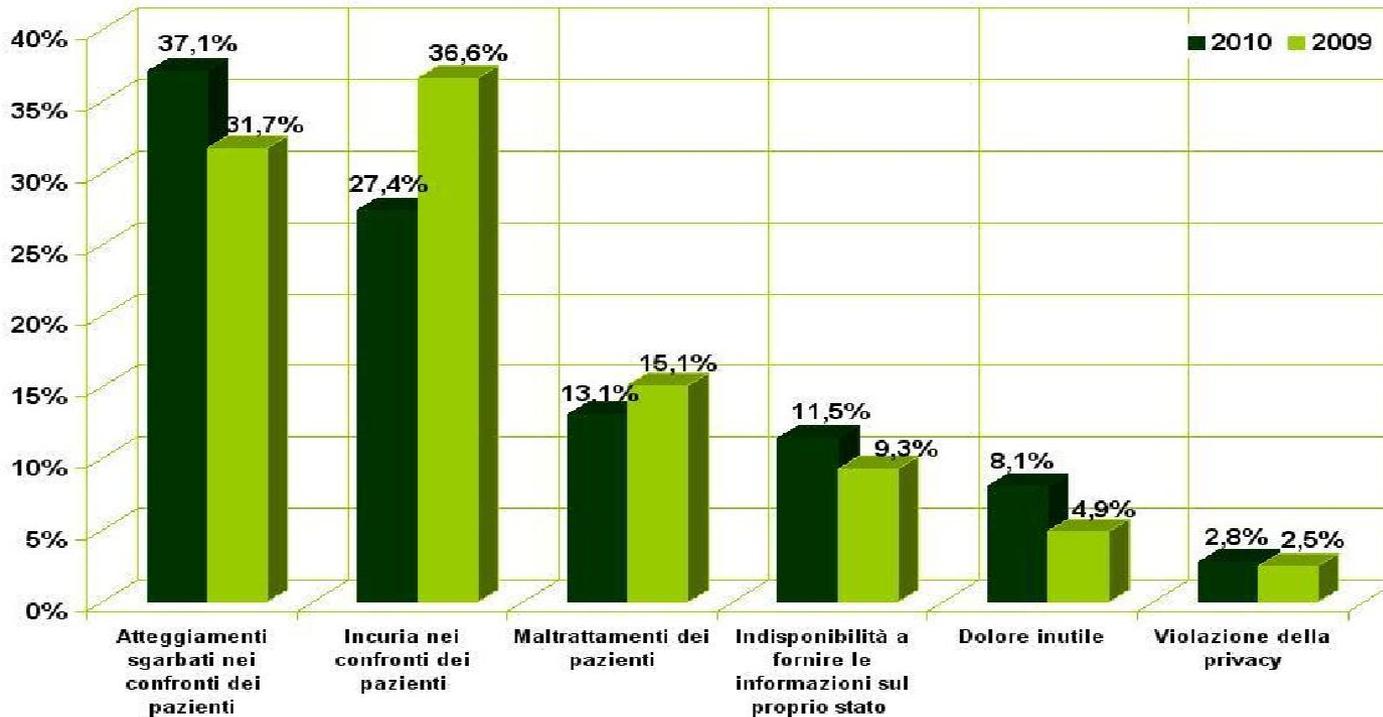
Changes are a source of pride, which should be recognised and formalised...

European Charter of Patients' Rights (2002)

1. Right to preventive measures
2. Right to access
3. Right to information
4. Right to consent
5. Right to free choice
6. Right to privacy and confidentiality
7. Right to respect patients' time
8. Right to respect of quality standards
9. Right to safety
10. Right to innovation
- 11. Right to avoid suffering and unnecessary pain**
12. Right to personalized treatment
13. Right to complain
14. Right to compensation

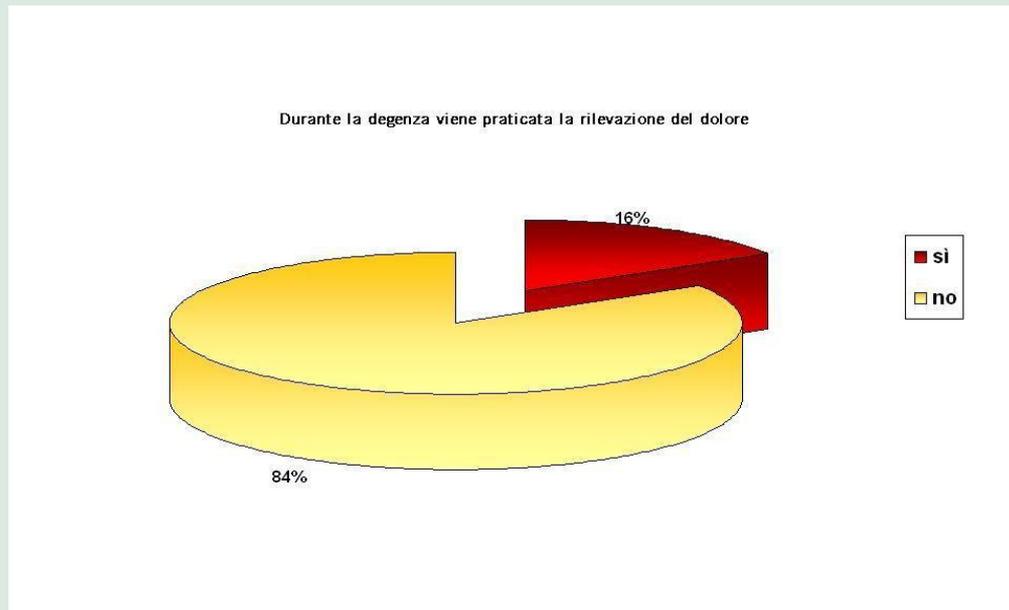
Citizens' reports

Segnalazioni inerenti la carenza di umanizzazione



Diritti al taglio – 14° Rapporto PIT Salute, Cittadinanzattiva – Tribunale per i diritti del malato

Pain in pediatric age



- Opioid therapy 17%
- Pain detection in integrated homecare assistance (6,3%)

Source: X Report on chronic and rare diseases, Cittadinanzattiva - CnAMC, 2011

Elderly pain

“The unbearable lightness of welfare”

- Pain is «underestimated»
- Pain is not detected and treated properly in hospitals
- Very little attention in post-acute residential structures (where pain measurement and treatment are a mirage)
- (Biologic) pain and (psychological, social and spiritual) suffering are considered as an ineluctable part of elderly life
- Low quality hospital units, because of organisational issues

Some activities to protect patients' rights 2012-2013...

- Information, consultancy and assistance – PIT Salute
- **Campaign IN-DOLORE**
- **European project Pain Patient Pathway Recommendations (PPPR)**

2014:

- **IN- DOLORE 2**
- Final recommendations on the project PPPR (Italian semester of EU Presidency)
- European Patients' Rights Day (focus on chronic pain)

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- Information, consultancy and assistance – PIT Salute
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2014:

- **IN- DOLORE (2nd edition)**
- Final recommendations on the project PPPR (Italian semester of EU Presidency)
- European Patients' Rights Day (focus on chronic pain)

- Target: citizens
- Tools : useful guide for citizens; support for Cittadinanzattiva's volunteers, posters and postcards
- Objectives:
 - contribute to the construction of a widespread culture on the right to avoid unnecessary pain
 - spread widely the contents of the law no. 38/10
 - Promote the collaboration among different stakeholders

IN-DOLORE

**“Non è una pubblicità!
Promuoviamo il tuo diritto
a non soffrire inutilmente”**

Al dolore bisogna
abituarsi, sopportarlo
vuol dire essere forti
FALSO

La Guida **IN-DOLORE** spiega cosa fare
e cosa **“pretendere”** per non soffrire,
a casa, dal medico di famiglia e nelle
strutture sanitarie.
La Legge 38 del 2010 è dalla tua parte
e ti tutela contro il dolore inutile.

Vuoi saperne di più?
Scarica la Guida IN-DOLORE su
www.cittadinanzattiva.it

Così il dolore non condiziona di

GRUNENTHAL

Sostenici,
non lasciare
i tuoi diritti
solo sulla carta

IBAN: IT 14J 02008 05240 000401362506



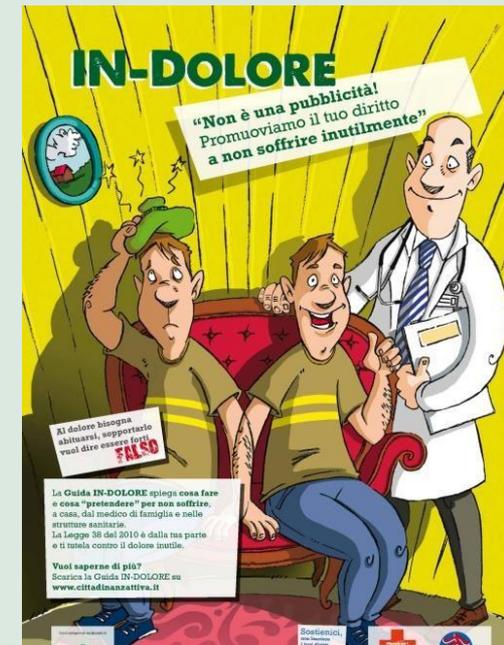
The **Campaign** was promoted by the
Tribunal for patients' rights of
Cittadinanzattiva together with:

- AISD
- ANMAR
- Antea Associazione Onlus
- Federazione Cure Palliative
- Federdolore – SICD
- FEDERFARMA
- FIMMG
- FONDAZIONE ISAL
- MINISTERO DELLA SALUTE
- SIIARTI
- SICP
- SIMG
- SISIP

con il contributo non condizionato di

OBJECTIVES

- Raise awareness about rights established by the law n. 38/10
- Offer suggestions and tools useful for people's self-protection
- Encourage people to discuss about pain, consult with doctors and build trust with them



CONTENTS

Information about the law no. 38/2010

Pain therapy and palliative care

How to talk about pain

How much do you suffer?

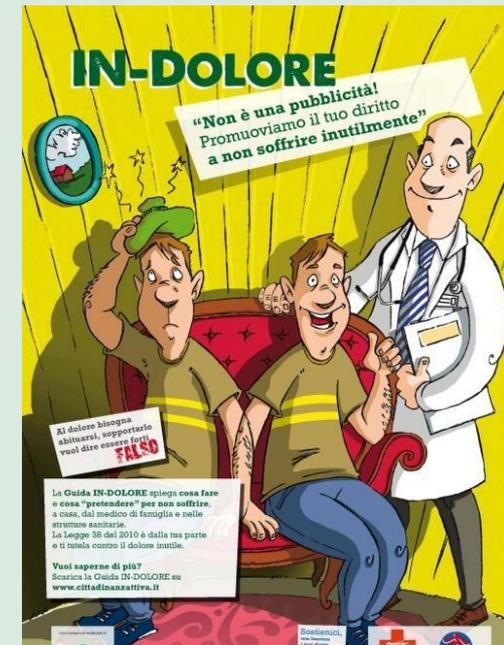
Who takes care of your pain

5 tips for citizens dealing with pain

Morphine & co., let's dispel a taboo!

Will you give birth without pain?

What if...



DIFFUSION : Guide – Posters – postcard in a simple language

Channels: physical closeness , internet, social networks, drugstores, etc.

DISSEMINATION :

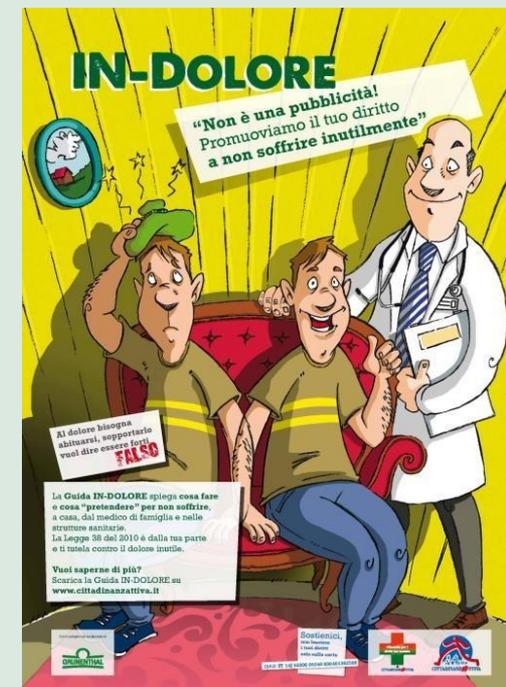
More than 70 informative initiatives

More than 300 local branches of the Tribunal for patients' rights

17300 drugstores involved

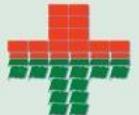
100 cities against pain

more 3500 download of the guide

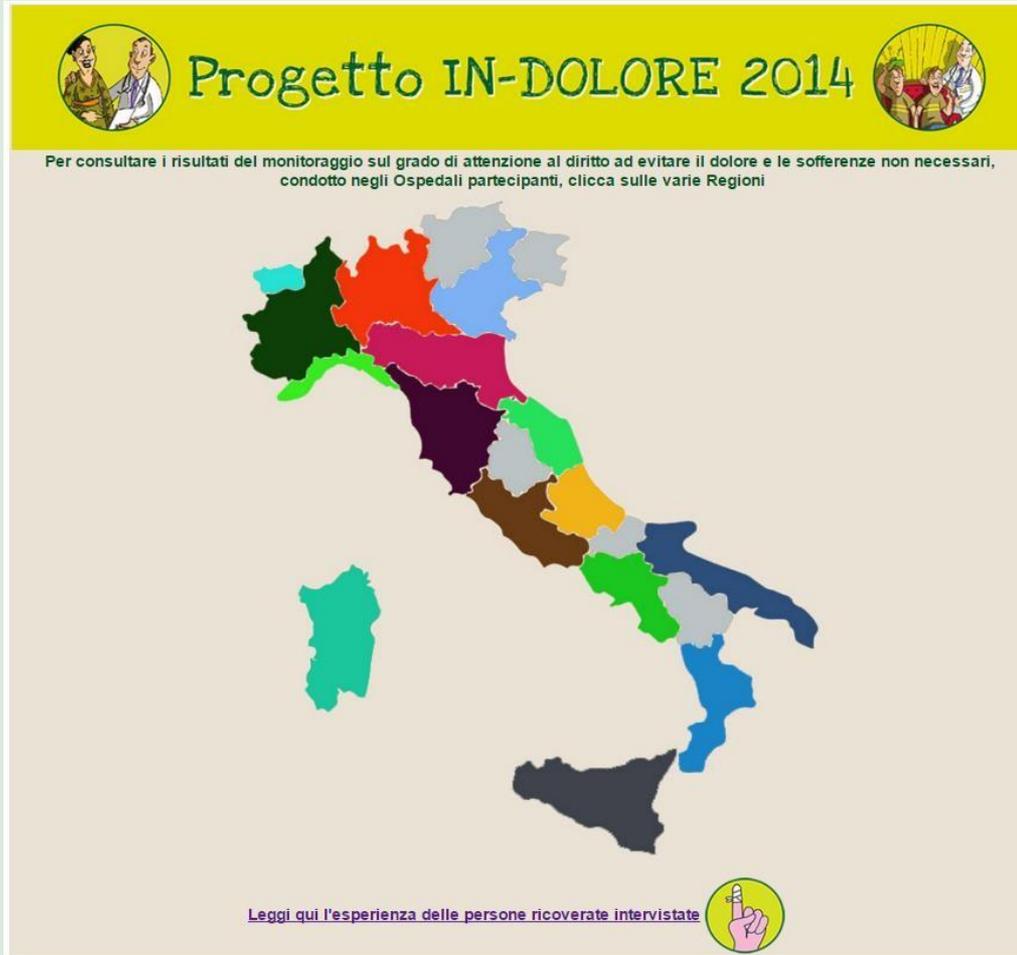


Evaluate and make public the attention of hospitals to reduce and control pain

- Audits
- Patients' interviews
- Discuss the results with the Hospital Committess «*Without pain*»
- Actions of improvements and assements of the changes



The project IN-DOLORE 2



Progetto IN-DOLORE 2014

Per consultare i risultati del monitoraggio sul grado di attenzione al diritto ad evitare il dolore e le sofferenze non necessari, condotto negli Ospedali partecipanti, clicca sulle varie Regioni



[Leggi qui l'esperienza delle persone ricoverate intervistate](#)

<http://www.cittadinanzattiva.it/form/salute-in-dolore/public/>

Patient Pathway Recommendations (2012-2014)

A three years multi-stakeholder project realized by ACN in partnership with Pain Alliance Europe in 18 European countries, to:

- realize a civic assessment on chronic pain policies in the EU countries
- create a greater awareness of chronic pain
- promote a European policy on chronic pain and reduce the impact of chronic pain on all areas of European society

Involving:

37 associations from 18 Countries

10 Ministries of Health

54 Health care Professionals

In the report presented by the Italian Ministry of Health during the informal meeting of the 28 European Health Ministries held on September 22nd and 23rd 2014 in Milan in the context of the Italian Presidency of the Council of the European the **civic recommendations** produced were recalled.

Making the invisible visible (2014)

A EU civic research-project as collection of good practices on chronic pain, with the aim to give evidence on existing good practices in several European countries in terms of struggle against pain.

Without considering the apps, the collection of good practices is split up into **46 examples from 11 countries** as follows:

- A first group of **good practices relates to specific diseases**: fibromyalgia; back pain/low back pain and neuropathic pain/localized neuropathic pain (LNP); dementia; rheumatoid arthritis; osteoarthritis; pelvic pain; facial pain; cephalalgia; pain in neck and shoulders; Machado-Joseph disease and diabetes.
- A second more substantial group relates to **good practices on chronic pain**, without entering into detail: in some cases because they involve communication campaigns aiming at increasing public awareness about the phenomenon, and provide reference points and useful information to patients suffering from chronic pain.



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.
- High concentration of events during the same period.
- Media focused the topic with articles, interviews, etc.
- Pain therapy and palliative care in many official political documents provided by EU Institutions and official statements.
- Increased accreditation of civic and patients associations dealing with pain therapy and palliative care to institutions and stakeholders.



This project will collect Good practices experiences on chronic pain, cancer & no cancer- related.

It will be a recognition of ongoing excellences and, after a lot of important national experiences, the first European new award: “EU Civic Prize on Chronic Pain”. In fact, there are several Prizes on the topic, but none at European level and led by citizens.



Thank you for the attention

www.cittadinanzattiva.it