



CIVIC SURVEY ON THE RESPECT OF UNNECESSARY PAIN PATIENTS' RIGHTS IN EUROPE

Report on the Patients' Right to avoid unnecessary suffering and pain
2nd Edition, 2013



Patients' approach to the improvement of pain management

- Despite the efforts at regional, national & European level, the condition of patients affected by chronic pain is still serious.
- A strong patient-oriented policy against chronic pain is therefore required.
- A multi-year (2012-2014) and multi-stakeholder project with a collaborative approach: Patients – Citizens – Industry



The political framework of the project is designed by Pain Alliance Europe (PAE) representing chronic pain patients in Europe.



Active Citizenship Network (ACN) is responsible for the scientific design and contents.



The pharmaceutical company Grünenthal GmbH (GRT) is responsible for financial and non-financial support.

37 CHRONIC PATIENTS' ASSOCIATIONS AND CIVIC ORGANIZATIONS INVOLVED IN THE SURVEY (I)

- Austria: Europäische Arbeitsgemeinschaft Österreich (Eurag-The European Federation of Older People Austria); LKH-Bruck-Mur.
- Belgium: Vlaamse Pijnliga.
- Bulgaria: Index Foundation; Together with You; Association for Reproductive Health, Pregnancy and Childcare 'Smile'; Alliance of Transplanted and Operated; 'Future for Everyone' Association of Patients with Cardiovascular Diseases.
- Cyprus: European social forum cyprus (Esfrc).
- France: Collectif interassociatif sur la santé; Association pour le droit de mourir dans la dignité; Association des paralysés de France; Fibromyalgie France; Tous contre la douleur; France Parkinson.
- Finland: Suomen Kipu ry (Finnish Pain Association).
- Germany: Deutsche Schmerzliga e.V. (German Pain League).
- Italy: Cittadinanzattiva.
- Latvia: Pacientu Ombuds (Patients' Ombud Office); Latvian Diabetes Association.
- Macedonia: Medicine and Ecology Research Centre (Merc); Nora.

37 CHRONIC PATIENTS' ASSOCIATIONS AND CIVIC ORGANIZATIONS INVOLVED IN THE SURVEY (II)

- Malta: Malta Health Network; Arthritis and Rheumatism Association Malta.
- Nederland: Stichting Pijn Platform Nederland; Foundation Pain-Hope; Fibromyalgie en Samenleving (Fes).
- Portugal: Rede Integrada de Associações de Doença Crónica nos Açores (Riadca); Associação Atlântica de Apoio Doente Machado-Joseph.
- Romania: Myeloma Euronet Romania.
- Slovenia: Zavod Viva; Fibromyalgia Patient Association.
- Spain: Red de Fibromialgia, Síndrome de Fatiga Crónica y Sensibilidad Química Múltiple (Redefmsfcsqm); Asociación Coruñesa de Fibromialgia y Fatiga Crónica (Acofifa).
- Sweden: Sveriges Fibromyalgiförbund (Fibromyalgia Association of Sweden).
- United kingdom: BackCare; Pelvic Pain Support Network.

3 TYPES OF INFORMATION RELATED TO 3 LEVELS OF INVESTIGATION:

- The first type concerns the degree to which institutional bodies are issuing norms and promoting policies and actions against unnecessary pain. These actions show the level of attention for people living with Chronic Pain at a national level. Sources: **Ministry of Health (10 Ministries interviewed)**
- The second type of information reflects the knowledge civic partner organisations have. They may offer a wide range of information on health care system, in connection with serious violations of rights they have become aware of in their role of “protectors” of rights of people living with Chronic Pain. Sources: **National Patients Associations or Citizens organizations dealing with Pain (Involved 37 patients and civic organizations).**
- The third type of information concerns the direct experience of key health professionals who daily manage the care-pathways of Chronic Pain patients. Sources: **the national representatives of the European Associations of Health professionals (54 professionals interviewed)**

INDICATORS AND “FACTORS OF EVALUATION”

Used 174 indicators collected to the following 5 “factors of evaluation”:

- **The patient's right to be believed** = *Each individual has the right to be listened to and believed when reporting personal pain.*
- **The patient's right to have pain treatment and management at the earliest possible stage** = *Each individual has the right to access the treatment needed to alleviate his/her pain.*
- **The patient's right of access to the best possible technologies and therapies for pain treatment and management** = *Each individual has the right to receive pain assistance, in observance with the latest, approved quality standards.*
- **The patient's right to be informed about all the pain management options available so that he/she can make the best decisions and choices for his/her wellbeing** = *Individuals have the right to actively participate in the decisions made regarding their pain management.*
- **The patient's right to live with the least amount of pain possible** = *Individuals have the right to have their pain alleviated as efficiently and rapidly as possible.*

THE ISSUE OF PAIN IN THE CHARTER OF RIGHTS

The objective of the Charters of Rights on health care is the enunciation of a "set of rights" which define and clarify the more general right to health.

A. The European Charter of Patients' Rights, promulgated in 2002 in a European context, specifically including the *right to avoid unnecessary suffering and pain*. It is the result of a joint effort between Cittadinanzattiva-Tribunal for Patients' Rights and 15 civic organizations partners of Active Citizenship Network (ACN).

B. Other two Charters, drafted in a National context, focus solely on the issue of the fight against unnecessary pain:

Charter of Rights for people living with Chronic Pain, written by Chronic Pain Ireland and approved by the Governing Body of Chronic Pain Ireland on 2009.

Charter of Rights against unnecessary pain, promoted by Cittadinanzattiva in 2005 with the aim to declare and protect a set of rights still too often violated.

HOW TO READ THE SURVEY

- A value was assigned to each answer. The **value from 0 to 100** expresses the degree to which the information gathered respects the legitimate expectations held by citizens. This means that for each answer, 100 is given whenever it is verified to be the best situation.
- For a more “immediate” reading of the results, an **average score** was assigned to each factor, i.e. a numeric value indicating the distance from the top according to the result obtained: **0-40 = WEAK; 41-70 = SUFFICIENT; 71-90 = GOOD; 91-100 = EXCELLENT.**
- Each evaluation factor based on the point of view of Ministries, professionals and civic organisations assesses the ability of each country to respect “the Right to avoid unnecessary suffering and pain” according to the following rating:
 - 0 – 50 = NOT RESPECTED;**
 - 51 – 60 = HARDLY RESPECTED;**
 - 61 – 70 = PARTLY RESPECTED;**
 - 71 – 90 = ALMOST RESPECTED;**
 - 91 – 100 = FULLY RESPECTED**

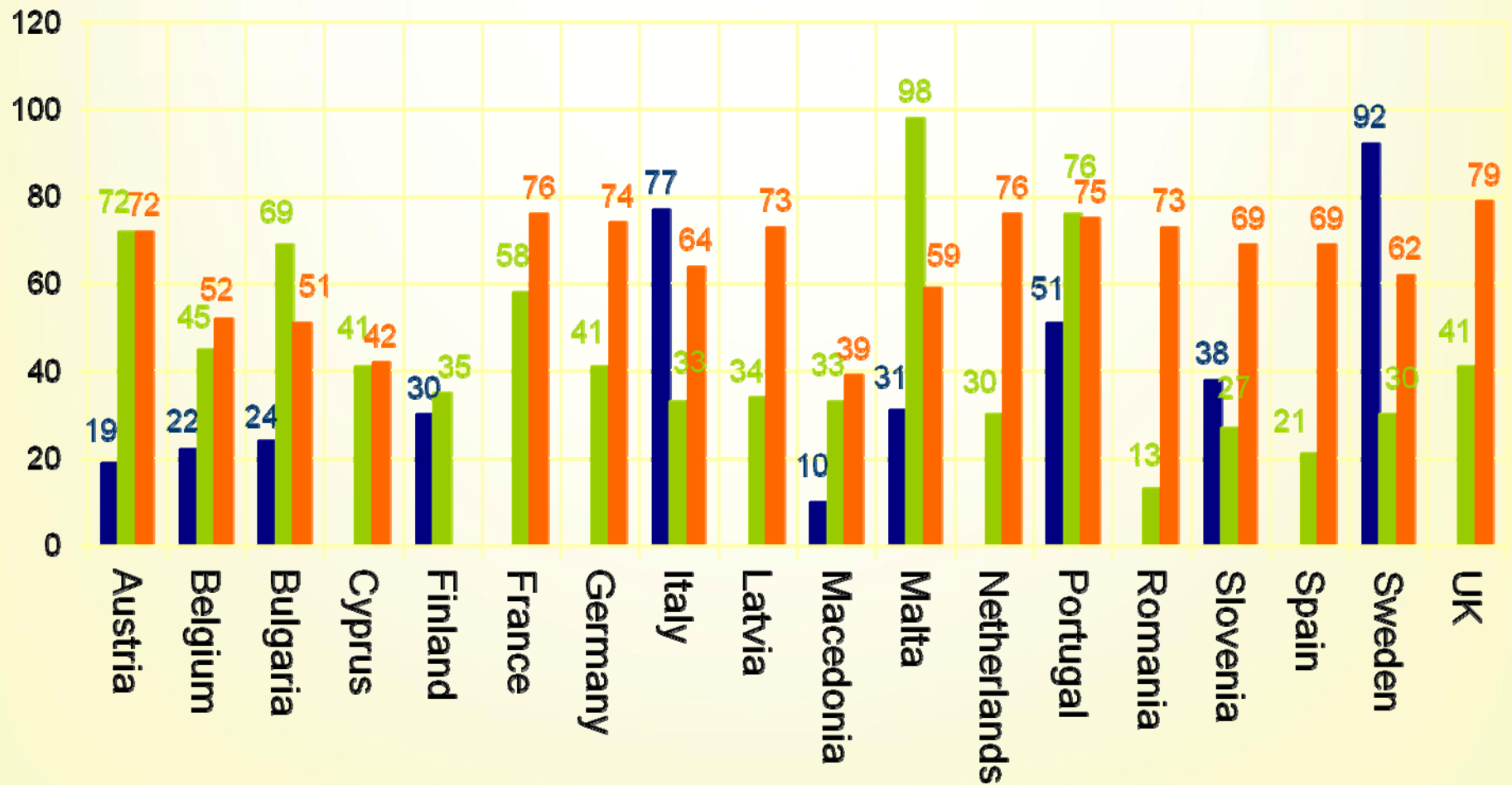
WHAT WE FIND BEHIND THE NUMBERS

- *The patient's right to be believed:* measuring pain; physicians' consultation; patient empowerment; post-surgical pain; measuring pain; guidelines /protocols; violation of the patient's rights.
- *The patient's right to have pain treated and managed at the earliest possible stage:* cost of treatment; restrictive laws; facilitate access to drugs; painkillers/morphine not administered; economic difficulties; violation of the patient's rights.
- *The patient's right of access to the best possible technologies and therapies in pain treatment and management:* professional updating/training; training for chronic pain patients' associations; analgesic equipment; violation of the patient's rights.
- *The patient's right to be informed about all the pain management options available so that he/she can make the best decisions and choices for his/her wellbeing:* communication campaign; involvement of chronic pain patients' associations; website; local services; difficulty in understanding medical language; lack of information; alternative care; overuse/abuse of drugs; violation of the patient's rights.
- *The patient's right to live with the least amount of pain possible:* national law; update; appointed official; socio-economic benefits; waiting for the diagnosis; refusal to prescribe opiates; lack of communication; socio-economic benefits; violation of the patient's rights.

Average value: Institutional level (39) – Organization level (44) – Professional level (65)

The patient's right to avoid unnecessary suffering and pain

■ Institutional level ■ Organization level ■ Professional level



	Institutional level	Organization level	Professional level
The patient's right to be believed	54 <i>Sufficient</i>	44 <i>Sufficient</i>	77 <i>Good</i>
The patient's right to have pain treated and managed at the earliest possible stage	44 <i>Sufficient</i>	45 <i>Sufficient</i>	68 <i>Sufficient</i>
The patient's right of access to the best possible technologies and therapies in pain treatment and management	14 <i>Weak</i>	45 <i>Sufficient</i>	70 <i>Sufficient</i>
The patient's right to be informed about all the pain management options available	13 <i>Weak</i>	41 <i>Weak</i>	61 <i>Sufficient</i>
The patient's right to live with least amount of pain possible	57 <i>Sufficient</i>	45 <i>Sufficient</i>	50 <i>Sufficient</i>
The Right to avoid unnecessary suffering and pain	39 <i>Not respected</i>	44 <i>Not respected</i>	65 <i>Partly respected</i>

Thanks for your attention!

Mariano Votta

Director Active Citizenship Network

m.votta@cittadinanzattiva.it

www.cittadinanzattiva.it

www.activecitizenship.net