



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

Report on the Patients' Right to avoid unnecessary suffering and pain  
2<sup>nd</sup> 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.*

## **MAIN STEPS OF THE PROJECT**

- ***Report on the Assessment of the EU Patient Right of Avoiding Unnecessary Suffering and Pain.*** The first edition was presented on May 2013 in a professional symposium, the second edition yesterday.
- ***Develop EU Pain Patient Pathways Recommendations:*** the Civic survey is a necessary step to understand which concrete proposals against pain can be put forward to European, National and local Institutions in order to identify pathways/recommendations against pain according to the patient's point of view for a good health policy on chronic pain relief.
- ***Submit these Civic Recommendations to the vote of the European institutions during the Italian EU Presidency in the 2nd half of 2014.*** Law no. 38 is a good law: therefore, the Italian institutions together with the patients' associations could make a joint effort in trying to have this issue included in the EU agenda.

### CIVIC SURVEY: SOME RELEVANT NUMBERS

- 3 types of information related to 3 level of investigation: Ministry of Health, National Patients Associations or Citizens organizations dealing with pain, the national representatives of the European Association of health professionals.
- 10 Ministries of health and 54 professionals interviewed.
- To study the “The right to avoid unnecessary suffering and pain” we have used 174 indicators collected to the following 5 “factors of evaluation”, linked to rights & principles described in the following “Charter of Rights”:
- **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).
- 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.

## 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.

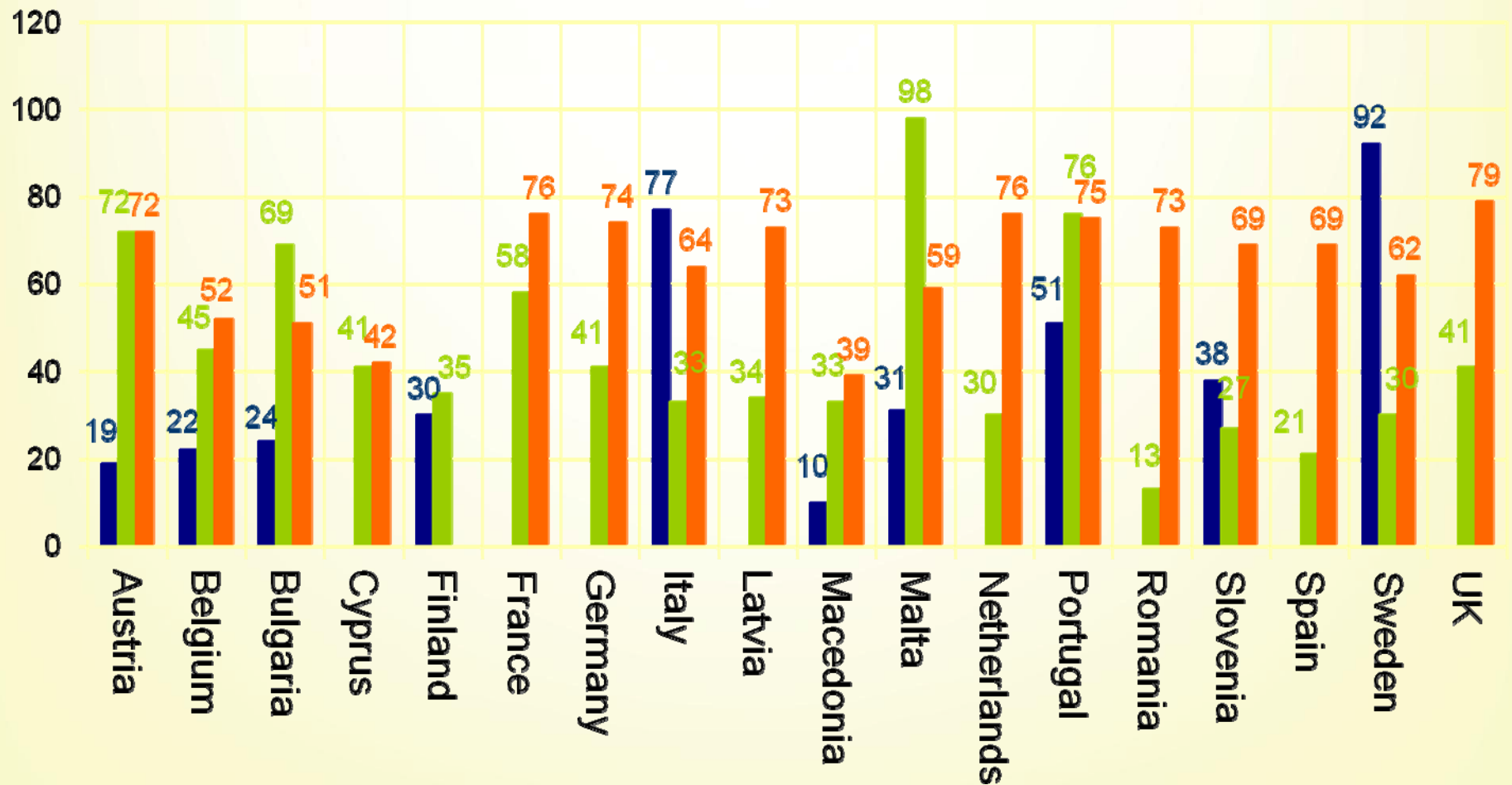
## **HOW TO READ THE SURVEY**

- 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**

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



## **GOOD PRACTICES FROM A CIVIC POINT OF VIEW**

- The associations from Austria, Cyprus, France, Macedonia, Malta, Romania, Slovenia and Spain have each reported Good Practices. Two have come from Belgium, three from The Netherlands and five from Italy.
- We have also received a list of Good Practices by the Ministries of Health of Belgium, Italy, Malta, Slovenia, the Comunidad Autónoma de Galicia (Spain) and the Autonomic Region of Azores (Portugal).

## **LIFE GOES ON, EVEN WITH PAIN, 7 DAYS A WEEK, 24 HOURS A DAY**

- The civic survey includes 20 direct testimonies of people who live with chronic pain. They are everyday stories from Belgium, Italy, Malta, the Netherlands and the UK (one for each country), Austria, Bulgaria, France, Macedonia, Spain, Sweden (two for each country), Slovenia (three).



**Thanks for your attention!**

**Mariano Votta**

*Director Active Citizenship Network*

*m.votta@cittadinanzattiva.it*

**[www.cittadinanzattiva.it](http://www.cittadinanzattiva.it)**

**[www.activecitizenship.net](http://www.activecitizenship.net)**