



CITTADINANZATTIVA ONLUS - SEDE NAZIONALE
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“Chronic pain: making the invisible visible. European collection of good practices”

2 October 2014

EESC - Room TTRE 7701

(7th floor, Trèves Bulding, 74, rue de Trèves, 1040 Brussels)

1. Geographical impact

The area of investigation affected the following 11 countries: Belgium (1 good practice), Bulgaria (2), France (5), Germany (1), Greece (1), Kosovo (2), Italy (15), Malta (2), Portugal (2), Spain (4), United Kingdom (11).

The event organized in Brussels by Active Citizenship Network (ACN) involves participants from 18 different Countries and discussants from 10 Countries (Belgium, Bulgaria, France, Germany, Greece, Kosovo, Italy, Malta, Portugal, Spain and United Kingdom) and from various background: leader of patients' organizations and representatives of health-focused NGO, healthcare professionals and their EU Networks, policymakers from member states and UE Institutions, the Good practices networks promoted by ACN, communication & public relation agency.

2. Characteristic of the good practices

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

- A first group of good practices relates to specific diseases. There are 6 examples related to patients suffering from fibromyalgia, 3 good practices each for back pain/low back pain and neuropathic pain/localized neuropathic pain (LNP); 2 for those suffering from dementia and 2 for those suffering from rheumatoid Arthritis/Arthritis and rheumatoid arthritis, osteoarthritis. There are also examples of good practice in the field of pelvic pain, facial pain, and cephalgia, 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. In other cases, because they are addressed to more than a specific pathology, including those mentioned above.

3. Who are they addressed to

- Most of the good practices are addressed to adult patients aged 20-70, with no particular age restrictions, to a lesser degree also to senior citizens over 70.
- Only one good practice is addressed exclusively to children: "Pain in the Paediatric Emergency Room", in Italy.
- There are three good practices addressed specifically to elderly patients (70-90 years old): "Program to reduce cephalgia and pain in the neck and shoulders", "Management



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prevent back pain from becoming chronic, secondly to improve quality of life of patients, thirdly to reduce costs by decreasing the time patients are absent from work due to pain and finally to reduce therapy costs for health insurance companies.

Diabetic neuropath. Information is a health promoter! Questionnaires to help identify symptoms and early diagnosis. Better management of diabetes – Bulgaria

This interactive project in the form of a game was promoted by the patients' organization "With you" in order to motivate citizens to check the sugar level in their blood and identify specific symptoms. It concerns empowerment, civic participation and awareness raising. The uniqueness is that questionnaires were disseminated through the social networks and people were encouraged to fill them up with the award in the form of new books given for free by the publishing company. We can talk about an innovative approach to health prevention.

Regional Plan for Pain Control - Portugal

Launched by the Regional Health Directorate, this 3 years Health Program involving 9 islands for a total of 246,102 inhabitants concerns patients' empowerment, civic participation and awareness raising. It consists of epidemiologic studies, evaluation in hospitals, screenings programs in the community and national and international celebration days.

Pain Simulator – Italy

Promoted by the Montescano Pain school, this pain simulator consists of a box reproducing the effects of pain and a questionnaire. The objective is to demonstrate how localized neuropathic pain feels like and to discuss the burden felt by patients suffering from this disease and their difficulty to express what they feel. The unique characteristic of the box is that it can reproduce the same feelings experienced by patients, through electrodes placed on the nerve tracts and mimic the neuropathic pain stimulus. All this is crucial also because improves communication between patients and physicians.

International conferences for pain treatment – Kosovo

Organized by the Professional Health Association (PHA), these conferences, combined with workshops, have been held every year since 2009 involving more than 400 participants with well-known international and national experts from different fields and countries. The targets are the implementation of pain therapy in Kosovo through encouraging methods and modern scientific research, education and training of people to enhance the quality of pain treatment standards.

Courses: Cancer and neuropathic pain treatment – Kosovo

Dedicated to the awareness raising, these courses are for general training adapted for both medical and law backgrounds and are supported by international counselling by pain therapy experts from different countries. They also include workshops with lessons, interactive questions and discussions about case studies covering many areas such as physiological and pharmacological principles, intervention procedures, opioid therapy for non-cancer pain, etc.

Priority criteria for low back pain - Italy

This project was promoted by the Local Health Service (ASL) of Palmanova and realized by a task force of specialists. It can be located in the field of empowerment, civic participation and awareness raising. It is defined a specific approach that links the general practitioner to



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the specialist in the field of low back pain to guarantee that the latter has a clear vision of the patient's problem and continuity of care among professionals. The innovative part is to be found in the finding of a decisional algorithm able to give a numerically measurable, transparent, comparable and repeatable score on which were drawn up a series of priority criteria to send the patients with low back pain to a specialist.

A study of the Effects of Shiatsu on Pain Management at the PainManagement Clinic of the University Hospital Aretaieion Athens - Greece

The main objective of this project is to assess the effect of Shiatsu, psychotherapy, acupuncture and reflexology on patients suffering from chronic pain involving almost 70 patients with an age range 30-85. It has a holistic approach that goes beyond merely addressing the origin of chronic pain as tackles also topics such as relief from secondary problems (intestinal disorders, stress, hormonal imbalances, etc) nutrition and regular exercise.

Research/Practice of Homeopathy for pain relief in chronic pain – Belgium

Realized by the Centre for Classical Homeopathy - Centrum voor Klassieke Homeopathie this project involves research, education and awareness raising through training, brochures and lectures for general public. More specifically, it is a project for the study of the characteristics of homeopathic treatment: individualization, holistic approach, measuring well-being and symptom relief.

Increase citizen's awareness through forum theatre for better prevention and dealing with chronic pain (Title of the play: Aie plus jamais ça – No, never again)- France

Realized by Douleurs Sans Frontières (DSF) – Pain without borders, this very unique project covers patients' empowerment, civic participation and awareness raising. This project represents an ideal cultural vehicle to surprise without raising alarm and a place where to question beliefs and attitudes. It helps to look at pain as a social issue and not only as a healthcare problem. Free entrance is a priority as a facilitating factor. To be highlighted that all written reports of the debates with the audience will be sent to the French Government. For further information, please see the video:

http://www.douleurs.org/article.php?ID=32&Type=Actualite#.VA7dc8V_ua4

Permanence d'accompagnement – France

Led by Association Francophone pour Vaincre les Douleurs (AFVD) - The French Association for the fight against pain, this is a project entirely dedicated to empowerment concerning pain out-patients treated within the framework of a collective project as well as those patients treated by local structures. The service of assistance is supplied by voluntary experts trained by AFVD and is set up in partnership with healthcare professionals. Assisting, supporting, informing and accompanying patients but also families and careers are crucial points.

National population-based system for pelvic pain - United Kingdom

Promoted by the Pelvic Pain Support Network, the project concerns empowerment, civic participation and awareness raising. The use of a Population-based Healthcare system is a unique approach to improve care because it allows to collect outcomes data in form of simple 1-2 sides A4 annual reports on how different services across England are performing. This program helps guide commissioners and providers on the critical deficiencies in their



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services and puts the patient at the center giving focus on personal, technical and allocative values.

7. The engagement of Cittadinanzattiva- Active Citizenship Network in the fight against unnecessary pain

Cittadinanzattiva and ACN are deeply involved in the European and national debate on patients' rights against unnecessary pain. The aim is to promote to a higher level the awareness on the issue of chronic pain therapy among European citizens, European and national policy and decision-makers and, over the longer term, to reduce the negative impact of chronic pain on European society as a whole. This would not only ensure a lasting legacy of the Italian Presidency of the Council of the European Union, but also pave the way to a better future for patients in Europe suffering from chronic pain. For further information:

- <http://www.activecitizenship.net/patients-rights/projects/83-the-engagement-ofcittadinanzattiva-in-the-fight-against-useless-pain.html>.

8. About Active Citizenship Network (ACN)

Active Citizenship Network was established in December 2001 as the European and international representative of the Italian organization for civic participation Cittadinanzattiva (Active Citizenship). ACN is a flexible network of European civic organizations which are involved as partners in its projects addressed to encourage active participation of citizens in European policy-making. It mirrors Cittadinanzattiva's Italian policies, such as healthcare, consumer protection, corporate social responsibility, education and training at global level. Its mission is to promote and support the construction of European citizenship as an "active citizenship" meaning the exercise of citizens' powers and responsibilities in policy-making. The European Charter of Patients' Rights and the promotion of the European Patients' Rights Day are its main initiatives.

Other information:

- The policy of Cittadinanzattiva on good practice:
www.cittadinanzattiva.it/approfondimenti/attivismo-civico/cittadinanza-dimpresa/4972-good-practice-the-policy-of-cittadinanzattiva.html
- Webpage of the research:
www.activecitizenship.net/patients-rights/projects/158-chronic-pain-making-the-invisible-visible-european-collection-of-good-practices.html
- Webpage of the event with all the presentation:
<http://activecitizenship.net/patients-rights/projects/158-chronic-pain-making-the-invisible-visible-european-collection-of-good-practices.html>

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