

Selecting Good Practices to Advance towards a European Network of Experts Fighting Against Chronic Pain

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Abstract

In continuation with the second edition of the research project “European Civic Prize on Chronic Pain – Collecting Good Practices”, the third edition of the initiative led by Active Citizenship Network, whose term has spanned from 2020-2021, has recently selected several good practices in the fight against chronic pain in the European Union [1]. The value of this EU project is not only to collect and promote the experiences related to chronic pain, but also to strengthen collaboration and encourage the exchange of information and knowledge on chronic pain among different actors. This is crucial for ensuring longer life to good practices and for being able to identify conditions to replicate or implement them in other contexts. This article will focus on three of the winning good practices of the categories of patients’ empowerment, clinical practices, and Covid-19 special actions, that have been selected by the Jury of experts and emphasizes the need for an advancement towards the establishment of a European network of good practices’ managers fighting against cancer and non-cancer related chronic pain.

Keywords: Chronic Pain, Good Practices, European Union, Patients’ Rights, Patients’ Empowerment, Civic Participation, Good Practices’ Managers, Civic Hub-incubator.

Introduction

The management of chronic pain, and the connecting factors that contribute to its prevalence across Europe have become of extreme importance for the patients’ quality of life and for the respect of their rights. It is necessary now more than ever not only to find effective remedies for patients dealing with chronic and extensive pain, but also to create conditions that allow for their replication in other contexts. This article will look at three of the winning good practices of the latest edition of the European Civic Prize on Chronic Pain organized by Active Citizenship Network, the European branch of the Italian NGO Cittadinanzattiva [2-4]. The initiatives that have been awarded are excellent examples of effective and innovative good practices that fall under more than one of the categories established by the Civic Prize. The categories, which will be examined later in detail, are: Patients’ Empower-

ment; Innovation; Clinical Practices; Professional Education; Covid-19 Special Action. This year, a special category focused on the initiatives that have been put in place or modified to face the Covid-19 pandemic consequences on chronic pain patients’ life has also been introduced.

The experiences which will be reviewed in this article have been carried out by the *Societal Impact of Pain* multi-stakeholder EU platform based in Brussels, Belgium, which calls for the implementation of the European Pillar of Social Rights; the *CONFESQ* patient organization of Madrid, Spain, which demands for a more precise and up-to-date guide for defining and treating the pathologies of Fibromyalgia, Chronic Fatigue Syndrome, Multiple Chemical Sensitivity, Electrosensitivity and Somatoform Disorders. The third experience has been carried out by the *Niguarda Hospital* of

Milan, Italy and has focused on the reliability and efficacy of pain management services during the recent Covid-19 pandemic.



Communication material produced in occasion of the III Edition of the “European Civic Prize on Chronic Pain – Collecting Good Practices”.

Materials and Methods

The aim of this section is to provide details on the categories the good practices must fall under and to analyze three of the best practices awarded by the selective committee, a Jury panel composed by independent experts coming from entities devoted to the topic.

Categories Covered by the European Civic Prize on Chronic Pain

Good practices can be very diverse. They may focus on information and awareness raising campaign; implement newly innovative Action Programmes in pain management in a hospital or clinic; create a new delivery service approach or a new tool, instrument, or guideline; carry out a Prevention Activity (i.e. a new screening for an early diagnosis on Chronic Pain); put in place a cross-cutting initiative to better identify the burden on pain in different public policy; promote advocacy and/or policy-making activities related to pain management, etc. The award is open to any healthcare stakeholder: patients’ associations, healthcare professionals, PAGs and civic organizations, institutions, private and public hospitals, universities, etc. As outlined in the Guidelines [5], what counts is that the good practice should demonstrate one or more of the following categories:

Patients’ Empowerment

Good practices providing information, creating information campaigns, supporting and fostering capacity-building for individual patients with chronic pain and their relatives, including their social, psychological, and other impacts. This also includes partnerships between patient organizations and other stakeholders (health professionals, public institutions, media, healthcare industry, etc.) to empower patient and civic organizations so that patients can understand their rights and make informed choices.

Innovation

Good practices concerning laws, technologies, apps, devices, events, theatrical performances, etc.

Clinical Practices

Good practices concerning pain management (prevention, diagnosis, treatment, and monitoring), dedicated units, therapeutic pathways, clinical records, ways of measuring pain, etc. Highly valuable are also practices involving patients.

Professional Education

Undergraduate and postgraduate education for healthcare professionals, training courses in hospitals/clinics, updating general practitioners, etc.

Covid-19 Special Action

Exceptionally, for the III edition 2020-2021, the Award recognizes outstanding initiatives that have been put in place/modified/updated to face and mitigate the Covid-19 pandemic consequences on chronic pain patients’ life and related healthcare services.



Marine Cotty, Director of Lucine Group (France), the winner of the Second Edition category “Innovation with the digital health solution” with “DTX for Pain”, awarded by the two Spanish members of the Jury Panel: Jordi Moya, President of Sine Dolorre European Pain Foundation, and Gemma Fernández, President of Asociación Española de Pacientes Contra el Dolor (APDOL). (Brussels, 6 November 2019) © Isabelle Pateer.

Sip’s Pledge to Uphold and Implement the European Pillar of Social Rights

(SIP - Societal Impact of Pain – Brussels, Belgium) [6]. This practice from the Societal Impact of Pain platform directly addresses the promotion and respect of patients’ rights across Europe, advocating primarily for adequate treatments for patients who live with forms of chronic pain. SIP calls on EU institutions and national governments to pay special attention on the implementation of the principles of the European Pillar of Social Rights that link directly to the following four priorities: initiate policies addressing the impact of pain on employment and include pain in relevant existing initiatives; prioritize pain education for healthcare professionals, patients, policymakers, and the general public; increase investment in research on the societal impact of pain; and develop instruments to assess the societal impact of pain (pain as a quality indicator). In Europe, a healthy relationship between EU institutions and public and private sectors is essential. For this reason, SIP’s pledge is to assist patients themselves and relevant organizations in their relationship with EU organizations and officials, through a direct approach which creates a more fluid and open dialogue between all the key actors. In this context, SIP has stated that it wishes to “help EU institutions in providing recommendations for policy actions highlighting opportunities for action and collaboration by the European Commission, Member States, and civil society to reduce the societal impact of pain” [7]. The practice is crucial as it defines a new transparent relationship between European citizens and the institutional spectrum of the European Union itself and it provides for the most effective care possible for patients living with pain,

empowering them to succeed in all areas of their own lives, such as facilitating their reintegration into the workplace, or in other relevant areas of life. Active Citizenship Network thanks Patrice Forget, Chair of SIP, for his testimony in occasion of the ceremony of June 17, 2021 [8].

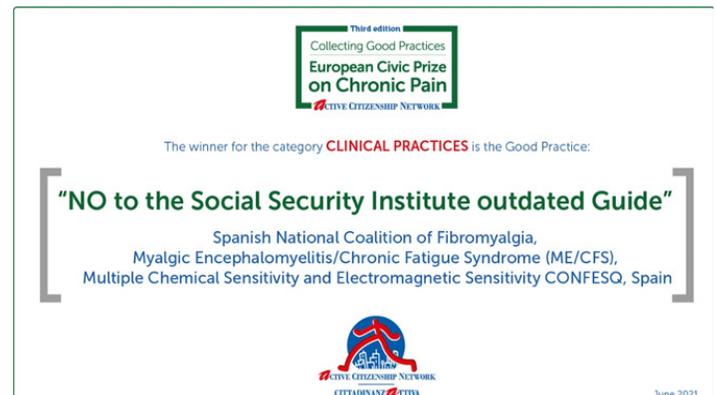


The plaque realized in the occasion of the ceremony of the III Edition of the Prize on June 17, 2021 and given to the Belgian Societal Impact of Pain (SIP).

No A La Guía Inss - No To the Social Security Institute Outdated Guide

(CONFESQ patient organization, the National Coalition of Fibromyalgia, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Multiple Chemical Sensitivity and Electromagnetic Sensitivity – Madrid, Spain) [9]. In Spain, there is no other official document by neither the Ministry of Health nor the Regional Health Departments that defines the pathologies of Fibromyalgia, Chronic Fatigue Syndrome, Multiple Chemical Sensitivity, Electrosensitivity and Somatoform Disorders. The only guide primary care doctors and social security inspectors can turn to when treating patients suffering from these diseases is the one published by the Spanish Social Security Institute in 2019, which however includes an outdated bibliography and incomplete definitions. Through this initiative, the Spanish organization has asked for the immediate withdrawal, non-distribution, and revision of the guide. The primary objective of the practice is to fairly represent the rights and interests of people affected by these diseases by: providing for a standard and common definition of each pathology according to medical experts and doctors with an updated bibliography; providing for suitable guidelines to primary care doctors to treat these diseases; and improving the diagnosis and treatment of the pathologies provided by healthcare and social security systems through better medical-scientific knowledge and investigation. CONFESQ achieved an enormous consensus among different sectors of society, involving patients' associations, medical experts and doctors, and patients themselves, who widely expressed their support on social networks. Counter-documents and studies were drafted, and the content of the guide was subjected to review by a committee of medical experts. The greatest lesson that can be learned by the success of the Spanish practice is that when all the various actors manage to join forces and work together, massive changes and steps forward can be made to improve patients' quality of life. Ac-

tive Citizenship Network thanks María José Félix Mora, President of CONFESQ, for her testimony in occasion of the ceremony of June 17, 2021 [10].



The plaque realized in the occasion of the ceremony of the III Edition of the Prize on June 17, 2021 and given to the Spanish patient organization CONFESQ.

Pain Management in COVID-19

(ASST Grande Ospedale Metropolitano Niguarda Milano – Milan, Italy) [11]. This practice coming from the Niguarda Hospital of Milan has two key points: it directs attention towards patients receiving practical and effective diagnoses and therapeutic treatments during the Covid-19 pandemic; and it places importance in assisting physicians and medical professionals in their recommendations on pain management practices and treatments received by patients affected from chronic pain. The general objective of their work is to provide to all healthcare professionals the best possible diagnostic and treatment pathway in Covid-19 patients with pain, and delirium, anxiety, or dissatisfaction with sleep quality or quantity associated with pain. Specific objectives are represented by the optimization of pain management in Covid-19 patients, the enhancement and sharing of expertise about pain management, and the promotion of the continuity of care.

The initiative also focuses on relieving several notable psychological conditions that have plagued many individuals in the last year and a half alone due to the pandemic, such as anxiety, stress, and other difficulties [12]. The Hospital's therapeutic recommendations and ways in which pain can be addressed and combated during such a difficult situation align well with the objectives of the European Civic Prize on Chronic Pain that focus on the promotion of patients' rights and on the research of innovative treatments that improve the quality of life of *European citizens who live with chronic pain*. Above all, the initiative was successful in disseminating information and guidance on good clinical practice and in supporting all the healthcare professionals involved in pain management, with a particular focus to Covid-19 patients. Active Citizenship Network thanks Paolo Notaro, Director of the Pain Medicine Department of the Niguarda Hospital, for his testimony in occasion of the ceremony of June 17, 2021 [13].



The plaque realized in the occasion of the ceremony of the III Edition of the Prize on June 17, 2021 and given to the Grande Ospedale Metropolitano Niguarda of Milan.

Ethic Statement

The authors have worked in full compliance with the Code of Conduct of Cittadinanzattiva APS [13].

Results

The results of the three good practices demonstrate that effective and diverse outcomes can be reached as long as collaboration and dialogue among all the key actors in the management and treatment of chronic pain are fostered. Also, for this reason, Active Citizenship Network has reinforced an official partnership with the network of doctors specialized in pain treatment called EMNIPRE - European Multidisciplinary Network in Pain, Research and Education and, most recently, another one with the Spanish scientific society on pain called SEMDOR - Sociedad Española Multidisciplinary del Dolor [14-15].

Described by the Jury Panel as a “good example of European collaboration of multiple stakeholders across Europe”, the Societal Impact of Pain’s practice highlights the need of creating an environment which enables different actors, among which patients themselves, to work together on improving the lives of chronic pain patients and of their families. The initiative was in the area of patients’ empowerment, and it included recommendations for policy action based directly on the promotion and respect of the principles outlined in the European Pillar of Social Rights.

The practice from CONFESQ, commented by the Jury panel as a “very good project which shows that collaboration of stakeholders can make a difference and can change things for the best of those concerned”, was the winner of the category of Clinical Practices. Despite the difficulties of dialogue and collaboration with the relevant government institutions, the initiative succeeded in modifying and updating the Spanish Social Security Institute’s guide on the diseases of Fibromyalgia, Chronic Fatigue Syndrome, Multiple Chemical Sensitivity, Electrosensitivity and Somatoform Disorders.

Last but not least, the practice of the Niguarda Hospital of Milan was awarded for the special category dealing with Covid-19. The target population was represented by both Covid-19 inpatients and outpatients with pain of RED Pain Network in Milan, regardless of sex and age [16].

This pathway was implemented in all the RED Pain Network healthcare structures, shared on the RED Network website and on the healthcare organization website. 70% of healthcare professionals have successfully used these recommendations and were able to have less than 10% of patients requiring emergency treatment and more than 70% of patients with controlled pain during the disease. According to Active Citizenship Network, this experience is particularly significant as the initiative was carried out within an Italian context in which the pandemic impact was extremely high.

Discussion and Conclusion

The experiences have highlighted a general need for the implementation and exchange of recommendations and actions centered on the treatment of pain. Especially during the Covid-19 pandemic, the public and private health sectors have faced unexpected delays and unfortunate failures in pain management due to the lack of a platform that allows for the spread of knowledge among healthcare professionals and organizations. Not by chance, during the pandemic, Active Citizenship Network has collected several testimonies of patients suffering from chronic pain. In particular, during the Award ceremony held on 17 June, 2021, one testimony of a patient affected by fibromyalgia, has emphasized the dramatic situation and the feeling of abandonment, isolation, and frustration in the context of the pandemic. The lack of the opportunity to receive adequate medical consultations or modify therapeutic plans during Covid-19 led to a point in which patients were no longer considered as such [17].

This third edition allows to continue expanding the ‘agora’ of operators with good practices on pain, encouraging the exchange of experiences among health professionals, healthcare providers, institutions, civic associations, and patient advocacy groups (PAGs). One of the main goals achieved is the increased constituency of actors across Europe that are active on this topic, year by year. The winning good practices of not only this last edition, but of all the ones of the Civic Prize, clearly demonstrate that it is often the team and not the individual that wins. For instance, collaboration between the public and private sectors and dialogue between the world of research and patient associations are always present in most of these experiences.

The added value of this Civic Prize is not only to promote good practices on chronic pain across Europe, but also to foster dialogue and collaboration among the key stakeholders involved in the healthcare sector. In this regard, Active Citizenship Network, together with the “Sine Dolore European Pain Foundation” promoted in June 2016 the “Pain Euro-Mediterranean Coalition”, the first civic hub-incubator of best practices against pain across Europe. The idea was launched during the event realized at the EU Parliament “Pain therapy and the degree of patient’s pain in the age of cross-border healthcare” and it received the support of the MEPs Interest Group “European Patients’ Rights and Cross-border Healthcare” [18-21]. The implementation of this initiative was driven by the promoters’ willingness of wanting to transfer what it has achieved from the European agenda into the European culture: that is, to join forces to raise awareness, fight stigma, improve quality of life for people suffering from acute and severe chronic pain, reduce the socio-economic impact of chronic pain in Europe and ensure that the right to avoid unnecessary suffering is guaran-

teed everywhere and to everyone.

Rather than an association or organization, the “Pain Euro-Mediterranean Coalition” aims at being an open multi-stakeholder platform and an agora of good practices’ managers on pain mainly addressed to the constituency dealing with pain relief at the local and national level across Europe. Before the Covid-19 pandemic, an annual meeting was organized in Spain in the framework of the “Sine Dolore World Park” based in Menorca Island, the only theme park in the world against pain and quality of life.



Pain Euro-Mediterranean Coalition Annual Meeting 2019 at the Sine Dolore World Park, Menorca Island, Spain.

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