

## RESEARCH ARTICLE

# Digital health solutions to fight pain awarded at the European level

Manuela Amadori<sup>1</sup> Daniela Quaggia<sup>2</sup> Mariano Votta<sup>2\*</sup>

**Abstract:** In 2017, Active Citizenship Network (ACN) launched the second edition of the bi-annual research-project conducted at the European level and entitled “EU Civic Prize on Chronic Pain - Collection of good practices”. This initiative aims to provide evidence of existing good practices in terms of struggle against pain across Europe. In particular, this second edition allowed ACN to give continuity to the successful collection of good practices in the struggle against pain that was started in 2015, as well as to expand the “agora” of operators of good practices on pain, encouraging the exchange of experiences among health professionals, healthcare providers, institutions, civic associations and patient advocacy groups. This article describes the main results of the second edition of the research: 40 good practices gathered from several EU countries and 4 winning best practices. The latter are all mobile apps and thus demonstrate the growing role of digital health in the treatment of chronic pain. The full research has been published in the Report entitled “Collecting Good Practices European Civic Prize on Chronic Pain Second Edition”, edited by Cittadinanzattiva Onlus (all rights reserved).

**Keywords:** digital health, good practices, pain, EU, civic activism

## 1 Introduction

In 2014, for the first time at the European level, the issue of chronic pain was included within the agenda of the EU institutions<sup>[1]</sup>. It is of paramount importance that the public feels empowered to voice their support. In the same year, the Italian citizens organization Cittadinanzattiva Onlus - through its EU branch called Active Citizenship Network (ACN) - started a research-project with the aim of giving evidence of existing good practices in European countries in terms of struggle against pain. These practices were presented at the EU Institutions two weeks later the EU Health Ministers’ discussion on pain therapy and palliative care.

In 2015, after several years of work on this issue, Active Citizenship Network started the multi annual research-project “European Civic Prize on Chronic Pain - Collecting Good Practices” with the following aims: to keep attention focused on chronic pain as a health prior-

ity locally, nationally, and at the EU level; to encourage the exchange of experiences between professionals and patients’ associations; to raise awareness among institutions about the need to identify chronic pain as a priority in health policies and programs at EU and national levels; to create a body of evidence that can be used to support the expansion of programs tailored to the care and treatment of patients with chronic pain; to raise awareness about the technological advances and their impact on the treatment of chronic pain.

The establishment of a “European Civic Prize on Chronic Pain”, based on the selection of the practices presented by different healthcare stakeholders (patients’ associations, health professionals, private and public hospitals, universities, etc.), provides an occasion for demonstrating what this community can offer in terms of experiences which are useful to raise awareness of the situation, enhancing the body of knowledge of positive cases and successes and strengthening commitment to this topic.

## 2 Text

Chronic pain is a serious healthcare condition that negatively affects the quality of life of patients at the physical as well as psychological level.

In Europe, patients’ associations and other organisations have already committed to fight unnecessary cancer and not cancer-related pain. Likewise, European Institu-

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\* **Correspondence to:** Mariano Votta, Active Citizenship Network, c/o Cittadinanzattiva Onlus, Via Cereate, 6-00183 Rome, Italy; Email: [m.votta@cittadinanzattiva.it](mailto:m.votta@cittadinanzattiva.it)

<sup>1</sup> International Development and past Project Assistant at Active Citizenship Network, 42 Rue de Gerlache, 1040 Etterbeek, Belgium

<sup>2</sup> Active Citizenship Network, c/o Cittadinanzattiva Onlus, Via Cereate, 6-00183 Rome, Italy

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tions and policy makers have understood the magnitude of the problem. It is evident that chronic pain requires a better legal and political support both at the national and European level. Despite there have been several improvements in the last few years, too many patients suffering from chronic pain are still not entitled to receive the necessary assistance. What is affirmed in theory, it is often denied in practice. Improvements and concrete actions against unnecessary pain are certainly needed everywhere.

Active Citizenship Network (ACN) is a citizen organization that deals with pain and that is therefore used to listen and collect complaints about the unmet needs of citizens and patients daily. For ACN, it is crucial to gather and share good practices, to identify priorities and recommendations, and to foster the commitment of patient associations, professionals and healthcare institutions. At the same time, it is also fundamental to promote concrete activities involving local and international stakeholders in order to transfer what we have achieved from the European agenda into the European culture. This means that it is time to raise awareness, fight stigma, improve the quality of life of people suffering from acute and severe chronic pain, and reduce the socio-economic impact of chronic pain in Europe by ensuring that the right to avoid unnecessary suffering is guaranteed everywhere and to everyone. Accordingly, and with the broader aim of making visible the invisible, Active Citizenship Network has decided to promote the project “EU Civic Prize on Chronic Pain - Collecting good practices”. The initiative was launched in 2015 and aimed at providing evidence of existing good practices in terms of struggle against pain in European countries.

Before going on to the description of the project, it is necessary to clarify what we mean by “good practice”. According to the citizens, good practices are identified as all those actions with a positive impact on the quality of public services, the protection of citizens’ rights, the promotion of civic participation, and the enhancement of human resources. In particular, they are very successful initiatives aimed at improving the efficiency (cost) and the effectiveness (as a way of appropriately meeting the needs and expectations of the citizens) of the management and provision of services of public utility.

The establishment of a “European Civic Prize on Chronic Pain” which selects and collects practices presented by different healthcare stakeholders (patients’ associations, health professionals, private and public hospitals, universities, etc.) provides an occasion for demonstrating what this community can offer in terms of good practices and experiences. The latter are indeed useful to raise awareness of the current situation, enhance the

body of knowledge of positive cases and successes, and strengthen commitment to this issue.

Throughout 2018 and 2019, this initiative has allowed us to collect 40 Good Practices coming from 12 different countries: Spain (13), Italy (10), Portugal (5) Belgium (3), France (2), Malta (1), Sweden (1), Germany (1), The Netherlands (1), Ireland (1), UK (1), and an extra EU country (1 from the Dominican Republic).

Divided into 4 categories (patients’ empowerment, innovation, professional education, clinical practices), the good practices were evaluated by a pool of international experts in chronic pain. Besides a representative of ACN, these experts came from the European Pain Federation (EFIC), the Sine Dolore European Pain Foundation, the European Hospital and Healthcare Federation (HOPE), the European Union of Private Hospitals (UEHP), the Pain Alliance Europe (PAE), the European Confederation of Care Home Organisations (ECHO), the European Multidisciplinary Network in Pain Research and Education (EMNIPRE), the European Headache and Migraine Alliance (EHMA) and from a retired university professor.

The main characteristic of the second edition of the “European Civic Prize on Chronic Pain” is that the 4 awarded best practices are all digital solutions for everyone, more precisely mobile apps. This underlines the growing role of digital health in the treatment of chronic pain. Indeed, today patients and Health Care Professionals have at their disposal a dizzying array of healthcare apps, which can be employed as part of the wellness, prevention or treatment regimes<sup>[2]</sup>. Although this is certainly an interesting opportunity, we also need to consider what level of empowerment is required for patients to be able to take full advantage of these apps. For instance, “there is some evidence that integrating digital health technology into older peoples’ pain self-management plan is feasible and acceptable. However, the provision of high-quality technological interventions informed by a thorough understanding of older people’s digital technology pain management needs is required to ensure greater integration of this technology in clinical practice”<sup>[3]</sup>.

### 3 Materials and methods

The aim of this paragraph is to provide enough details for each best practice awarded by the experts.

#### 3.1 “MyDystonia” – winner for the category “patients’ empowerment”



MyDystonia, developed by Dystonia Europe (Belgium), is an electronic diary available as a web-based service and as a mobile APP for dystonia patients to record and analyze the impact of the disease on everyday life. By answering predefined questions (*e.g.* core symptoms like overactive muscles or pain; impact on daily living; *etc.*), the user is able to examine and to visualize their well-being according to the treatment schedule. The digital diary is designed to support and potentially improve patient-physician communication as the collected data can be presented and discussed with the treating physician or other patients in order to track the treatment's outcome and to define potential treatment goals in order to attempt an optimized treatment approach. In the long-term, the objective is that all dystonia patients use the MyDystonia APP. The collected anonymized data can provide important information and knowledge on the daily life of dystonia patients and could lead to further research projects, improved treatments and hopefully a better quality of life for people living with dystonia.

### 3.2 “DTX for PAIN” – winner for the category “innovation”



It is a digital therapeutics – developed by Lucine Group (France) – able to relieve patient's pain through active substances allowing analgesic neurostimulation. Customized, this option is adapted to each patient thanks to the measurement and analysis of pain through facial, vocal, and postural recognition. “DTX for PAIN” is the first digital solution that can measure and analyze patient's pain level using facial, postural, vocal and environmental recognition. The smartphone's camera analyzes the mobility of the face, the body, the emotional expressions, the semiotics of the language and the modulation of the patient's voice. After analyzing the data, “DTX for PAIN” delivers an objective measurement of the patient's pain level on a scale from 1 to 100 and analyses pain biomarkers. It is the first digital therapeutics to provide health solutions that act as an analgesic without the absorption of a conventional molecule. Thus, to relieve pain, it offers a library of “digital health therapeutics”. By relying on the cognitive and chemical abilities of the patient's brain, “DTX for PAIN” can lead to a chain of chemical antalgic responses thanks to auditory, visual and sensory stimulations. It uses two technological bricks: the first one is the machine's learning and deep-learning process for the identification of sub-

jective and objective pain biomarkers; the second one is the use of external stimuli leading to the physiological production of natural painkillers such as B-endorphin, serotonin, dopamine, etc. The use of behavioral therapies for a deep transformation of pain mechanisms is extremely important.

### 3.3 “RED App” – winner for the category “professional education”



Developed by Niguarda Hospital (Italy), RED App is a mobile application with 4 main objectives: a) being a compass for citizens and general practitioners by providing information about pain care and the local Pain Care Network of Milan (“RED network”: centers, services, settings, contacts); b) facilitating communication between patients/primary care physician and pain care centers; c) sharing information and documents for physicians and patients on clinical pathway protocols and treatments; d) supporting the patient empowerment and the patient flow management within the network. The final goals are to enable the prompt access of patients referred by their general practitioners to the pain care specialists and - second - to improve the quality of pain care throughout the health-care system by defining and sharing care protocols on the most common pain syndromes.

### 3.4 “Rise-uP” – winner for the category “clinical practices”



Schmerznetz  
Bayern

“Rise-uP” is the main output of a project developed by Center of Interdisciplinary

Pain Medicine, Dep. of Neurology, MRI Munich, Technical University of Munich, Germany.

It aims to overcome the less structured treatment of acute and subacute unspecific low back pain in Germany. Although evidence has been provided which underlines the insufficient long-term efficacy of the present practice, *i.e.* not indicated surgery, medication or imaging, these measures still prevail with high costs for the health care system. In contrast, evidence-based interventions fostering patients' empowerment are widely neglected. Furthermore, patients with increased risk of developing chronic pain are often not identified and treated insufficiently. Rise-uP aims to establish a guidelines-oriented treatment algorithm including telemedicine and mHealth coordinated by the general physician. The cores of the concept are twofold. Firstly, the main intervention is the Kaia App, a multidisciplinary back pain app providing the pillars of the multimodal pain therapy - physical

exercise, psychological elements (mindfulness) and educational content about low back pain - on the patient's mobile device. A daily training program is tailored to the particular patient via an algorithm and the patient is recommended to use the app "as often as possible". Secondly, the risk of developing chronic pain is determined in the beginning of the treatment via a questionnaire (StartBack). Furthermore, questionnaires regarding pain intensity, functional ability, psychopathological symptoms and life quality are completed by the patient on a tablet on the first appointment with the GP. Then these data are transferred to a server. Patients with a high risk of developing chronic pain are monitored. Additionally, a pain specialist gets involved via telemedicine from the beginning of the treatment to maximally prevent the development of chronic pain. A shared electronic case report form which also guides the general practitioner through the treatment algorithm provides access to the patients' data to all involved professionals.

### 3.5 Ethic statement

The authors have worked in full compliance with the Code of Conduct of Cittadinanzattiva Onlus<sup>[4]</sup>.

## 4 Results

The four good practices awarded highlight the growing importance of smart and cost-effective solutions offered by eHealth & mHealth. At the same time, however, these innovations make us wonder if such opportunities are actually available to everyone or if – due to the digital divide existing among the different population's groups within and especially between countries – they could involuntarily sharpen health disparities. After all, according to the Digital Economy and Society Index (DESI), over the past few years all EU countries have improved their digital performance. Yet, some countries still have a long way ahead, and the EU as a whole needs improvement to be able to compete on the global stage<sup>[5]</sup>. Therefore, we find it necessary to complement innovation for the benefit of patients with a simultaneous investment into patient empowerment, also calling for the effort of caregiver and advocacy groups.

Overall, the 40 good practices that have been collected during the second edition of the initiative, together with the 30 practices gathered during the first cycle of the research (2016/2017), constitute an asset that deserves to be value as much as possible. Consequently, these practices will be shared in the framework of the "EU Health Policy Platform" expert group on pain hosted by the European Commission and called "Societal Impact of Pain- Stakeholder network group". Meanwhile, we

are working on the creation of an informal network of operators of good practices, which is meant to become the first civic center for the incubation of best practices against pain in Europe.

Furthermore, better cooperation with the European Commission will be encouraged in order to:

a) value the good practices collected during the different editions of the "European Civic Prize on Chronic Pain" by hosting them within the EU Best Practice Portal promoted by the EU Commission;

b) consider a potential expansion of the "Area/Topic of interest" search list on the EU Best Practice Portal by adding a new specific subject area: Pain/Chronic Pain, cancer and non-cancer related.

## 5 Discussion and Conclusion

The experience and the main output of the research-project suggest how relevant is it, in the field of pain, to develop a policy on good practices rather than only spot initiatives, so as to act in line with the practices of EU Institutions which stimulate the collection of good practices in each field of action. The initiative testifies the positive role played by professionals, users, citizens, public bodies as well as private actors involved in public policies. Despite their tendency to criticise the failures and weaknesses existing within the system, they have demonstrated their appreciations and support of successful practices. Moreover, the project shows that the role of advocacy groups is that of identifying not only emerging problems, but also possible solutions to denounce what doesn't work properly and to appreciate what proves to be successful.

As for us, we have been committed to this research-project for years and, consequently, we will strive to recover and promote as many good practices as possible. We are well aware that the constituency of actors sensitive to the fight against pain becomes wider and stronger every year and we are very happy of this outcome, given the role that we would like to play in this area.

### Conflict of interest and funding

The second cycle of the bi-annual research-project entitled "EU Civic Prize on Chronic Pain - Collection of good practices" has been made possible thanks to an unrestricted grant from Grünenthal GmbH and Pfizer Inc.

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