First edition

Collecting Good Practices

European Civic Prize on Chronic Pain

ACTIVE CITIZENSHIP NETWORK

BEST PRACTICE RECOGNIZED BY
ACTIVE CITIZENSHIP NETWORK

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CHAPTER 1 - Introduction

1. Foreword

On 11 January 2014, the Italian Council of Ministers adopted a document laying out the preliminary plans of the Italian Presidency of the Council of the European Union indicating pain therapy and palliative care as areas of focus during the Italian Presidency.

Putting pain therapy and palliative care on its agenda allowed the Italian Presidency to position Italy as a pioneer in this field and share the Italian experience with other Member States (especially with regard to the best practice law 38/2010 on palliative care and pain therapy).

Above all, it promoted also a greater awareness of the issue of chronic pain therapy among EU and national policy and decision-makers and over the longer term, in order to reduce the negative impact of chronic pain on EU society. This could pave the way to a better future for patients in Europe suffering from chronic pain.

Cittadinanzattiva Onlus and its European branch Active Citizenship Network (ACN), being deeply involved in the European and national debate on patients' rights against unnecessary and useless pain, welcomes the EU Institutions' commitment to tackle the issue of pain therapy and palliative care and would be delighted to contribute to the agenda and content setting with this regard. Based on the activities undertaken by previous Presidencies in the area of health, the initiative outlined below (solely or combined with an integrated approach) could be considered by the EU Institutions and relevant stakeholders in order to promote the debate on palliative care and pain therapy in the EU agenda.

2. Background

Cittadinanzattiva Onlus has more than 30 years' experience in protecting citizens' rights in the health sector, which began at national level with the Tribunale per i diritti del malato ("Tribunal for Patients' Rights" or TDM) in 1980 and was later strengthened through the Coordinamento Nazionale Associazioni Malati Cronici ("National Coordination Centre of Chronic Patients' Associations") in 1996. Since 2001, with Active Citizenship Network (ACN), Cittadinanzattiva started to promote civic participation and protection's rights at European level too, gathering almost 100 civic and patients organisations all over the Continent.

Over the last 15 years, Cittadinanzattiva and Active Citizenship Network have been increasing their contributions to the promotion and protection of citizens' rights against useless pain by supporting:

- Protection against violations of the right of individual citizens;
- Promotion of information and awareness-raising campaigns;
- Actions designed to promote cultural changes;
- Institutional mediation;
- Production of citizens' information;
- Collection and dissemination of best practices.

Cittadinanzattiva's commitment to the promotion and provision of incentives for service improvement, innovative approaches, and policies focused on community orientation has very deep roots. In 1988, during the tour of the “Minibus of rights”, Cittadinanzattiva rewarded health services operators for favouring the protection of citizens' rights. These service improvements that led to the sharing of knowledge between policymakers, patient organisations, and, most importantly, the improvement of the lives of those living with chronic pain. Over the years, Cittadinanzattiva has refined and honed its assessment tools to establish a definition of Good Practices that identify the key programmatic features as well as instituting awards dedicated to the public acknowledgement of these Good Practices and real databases. Concurrently, Good Practices began to be identified in many and varied contexts, with a consequent increase in the number of health service awards and recognitions distributed in Italy. In the space of chronic non-cancer pain, Good Practices are an important part of the policy pursued by Cittadinanzattiva at national and European level. At the Italian level, for example, Cittadinanzattiva manages an important prize, the "Andrea Alesini Award for the humanisation of care" in which the pain management is relevant. At European level, in 2012-2013, ACN and Pain Alliance Europe published a report highlighting a collection of Good Practices to avoid unnecessary suffering and pain.

In 2014, for the first time, the issue of chronic pain was put on the agenda of the EU institutions. It is of paramount importance that the public feels empowered to voice their support.

A few of Cittadinanzattiva and Active Citizenship Network's initiatives promoted and implemented can be read here: http://activecitizenship.net/patients-rights/projects/83-the-engagement-of-cittadinanzattiva-in-the-fight-against-useless-pain.html

3. Project Description

In 2015, Active Citizenship Network (ACN) started a research-project, that is the **"European Civic Prize on Chronic Pain - Collecting Good Practices"**[1] with the aim of giving evidence on existing good practices in several European countries in terms of struggle against pain. In particular, the research allowed ACN to give continuity - expanding it with some specificity – to the investigation for good practices in the struggle against pain started in 2012.

Aims of the project:

1. Raise awareness among Institutions about the need to identify chronic pain as a priority in health policies and programmes at EU and national levels;
2. Encourage the exchange of experiences between professionals and patient associations;
3. 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;
4. Raise awareness about the technological advances and their impact of the care and treatment of chronic pain.

This project has collected Good Practices on chronic pain (cancer & non-cancer related) which will be presented in a public event and shared by this report. The final event of the Prize is going to be celebrated during the SIP - Societal Impact of Pain Symposium 2017 - taking place in Malta on 8-9 June 2017, during the Maltese Presidency of the EU Council. It will be a recognition of ongoing excellences and, after a lot of important national

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[1] http://activecitizenship.net/patients-rights/projects/204-european-civic-prize-on-chronic-pain-collecting-good-practices.html

recognitions[2], the FIRST EUROPEAN award too: "EU Civic Prize on Chronic Pain".

The collection of Good Practices has involved the networks and contacts of ACN in Europe. A Jury panel (composed of experts, doctors, leaders of patient organisations, representatives of Institutions) has been created as well. Its role has been mainly focused on the definition of methodological aspects of the project, of criteria and categories for collecting good practices as well as on the selection of the winners.

Members of the Jury panel

Organization	Jury Member	Delegate
European Union of Private Hospitals	Paul Garassus	Ilaria Giannico

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[2] Over the years, Cittadinanzattiva has established specific national awards for the humanization of medical treatment and fight against pain: the "Andrea Alesini Award for the humanization of care" (since 1997) in which pain management is an important issue; the "National Prize on Chronic Pain Nottola - Mario Luzi" (since 1997) organised by Cittadinanzattiva-Tuscany.

Moreover, other Italian awards related to pain are: the Journalist Award "38 VOLTE BASTA!" promoted by Antea Onlus; Premio Giornalistico "Vivere senza dolore" promoted by the patient association "Vivere senza dolore"; the national award "Un ospedale con più Sollievo" promoted by the Fondazione Ghirotti; "Gerbera d'oro 2014" awarded by the Conferenza delle Regioni and by the Fondazione Ghirotti to healthcare structures which are in the front line in fighting unnecessary pain; "Isico Award", promoted by Isico (Istituto Scientifico Italiano Colonna Vertebrale) to award research and studies in localized pain (headache, cervical pain).

In Spain, "Premio ALGOS" to help raise awareness of pain in children, promoted by ALGOS, a research group dedicated to the study and treatment of pain.

European Confederation of Care Home Organisations	Alba Malara	
The European Pain Federation EFIC	Chris Wells	Brona Fullen
European Multidisciplinary Network in Pain Research and Education	Jordy Moya	
PAE-Pain Alliance Europe	Joop Van Griesven	Marian Jill Nicholson
Ligue Nationale contre le cancer, Cancer Contribution (France)	Silvia Rossi	
HOPE European Hospital and Healthcare Federation	Pascal Garel	
Active Citizenship Network	Mariano Votta	Daniela Quaggia
Indipendent Expert (*Emeritus Consultant in Pain Medicine University Hospitals of Leicester NHS Trust*)	Beverly Collett **President of the Jury Panel**	

CHAPTER 2 - Guidelines for the collection of Good Practices

Applicants have identified and given details of initiatives that they or their organisation have experienced firsthand and which met four basic criteria. Applicants submitted an online form on ACN website[3] divided into the following parts:

- **contact details** (name and surname, organisation, country, email) with a short description of the person/organization;
- **description** of the good practice: title, category (innovation – clinical practice – patients' empowerment – professional education), actors involved, location (where the initiative took place), duration (start and ending dates), brief description of its objectives, outcomes/impact on participants (explaining which benefits have been identified as a result of the good practice), indispensable resources to carry out the initiative (human and financial resources, logistic facilities, information, experiences, etc.);
- **analysis**: development of the good practice (brief description of the main activities), obstacles faced (economical, cultural, managerial, etc.) and means used to overcome or remove them, factors enabling the process;
- **evaluation**: the criteria to be met are 1)reproducibility (is it possible to reproduce and implement the good practice in other situations and places?), 2)innovation (has the good practice produced any innovative solutions?),3) added value (was the good practice more helpful than the solutions previously used?), 4)appropriateness (has the good practice produced an efficient problem management?);

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[3] http://activecitizenship.net/patients-rights/projects/204-european-civic-prize-on-chronic-pain-collecting-good-practices.html

- **next steps:** answers to these questions: if another country/organisation attempts to implement your good practice, what advice would you give them regarding the lessons learned? What are the two key ‘take home messages’ about your good practice that you want to convey?
  If applicable, what are the next steps of your organisation for your good practice?
- **other information:** add any other relevant information not mentioned in the form (i.e. links to web pages, etc.).

Criteria used to select the good practices:
In order to be considered as a Good Practice, the identified initiatives must be concluded or be ongoing and must meet all the following criteria:
1. Reproducibility – It must be possible to transfer and implement the identified practices in situations and places different from the ones where they were observed. → What is it? A practice that could be reproduced in another country/hospital/patient/university etc. → What is it not? Cases where the conditions that make the initiative possible are exceptional.
2. Innovativeness – The capacity of producing new solutions. → What is it not? The mere application of an existing guideline, regulation or law. However, an example of a good practice could be where an existing guideline, etc. is applied in a particularly innovative way.
3. Added Value – The capacity of the identified practice to produce a greater impact on the situation.
4. Appropriateness – A practice enabling an efficient and effective management of an issue. → What is it not? Example: a series of meetings between the mayor of Rome and citizens was implemented at the neighborhood level in order to fill the gap between the city administration and the people. Thousands of persons participated in these meetings but each one expressed their individual demands and these were too specific, thus

hindering the possibility of answering the population's general demands.

Specific categories:

The good practices must fall under one of the following categories:

- **Patients' empowerment**

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

- **Innovation** (legislative and technological)

Good practices concerning: laws, technologies, apps, etc.

- **Clinical practices**

Good practices concerning: pain management (prevention, diagnosis, treatment and monitoring), dedicated units, therapeutic pathways, clinical records, ways of measuring pain, etc. Practices involving patients were highly valuable.

- **Professional education**

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

These categories are based on the Pain Patient Pathway Recommendations developed and subscribed by 21 civic and patients organizations dealing with chronic pain[4] in 2012-2014.

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[4] http://www.activecitizenship.net/patients-rights/projects/87-pain-patient-pathway-recommendations.html

CHAPTER 3 – Good Practices and the Winners

1. Good practice: the policy of Cittadinanzattiva at National and European level

The process of seeking, encouraging, rewarding and promoting good practices is - today more than ever - one of the imperatives of the mission of Cittadinanzattiva, that is to contribute to turn the individual experiences into a “system” and place citizens at the heart of services. It is therefore important to acknowledge the spirit of human research in contributing to the service and the promotion of actions of individual citizens, with the view of creating a network of “good operators" which shall bring a bottom-up change in the relationship between citizens and Public Healthcare providers and according to the principle of subsidiarity. Cittadinanzattiva has developed over the time a unified strategy in the definition and identification of good practices that goes beyond the scope of specific areas of reference (healthcare, education, etc.) and uses the same evaluation criteria. Even the goals and the tools used to collect best practices are the same: press, network, databases, juries of experts to evaluate the projects reported on the basis of the above four criteria.

2. Definition of Good Practice

The collection and dissemination of good practices have a key role in the protection of citizens and patients’ rights since they allow to:

- bring to light the possibility of immediate change in the organisation of services without new laws or particular investments;
- valorise the action of those who strive to improve their work and “draw them to one’s own side” stigmatising, conversely, negative behaviours unjustifiable in front of good practices;
- introduce incentives in the organization of services in order to empower those involved;
- promote the spirit of emulation.

Given the difficulty of collecting good practices through occasional initiatives and actions, the best way to deal with this issue is promoting specific programmes aimed at this purpose. Among the most useful and most effective ones there is certainly the promotion of awards and competitions. But what is a good practice? Good practices are actions whose very nature lies in the impact on the quality of 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 to meet, in an appropriate manner, the needs and expectations of citizens) of the management and provision of services.

3. Geographical impact of the collected good practices

This collection allowed us to receive **30 Good Practices.**
They come from 11 different countries:

(Malta 2; UK 6; Spain 8; Portugal 2; Ireland 1; Italy 6; Germany 1; Denmark 1; Finland 1; Netherlands 1; Russia 1)

4. About the categories

Regarding the Categories (-Innovation -Clinical practice -Patients -Empowerment -Professional Education) most of them are related to patients' empowerment (22 out of 30); about half of them (12 out of 30) are related to Innovation and Professional Education and just 9 out of 30 to Clinical practice. [Considering that the applicant could chose more than one category].

5. Actors and promoters

The principal actors of the good practices are, first of all, national and European patient associations, then universities and (public and private) hospitals. National or regional health institutions are involved or promoters of good practices.

6. The 4 Winners

On 28 February 2017 the Jury has selected the 4 winners of the prize, evaluating them for each of the four Criteria described above (reproducibility -innovation -added value -appropriateness), one for each requested category. The winners will be given an expenses-paid visit to other winners’ headquarters and a publication in English on a suitable journal.

The winner for the category CLINICAL PRACTICES is the Good Practice number 3:
"Physical activity in women with fibromyalgia: the al-Ándalus project" from the Department of Physical Education and Sport, Faculty of Sport Sciences, University of Granada, Spain.

Beverly Collett, President of the Jury Panel commented: *"This is an excellent well-organised collaborative project involving 8 universities in Andalusia, multidisciplinary teams and patient organisations. Also, an external academic link for researchers has been established. This work has incorporated sites outside of the traditional health care settings, i.e. private gyms, and swimming pools and investigated a condition that is often neglected by health care professionals".*

The winner for the category PATIENTS' EMPOWERMENT is the Good Practice number 21:
"At lessons from the expert patients: advices for the physicians to improve their care of cluster headache patients" from the Alleanza Cefalalgici Cluster, European Headache Alliance, Italy

Beverly Collett, President of the Jury Panel commented: *This work showed great innovation in gathering expert patients in four countries across Europe to assist health care practitioners in the management of Cluster Headaches. It is a very well thought out submission on an uncommon, but important, painful condition. It is good to see everyone working together to highlight this condition, which if recognised should improve the management of patients with this condition and improve their quality of life.*

The winner for the category INNOVATION is the Good Practice number 12:
"Non pharmacological treatment of chronic pain: a multimodal approach." from San Raffaele Hospital, Italy

Beverly Collett, President of the Jury Panel commented: *"This work is truly innovative. The team are using virtual reality setting plus neuropsychological support to permit the development of personalised specific rehabilitative exercises, plus remote communication with patients home. It is really very exciting".*

The winner for the category PROFESSIONAL EDUCATION is the Good Practice number 16:
"Patients as Teachers in Health Professional Education" from the Pelvic Pain Support Network (PPSN), UK

Beverly Collett, President of the Jury Panel commented: "*Many universities are using patients as part of undergraduate education, but this is the first time that I have seen the course formally written up. It is excellent that this now involves two universities, and I hope that there are plans to increase uptake of this type of education in other universities and for other conditions. Excellent that the patient and a family member have been involved as this does emphasise the family impact of pain. Well worked systematic involvement of patients in formal nursing and medical education. Shows good collaboration between patients, educators and clinicians".*

2. Good practices list:

Good Practice Number 1	
CONTACT PERSON	
Name:	Jake
Surname:	Fenech
Organisation:	University of Malta, Faculty of Health Sciences
Position:	Undergraduate Student
Country:	Malta
Email:	jake.fenech.12@um.edu.mt
Short description of the person submitting this project	She is a physiotherapy student currently in her final year of studies to graduate as a physiotherapist. As part of her final year, she performed a study on chronic pain patients with satisfactory results.
DESCRIPTION	
Title of the good practice:	Newly developed application for chronic low back pain
Category:	Innovation Clinical practices
Who are the stakeholders involved in the Good Practice?	
Healthcare Organisation(s) :	National Musculoskeletal O/P departments

Health Professionals:	Physiotherapists
University:	University of Malta
Location:	G' Mangia, Marsa Malta
Start Date:	04/2015
End Date:	05/2016
Objectives:	1) To design a patient-centered smartphone application serving as a pain assessment tool with the main function of recording and tracking pain. 2) To create a functional application that is feasible for both the patient and the health care professional. 3) To scientifically evaluate the validity, reliability and usability of the application.
Outcomes **Impact on participants:**	After testing the application and comparing it to the NRS, it was found to be a valid and reliable tool as all the participants showed a positive attitude towards the usability of the application. The researcher acknowledges that generalizations should not be made and though the application worked in these restricted circumstances, results may vary with other conditions. The researcher also recognizes that the application is still in its prototypical stage so further developments would be required. Nonetheless, the results obtained show a great potential and a satisfactory proof- of-concept. Ultimately, the aim of creating a smartphone based application that is valid, reliable and usable was reached. Hence,

	within these restricted parameters, the presented hypothesis of no statistical difference between the application and the NRS can be supported.
Resources:	Dr. Carlo Conti (dissertation supervisor), Lecturers of Physiotherapy at the University of Malta, Physiotherapists at the Musculoskeletal O/P department, Patients that were willing to take part in the study.
ANALYSIS	
Development of the good practice	A random sampling technique was chosen to recruit participants in the study. CLBP patients that were being treated by a physiotherapist at a musculoskeletal outpatient department were chosen as the study population due to their frequency and constant nature of their pain. An application, called “Pain in the App”, was developed for this study in collaboration with the Faculty of Information and Technology at the University of Malta. After approving to take part, the application was transferred onto the participants’ smartphone for the 30 day collection period. Patients were suggested to input data 3 times a day and/or any time their pain had fluctuated. The application recorded data regarding the intensity of the pain, the location by drawing on a 3D body diagram inbuilt into the application, a description of the pain and any additional information regarding what caused or eased

	the pain. Following data collection, a modified questionnaire was distributed to the participants. Statistical analysis was then performed to see whether the objectives were reached.
Means used to overcome or remove the obstacles detailed above	1) Numerous meetings and testing until the application was smooth running and able to collect data. 2) Including more than 1 musculoskeletal O/P department to increase the chance of finding eligible participant. 3) Using the save function were information is saved on the participants phone prior to being sent
Factors enabling the process	Physiotherapists willing to help recruit as many eligible participants willing to take the time to fill in the data and meet up in order to fill in the questionnaire
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	As of yet, it is unknown whether it is reproducible as it was done on a limited amount of people suffering from a particular condition. Further studies would be required on a larger population and on various conditions.
Innovativeness:	No such tool is currently in use in Malta. As part of the literature review, I looked at what studies regarding such applications concluded. The research yielded information of lack of scientific evaluation

	of such applications or lack of research behind their design. To the best of my research none of the applications were evaluated for its validity, reliability and usability and no such study has been performed here in Malta.
Added value:	Able to give more accurate and representative data regarding the patient's pain. It gives a sense of empowerment and active role in managing this condition.
Appropriateness:	Allowed more accurate representation of the data and subsequently avoided the need for remembrance of the data
NEXT STEPS	
Lessons Learned:	Such applications have a great potential in recording data and would allow for a more accurate representation of the painful episode, guiding the physiotherapist better for a more effective treatment
Key Takeaways:	The application developed was found to be valid, records data in a reliable manner and is liked by the participants that used it.
Next Steps:	The next step is to further test on a larger sample of people and to include not only a different range of musculoskeletal conditions, but also a number of different patients, such as those with cardiac and neurological issues, amputees, etc.

Good Practice Number 2

CONTACT PERSON	
Name:	Susan
Surname:	Childs
Organisation:	Chelsea and Westminster Hospital NHS Foundation Trust
Position:	Consultant Clinical Psychologist
Country:	United Kingdom
Email:	susan.childs@chelwest.nhs.uk
Short description of the person submitting this project	She is the joint project leader with Dr. Bianca Kuehler (Specialty Pain Doctor). They wrote the project together after observing that survivors of torture did not attend scheduled pain management psychology sessions well, despite often presenting with symptoms and difficulties that were associated with psychological distress. They realised that they needed a more holistic approach to accessing pain management advice and interventions. Dr. Susan Childs, Clin Psych D., is a Consultant Clinical Psychologist who works in a major London based NHS Trust and provides the lead for the therapies arm of their pain management services. She has specialised in Chronic Pain since her doctorate in 1999 and has written and provided both 1:1 and group services for a number of trusts. Susan specialises in writing and providing pain management services matched with local populations that are

	sensitive to population and cultural needs. Dr Bianca Kuehler, is a Speciality Doctor in Pain Management. She initially qualified in Germany as an Anaesthetist in 1993 and is on the specialist register in the UK. In 1997 she began to focus on acute and chronic pain and later specialised in this field. After moving to the UK she obtained a Diploma in Occupational Health to supplement the understanding and implication of chronic pain on the work environment. She has worked over the past few years to provide outstanding multidisciplinary services in the treatment of chronic and acute pain.
DESCRIPTION	
Title of the good practice:	A one stop multidisciplinary pain clinic for Survivors Of Torture
Category:	Empowerment Innovation Clinical practices Professional education
Who are the stakeholders involved in the Good Practice?	
Civic Organisation(s):	National Health Service
Healthcare Organisation(s) :	The Chelsea & Westminster Hospital, 369 Fulham Road, SW10 9NH. Freedom from

	Torture Foundation The Helen Bamber Foundation
Health Professionals:	Dr Susan Childs: Clinical Psychologist Dr Bianca Kuehler: Specialty Doctor Ms Sarah Thomas: Clinical Nurse Specialist Lead Mr Nikola Petrovic: Assistant Psychologist Ms Felicity Gibbons: Assistant Psychologist Ms Katy Benneworth: Specialist Pain Management Physiotherapist
Location:	London, United Kingdom
Start Date:	01/2015
End Date:	08/2026
Objectives:	A. To identify Survivor of Torture (SoT) patients in a timely manner and offer direct access into appropriate services for SoT, thereby reducing risk of vicarious retraumatisation. B. The one stop format of this assessment clinic aims to reduce unnecessary retraumatising by having multiple appointments with different health care professionals. C. To offer SoT clinics during quieter periods in the outpatient department insuring less chance of psychological distress. D. To offer a medications review clinic to minimise risk of occidental/intentional overdose and contraindication issues. E. To educate SoT patients about pain medications and counter possible cultural beliefs about Western medication being stronger, or “the bigger the dose the better the effect.” F. To offer a pain physician and psychological assessment in a safe and culturally sensitive environment so that SoT patients have a clear pathway to

	investigations and treatments and time to understand what these involve reducing vicarious retraumatisation. G. To help SoT patients understand better why chronic pain is different from acute pain and that the central nervous system is involved. H. To look how much central sensitization plays a role in the presentation of their symptoms. I. To offer matched investigations and treatments to the patient's needs and identified life values and goals. J. To develop a new compassion focused therapy group to introduce and practice pain management strategies. K. To offer SoT patients the opportunity to work with defined staff members to allow a relationship of trust to develop. L. Swift referral to psychiatric services for patients who have severe mental health issues.
Outcomes Impact on participants:	This group of patients would typically avoid attending psychology appointments; as though they feared their pain and suffering would be explained away by mental illness. They might present with uncontrolled psychological illness/symptoms. They decided that the easiest way forward is to offer a combined appointment. Little is currently known about the impact of chronic pain on survivors of torture in the UK and they have started trying to understand the presentation issues more fully for this vulnerable patient group. Outcomes collected to date include: 1. Survivors of torture now attend more frequently to the pain clinic than before the specialist SoT clinic began (evidenced by attendance rate /

	DNA's). Previously nonattendance (DNA) rates were higher than for other pain patients. 2.Telephone interviews with 6 SoT patients who attended when the service was first created indicate higher patient satisfaction and knowledge of what treatments were offered. 3.Survivors of torture are facilitated access to physiotherapy and pain management sessions with a psychologist (evidenced by attendance rate / DNA's). 4. Clinicians have gained a better understanding of this patient group and their beliefs and the impact of their pain upon their lives and self-efficacy. (As evidenced by the Brief Pain Inventory (English & Arabic)). Additionally they are collecting audit data to observe SoT patient mood levels on using the PHQ9, GAD7 & BPI, + newly developed pain sensitivity scale (PSQ) & meds.
Resources:	With a focus on this vulnerable patient groups' needs. They recently won £10,000 of prize money from the Grünenthal Pain Awards. They plan to utilise this money for to hire limited amount of a psychiatry input per month and for further training of the existing staff.

ANALYSIS	
Development of the good practice	1. They sought out specialist training from the Freedom from Torture Foundation in order to help staff from the pain clinic understand, recognise and communicate sensitively and effectively with survivors of torture. 2. They carried out a full literature search, endeavored to contact other services offering pain management to Survivors of torture worldwide and met with some medicines sans frontiers psychologists who were working with Survivors of torture on the front line in Syria to gain better understanding of effective working practices for this vulnerable population. 3. They carried out some telephone interviews with 6 Survivors of torture patients who had been through the clinic to gain an understanding of how helpful they found this type of clinic. 4. They plan to have some further face to face interviews to see if it is possible to gather a focus group to get information about how to improve the service. 5. They offer Arabic interpreted questionnaires and interpreters as requested (UK's highest speaking population is Arabic). 6. They have approached the arts charity at the Chelsea & Westminster Hospital who have replaced the television in the waiting area (that previously displayed news that patients reported was retraumatising) with a calming 3D moving images picture.
Means used to overcome or remove the obstacles detailed above	1. They discussed the clinic with the hospital Consultant colleagues to raise awareness of the patient population, sent out a newsletter to GP's in the surrounding boroughs and applied for the Grunenthal pain award (where they achieved the

	overall 1st place for innovation in the field of pain management) which has resulted in profile raising articles. 2. They decided to combine and align these existing clinics to provide a specialist clinic. It required no extra funding and they have matched the clinic numbers to the yearly inward population. 3. They have started printing out the copies of the SoT patient's letters and highlight the important passages so they can draw their GP's awareness to their issues.
Factors enabling the process	1. They sought support from the Freedom from Torture and Helen Bamber Foundations to build knowledge and skills. This helped the existing clinical staff to gain invaluable knowledge and greater insight into the unique difficulties that can occur when working with SoT patients. 2. They won the Grunenthal Pain award which has allowed us to advertise for limited psychiatric sessions for those patients who required immediate or urgent psychiatric input, and has provided much needed increase in awareness of both the needs of the patients, and the availability of a new service aimed at helping this group of individuals.

<table>
<tr><th colspan="2">EVALUATION</th></tr>
<tr><td colspan="2">**How** your **good practice** meets the criteria below:</td></tr>
<tr><td>**Reproducibility:**</td><td>This clinic is easily reproducible and part of the drive to raise its profile is to share this service model with other NHS trusts that have similar populations. It has a zero extra funding policy and could be easily mirrored elsewhere by amending the structure of preexisting services to cater for SoT patients.</td></tr>
<tr><td>**Innovativeness:**</td><td>It is the first pain service in the UK to offer a clinic for survivors of torture. These patients might be seen by physicians in a pain clinic elsewhere and later by a psychologist at another appointment, but nobody else offers a specific and tailored service as they do. Often the psychological aspect gets addressed and pain is left out of the treatment, or pain gets treated but outcome is often frustrating and disjointed for both specialties and therefore not benefitting the patient. They find that there are two groups of patients, one that has been obviously tortured and presents with symptoms directly relating to the torture. The other group are patients who initially did not have ongoing chronic pain after torture, but present with severe pain after developing another pain, for example low back pain. They might present with significant pain behaviors. If the pain is then not understood in context of previous torture these patients might be massively over treated or dismissed. Pain for this group of patients is most likely experienced as threat and a constant reminder of the torture,</td></tr>
</table>

	maybe not consciously but subconsciously. If this aspect is not addressed or left too late they can become severely deconditioned and stop participating in normal activities of daily living. They also would not respond to usual treatment for pain symptoms. By identifying both these groups of patients earlier, they are able to offer better targeted treatments and interventions.
Added value:	The lack of a dedicated pathway for SoT patients at present often leads to difficulty for clinicians in knowing how to care for their patients. Many clinicians are not trained, or may lack confidence in knowing how to deal with a SoT patient. This has historically resulted in patients being bounced around from service to service, which can be both distressing for the patient (demoralising, or increasing risk of vicarious retraumatisation), and often leads to increased demand on hospital and specialist service resources and greater incidence of patients failing to attend appointments. By increasing awareness of this vulnerable group they have already begun to see improved patient attendance rates, patients have more time and opportunity to ask questions, voice their concerns and to get more involved in their treatment pathways. There is a hope that long term outcome data will show improvements in patient mood, satisfaction with treatment, and self-efficacy. Better understanding of the patient needs through this specialist clinic should also help facilitate better targeted onward referrals, thereby reducing unnecessary appointments and potentially unhelpful interventions. They have carried out interviews and satisfaction feedback with a limited

	sample of the patients they have already offered the one stop assessment clinic to. These reported that they found the service very helpful and that they felt “cared for”. They plan to carry out such interviews on an annual basis to monitor opinion.
Appropriateness:	This clinic originated from the specialty pain doctor and the clinical psychologist noticing that survivors of torture often presented with high levels of retraumatisation after being moved through multiple treatments because they did not feel safe enough to disclose the reason for or their true pain(s). They have strived to ensure the most appropriate setting, measures, language, treatments and therapies to these vulnerable and sensitive patients. As the Chelsea & Westminster Hospital pain department is a tertiary centre, it is able to accept referrals from any area (which ensures equity) and have slowly been receiving direct referrals in response to an informational campaign which began last year with GP’s in surrounding areas. The advice and experience sought and gained from specialist charitable organisations has taught how - through making small adjustments to the delivery of the clinics here at the Chelsea and Westminster Hospital - it is possible to make meaningful changes which make the appointments for SoT patients more meaningful, and better suited to their needs and expectations.
NEXT STEPS	
Lessons Learned:	1. That interpreted questionnaires and literature may not always capture the required information.

	Many survivors of torture do not write or read in any language and many of the standard ways of assessing how people live their lives (such as quality of life measures) may not apply to people who have endured enforced migration. 2. That Survivors of Torture have responded very well to an all-female clinician team as they often report that the perpetrators were male (and even healthcare professionals [more often male] could have been complicit in torture). 3. That reception staff need at the least basic training to help manage survivors of torture. 4. That the clinic environment (patient surrounding in clinic and the waiting area, timing of clinics and not being able to tolerate crowds and noise) is very important.
Key Takeaways:	Patients who are Survivors of Torture do not fit into the usual approach of pain clinics and in a busy clinic their complex actual pain might not disclosed. Therefore education of colleagues and team members and vigilance is essential. The aim is offering a service to a vulnerable group of patients that is tailored to their specific needs taking into account that they should receive the most appropriate evidence based treatment available. As their needs are both physical and psychological a one dimensional approach would not be able to cover this. In this clinic a specialist pain clinic appointment is combined with a medication review clinic and a psychology assessment in one setup. Any pain service with a MDT team is able to offer this service and only a bit of clinic reorganisation and additional staff training would be needed to make a big difference for this patient group.

Next Steps:	1. To use the Grunenthal prize monies to buy a limited service from a psychiatrist. This would allow the small population of Survivors of Torture to access timely and specialised psychiatry clinics. 2. To have some training in compassion-focused therapies as literature suggests that this useful with PTSD. The idea is to see if this model could be used in a pain management setting with survivors of torture. 3. To offer further training for the physiotherapists who help treat and management survivor of torture patients to facilitate their treatment and communication styles. 4. To offer the reception staff training to help them understand these patients and their presenting issues and needs so that as they present at clinic they can help them effectively attend their appointments. 5. To offer a method of having regular, ongoing feedback about how useful patients are finding the clinic and its subsequent treatments and how to improve these. 6. To continue to raise the profile of the clinic so that it may become a national model for Survivors of Torture and ensure that they access the most appropriate and sensitive treatments for their chronic pain. 7. To find a sensitive way of helping other departments in the hospital / trust understand key treatment issues without losing confidentiality about what they may not be able to tolerate (such as no injection therapies following torture with needles).

Good Practice Number 3

CONTACT PERSON	
Name:	Manuel
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Organisation:	Department of Physical Education and Sport, University of Granada, Granada, Spain
Position:	Professor (with a Chair)
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Short description of the person submitting this project	Manuel Delgado Fernández is Professor (with a Chair) at the Department of Physical Education and Sport, Faculty of Sport Sciences, University of Granada, Granada, Spain (since April, 2012). Manuel got his BSc and PhD in Biomedical Research at University of Granada in 1988 and 1991, respectively. Then he started to work at University of Granada as an Assistant Professor in 1991. Since 2014, he is the director of the MSc in Research in Sport Sciences at University of Granada. In 2012, he was awarded as an Excellent Teacher with a score of 97 out of 100. He has been supervisor of 27 PhD thesis. He is currently supervising 8 thesis. From 2004 to 2015, he was the Director of the Research Group “Physical Activity, Sport, and Ergonomics for Quality of Life”. From 2016, he is the Director of a new Research Group named “Physical Activity for Health Promotion”. He is author of more than 150

	scientific papers in peer reviewed journals (81 in PUBMED), 8 books, 40 books chapters, and Editor of 5 books. He has participated in 25 Research Projects; 14 as the Principal Investigator. He has been invited as Speaker in 25 conferences; 15 of them were international. He has been author of more than 175 communications in conferences; more than 120 were international. The National Board of Sport and Physical Activity Professionals awarded his professional labour. Manuel Delgado Fernández is the project leader of the good practices presented here.
DESCRIPTION	
Title of the good practice:	Physical activity in women with fibromyalgia: effects on pain, health status, and quality of life.
Category:	Clinical practices
Who are the stakeholders involved in the Good Practice?	
Civic Organization(s)	The Andalusian Federation of people with fibromyalgia and local patients associations from all the provinces of Andalusia.
Healthcare Organisation(s)	The Andalusian Ministry of Health and Wellbeing and Andalusian Institute of Sport Medicine.
Health Professionals:	Sport Scientists, Rheumatologists, Psychologists, Physiotherapists, Occupational therapists, and Biologists
University:	Eight Universities from Andalusia (University of Granada, University of Cádiz, University of

	Huelva, University of Almería, University of Sevilla, University of Jaén, University of Málaga, and University of Córdoba).
Other:	Spanish Ministry of Economy and Competitiveness
Location:	Granada, Cádiz, Huelva, Almería, Sevilla, Jaén, Málaga and Córdoba
Start Date:	01/2011
End Date:	12/2017
Objectives:	Overall aim: To determine the role of physical activity on the development and treatment of fibromyalgia in female patients. Specific aims: 1. To analyse the levels and patterns of physical activity and sedentary behaviours (objectively measured by accelerometry), functional capacity, pain, overall health status and quality of life of 300 Spanish women with fibromyalgia aged 35-65 years; cross-sectional study. 2. To track the levels and patterns of physical activity and sedentary behaviours (objectively measured by accelerometry), functional capacity, pain, overall health status and quality of life of 300 Spanish women with fibromyalgia aged 35-65 years over a 2-year period; 2-year follow-up study 3. To determine the effect of two types of exercise training interventions (water and land-based aerobic strength training vs. a control group) on pain (primary aim), health and quality of life (secondary aim) in women (n=180) aged 35-65 years with

	fibromyalgia; Intervention (randomised controlled trial) study.
Outcomes Impact on participants:	The main variables of the study were: body composition by bioelectrical impedance analyses (InBody R20, Biospace, Seoul, South Korea). Physical fitness by standardised performance based tests (e.g., the back scratch, arm curl, and 6 minutes' walk tests). Fibromyalgia impact and quality of life by the Fibromyalgia Impact Questionnaire (FIQ) and Short Form Health Survey 36 (SF36). Sleep quality and fatigue by the Pittsburgh Sleep Quality Index and Multidimensional Fatigue Inventory. Tenderness by a physical examination with a standard pressure algometer (FKP 20; Wagner Instruments, Greenwich, CT, USA) at 18 tender points according to the American College of Rheumatology (ACR). Pain by subscales of the FIQ (pain), SF36 (bodily pain), and the ACR questionnaire for the modified 2010 preliminary criteria (widespread pain index), and visual analogue scales. Physical activity and sedentary behaviors with triaxial GT3X+ accelerometers (Actigraph, Pensacola, FL, USA) over 7 consecutive days. Cognitive performance by the Paced Auditory Serial Addition Task and Rey Auditory Verbal

	Learning Test to measure working memory and declarative memory. The alÁndalus Project is unique because of the inclusion of subjective assessments (e.g., patient reported outcomes) and objective measurements (e.g., performance based tests). To avoid patients' flare-ups, the assessments were distributed over 3 consecutive days.
Resources:	Human resources: more than 50 researchers from national and international Universities are involved. Only some of them are mentioned. National researchers from Universities of Granada (Manuel Delgado Fernández, Jonatan Ruiz, Francisco B. Ortega, and Inmaculada C. Álvarez Gallardo), Cádiz (Ana CarbonellBaeza, and Víctor Segura Jiménez), Almería (Alberto Soriano Maldonado), Sevilla (Diego Munguía), Huelva (Ángela Sierra), and Jaén (Pedro Latorre). International researchers from Vrije University (Virginia A. Aparicio), Utrecht University (Rinie Geenen), Ulster University (Joe McVeigh), the Parker Institute (Marius Henriksen), and University of Porto (Pedro Silva), among others. Funding: awarded with a total of € 559,000: € 159,000 for equipment (e.g., accelerometers, bioelectrical impedance analyzer, computers) and € 400,000 for hiring PhD candidates and Research Assistants. Recently, the alÁndalus project has been funded with € 501,500 for the coming years (see, next steps section) as follows: € 104,500 for equipment and € 240,000 for hiring PhD Candidates and Research Assistants. Overall, the funding of this project is over € 900,000. Main funder: the Spanish Ministry of Economy and Competitiveness. Infrastructures: facilities of both Universities and fibromyalgia patients associations.

	The physical training of the randomised controlled trial (RCT) study was carried out on the abovementioned settings and, also, in private sport gyms or swimming pools.
ANALYSIS	
Development of the good practice	1) Cross-sectional and 2-year follow-up studies. Participants: a representative sample of women with fibromyalgia from Andalusia was recruited. A total of 960 participants, 646 people with fibromyalgia (i.e., cases) and 314 controls participated. Variables: see outcomes section. 2) Intervention (randomised controlled trial) study. Participants: A total of 180 women with fibromyalgia, not participating in the longitudinal study, were randomly allocated to the water-based, the land-based, or the usual care (control) group after the baseline measurements. Intervention: The intervention groups trained 3 days/week (45-60 min per session) for a 24-week period. The intensity was adapted during the program and ranged from 50% (at the beginning of the program) to 80% (the last month of the program) of maximum heart rate (2090.73 x age). The water-based intervention group trained in a chest high warm pool (~32ºC). Each session included 10 minutes of warmup with slow walks and mobility exercises; 35-40 minutes of aerobic strength exercises; and 10 minutes of cooling down with low-intensity and relaxation exercises. The land-based training sessions were divided into 3 sections: cardiovascular, strength training, and flexibility. Cardiovascular exercises incorporated

	displacements, choreographies and games. Strength training exercises included body weight, hand weights, and elastic bands. Flexibility was trained by static stretching at the cooldown. The intervention program met the minimum training standards of the American College of Sports Medicine. Participants randomly assigned to the usual care (control) group received general advices and pamphlets from the exercise specialist about the positive effects of physical activity and guidelines about how to increase the daily physical activity levels. Variables: See outcomes section. The primary outcome was pain.
Means used to overcome or remove the obstacles detailed above	1) Generic for the 2-year follow-up and intervention (RCT) studies. 1. To deliver personal assessment reports of the main measurements to the study participants. 2) Specific for the 2-year follow-up study. 1. To remember the social, clinical, and research importance of the study to the participants (via phone calls and letters). 2. To organise conferences twice a year, where the main findings of the study were presented to participants; in an appropriately easy and plain language. 3. To participate in mass media presenting the main findings of the study; also in an easy and plain way. When possible, participants were invited to talk in mass media about their experiences taking part in the study. Patients' participation on TV, radio, and print press is the most effective way to promote the importance of this work to this illness, to create awareness and to improve their adherence. 3)

	Intervention (RCT) study. 1. To reduce participants' drop-out and to maintain their adherence to the training program, all sessions were accompanied with music, exercises were adapted to the characteristics of participants when it was necessary and designed to their preferences.
Factors enabling the process	1. Support provided by the Federation of Fibromyalgia patients from Andalusia, which was very helpful in particular when the study was designed and when participants were recruited. 2. Multidisciplinary team composed by Sport Scientists, Rheumatologists, Psychologists, Physiotherapists, Occupational therapists and Biologists. 3. Previous experience working with people with fibromyalgia. The Principal Investigator and five researchers started to conduct research among people with fibromyalgia in 2007. Previous studies with physical exercise programs carried out were particularly valuable. 4. Research team composed by enthusiastic and bright team players. The burden of fieldwork imposed by the logistic of the alÁndalus project has been huge. However, the combination of enthusiastic and bright (senior and junior) researchers with a strong team attitude made possible to build a positive environment to face adversities (e.g., very long working days). 5. Collaborations with top researchers in the field. Around 20% of the manuscripts published involved top international researchers, which was very enriching for this work. For instance, a permanent collaboration with Prof Dr. Rinie Geenen from Utrecht has

	been established. University: four PhD candidates have done short stays where they acquired generic skills (e.g., data analyses) and specific knowledge (e.g., potential mechanisms of fibromyalgia). Currently, one of the predoctoral researchers coming from the University of Granada is doing his PhD at Utrecht University.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility	All the assessments were carried out by researchers fully trained to standard measurement and assessment protocols to reduce inter-examiner error. Additionally, valid and reliable instruments, which allow reproducibility, were used. Some questionnaires in this population have also been validated. Moreover, most of the assessments carried out are easy and cheap. To guarantee reproducibility of the physical exercise programs (intervention RCT study), a book showing all the exercises and sessions of the intervention is being written: it is in progress and will be available freely in the next months. Furthermore, a methodological paper indicating all the specific aspects of the intervention in order to allow the reproducibility has been published.
Innovativeness	The combination of the longitudinal and intervention studies is an innovative aspect of the project. In addition to that, and despite the important clinical implications, no study has

	tracked the levels and patterns of objectively measured physical activity and sedentary behaviours, functional capacity, body composition, pain, and overall health status and quality of life in women with fibromyalgia over a 2-year period. Another innovative aspect of the project is that the study design (longitudinal) will allow to examine in deep the prognostic value of physical activity, functional capacity, pain, health and quality of life in women with fibromyalgia. The assessment of a relative high number of women with fibromyalgia (which was representative from Andalusia) allowed to provide reference values for this region in Spain of a wide range of health-related dimensions, which will be highly valuable to evaluate the effects of interventions as well as to identify the patient's status and to compare it with other patients of the same age and sex, evolution of the disease, etc. The evaluation of the effectiveness of water and land-based aerobic strength intervention training was also innovative. If the benefits of land-based exercise are similar to those observed in the water is not fully understood yet. A better understanding of this issue is also of a novel contribution of the project.
Added value:	1. Accessible physical exercise therapy for people with fibromyalgia. Previously to the alÁndalus project there were no sport facilities with professionals specialised in fibromyalgia. Education about physical exercise programs for fibromyalgia has been provided to physical

	trainers of gyms and swimming pools, university students, and health professionals, among others. In Andalusia now there are private facilities offering appropriate physical exercise programs for fibromyalgia and there is a possibility for university students to do their internships in exercise programs for fibromyalgia. After completing the physical exercise intervention (RCT) study, participants interested in continuing (for free, without any economic costs) have been offered an exercise program for as long as they want. This is an internal policy of this research group since 2007 and some patients are benefiting of this policy since 10 years ago. 2. Individual reports of health status related assessments. One of the main complaints of participants about the Spanish health system is that they are usually invalidated when claiming for a disability pensions. Therefore, they have been provided with an individual report showing their health status and providing their percentile in relation with normative data of the population with fibromyalgia from Andalusia.
Appropriateness	The alÁndalus project has helped to efficient and effectively manage some issues related with fibromyalgia. First, the consequences of fibromyalgia on people's daily life are often invisible. A cornerstone of the alÁndalus project is to make the society aware of them by disseminating the main findings in a plain and easy language to mass media, by educating university students and healthcare

	providers, and by delivering personal assessment reports showing that people with fibromyalgia perceive difficulties which can be observed also in objective clinical tests. Second, the diagnosis of fibromyalgia is controversial. The performance on physical fitness tests (very easy to standardise and cheap) is a complementary tool in the diagnosis of fibromyalgia. Third, given the complex symptomatology of fibromyalgia and its unknown aetiology, to identify modifiable factors associated with a better prognosis of the disease and of clinical interests too. The alÁndalus project has clearly identified high physical fitness, high levels of physical activity and low levels of sedentary time as powerful marker of health in fibromyalgia. Fourth, physical exercise programs are advised as a first step in the treatment of fibromyalgia. This intervention (RCT) study comparing the effectiveness of water vs. land-based exercise will inform which one suits better for fibromyalgia, in the case that effectiveness is different between modalities.
NEXT STEPS	
Lessons Learned:	For potential research groups interested in replicating the alÁndalus project in other countries or Spanish regions the main suggestions would be as follows: first, when designing the study is crucial to create a multidisciplinary team in which patients are also involved. People with fibromyalgia are always willing to help. Second, to include performance-based measures is of interest as well.

	In that case, it is better to distribute these measurements in different days to avoid fibromyalgia symptoms to flare up. Third, take your time to plan and develop strategies to reduce the potential high loss to follow up when measures across time are planned. To deliver personal assessment reports. Fourth, to actively participate in mass media disseminating the main findings will be very appreciated by patients and their relatives. When possible, giving the opportunity to patients to talk about their experience in such events is highly appreciated by them too. Fifth, focus on improving society. Plan to use part of the time to provide education about how to design and develop appropriate physical exercise programs for people with fibromyalgia.
Key Takeaways	First, using cross-sectional data, strong associations of physical fitness, physical activity, and sedentary time with pain, health status, and quality of life in fibromyalgia: they are suggested as potential powerful markers of health in fibromyalgia. This finding has to be corroborated in the 2-year follow-up study. Second, results from the intervention (RCT) study will help better assess the potential of exercise interventions in the treatment of fibromyalgia. If the interventions proved to be effective and safe, this study would provide low-cost and feasible alternatives for health professionals in the management of fibromyalgia.
Next Steps:	The research group is currently finishing the datasets of the intervention (RCT) and the 2-year studies. In November 2016 they have started writing a set of manuscripts showing the main

	findings. Additionally, the have been recently awarded with more funding with three new purposes. First, to run another intervention (RCT) study to compare the effectiveness of hydrotherapy per se or in combination with doing physical activity in hot water. Second, to carry out a 5-year follow-up of the participants. Third, to collect saliva samples from participants and to perform a candidate gene study including 52 single nucleotide polymorphisms involved in either fibromyalgia susceptibility or fibromyalgia symptoms. Thanks to these new studies, it will be possible to determine: (i) whether hydrotherapy per se without doing exercise is effective for fibromyalgia symptoms, (ii) whether the potential role of physical fitness, physical activity, and sedentary time as marker of health is also confirmed in a 5-year follow-up period, (iii) whether single nucleotide polymorphisms of particular candidate gene are associated with either higher susceptibility to fibromyalgia or to a better prognosis of fibromyalgia symptomatology, (iv) whether the effectiveness of the physical exercise program is different due to the particular genotype of people with fibromyalgia.
OTHER INFORMATION	
Notes:	Webpage of the project to interact with people with fibromyalgia: http://www.alandalusfibromialgia.com/ Publications of Manuel DelgadoFernández (Professor and project leader, University of Granada, Granada, Spain) and citations (google scholar): https://scholar.google.com/citations?user=zOUCRxAAAAAJ&hl=en&oi=ao

	Publications of Jonatan Ruiz Ruiz (senior researcher, University of Granada, Granada, Spain) and citations (google scholar): https://scholar.google.com/citations?user=G224m6YAAAAJ&hl=en Publications of Francisco B Ortega (senior researcher, University of Granada, Granada, Spain) and citations (google scholar): https://scholar.google.com/citations?user=jZ1oU8cAAAAJ&hl=en Publications of Ana Carbonell Baeza (senior researcher, University of Cádiz, Cádiz, Spain) and citations (google scholar): https://scholar.google.com/citations?user=IjQIr0IAAAAJ&hl=en Publications of Virginia A Aparicio (Postdoc researcher, VU University, Amsterdam, The Netherlands) and citations (google scholar): https://scholar.google.com/citations?user=sHKqCuMAAAAJ&hl=en Publications of Rinie Geenen (Professor, Utrecht University, Utrecht, The Netherlands) and citations (google scholar): https://scholar.google.com/citations?user=yJ600ZUAAAAJ&hl=en

Good Practice Number 4

CONTACT PERSON

Name:	Gertrude
Surname:	Buttigieg
Organisation:	Malta Health Network (MHN)
Position:	Honorary Secretary
Country:	Malta
Email:	info@maltahealthnetwork.org
Short description of the person submitting this project	Gertrude Buttigieg is Honorary Secretary of the Malta Health Network. Ms. Buttigieg has been Secretary to the MHN on a voluntary basis since 2007, she has led or coordinated various projects for MHN including Patients' Rights, awareness on the Patients' Rights in the Cross Border Directive and raising awareness on Chronic Pain. She has represented MHN as a participant and speaker in several local and European events.

DESCRIPTION

Title of the good practice:	Relieving the Suffering of Chronic Pain Patients
Category:	Empowerment Professional education

Who are the stakeholders involved in the Good Practice?

Civic	Malta Health Network (MHN)

Organization(s):	
Other:	Working closely with Pete Moore http://www.paintoolkit.org
Location:	Malta on a national level
Start Date:	02/2016
End Date:	02/2017
Objectives:	On a local level MHN brings together patient groups who suffer from chronic pain as part of their condition or secondary to their condition. The past campaigns indicated a need for more training and resources to be made available locally for patients, for public in general and professionals. Thanks to collaboration with other entities including Societal Impact of Pain (SIP) and ISAL Foundation, over the past years MHN has distributed copies of the Pain Tool Kit Booklet in English and this was gladly accepted however patients and professionals asked for material in Maltese language. The main objectives of the projects are • To train and educate patients on ways of dealing with chronic pain – currently there are too many patients who are not sufficiently informed on how to deal with chronic pain affordably • To facilitate the cooperation of NGOs representing patients and professionals in the field of chronic pain leading toward raising awareness on self-help and empowerment. • To have information in Maltese available as a publication and also some information in

	electronic format on MHN website. • To offer training to professionals and patients on pain management.
Outcomes Impact on participants:	Having information for patients and professionals available aims at having a positive impact on the quality of life of patients with chronic pain and of their families. Information is also beneficial for the general public to educate people who are currently non-patients to look after their health and also be more understanding of people with chronic pain. Having better trained professionals will possibly have a positive impact on the service they offer to patients. Empowering patients to take the responsibility of their care. Training sessions for patients (about 40 people attended the 2 sessions) and professionals (30 in one session) were attended with enthusiasm and from the feedback forms collected after the sessions the content resulted very interesting and relevant to daily life. Feedbacks were also very positive about the impact on patients and indicated that such sessions were very helpful and should be repeated at different places to reach out more people. Professionals had the same positive comments and indicated that having booklets and reference material for use in their professional practice has been extremely useful indeed. MHN has also raised awareness amongst the Ministry of Health and the Health Promotion Department and they asked to carry out similar sessions in the

	future - this is a work in progress and through them MHN hopes to reach a much wider audience.
Resources:	An indispensable resource was getting to know about the Pain ToolKit and getting permission to translate it into Maltese. This was very generously given by Pete Moore. Mr. Moore delivered the training workshops in Malta for patients and professionals. Funding was needed to translate, print and make material adaptable for electronic dissemination and to host and hold workshops. Funding was obtained through the Small Initiatives Support (SIS) Fund by the Malta Council of the Voluntary Sector and Grünenthal GmbH. Translations were carried out by volunteers and support from the office of the Maltese MEP Dr. Roberta Metsola. Human resources to organise all logistics and checking things to ensure implementation in a professional and accountable manner. Working with Web developers to have all resources easily available also electronically.
ANALYSIS	
Development of the good practice	The idea for the Best Practice came from a need which was not met primarily on more information for patients and professionals on chronic pain management other than medical interventions. MHN submitted a proposal for funding through the SIS Fund in 2015 to carry out the project in 2016 and it was awarded a sum of money which initially

	seemed sufficient. When MHN started planning out the implementation, it resulted that more funds were needed, mainly for the training sessions and have them done by a professional. It made sense to have Pete Moore himself deliver this trainings since he could amplify on the content of the Pain toolkit. Meetings were held with MHN members and other entities interested in pain and it was agreed to have 3 main outputs the translation and printing of the Pain Toolkit in Maltese language, to have training sessions for patients and professionals and to organise a press release to create awareness on a national level and reach out to people who may not necessarily realise that something can be done to help in their pain management. The third thing is to have material available on website, not just that produced in Maltese but also to have links to other websites who promote good practices to fight chronic pain.
Means used to overcome or remove the obstacles detailed above	Support was sought from sponsors to cover the fees for the training sessions for patients and professionals since these were considered essential for the success of the project. Sponsorship was obtained from Grünenthal GmbH. Additional support to get professional translation and proofreading was obtained through Maltese MEP Roberta Metsola.
Factors enabling the process	Believing in the cause, good will and backup from MHN board and others. MHN has built

	positive contact with various entities and individuals such as MEPs who believe and support its work. So, when it came to asking for this support MHN was very generously helped. MHN is transparent in the way it manages its finances being registered and in line with local Voluntary Organisations legislation and compliant with legal obligations as evaluated by the Commissioner for Voluntary Organisations.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	It can be reproduced. The Pain Toolkit has been translated in several languages and these are available through the Pain Toolkit website. Possibly, if Pete Moore and his team were to start training people in different places to give out their courses it would be even more possible to carry out.
Innovativeness:	Since that chronic pain is almost new to the Maltese scene (through past campaigns in promoting the World Day against pain) having information available will increase the awareness. The novel thing in this is that Pete Moore is a patient himself and not a Professor and, thus, it is in itself empowering to other patients. The Pain toolkit offers an alternative healthy lifestyle to a life of pain, helplessness and dependence on medication. Patients are given information on how to be more positive and know more themselves. They are encouraged to have more open

	dialogue and communication with their professionals which for Malta is very novel as doctors still have a very paternalistic approach when dealing with patients.
Added value:	MHN was positively surprised at the support received and at the interest in the field and thus what started as a small project is now gaining interest. Many people are stopping and thinking what that they can do to relieve pain. There is demand to have the booklets available in various places including public and private clinics; other organisations not directly related to pain are joining forces to help these patients.
Appropriateness:	This was an appropriate way of working as it arose from an expressed need however the training sessions and publication in Maltese and information are available since the end of 2016. The booklets are written in a very easy way to understand and thus these are appropriate for every category of patients. Having online access to the information is also very important in this day and age where everything is online. However, in Malta people still like to have their personal copy and thus this project has met the needs of people.
NEXT STEPS	
Lessons Learned:	Translations are not as easy and straightforward as one may believe as it also needs some cultural adaptation. So, apart from having professional translators (which

	can be expensive) it is good to have professionals and patients to contribute with their views to arrive to the final product.
Key Takeaways:	There are good practices which if shared can lead to an impact in the life of people elsewhere so it is very positive to share. Believe in what you are doing and do it!
Next Steps:	Help people access information both through the booklets and electronically and hopefully lead a better life. Through the website data will be collected about the number of people affected by chronic pain and what strategies are helpful and what is available for them. MHN together with No Pain Foundation will co-host the SIP Symposium 2017 in Malta during the calendar of the Maltese Presidency of the Council of Europe. Thus, MHN can help patients with chronic pain at all levels from a personal approach to policies.

Good Practice Number 5

CONTACT PERSON

Name:	Felicia
Surname:	Cox
Organisation:	Royal College of Nursing
Position:	Chair, Royal College of Nursing Pain and Palliative Care Forum
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Short description of the person submitting this project	Felicia Cox MSc RN is a specialist pain management nurse who is the current Chair of the Royal College of Nursing Pain and Palliative Care Forum. She is the lead for this innovative and extensive project which has developed a national knowledge and skills framework which aims to empower nurses to assess and manage pain more effectively. Felicia is the Editor of the British Journal of Pain for the British Pain Society (BPS) and was awarded Honorary Membership in 2015. She has published extensively on the assessment, management and impact of both acute and chronic pain.

DESCRIPTION

Title of the good practice:	RCN Pain Knowledge and Skills Framework for the Nursing Team

Category:	Professional education
Who are the stakeholders involved in the Good Practice?	
Healthcare Organisation(s) :	Royal College of Nursing, British Pain Society
Health Professionals:	Nurses
Location:	England, Scotland, Wales and Northern Ireland
Start Date:	11/2013
End Date:	08/2016
Objectives:	The Royal College of Nursing (RCN) Knowledge and Skills Framework for Nurses (KSF) is a 52-page document produced as a national initiative funded by the RCN. It aims to provide a framework that supports the development of competence in managing pain for the entire nursing team; from unregistered care assistants to registered nurse consultants. The framework contains the eight aspects of care identified at a roundtable discussion of nursing experts from the RCN Pain and Palliative Care Forum held in November 2013. It has been designed to be used alongside local competency documents and illustrates Benner's vision of individual nurse's migration from novice to expert (Benner 1984). There is clear progression in the knowledge, practice and experience of nursing staff working within the framework. Firstly the career framework

	(Skills for Health 2010) is mapped against both Benner's levels of performance (novice, advanced beginner, competent, proficient, expert). These two, in turn, are mapped against levels of education across the spectrum from the care certificate through to doctoral studies. Content has been split to meet the specific needs of unregistered (care support workers) and registered members (Registered Nurses) of the nursing team. Each staff group has their own framework summary based on Benner's 1984 novice to expert levels of practice mapped against levels one to eight of the Skills for Health Career Framework (SFH 2010). The document also supports the Pain Patient Pathway Recommendations; to prioritise, raise awareness and educate about chronic pain. Prior to the publication of this document, there were no nationally agreed standards, competencies or frameworks for pain management nursing in the UK or Europe. It is available to download from https://www.rcn.org.uk/professionaldevelopment/publications/pub004984.
Outcomes **Impact on participants:**	The KSF was launched simultaneously across the four countries (England, Wales, Scotland and Northern Ireland) of the United Kingdom and in Europe at the 2015 EFIC meeting in Vienna. As there are some differences in nursing care and pain management provision, representatives across the four countries all contributed to the development and launch of the document. No formal evaluation of the impact of the KSF has yet been undertaken as the launch was only conducted in late 2015. An electronic survey of all

	UK acute and chronic pain services (n=214) in early 2017 is planned to establish the dissemination, implementation and local impact. It is intended to undertake qualitative exploration of the impact of the framework by early adopters using focus groups in mid-2017. This work will build on the National Pain Audit Report 2010-2012 (British Pain Society www.nationalpainaudit.org) which indicated that 'specialty interest groups in each profession should provide guidance on which competency and skills are required in order to meet patients' needs and to support commissioners and providers in identifying more clearly what skills are commissioned from particular services' (BPS 2012 p.8). It is anticipated that the document will standardise roles and responsibilities, and by mapping education against experience this should provide specialist nurses with support for their practice and to develop and expand services to meet local and regional service user (patient) needs.

Resources:	Indispensable to this project was access to the clinical and academic wealth of experience that the RCN was able to bring together. The collaboration was supported financially and logistically by the RCN at their accessible headquarters in the capital city, London. Use was also made of social media, electronic mail and teleconferencing. Each collaborator was able to use his extended network of contacts to sense check and validate the initiative as it developed. This resulted in a document that was generalisable and fit for purpose, adding value to both staff and patient experience. Three specific resources were required to support the success of this initiative. Firstly, nurses needed access to regional and national support structures to help them develop local teams and services that meet patient's needs. This in turn built their clinical leadership and management skills. Secondly, the major building block of the KSF was the role that education played in improving the nursing contribution to enhance patient outcomes. Specialist nurses continue to need access to specialist education and in the UK a Masters level qualification supports the development of specialist knowledge and skills and is considered essential. Finally, the continued development of a national Forum enabled members (n=14 500) to share good practice, exchange ideas and provide a platform for continued development thus enhancing patient care and reducing the burden of chronic pain.
ANALYSIS	

Development of the good practice	The expert panel roundtable discussion, chaired by Prof Nick Allcock in 2013, identified two work streams: (a) to produce accessible information about pain in an EasyRead format and (b) a framework (KSF) for pain knowledge and skills for nurses in the UK. EasyRead The RCN EasyRead working party led by Felicia Cox, Chair RCN Pain and Palliative Care Forum, has published well reviewed accessible patient information on pain. These documents are aimed at people with a learning disability but they are also useful for professionals and carers to use for people with a cognitive impairment or communication difficulties. Some examples include EasyRead for chronic pain (https://www.rcn.org.uk/professionaldevelopment/publications/pub005559), and managing pain at the end of life (https://www.rcn.org.uk/professionaldevelopment/publications/pub005591). Further examples are available from www.rcn.org.uk/professionaldevelopment/publications. KSF The development of the RCN KSF was led by Felicia Cox, Karin Cannons and Sarah Lewis. Additional working party contributors included Donna Brown, Denise Everitt, Janet Roberts, Rachel Townsend and Steve Ward. During the one month consultation period, the draft document was circulated widely and hosted on RCN webpages. The circulation list included RCN Fora, Royal Colleges, Professional Colleges, organisations supporting people with pain (patient groups) and specialist

	pain nursing networks in the UK, Ireland and New Zealand. All feedback was collated and used to inform the final document.
Means used to overcome or remove the obstacles detailed above	Please see above and below for details.
Factors enabling the process	The success of the project is due to the excellent established networks supported and encouraged by the RCN. The leadership provided by the Forum Chair, supported by experts in clinical and academic practice, ensure nurses working in pain management are actively engaged and have a strong voice. The Forum has a high local, national and international profile, which enables effective dissemination and ensures that the pain nursing voice advocating for patients is heard. The RCN has a coopted seat on the Council of the local IASP chapter, the BPS. This interdisciplinary society also has strong patient representation and actively supports work streams that all members contribute to. The BPS has endorsed the KSF. The

	RCN is also an active member of the Chronic Pain Policy Coalition (CPPC) to unite patients, professionals and parliamentarians in a mission to develop an improved strategy for the prevention, treatment and management of chronic pain and its associated conditions. The KSF could have appeared an isolated professional activity. The support of the multidisciplinary membership of the BPS and CPPC was vital to demonstrating the KSF's fitness for purpose. The principle authors have been invited to speak at national conferences and local nursing fora, interviewed for media articles in professional journals and successfully submitted posters for oral and visual presentation at national and international meetings.

EVALUATION

How your **good practice** meets the criteria below:

Reproducibility:	The KSF provides a framework for the assessment and management of pain in all nursing settings from a person's home to an acute hospital. It promotes the importance of education and training for all members of the nursing team and identifies nine aspects of care that can be used globally: • Awareness of painful conditions; • Holistic pain assessment; • Physical strategies; • Psychological and behavioural strategies; • Self-management strategies; • Pharmacological strategies; • Interventional therapies ; • Service development;

	• Complex case management Nurses involved in the development of the New Zealand Pain KSF (New Zealand Pain Society Nurses' Interest Group 2013) have indicated that they will soon be revising their current document and incorporating many features of the UK version. It is hoped that as undergraduate and specialist postgraduate pain education for nurses increases across Europe that other European states will adopt aspects of the KSF and adapt for local use. The guide for implementation (page 11) provides a structure for introduction and universal adaptation. The importance of interdisciplinary working is stressed throughout the KSF. Other professions should find that the framework has utility for them as they develop competency in pain management. The framework could be used in developing countries and is free to all electronically.
Innovativeness:	Prior to the publication of this document, there were no nationally agreed standards, competencies or frameworks for pain management nursing in the UK or Europe. This novel document not only identifies standards for care for pain assessment and management it provides more experienced (including expert) pain specialist nurses who hold specialist qualifications with guidance on service development. This innovation promotes the use of routine data collection to measure quality of care and the sharing of best practice initiatives. The formal quantitative and qualitative evaluation of the impact of the KSF in 2017

	should provide useful data that will be used to identify strengths and weaknesses of the dissemination strategy and local/regional implementation. Nurses within all four countries of the UK and beyond (e.g. Australia and New Zealand) are cutting and pasting KSF content and integrating with local performance review and competency documentation. This demonstrates the global utility of this novel document and shows it to be dynamic, translatable and flexible.
Added value:	The development of a shared vision at the initial roundtable discussion facilitated the development of the two work streams. The importance of a face-to-face meeting to identify goals and objectives then to plan the project was undervalued. In retrospect it was extremely important to establish relationships between geographically diverse individuals. With slightly different referral and clinical processes but who shared the same vision and would agree to work together to develop aspects (standards) of care. The RCN has recognised the complexities of the process and the innovative ways of overcoming the obstacles encountered. They plan to use this format as a template for other groups of specialist nurses tackling similar clinical issues. This work stream raised the profile of nursing within the BPS and pain management nursing within the RCN. Launching the KSF at EFIC in 2015 and being invited to present the work orally at the Annual Scientific Meeting of the BPS in 2016 has ensured a global audience.

	The Chair has been invited to present the work at the RCN International Centenary Conference in late 2016. The ability of individuals and teams to select portions of content and choose how to use this within the context of their own environment, is an innovative step in evidencing and developing pain management practice.
Appropriateness:	Article three of the International Association for the Study of Pain (IASP) Declaration of Montreal (IASP 2010) cites the right of all people with pain to have access to appropriate assessment and treatment of the pain by adequately trained health care professionals. The absence of any existing guidance for pain management nurses had led to a potential skills vacuum in terms of compliance of the Declaration. The KSF will enable nurses within the UK and beyond to meet the needs of people experiencing pain, particularly persistent pain as this is often under identified and poorly managed. The 2006 survey of chronic pain in Europe (Breivik et al 2006) reported that chronic pain of moderate intensity occurs in 19% of adult Europeans, seriously affecting the quality of their social and working lives. One in five patients reported that their chronic pain resulted in depression, 60% had visited their doctor 29 times in the previous six months yet 4% received inadequate pain management. It is difficult to quantify at present as no hard data exist to identify any changes in education, pain assessment practices and clinical decision

	making/onward referral. The plans for 2017 data capture are being formulated. Total downloads of the document as at the end of July 2016 were in excess of 4 500. The number of hard copies provided free of charge to RCN members is not available at present (initial print run was 1000 copies).
NEXT STEPS	
Lessons Learned:	The principle authors have identified ten lessons they have learned from this project: 1. Keep the person in pain the centre of all that you plan and do. 2. Gain consensus at the initial face to face meeting to ensure that all populations and care settings will be addressed if you are developing a national framework. Ensure that the regional voice is heard. 3. Ensure agreed goals and timeframes are clear and achievable. 4. Keep the structure of the document as simple as possible to ensure it is usable for your target audience and those in their care. 5. Identify leaders for individual work streams that have a track record of meeting targets and deadlines. 6. Maintain open channels of communication so that progress is monitored and assistance is given where needed. 7. Identify one person as the overall leader/coordinator so that there is a central point of contact for all contributors and interested parties. 8. Have a clear dissemination strategy at the

	outset. 9. Develop ideas and strategies/methodologies to measure the impact and identify desired outcomes during the initial planning phase. 10. Have courage and conviction in your vision. There will be set backs and times when giving up is tempting. Keep going. Without people who are doing the job writing frameworks like this to guide and support colleagues, progress is impossible.
Key Takeaways:	Assessing and managing pain are essential components of nursing practice. Pain is a complex physical, psychological and social phenomenon that is uniquely subjective. A key fundamental of nursing care, people continue to report unrelieved pain during procedures, after surgery, during episodes of acute illness, in the community and in care homes. Pain traverses all clinical settings and the age spectrum, yet is often poorly assessed and managed by nurses. Article three of the International Association for the Study of Pain (IASP) Declaration of Montreal (IASP 2010) cites the right of all people with pain to have access to appropriate assessment and treatment of the pain by adequately trained health care professionals. Chronic pain has a strong association with anxiety, depression, quality of life and the ability to sleep, communicate and work. The key common findings of surveys of chronic pain report that one in five people of all ages have moderate to severe chronic pain and one third of individuals of working age who have chronic pain have lost the ability to perform wage earning or other work

	(IASP 2011). The RCN launched this BPS endorsed document in all four UK countries simultaneously and it was presented at the 2015 EFIC meeting in hard copy format. It is hoped that this framework document will enable a common understanding and terminology to develop, so that levels of competency can be understood across the nursing continuum in all four countries. And beyond.
Next Steps:	There has no formal evaluation of the impact of the KSF, as the launch was only conducted in late 2015. An electronic survey of all UK acute and chronic pain services (n=214) in early 2017 is planned to establish the dissemination, implementation and local impact of the KSF. It is also intended to undertake qualitative exploration of the impact of the framework by early adopters using focus groups in mid-2017. This work will build on the National Pain Audit Report 2010-2012 (BPS 2012) which indicated that 'specialty interest groups in each profession should provide guidance on which competency and skills are required in order to meet patients' needs and to support commissioners and providers in identifying more clearly what skills are commissioned from particular services' (BPS 2012 p.8). It is hoped to identify if the document has contributed to the standardisation of nursing roles and responsibilities. This framework maps education against experience, thus providing all nurses, registered and unregistered, with structured support to develop competence in their practice. This should enable them to develop and expand services to meet the

	needs of people living with pain. The document will be disseminated and its profile raised wherever and whenever possible.
OTHER INFORMATION	
Notes:	References Benner P (1984) From novice to expert: Excellence and power in clinical nursing practice. Menlo Park, CA, AddisonWesley Breivik H, Collett B, Ventafridda V, et al (2006) Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. European Journal of Pain 10(4):287333. British Pain Society (2012) National Pain Audit Final Report 20102012. Available from: http://www.nationalpainaudit.org/media/files/NationalPainAudit2012.pdf IASP (2010) Declaration of Montreal. Available from http://www.iasppain.org/DeclarationofMontreal IASP(2011) Desirable characteristics of national pain strategies; recommendations by the International Association for the Study of Pain.Available from: http://www.iasppain.org/files/Content/NavigationMenu/Advocacy/DesirableCharacteristics_Nov2011.pdf New Zealand Pain Society Nurses' Interest Group (2013) New Zealand Pain Management Nursing Knowledge and Skills Framework for Registered Nurses. Available from http://www.nzps.org.nz Royal College of Nursing (2015) Knowledge and Skills Framework for the Nursing Team. London, RCN Skills for Health (2010) Key elements of the career framework. Available from: http://www.skillsforhealth.org.uk/resources/guidancedocuments

Good Practice Number 6

CONTACT PERSON	
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Short description of the person submitting this project	Leader of Regional Pain Control Program 20092013 and Chronic Pain Strategies 20142016 Physician, specialist in Anesthesiology 1981, Pain Medicine 2004, Health Service Management 2003, Master in Palliative Care 2014. Advanced Studies Course on Biomedical Ethics at the end of human life, Bereavement and counselling Courses. Since 1997 pioneer in the fight against pain and implementation of palliative care in the Autonomic Region of Azores (Portuguese Islands) and pioneer in prevention of suffering since 2001, when started the first Pain Consultation in Azores. Member of the Palliative Care Teams of the Divino Espírito Santo Hospital, Ponta Delgada 2010 to 2016. Coordinator of Multidisciplinary Pain Unit 2001 to 2016. Consultant of Azorean Chronic Pain Patients Association (ADDCA), Coordinator of the

	Social Network of Volunteers in Community in Seniors Association of São Miguel (ASSM). Visiting Professor at the Azorean University since 1983 and Teacher for Anesthesiology, Pain, Palliative Care in Hospital, Regional Health Directorate, Basic courses of National Palliative Care Association, Specific courses for Volunteers. Member of the Bioethics Research Group, Azores Center (CEB Açores) and other professional Associations: International Association for the Study of Pain (IASP) and Special Interested Groups on Pain in Older Persons and Pain Education; European Association for Palliative Care (EAPC); European Union of Medical Specialists.
DESCRIPTION	
Title of the good practice:	Regional Pain Control Program
Category:	Professional education
Who are the stakeholders involved in the Good Practice?	
Civic Organisation(s):	Azorean Chronic Pain Patient Association (ADDCA)
Healthcare Organisation(s) :	Regional Health Directorate; Hospital do Divino Espírito Santo in Ponta Delgada, S. Miguel Island; Hospital Santo Espírito da Ilha Terceira in Angra do Heroísmo, Terceira Island; Hospital da Horta in Faial Island. 17 Community Health Centers grouped in 9 Health Units

Health Professionals:	Regional Health Secretary; Regional Health Directorate; Hospitals Administrations; Anesthesia Department Directors; Health Units Administrators; Education Departments in hospitals and Community.
University:	Azorean University (UAç)
Other:	Pharmaceutical Industry; local media (TV, radio and papers)
Location:	Açores, Portuguese Archipelago of 9 Islands 246 102 inhabitants
Start Date:	01/2009
End Date:	12/2016
Objectives:	Since 2009 ADDCA has organised a Program for Acute Pain, Chronic Pain and Delivery Pain, applying national and international guidelines. Priorities were: education of professionals and public information (campaigns, partnerships, patient associations). The Objectives were well defined: to develop regional policies to organise structures for pain control in hospitals; to educate professionals before and after the graduation; to coordinate the care systems to ensure timely access to the right support; to find funding for pain research; to improve treatment of pain; to reduce the prevalence of pain; to reduce major physiological, psychological, economic, and social consequences for patients, their families, and society; to promote better quality of life; to reduce costs of pain

	patients. Activities planned: 1. Pain courses for physicians, nurses, other healthcare technicians, nursing students; 2. Post graduation trainings for physicians; 3. Thematic courses related with pain, such as palliative care, teamwork, burnout, giving bad news; 4. Organisation of conferences, workshops; 5. Commemoration and information in national days and international days about pain and palliative care; 6. Articles and interviews in papers and TV.
Outcomes Impact on participants:	The three hospitals organised Multidisciplinary Pain Units, Acute Pain Units, Pain in Delivery, to meet the human rights of those in pain. Professionals are aware about pain evaluation and treatment, pain impact, drugs, etc. They refer more patients to Pain Units; they are able to prescribe opioids. Citizens know the burden of pain, its impact, and what should be done in terms of policy interventions to reduce these problems; they changed to healthy life styles and improved Life Quality. Public knows the impact of chronic pain. The indicators who were programmed: education of all physicians about national guidelines and all nurses about pain evaluation as the 5th vital sign; number of those who attended the courses; number of nursing students and

	number of hours to teach pain; number of physicians who attended post-graduate courses about pain; number of courses (2-4 hours, 2 days); number of workshops (4 hours); number of first consultations for chronic pain patients (increased From 400 to >500); number of surgical patients with analgesic techniques (>80%); number of deliveries with epidural analgesia (>60%); waiting times for chronic pain consultations; opioid consumption.
Resources:	Human resources regional Health Directorate; the program coordinator; a regional Commission (5) to supervise the regional Health Plan; local coordinators in Health Community Centers (17); Hospital Administrators (9); Anesthesia Department Directors (3); departments for education in all Institutions (12); Health Teachers in the University (Nurse Schools); Directors for residents in hospitals and General Practitioners (6). Professors in universities and in pain courses and workshops were also involved. Financial resources: a post-graduate course 25.000 €; travels within the islands: flight 150 €; hotel 60 €. Materials were provided by the Institutions. Logistics: annual plans for actions; workers in the regional Health Directorate organised the travels and courses; the Coordinator had contacted other partnerships. Others:there are pharmaceutical companies that support some educational courses in pain in Portugal and they were invited to come to Azores too.

ANALYSIS	
Development of the good practice	The Coordinator was familiar with the development of the National Program; the project according to the specificities of a small and archipelagic region. The government accepted and it was included in the Regional Health Plan for the years 2009-2014; after that period, the same strategies went into the next plan 2014-2016. A Commission was nominated and the Coordinator presented the annual plans. The main Hospital has a Multidisciplinary Pain Unit since 2001; the remaining two Hospitals have a Pain Consultation since 2010. The three Hospitals treat Pain in Delivery and have Acute Pain Units. One of them has also a Palliative Care Unit. The education in pain for all the professionals was the priority: the Coordinator went to all the islands and organised courses for physicians, nurses (or together) and included other techniques. The reason is that some islands have few professionals, and also because there is a high turnover rate. The courses lasted 2 hours, 4 hours or 8 hours. The supported courses in partnership with other Institutions lasted one or two days (8); some of them were web streamed too. Additionally ADDCA organises every year a course for residents. In 2014 the target reached was of: 421 physicians and 953 nurses in hospitals; 153 physicians, 503 nurses in Community Centers; about 50 students a year in the

	Nurse School. In the hospitals, from 2009 to 2016, the complementary divulgation happens with clinical meetings all over the year (registered in Education Department): 25 meetings. The workshops were 10; the Congresses were 4. 5 physicians attended the post-graduate course in Pain Medicine. Now, in some islands, it is the second or third round of courses; all the professionals will be included soon. Every year, in October, the National Day Against Pain and the IASP International Year is celebrated with several activities. Since 2014, the cities involved have organised public divulgations in the Italian event One Hundred Cities Against Pain.
Means used to overcome or remove the obstacles detailed above	Critical factors for success were: gathering evidence of the burden of pain to the government, politicians, regional media; gathering information on access to care; keep always with the same ideas, the same enthusiasm and motivation; supporting the government policy on pain services with national and international guidelines; establishment of a broad coalition of stakeholders supported by patient associations; a clear plan to achieve strategic actions: pain evaluation as the 5th vital sign, disseminate the instruments for evaluation, to fight the myths of opioids, to bring national strategies, people from other Centers, changing experiences in congresses. The economical barrier still limits the use of technologies for education or even

	treatments. The presence of a persistent leader is the final secret.
Factors enabling the process	The positive factors were: the local and national media started to talk about the European and even worldwide actions to make the need to treat pain a human right. They resumed all the initiatives and this supported the local messages. The National Program was revised in 2008 and new strategies were developed. Networking at regional and national level; national and international commemorative days are the best way to reach the pubic: with the support of the patient associations and case histories the messages are widespread at their best. All campaigns were well accepted and realised at the same time in the three hospitals. Research and evaluation of the first indicators have started. The certification of Institutions needs good organisation in evaluation and pain treatment.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	The reproducibility inside the Program was a positive factor and made the courses homogeneous enabling the professionals to attend courses in other institutions. The articulation with national strategies made the same philosophy to approach the person with pain and facilitate the networking with stakeholders. The same program for the Courses according to IASP orientations make

	them universals. The uniformity of the Courses make them adaptable for new technologies in future.
Innovativeness:	The Program was pioneer in the region because it started the education, the organisation of pain services, the networking and the information to potential patients. It was the first chance to talk about pain, suffering, end of life. It was the beginning of health humanisation. It was the potential key to palliative care organisation. It is recognised by the movement of the Coordinator to multiple meetings in loco and discussing of local problems. It is a practical and demonstrative example of learning.
Added value:	Improving the dissemination of chronic disease control; professionals and public know better what chronic pain is, its consequences and how to minimise this impact; patients are informed about the need of treatment, the prevention of risk factors and the importance of early treatment; defining measures to improve quality of life for patient with chronic pain; with screenings, it is possible to implement low cost initiatives, getting volunteers (among students). Encourage the associationism.
Appropriateness:	Patients and professionals when "speaking the same language", can find the best ways to efficient management of needs. Patients know that the doctor can understand the complaints and that increases confidence in the relationship patient-doctor. Together,

	patients and professionals can look for better assistance and empower their rights.
NEXT STEPS	
Lessons Learned:	To get a well-motivated team, and to believe that ideas are good. To come from national level to regional and to local levels with interested leaders. To find carefully your partners and influence others. To get the support of the politicians and Institutions. To be obstinate and persevering.
Key Takeaways:	First: to have a leader and convince the politicians. Second: national laws are not good enough if you do not reach the regional or even local level to apply and evaluate them. Do well what you believe; be informed, show your work, exchange experiences and follow the national and international scientific community.
Next Steps:	All physicians must be educated in pain evaluation and treatment. All nurses are educated and motivated to evaluate and register the 5th vital sign. These are the first steps to recognise the right to pain treatment.

OTHER INFORMATION	
Notes:	ADDCA attended the international Pain Submit and signed the Declaration of Montreal that states that if pain treatment is profoundly wrong, leading to unnecessary suffering, is harmful. It also declared that the following human rights must be recognised throughout the world: Article 1. The right of all people to have access to pain management without discrimination; Article 2. The right of people in pain to acknowledgment of their pain and to be informed about how it can be assessed and managed; Article 3. The right of all people with pain to have access to appropriate assessment and treatment of the pain by adequately trained healthcare professionals. The Azorean Regional Pain Control Program was presented as a Good Practice in Lisbon, in 2013, and it was classified in the first Group of 11 Projects out of a total of 75. It was presented as a Good Practice in Brussels in 2014 and in a health meeting in Azores in 2015. ADDCA shared its experience with the colleagues in Ukraine in the second west Pain Congress in Odessa, in June 2016. ADDCA also supported the Prague Chart to access palliative care as a human right and invite governments to: develop health policies to help patients at the end of life; to ensure access to treatments and the professionals' training to treat pain and know about palliative care; to integrate palliative care in

	health systems. ADDCA have been joined all the SIP meetings and it is also member of the MEPs Interest Group “European Patients' Rights & Cross Border Healthcare”.

Good Practice Number 7	
CONTACT PERSON	
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Short description of the person submitting this project	She holds a PhD in Science, Technology and Humanities obtained with a thesis in Philosophy of Medicine on the acknowledgment of chronic pain as a disease. She has been working for Fondazione ISAL for 2 years. She cooperates with other members of the Foundation in the organisation of the events and she also maintains the relations with foreign institutions and associations. In addition to this, she participates in the Foundation's research projects.
DESCRIPTION	
Title of the good practice:	Hundred Cities Against Pain
Category:	Empowerment
Who are the stakeholders involved in the Good Practice?	

Civic Organisation(s):	Fondazione ISAL
Healthcare Organisation(s) :	In the healthcare field, ISAL Foundation has the endorsement of the Italian Ministry of Health, of FIMMG, Agenas, Federsanità, PAE, EFIC, MEP
Health Professionals:	Several pain physicians all over Italy and abroad
Other:	Several national and local pain patients associations
Location:	Italy and other European Countries
Start Date:	10/2016
End Date:	10/2016 annual
Objectives:	The aim of the Day – celebrated in 2016 on 1st October– is to sensitise and inform people about pain, to recognise chronic pain as a preventable and treatable disease, to support healthcare efforts to prevent and manage chronic pain, to promote fundraising for research, to involve media in pain fighting. Hundred Cities Against Pain is also supported by the Web campaign #Zeropain16, a campaign that brings together people from all over the world and that during the International Day share their selfies and comments to say "No!" to chronic pain. ISAL Foundation strives also for creating a supportive social network which can link up chronic pain's suffering patients all over the world and for raising awareness about this global public health issue. 135 Italian cities,

	including hospitals and local associations and 16 European cities are involved in the event.
Outcomes **Impact on participants:**	ISAL Foundation promoted the development of a national network of physicians and pain patients working together to improve the knowledge of pain treatment centers, therapeutic options and possibility of cure. Its main success is related to the increase of cities participating to the event year after year.
Resources:	All the members of ISAL Foundation are involved in the organizsation of the event and on 1st October every member is present in one city. The organisation of the Day (particularly for the activation of the network) requires a full year of work for the Foundation. The event is sponsored by the Foundation itself and some companies helping offering services free of charge (e.g. for the delivery of the materials) Pharmaceutical companies are supporting the initiative.
ANALYSIS	
Development of the good practice	The organisation is fully handled by Fondazione ISAL. During the year contacts are made with national and international physicians and associations to create the network; arrangements are made for the practical organisation of the event: e.g. producing and printing informative material and for the fundraising. The campaign to promote the event usually increases in

	September through the social media (#zeropain), a press conference at the Senate's Library and the dissemination of the information on the web.
Means used to overcome or remove the obstacles detailed above	The preparatory work begins in the first part of the year and goes on until October.
Factors enabling the process	The fact that all ISAL members believe in the importance of the event and in its aims and that most people participating to the Day recognise the importance of raising awareness on the issue.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	Sure it is reproducible. Every year ISAL Foundation tries to involve foreign cities in order to transform the Day from national into international. It is only about creating and mantaining networks.
Innovativeness:	The innovative aspect of this event is related to the cooperation of physicians as well as of patients, associations and individuals.
Added value:	Hundred Cities Against Pain helps in promoting the knowledge of the healthcare issue represented by chronic pain and of the extent of this issue, particularly in terms of the need to improve the national and international network of treatment and

	support options available to patients too. Also, the Day helps in raising awareness on the problem affecting 1 millions of Italians by promoting the message that chronic pain is a real disease and that it can be treated.
Appropriateness:	Hundred Cities Against Pain brings together the experiences and the voices as well as the knowledge of patients and physicians concerning the issue of chronic pain and of its treatment.
NEXT STEPS	
Lessons Learned:	The organisation of an event like this requires a constant, annual work in order to be arranged properly.
Key Takeaways:	Believing in the importance of the practice and of its aim is the first step towards success.
Next Steps:	Together we can fight pain.

OTHER INFORMATION	
Notes:	All the information on the event can be found on the following website with a list of the cities involved and of the events organised http://www.fondazioneisal.it/blog/

Good Practice Number 8

CONTACT PERSON	
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DESCRIPTION	
Title of the good practice:	ISAL School of Algological Sciences
Category:	Professional education
Who are the stakeholders involved in the Good Practice?	
Civic Organisation(s):	Fondazione ISAL
Health Professionals:	Pain Physicians

Location:	Rimini, Emilia Romagna Region
Start Date:	1993
End Date:	no end date - ongoing
Objectives:	The School was founded in 1993 as the first Italian Institute for the Study of Pain and its treatment. The mission of the School is to train medical experts in the field of pain therapy in order to create a network of evidence-based competences.
Outcomes **Impact on participants:**	Since its foundation, the School has entitled about 500 physicians to the practice of pain therapy and promoted several specialistic seminars and developed a network of professors who operate towards a widespread diffusion of the knowledge in the field. The Italian Ministry of Health has recognised the School as provider of ECM credits for medical education.
Resources:	Human resources are the core of the School with several renewed Italian pain physicians teaching and a person working as administrative secretary.

ANALYSIS	
Development of the good practice	The School offers certificated biannual courses in Algological Sciences and also the possibility to take part to specific seminars. The value of the program is guaranteed by the Scientific Committee of the School composed by important Italian and foreign experts in the field.
Factors enabling the process	Among the main factors enabling the good practice there is the participation of several Italian experts in pain medicine deciding to participate to the project with the mission to constitute a cultural framework underlying pain therapy medical practice.

EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	Yes, it is with the support of an operative centre and the participants' good will.
Innovativeness:	ISAL School of Algological Sciences was the first Institute for the High Degree post-lauream education in Pain Therapy in Italy and among the first ones in Europe.
Added value:	Yes. First of all, it enabled the development of a Culture of Pain Therapy which contributed also with its participants to the development of the crucial law 38/10 in Italy aimed at safeguarding the citizens' right to access to adequate pain therapies and palliative ones. Also, the School always had an international vocation manifested e.g. by the promotion in 2007 of the first Italian American campus in

	the field, having among its members the representatives of main European societies in the field. At the same time, the School worked also towards the constitution of an Italian network of education by promoting the activation of several other branches. The last crucial action of the School was to promote the constitution in Sulmona (AQ) of the first European High School in Algological Sciences devoted to the diffusion of a medical culture in pain therapies and especially on the appropriate use of new drugs such as opioids.
Appropriateness:	Yes, it is appropriate and this has also been recognised abroad (in 1995 it was mentioned on IASP website) and in Italy (Italian Ministry of Health).
NEXT STEPS	
Lessons Learned:	There has to be a strong will towards this aim grounded on a mission which is primarily a cultural and humanitarian one.
Key Takeaways:	Education; Networking is crucial
Next Steps:	Try to foresee the future as the School did by contributing to the knowledge on the new drugs available for pain treatment by showing their pros and cons (in 2004 ISAL participated to the activation and implementation of a registry on the good use of opioids).

OTHER INFORMATION	
Notes:	Information on the School are available (in Italian at the moment) on the website http://www.fondazioneisal.it/lascuoladiformazioneisal/

Good Practice Number 9

CONTACT PERSON	
Name:	Jane
Surname:	Whelan
Organisation:	European Headache Alliance
Position:	General manager
Country:	Ireland
Email:	generalmanager@europeanheadachealliance.org
Short description of the person submitting this project	Project submitted on behalf of the European Headache Alliance, a nonprofit, patient umbrella group which was launched in 2006. Since then, the Alliance has grown to represent 25 patient groups from across the continent. EHA was setup to: voice the views and concerns of headache patients across Europe Inform and influence policy makers on headache disorders; work in partnership with other relevant organisations to promote common aims and goals; coordinate the efforts of national advocacy groups in Europe. EHA aims to: promote awareness and understanding of migraine and other primary headache disorders Improve access to appropriate diagnosis and treatment for people affected by a headache disorder.

DESCRIPTION	
Title of the good practice:	"What's Under the Hat?" campaign
Category:	Empowerment Innovation
Who are the stakeholders involved in the Good Practice?	
Civic Organisation(s):	European Headache Alliance and member organisations
Location:	PanEuropean
Start Date:	09/2015
End Date:	12/2018
Objectives:	The European Headache Alliance (EHA) devised an innovative pan-European public awareness campaign to raise awareness across Europe of the extreme effects of headache disorders and the number of people affected (over 88 million). The 'What's Under the Hat?' campaign was devised by EHA in conjunction with its members to address the key issues they reported: 1. The lack of public compassion for headache sufferers; 2. The need to make the invisible visible; 3. The lack of a platform to give those living with headache disorders a voice. The lack of recognition and 'branding' of headache disorders was deemed key to address these issues. By devising the 'What's Under the Hat?' campaign. EHA aimed to: • Increase awareness and understanding of

	the real severity and impact of headache disorders; • Empower those living with a headache disorder to access better information and support; • Provide platform to give those living with a disorder a voice. People living with a headache disorder were asked to share their headache story by: • Sharing a photo of them wearing a hat on Facebook or twitter with the hashtag #underthehat; • Creating a short video to post on YouTube tagging it with Underthehat ; • Writing a blog post to share online The campaign aims to empower people living with a headache disorder to seek support and advice, speak up and educate others on headache disorders.
Outcomes Impact on participants:	The toolkit created gave patient groups materials and branding to adapt and use to support their work on a national level. Most organisations used the hashtag #UndertheHat with several other created in other languages: e.g. #ponteunsombrero. The campaign online generated stories and photographs of people living with headache disorders, their families and friends. Stories shared empowered and encouraged others to post and share on Facebook and twitter. Most stories focused on the impact and burden of living with a headache disorders on day to day life, with those suffering sharing their feelings of frustration, anger and

	resignation. Increased posting and sharing was noted around the launch date on European Migraine Day of Action (12th September) and again for Cluster Headache Day (21st March). Facebook posts and tweets with photos were shared with the hashtag #underthehat however many people shared their photo in a private Facebook group e.g. closed cluster headache Facebook groups, indicating how many people are not willing to share their disorder publicly. However other people felt empowered and encouraged to share their photo and story publicly and welcomed the initiative. Many reported feeling isolated and that the campaign was needed to let other people know: 1) about the impact and severity of their disorder on their daily life; 2) of the available treatment options and support groups available in their country.
Resources:	The campaign required considerable resources, financial and human. The planning phase required a workshop with representatives from all EHA member organisations participating to contribute their ideas and ensure buy in from the EHA member network. Advice from social media experts with experience in online campaigning was invaluable in ensuring best practice was followed when finalising the toolkit and launch materials. Limited resources were available to produce promotional materials or translation budget

	for members to adapt materials. Key events in the headache calendar were optimised to create a buzz and highlight the campaign e.g.: at the International Headache Congress 2015, European Migraine Day of Action, Cluster Headache Day.
ANALYSIS	
Development of the good practice	A planning workshop was held with EHA member organisations to obtain ideas and feedback and ensure the campaign messages were agreed upon. Professional advice was obtained from social media experts with a designer engaged to create a toolkit comprising of campaign logos, sample photos/ videos, texts, press releases, instructions for making video stories etc. fundraising ideas and awareness raising event ideas. The toolkit was shared with EHA member organisations for them to adapt and use nationally to support their activities. An online platform was created including expansion of the EHA website to setup a site www.underthehat.eu. A Facebook page www.facebook.com/EHAUndertheHat, twitter account @EHAUndertheHat and Youtube channel were setup to post and share content. A hashtag #underthehat was created for the campaign. Printed and promotional materials such as banners, leaflets and the campaign were produced for use at events such as international congresses, awareness events at the European Parliament in Brussels. The

	campaign was officially launched on European Migraine Day of Action on 12th September 2015; with 21st March 2016, Cluster Headache Day used to give the campaign a boost. Campaign reach and engagement is measured on an ongoing basis and evaluated by the EHA board to keep the campaign in line with the EHA strategic aims.
Means used to overcome or remove the obstacles detailed above	Identifying patient advocates who would speak about their disorder and publicly share their story was key to obtaining initial photos and stories. Engaging with those already speaking up publicly about their disorder, created a sense of community, empowering others to share their story online. Focus on online channels, using social media accounts already setup by headache groups to share the campaign messages overcame the issue of limited resources for advertising, posters / banners. 3 strategies for engaging with the campaign were devised and included in the campaign toolkit to guide and support organisations depending on their size. Support from other neurology groups such as the European Federation of Neurological Associations, European Headache Federation, European Academy of Neurology was key to obtaining online traction on social media channels. Although members of the general population may not be aware of these organisations or engage with them online, many policy makers and journalists do. Sharing of online content via these partners

	has been important to support EHA's advocacy work on a European level.
Factors enabling the process	The ease and availability of mobile devices to capture photos and videos and post them to social media Goodwill and support from other neurological and patient groups helped spread the campaign information and key messages. Political support in hosting key events for the launch event and Cluster Headache Day were greatly appreciated by EHA to raise awareness among policy makers.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	The campaign materials were devised to be adapted and used by any patient group in Europe. Several EHA member organisations held activities such as media events / information seminars incorporating the 'What's Under the Hat?' campaign, encouraging members of the public to post photos of themselves online. The EHA General Assembly provides an opportunity for member organisations to share their activities and ideas and learn from each other how best to reproduce the campaign nationally with best effect.
Innovativeness:	Headache disorders have not received due attention up until now. The lack of a brand or image and the perception of the word 'headache' as a soft term has meant

	headache disorders have been largely neglected. No pan-European Awareness campaign has been created previously for headache disorders. The use of digital technologies and harnessing the use of social media and mobile phones led to an innovative approach to highlighting the impact and burden of headache disorders.
Added value:	Although devised as a European campaign, the lack of awareness and understanding of headache disorders worldwide led to great interest from outside of Europe in particular in English speaking countries where patient groups exist but have limited impact. The campaign had envisaged greater cohesion between European member organisations and the headache disorder community. However campaign activity has demonstrated the possibility of a nurturing an international community of headache sufferers and offers potential for patient advocates both in Europe and outside of Europe to work together for their cause. The campaign has also sparked the interest of other advocacy groups, industry partners and other healthcare stakeholders. Building on this interest to add value to the work of national organisations will be a key objective of the next phase of the campaign.
Appropriateness:	An analysis of a sample of patient stories shared demonstrated that the campaign and stories shared were appropriate. Having one platform to speak as one voice to policy

	makers has been effective in demonstrating the commitment and cohesion between national organisations.
NEXT STEPS	
Lessons Learned:	A fundraising element of the campaign was part of the original concept. However EHA member organisations agreed awareness raising had to be prioritised before fundraising could be incorporated. Organisations with limited resources cannot be expected to add another activity to their plans without sufficient guidance and support. Getting people to share their story is not as easy as it might appear. Stigma and discrimination felt by those living with a severe headache disorder meant members of the public were not as willing to share their experience publicly as expected. Most stories shared demonstrated the negative aspects (frustration, fear, anger) of living with a disorder that is not given due recognition.
Key Takeaways:	Engaging with partners and key stakeholders is vital to spread the message. Sustaining an online awareness campaign requires constant input and resources from the supporting organisation.
Next Steps:	Next steps for the campaign will be to seek funding to take the campaign further – to engage a social media / community manager to support and guide national organisations to use the campaign materials to support their awareness work and replicate activities.

Good Practice Number 10

CONTACT PERSON

Name:	Marian
Surname:	Nicholson
Organisation:	Shingles Support Society
Position:	Director
Country:	UK
Email:	marian@hva.org.uk
Short description of the person submitting this project	She is the director of the shingles support society. Since 1989, the Shingles Support Society responds to questions about shingles (Herpes Zoster): its infectivity, its treatment, what self-help can do.

DESCRIPTION

Title of the good practice:	Shingles & PHN information pack
Category:	Empowerment Professional education

Who are the stakeholders involved in the Good Practice?

Civic Organization(s):	Shingles Support Society
Healthcare	Shingles Support Society

Organisation(s) :	
Health Professionals:	Dr Pamela Bell, Dr Martin Johnson
Location:	London
Start Date:	11/2014
End Date:	11/2016
Objectives:	Patients ask the charity about shingles and post herpetic neuralgia. Shingles is a rash caused by the reactivated chickenpox virus coming back to the skin surface, often many years after chickenpox was first caught. People who have not had chickenpox cannot get shingles. Sometimes something ‘triggers’ the virus to awaken or reactivate and shingles appears. It can happen at any age, but is more likely to affect older people. About 60 % of 85 year olds will have had shingles. After the shingles has healed, some people are left with pain in the area affected by the shingles. This is called post herpetic neuralgia and is more common in older people. Patients reported that family doctors (GPs) did not how shingles was transmitted nor did they know how to treat post herpetic neuralgia. This is a neuropathic pain which does not respond to ‘ordinary painkillers’. This neuropathic pain varies in intensity from patient to patient, but in the worst cases it can “render the patients’ final years an unendurable misery” as one pain doctor told us. Shingles Support Society decided to create an information pack that would supply all the information that a patient

	with shingles or post herpetic neuralgia will need. It includes four pages of detailed and referenced treatment information for the GP, written by pain specialist (consultant in anaesthesia), as well as leaflets on other aspects of shingles and post herpetic neuralgia.
Outcomes Impact on participants:	The information pack on shingles and post herpetic neuralgia allows the patient to ask the GP for pain treatments which have not been considered. These may correctly treat the pain. If the patient is lucky enough to respond well, normal life can resume. Even when the patient only gets partial relief, this can sometimes be enough to allow the patient to leave the house, partake in social events and even resume work. The pack also includes a full explanation of what shingles is and how it not infectious in social situation, two pages of self-help suggestions, two pages on the use of TENS machines, two pages of contact details given by patients who are happy to talk/email other patients.
Resources:	Writers in the Shingles Support Society created pages introducing the topic, explaining infectivity, outlining medical treatment, listing self-help suggestions that other sufferers of post herpetic neuralgia had reported helping. From another pain charity, a leaflet on TENS treatment was adopted. The four-page information from a GP was created by Dr. Mike Serpell and he was paid £1000. The Shingle Support Society obtained that money

	as a grant from a pharmaceutical company.
ANALYSIS	
Development of the good practice	The Shingles Support Society produces information according to the guidelines laid down by The Information Standard. https://www.england.nhs.uk/tis/ This is a programme established by the NHS (national health service) to ensure that patient information materials are produced with up-to-date information in an easy to read manner, and in a way that is suitable for the intended audience. It requires the writers to show that they have consulted appropriate medical sources. It requires information products to be tested on readers who mirror the intended audience. It requires the leaflets to be validated by a suitable medical expert – in this case a doctor who has expertise in treating this chronic pain.
Means used to overcome or remove the obstacles detailed above	There were some earlier leaflets that could be used as an example of what was going to be needed. This shortened the work that was needed. Fortunately, Sanofi Pasteur kindly provided a grant to allow a pain specialist to create the instruction leaflet for GPs.
Factors enabling the process	The factors that enabled the above two points were the long experience of the leaflets' writers. Regarding the financial assistance, the fact that Sanofi Pasteur has a well-established contact with patient groups meant that

	Shingles Support Society were able to approach them for funding.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	The Information Standard produces detailed guidelines on https://www.england.nhs.uk/tis/ which offer advice on how to produce high quality patient information – if the person producing the leaflets follows their guidance.
Innovativeness:	There was no patient information on shingles and post herpetic neuralgia. Any patient support group will learn from the questions that it gets from callers/writers what information is needed. Shingles Support Society were responding to a need that was obvious to them.
Added value:	Patients who are left with untreated post herpetic neuralgia may have almost no quality of life. They may be totally dependent on their carers. If appropriate treatment is given and if it works for that patient, they may be able to resume a normal life.
Appropriateness:	Each year, patients become more demanding of their doctors. With the internet, they are able to access information and can challenge their doctors with ideas for treatment that they find on the web. However, the internet enables the patient to discover the existence Shingles Support Society and the help that is offered by this charity. It provides patients with a resource where they can find the up-to-date

	treatment advice they need. By downloading pages from the website, or ordering the 19-page information pack to be sent to them by post, they are empowered to talk with their doctors over the optimum treatment for their condition.
NEXT STEPS	
Lessons Learned:	If patients need information on a particular condition/treatment, they can only challenge their doctors if they have top quality information in their hands. This is where the guidelines offered by the Information Standard were helpful, to ensure that the leaflets could not be challenged by the GPs.
Key Takeaways:	Identify the need you are going to fill. If necessary, convene a forum to discuss what information is wanted by patients Produce information that is top quality. The content is more important than the appearance.
Next Steps:	as above
OTHER INFORMATION	
Notes:	https://www.england.nhs.uk/tis/ http://www.herpes.org.uk/shinglessupportsociety

Good Practice Number 11

CONTACT PERSON

Name:	Gemma
Surname:	Fernandez Bosch
Organisation:	Asociacion Sine Dolore
Country:	Spain
Email:	gemmafernandezbosch@gmail.com
Short description of the person submitting this project	Gemma is the president of the association, together with the team of Sine dolore she carries out the activities.

DESCRIPTION

Title of the good practice:	Patients' School
Category:	Empowerment Clinical practices

Who are the stakeholders involved in the Good Practice?

Civic Organisation(s):	Sine dolore
Healthcare Organisation(s) :	Hall town
Health Professionals:	Doctors

Location:	This activity is in Menorca, Baleares Islands, Spain
Start Date:	10/2016
End Date:	10/2016
Objectives:	The main objective of the patient school is to educate, raise awareness and improve the quality of life of patients with pain. Also, to make familiar to the chronic pain problem. The school consists of small talks given by pain specialists. One of its characteristics is that the doctor speaks in plain language, easy to understand.
Outcomes **Impact on participants:**	The biggest impact is that many of the participants understand their problem or their family member's problem. Helping to improve the quality of life of the person affected by pain. It is a very important annual activity because there are many people who require medical attention and cannot access it. Thanks to these annual meetings, doctors can be contacted and personally advised, since the most important of the talks is the interaction between doctor and the patient. That is, the patient can ask the doctor about his problem and the doctor helps him with the best answer.
Resources:	In order to carry out this activity the main thing is to find doctors who are willing to collaborate and travel to Menorca. Usually, Asociacion Sine Dolore chooses a suitable place and easy to access for the public, such as spaces in town halls, because the

	Institutions leave them for free. All the board members of Asociacion Sine Dolore are in charge of informing people, in addition to advertising these meetings with different the means of communication. Asociacion Sine Dolore helps patients who require special care. Furthermore, it always tries to organise activities with the least possible economic cost, since we do not have economic aid of public institutions.
ANALYSIS	
Development of the good practice	In order to carry out this activity the main thing is to find doctors who are willing to collaborate and travel to Menorca. Usually, Asociacion Sine Dolore choose a suitable place and easy access for the public, such as spaces in town halls, because the Institutions leave them for free. All the board members of Asociacion Sine Dolore are in charge of informing people, in addition to advertising these meetings with different the means of communication. Asociacion Sine Dolore helps patients who require special care. Furthermore, it always tries to organise activities with the least possible economic cost, since we do not have economic aid public institutions.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	It can be implemented anywhere in the

	world. All you need is to find a suitable location, some doctors willing to participate and promote the iniviative in medical centres, media and so on.
Innovativeness:	The advances in medicine are always made known, the different techniques that they use in different hospitals.
Added value:	Advances in medicine against pain
NEXT STEPS	
Lessons Learned:	Choose the best doctors who know about pain and ask them to be clear in their explanations so that everyone understands their guidelines and advice. Promoting extensively the meetings is the way to ensure the success of this initiative.
Key Takeaways:	Relieve pain and suffering, increase the quality of life of patients
Next Steps:	Relieve pain and suffering, increase the quality of life
OTHER INFORMATION	
Notes:	Asociacion Sine Dolore's slogan: Make visible the invisible evil: THE PAIN

Good Practice Number 12

CONTACT PERSON	
Name:	Elise
Surname:	Houdayer
Organisation:	Ospedale San Raffaele
Position:	Researcher
Country:	Italy
Email:	elisehoudayer@gmail.com
Short description of the person submitting this project	Elise Houdayer (PhD) is a passionate 36 y.o. Neuroscience researcher (H index 16) specialised in the study and treatment of cognitive and sensorimotor disorders using neurophysiological tools such as noninvasive brain stimulation (transcranial magnetic stimulation – TMS, or transcranial direct current stimulation), neurorehabilitation based on computer generated 3D environments and high density electroencephalography. During her PhD she collaborated with neurosurgeons on the study and treatment of neuropathic pain and published 2 papers (1 in second and 1 in last author) on the effect of motor cortex stimulation on pain and brain activity in patients with sensory differentiation. Recently, she won a grant of the Italian Multiple Sclerosis Foundation (FISM) for a project aiming at using repetitive TMS to reduce chronic neuropathic pain in multiple

	sclerosis patients. Elise is a communicative, empathic person who always sought patient's contact and collaborative interactions within or between groups. This reflects on her publications (for example, during her 3 years of PhD she published 4 papers in first author and 11 papers in coauthor). Same efforts were pursued on publication and congress attendance during her postdoctoral fellowships, demonstrating a real interest toward the constant innovations in her field. Elise is also a dedicated teacher and mentor. She is thus a highly specialized, motivated and empathic researcher who perfectly endorses her role of project leader
DESCRIPTION	
Title of the good practice:	Nonpharmacological treatment of chronic pain: a multimodal approach.
Category:	Innovation Clinical practices
Who are the stakeholders involved in the Good Practice?	
Civic Organisation(s):	Associazione Medici Riabilitatori Specialisti Ospedalità Privata (ARSOP). ARSOP is a scientific society organised in networks of rehabilitation units of private Italian hospitals that regularly organises meetings on the prevention of chronic diseases.
Healthcare Organisation(s) :	San Raffaele Hospital, Milan, Italy
Health	Dr. Sandro Iannaccone, neurologist Dr.

Professionals:	Federica Alemanno, psychologist, neuropsychologist Dr. Pietro Mortini, neurosurgeon Dr. Carlo Mandelli, neurosurgeon Dr. Matteo Locatelli, physiotherapist, Dr. Daniele Emedoli, physiotherapist	
University:	Università Vita Salute San Raffaele, Milan, Italy	
Location:	Milan, Lombardy, Italy	
Start Date:	09/2016	
End Date:	09/2018	
Objectives:	Chronic pain is a highly disabling condition severely degrading people's quality of life. Low back pain, as well as trigeminal neuralgia, is a common condition of chronic neuropathic pain. Pharmacological therapies are effective only in a minority of patients and alternative treatments have to be developed to relieve patients' pain. Apart from the devastating symptoms patients may experience such as spontaneous burning feeling, sensation of "pins and needles" or continuous crushing pain, neuropathic pain can also lead to severe anxiety or depression disorders. The chronicity of pain acting on mood can also lead to a distortion of patient's own body perception. Since clinical evaluation of pain is based on the subjective reports of patients, a "distortion of self" can lead to incorrect pain rating leading to incorrect treatment. This project aims thus at	

	defining an innovative neuro-rehabilitative strategy helping patients to regain a correct somatotopic sensibility using a multimodal approach. The project combines highly technological rehabilitation tools (virtual reality) with neuropsychological support. Importantly, the patient is placed in the core of a multidisciplinary team composed of neurologists, neuropsychologists, neurophysiologists, neurosurgeons and physiotherapists, all working in close interactions to provide patients with a personalized rehabilitative strategy. Psychological effects of pain in each patient were first measured using a detailed neuropsychological evaluation. Then, the multidisciplinary team defines a neuro-rehabilitative plan based on virtual reality rehabilitation combined with psychological support. The virtual reality setting reinforces patients' feedback in a multisensory point of view (visual, auditory and proprioceptive) and has the advantage of increasing patients' compliance and motivation. The setting also permits remote communication with patients' home from the hospital, allowing close follow-ups after hospital-based rehabilitation.
Outcomes Impact on participants:	This multimodal approach to chronic pain treatment had so far the great benefit of improving patients' quality of life, assessed by appropriate scales, and of reducing chronic drug abuse. This treatment offers each patient a complete neuropsychological evaluation, a psychological support, and an

	innovative and efficient neuro-rehabilitative treatment which is also associated with a better compliance of patients compared to standard rehabilitation. Moreover, a remote control communication platform was developed to allow close follow-ups of patients when they end their rehabilitative period, directly from their homes.
Resources:	In this initiative, the multidisciplinary aspect of the team is crucial. It is thus necessary to create close interactions between neurologists, neurosurgeons, psychologists, and physiotherapists. The psychologists need to have experience in neuropsychology and need to be trained to the specific testing. Experienced physiotherapists able to design adequate rehabilitative training are also needed. The virtual reality setting indeed allows for the development of personalised, specific exercises that can be easily implemented in the software. A rehabilitative health care professional has also to be dedicated to the treatment. The whole treatment can take place in only one dedicated room containing the virtual reality setting that would have to be purchased by the health care centre.
ANALYSIS	
Development of the good practice	A specific protocol was designed; it can be resumed as follows. The patient is first seen in the clinic by a neurologist or a

	neurosurgeon. If this is not the case, the patient has to be first addressed to one of these therapists to confirm the diagnosis and define whether this good practice could benefit the patient. Then the patient has to be addressed to a specialized neuropsychologist who performs a detailed neuropsychological evaluation. This evaluation is mainly composed of scales and questionnaires aiming at better defining patients’ pain and testing for the following factors: attention, memory, executive functions, quality of life, depression and anxiety. After having performed a deep evaluation of the patient, the multidisciplinary team meets to confront their evaluations and define a personalised neuro-rehabilitative plan together with the physiotherapists who are particularly involved in the design of the motor exercises that will be performed with the virtual reality equipment. Then patient’s visits are scheduled, at a frequency of 3 per week for at least 6 weeks. Each neuro-rehabilitative visit lasts 1 hour. During this hour, the patient is equipped with the virtual reality sensors and performs the exercises standing, sitting or lying on a medical bed if needed. Patient’s quality of life and clinical evaluations are performed every 3 weeks for follow-up. After the rehabilitative period, these follow-ups continue directly from patients’ homes, thanks to a special platform that allows remote communication between health care personals and patients. This

	remote control station, developed by the same company producing the virtual reality settings, permits visual and auditory connection via a portable device that the patient takes home (for example a tablet). Apart from establishing good quality communication with the patient, this device allows monitoring of vital signs and thus constitutes a perfect tool to follow-up on patients when they go home.
Means used to overcome or remove the obstacles	A deepened communication with patients as well as within the whole professional team is a key answer to overcome cultural obstacles. Indeed, as mentioned above, this protocol necessitates a multidisciplinary team implying thus a clear rearrangement of healthcare professionals' interactions/communication. The answer is thus a clear communication in the medical team and the placement of the patient in the core of these interactions. Moreover, it is highly important to explain the patients in details the benefits of such nonpharmacological approach of chronic pain treatment. The neurologist or neurosurgeon who first sees the patient has usually the role of the first contact with the patient and has to take the time to explain in details such innovative, multimodal and multidisciplinary approach. It is then important to insist on the fact that an answer can be found with a nonpharmacological treatment, using instead innovative neurorehabilitation tools.

Factors enabling the process	A deepened communication between the main agents of the multidisciplinary team drastically improved this good practice. Indeed, patients are usually not aware of these alternative strategies when they meet with neurologists or neurosurgeons. It is thus important that the knowledge of the good practice passes through every health care professional who can in turn correctly orientate patients toward the best treatment.

EVALUATION

How your **good practice** meets the criteria below:

Reproducibility:	This rehabilitative practice can be implemented in any healthcare centre, either in a general or specialised hospital, as well as at private practitioners. Importantly, the remote control module offers the possibility to create a tele-rehabilitative network that could involve many different national (or international) centres. Ospedale San Raffaele is indeed currently generating the first Italian network of such tele-rehabilitation. It is noteworthy to specify that these networks not only involve healthcare professionals, but allows also direct connections with patients from the entire national territory. Moreover, this good clinical practice can be implemented in many other types of sensorimotor or cognitive neurorehabilitation treatments, such as post-neurosurgical rehabilitation, post-stroke rehabilitation or cognitive rehabilitation.

Innovativeness:	This practice uses innovative, new technologies combining the most up-to-date computer-generated 3D environment with well-validated and multimodal neurorehabilitation techniques in order to produce highly performing and personalised treatments to each patient. Moreover, since Ospedale San Raffaele constantly interacts with the company producing the virtual reality settings, it regularly gives them feedback and suggestions to keep on improving the system according to patient's needs, to benefit from the best technological breakthrough for its rehabilitative strategies. Ospedale San Raffaele is currently working on complementing the virtual reality system with online noninvasive brain stimulation using a compatible transcranial direct current stimulation (tDCS) system, specially designed to stimulate targeted brain areas during virtual reality rehabilitation. This synergic treatment should have the benefice of enhancing the positive effects of neurorehabilitation through an improved cortical plasticity. Combining different neuro-rehabilitative treatments to enhance their curing effects is also an innovative strategy that has been eliciting more and more interest in the past few years.
Added value:	This innovative approach to chronic pain has the advantage of reducing the use of pharmacological treatments since it is based on multimodal feedbacks and psychological support to improve patients' quality of life.

	Thus, this treatment helps preventing chronic drug abuse. The remote control platform allows close personalised follow-ups after the rehabilitative period. Moreover, this continuous multimodal telecommunication with patients helps reducing the risk of relapse after rehabilitation. Indeed, we know that when patients regain their homes after a period of recovery and neuro-rehabilitative training, it can be difficult for them to regularly meet with a healthcare professionals, either because of the cost, or because of the logistic or physical difficulties for the patient to go to the health care center/ physician. The remote communication platform facilitates home contact with patients, reducing thus relapses after rehabilitation discharge.
Appropriateness:	This innovative approach to chronic pain brought the following advantages of pain management: • This nonpharmacological treatment helps reducing the intake of drugs and thus reduces their collateral effects. • The telecommunication platform helps reducing patients' displacements which is seen as a great advantage for patients who can often have difficulties to come to the hospital for regular visits. • The construction of a tele-rehabilitation network allows sharing of protocols, treatments and results between national and international centers. It is thus a way of simplifying and extending at large scales a

	good quality sharing of knowledge.
NEXT STEPS	
Lessons Learned:	As mentioned earlier, a good communication between the different parts of the curing team is crucial. It is highly important that patients and health care professionals are well-informed on the procedure and that patients are addressed this kind of solution as soon as possible. Since the compliance of the patient is crucial, it is also of great importance that the patient will be able to attend all the scheduled sessions, for a long period of time. Thus, one should take into consideration the logistic capacities of patients to attend the scheduled visits to the treating center.
Key Takeaways:	Considering the multimodality aspects of chronic pain (physical, psychological, emotional, social), it is important to propose a multidisciplinary approach to improve patients’ quality of life, combining innovative neurorehabilitation with quality psychological support. In this multimodal treatment, the patient has to be placed in the core of the medical team. Moreover, a good interaction and communication between every part of the curing team is absolutely necessary for a successful treatment. In this multimodal approach, the psychological support of patient is absolutely essential as well as it is essential to clearly define the psychological influence of chronic pain on patients’ body perception before starting the rehabilitation.

	This psychological support is indeed of capital importance to efficiently improve patients’ quality of life.
Next Steps:	As explained above, Ospedale San Raffaele is currently working on the construction of a national network of such neuro-rehabilitative treatments. This network would reunite many healthcare centers all over the national territory, allowing sharing of protocols, ideas and results. The construction of such network is absolutely essential for a good quality sharing of knowledge, to constantly keep on improving chronic pain patients support.
OTHER INFORMATION	
Notes:	This protocol benefits from the organisational support of: • A network of tele neurorehabilitation of Italian Scientific Institutes of Recovery and Cures (IRCCS) funded and organized by the Italian Ministry of Health; • ARSOP (Associazione Medici Riabilitatori Specialisti Ospedalità Privata), which is a scientific society organised in networks of rehabilitation units of private Italian hospitals that regularly organises meetings on the prevention of chronic diseases.

Good Practice Number 13

CONTACT PERSON

Name:	Dr. Meissner
Surname:	Winfried
Organisation:	Jena University Hospital, Pain Unit
Position:	Chair
Country:	Germany
Email:	meissner@med.unijena.de
Short description of the person submitting this project	Chair of Pain Unit, Dep. of Anesthesiology and Intensive Care, Chair of Palliative Care Dep., Jena University Hospital Professor Patient Care, Research, Teaching.

DESCRIPTION

Title of the good practice:	Tele-medical support for patients with chronic pain
Category:	Empowerment Innovation

Who are the stakeholders involved in the Good Practice?

Health Professionals:	Kevean Moenchgesang, Winfried Meissner, Ulrich Smolenski, and the team of nurses, psychologists and physiotherapists
University:	Jena University

Location:	Jena, Thunringen
Start Date:	05/2015
End Date:	02/2016
Objectives:	Aim of this study was to assess acceptance and feasibility of a telemedicine support after chronic pain patients have passed a comprehensive multimodal pain management programme. In addition, effects on pain intensity, perception of impairments and well-being were analysed as secondary outcome parameters. After the end of their standard therapy, the intervention group (n=23, from 05/2015 to 02/2016) of patients from the interdisciplinary outpatient pain clinic received text messages (SMS) over a 4-week period. There were 2 SMS categories: Treatment SMS (based on standard therapy topics) and Feedback SMS (questions about impairments in daily life, well-being, dealing with pain, average pain intensity). Secondary outcome parameters were compared to the historical patient group.
Outcomes **Impact on participants:**	93.5 % of all Feedback SMS were answered. 76 % of respondents assessed getting the text messages as (very) helpful, no one as bothering. Almost 74 % were willing to get further Feedback SMS, 90 % would appreciate further Treatment SMS. Regarding secondary outcome parameters, no statistically significant differences could be observed.

Resources:	SMS were developed by the multidisciplinary pain management team including nurses, psychologists and physiotherapists. A computer was programmed to send out SMS automatically. Answers were recorded automatically as well. Resources needed were very low.
ANALYSIS	
Development of the good practice	1. Deficit analysis: short-term success of multimodal pain management programme was very high but declined when patients returned to usual care. 2. As repeated personal encounters were not feasible and/or affordable, a method to stay in contact with patients was searched, to empower function restoration and pain control, to remind patients of the information they had learned during the multimodal pain management programme, and to give them the feeling they are not alone. 3. The decision to develop SMS because came out from the fact that almost all patients have cell phones. 4. The content of SMS was developed using a multidisciplinary approach (e.g. education, relaxation, positive thinking, physical exercise, functional and pain assessment).
Means used to overcome or remove the obstacles	In the future, SMS will be individualised to specific patient conditions. Possibly, also physical activity will be tracked physical and personal communication offered.
Factors enabling	The positive feedback from patients was the

the process	major factor motivating the team.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	It is easily possible to reproduce and/or adapt this approach.
Innovativeness:	There is only few research on this field so far, mostly done in the field of psychiatry and neurology.
Added value:	Telemedicine and mobile health solutions add enormous value to the treatment of chronic pain conditions. Their main value is to continue and to sustain treatment success gained by multimodal pain management. However, these techniques cannot replace multimodal pain management and personal contact between patients and care givers.
Appropriateness:	Yes
NEXT STEPS	
Lessons Learned:	See above. This approach is easily reproducible.
Key Takeaways:	1. Tele-medical support of chronic pain patients after having passed a multimodal pain management program is feasible. 2. There is need for further research on the content and intensity of such support.
Next Steps:	Depending on funding: developing of individualised SMS contents.

Good Practice Number 14

CONTACT PERSON

Name:	Serena
Surname:	Mingolla
Organisation:	APMAR - National Association of People with Rheumatic and Rare Diseases
Position:	APMAR Communication Officer
Country:	Italy
Email:	mingollaserena@gmail.com
Short description of the person submitting this project	Serena Mingolla is Director of Morfologie, the journal of APMAR - National Association of People with Rheumatic and Rare Diseases. As volunteer and communication expert, she helped draft the present good practice, raise awareness for the project and involve participants. The project leader is Antonella Celano, President of APMAR.

DESCRIPTION

Title of the good practice:	A PAIN TO LISTEN
Category:	Empowerment

Who are the stakeholders involved in the Good Practice?

Civic Organization(s):	APMAR National Association of People with Rheumatic and Rare Diseases
Healthcare Organisation(s) :	Rheumatology Department of Taranto (Puglia) Hospital
Health Professionals:	Psycologists and Rheumatologists
University:	Department of Mental Health and Department of Human Sciences of the University of Urbino (Umbria – Italy dynamic clinical Psycho-diagnosis and Sciences Biomolecular Faculty)
Other:	Institute of Psychotherapy "Psicoumanitas" SIPSItalian Society of Psychology Family Counseling "Agostino Gemelli" of Taranto (Puglia Italy)
Location:	Taranto (Puglia)
Start Date:	01/2015
End Date:	12/2016
Objectives:	The project "A pain to listen - un dolore da ascoltare" is a multidisciplinary and multifactorial project addressed to women with Fibromyalgia. Fibromyalgia pain has no boundaries. People describe the pain as deep muscular aching, throbbing, shooting, stabbing, or intense burning. Quite often, the pain and stiffness are worse in the morning, and muscle groups which are used repetitively may hurt more. In addition, the severity of regional pains (particularly those in the head, neck, shoulders and lower back) are a strong predictor of a person's overall pain rating. Pain in every muscle and the profound exhaustion are not

	symptoms that people can see, but they are real and may be devastating for the person with fibromyalgia. Although the invisible nature of the condition causes credibility dilemmas for patients. Despite recent gains in understanding this condition, the lack of an easy “gauge” for chronic pain makes it difficult for people to grasp how fibromyalgia may cause so many symptoms and seriously jeopardize every aspect of a person’s quality of life. The project “A pain to listen - dolore da ascoltare” includes: psychological support to women suffering from Fibromyalgia, self-help groups where women talk, meet, discuss the pain and jointly organise events and other projects; information, through the creation of brochures and different kind of materials; an info point managed by APMAR and a toll-free number that provides information and immediate help for women feeling lonely. The project aims at improving the quality of life of women with Fibromyalgia. It has the main following objectives: provide information about Fibromyalgia, raise public awareness, collect useful data for research development, give support to the person, reinforcing third sector, provide mediation of the recognition process and bioenergy structuring activities and exercises classes tailored to symptoms (stiffness and fatigue) useful to boost endurance.
Outcomes Impact on participants:	Main outcomes were: psychological and physical well-being of women with Fibromyalgia syndrome were enhanced by social support. Chronic pain, depression, self-efficacy, helplessness, mood disturbance, health status, impact of FMS, were improved. Psychologists involved in the project

	observed a decrease of alexithymia and depression, greater security and openness in relations. Women started processing and overcoming the sense of loneliness and isolation, increasing knowledge and therefore awareness, acceptance of the disease. Regression analyses indicated that the created social support networks were associated with greater levels of self-efficacy for pain and symptom management, while the perceived quality of social support was associated with lower levels of depression, helplessness, mood disturbance, impact of Fibromyalgia, higher levels of self-efficacy for function and symptom management, as well as overall psychological well-being.
Resources:	Human resources: doctors, therapists, health professionals were all volunteers. They leaded the main activities of the project as far the individual support, the work in group, the organisation of a path of awareness events. Furthermore we counted on the support of more than 10 volunteers from APMAR National Association of People with Rheumatic and Rare Diseases. Among the resources, APMAR drafted several informative instruments aiming at rising awareness and empowerment of women with Fibromyalgia, as the publication “Fibromyalgia , a pain to listen", distributed through an info point but also through a social media campaign. Please find the link below: http://www.apmar.it/documenti/notizie/Opuscoli/APMAR_Onlus_-_OPUSCOLO_fibromialgia.pdf
ANALYSIS	

Development of the good practice	The project started at the end of 2014 at the Family Counseling “Agostino Gemelli” in Taranto, a coastal city in Apulia, Southern Italy with a population of 200,154. Three doctors and researches Drs. Ilaria Cinieri, Selenia De Pasquale and Gabriella Chiochia – specialised in the cure of Fibromyalgia had the idea to develop a series of activities to help women to face their chronic pain and improve together the quality of their lives, coming out of the solitude. In January 2015 the idea was espoused by APMAR- National Association of People with Rheumatic and Rare Diseases and its volunteers (among which there are many women with Fibromyalgia), and so the project “A pain to listen un dolore da ascoltare” was born. The project was launched with a communication campaign and supervised by the group of psychologists promoting the use of humanistic bioenergetics therapy for individual consultations and collective supporting group of discussions. Participants were 50 women with a confirmed diagnosis of FMS. In June 2015 APMAR Onlus founded its first “Group for Pathology” and launched new tools as an info point and a toll-free number. In November 2016, the project launched the brochure about fibromyalgia, presented it to the media, and also in the schools of Taranto to involve students and professors.
Factors enabling the process	The project has had the capacity to underline women’s determination, their desire for revenge, their desire to "take back their lives". Speaking about pain, participants told that it is important to understand that chronic pain is not a condition of

	loneliness, and that acting as a group made the difference.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	The project is based on a clinical methodology and on a detailed work plan; it has a working group - supported by APMAR volunteers - with specific roles for the successful implementation of activities. Therefore, it is replicable geographically both in other cities or places and in larger contexts (a region, or a state). It is also replicable temporally, including a range of services that can have a steady and reliable durability.
Innovativeness:	The project was innovative because, first, it was perfectly in line with the "New guidelines for the management of fibromyalgia" presented at the EULAR Congress, on 9 June, 2016 in London. In fact, as stated by the guidelines, "full understanding of fibromyalgia requires comprehensive assessment of pain, function and psychosocial context". This multilateral approach was very empowering and allowed women to work in the same direction to improve healthcare outcomes for people in the same conditions. Furthermore, it helped women with fibromyalgia get more control over their life, and promote understanding of patient empowerment. The project was also a call to action, not only among patients and health professionals, but also among all the other stakeholders: students, media, local policy

	makers and other civic organisations.
Added value:	The use of a comprehensive and diversified media plan which allowed the activation of an effective communication campaign on chronic pain and on the importance of the empowerment of women with Fibromyalgia. The media plan included: the establisment of a dedicated info point; the toll-free number; the activities of the psychologists, both at individual and group level, the support groups of women for the other women and the information campaign in schools.
Appropriateness:	The project was designed on the main characteristics of this peculiar pathology: fibromyalgia affects 3 to 5 percent of the general population. It occurs in people of all ages, even children. Men develop fibromyalgia too, although more women are diagnosed with it. Symptoms are chronic but may fluctuate throughout the day. Roughly one quarter of people with fibromyalgia are not able to work.
NEXT STEPS	
Lessons Learned:	It is important to involve the main target, in this case women with Fibromyalgia, from the beginning of the project and also in the implementation face. No one can help to build a suitable empowerment path more than the target itself!
Key Take Aways:	It is important to have a social life for people living with a chronic pain: loneliness is painful too.

Next Steps:	In the second edition of this project, the plan is to broad the geographical impact of the services and to involve other stakeholders.
OTHER INFORMATION	
Notes:	APMAR - National Association of People with Rheumatic and Rare Diseases, was born because some citizens started to organise themselves autonomously, pursuing targeted operational decisions to improve the lives of people with rheumatic and rare diseases. APMAR's purposes include raising awareness about rheumatic and rare disorders, as well as the treatments, prevention and rehabilitation within these pathologies. The primary goal of APMAR is to advocate for these pathologies to find their proper dignity and attention to public opinion and to political class. It is important to take social and health problems at national level, and spread information about these chronic diseases that irreversibly alter the personal, social, family and professional life of the person, acting also on a psychological level. Despite the significant numbers of these chronic diseases, rheumatic unfortunately are still "little known" diseases and especially "little recognised" ones at a social level. In the last years, APMAR has extended its activities to the rheumatic diseases of childhood and rare diseases. APMAR is among the founding members of FESCA Federation of European Scleroderma Association; it adheres to international bodies such as AGORA Platform of Organizations of People with Rheumatic Diseases in Southern Europe, EURORDIS Rare Diseases Europe, to national bodies, such as the CNMR National Centre for Rare Diseases

	National Institute of Health, MIR Rare Italian movement.

Good Practice Number 15

CONTACT PERSON	
Name:	Pete
Surname:	Moore
Organisation:	Pain Toolkit
Position:	Author and Trainer
Country:	England
Email:	pete.moore@paintoolkit.org
Short description of the person submitting this project	Author and Trainer of the Pain Toolkit Quiz http://quiz.paintoolkit.org

DESCRIPTION	
Title of the good practice:	Empowering people to self-manage their pain
Category:	Empowerment Innovation Professional education

Who are the stakeholders involved in the Good Practice?	
Civic Organization(s):	Pete Moore
Health Professionals:	Physiotherapist, GP, Occupational Therapist and two patients

Location:	UK
Start Date:	05/2016
End Date:	12/2026
Objectives:	To make the learning pain self-management more interesting and fun for patients and the healthcare professionals
Outcomes **Impact on participants:**	Participants (both patients and healthcare professionals) get feedback from the Pain Toolkit Quiz. Which questions they got right and which ones they didn't. They can also go return to the quiz to increase their score and knowledge.
Resources:	Expert summaries from patients and healthcare professionals before people do the quiz via http://quiz.paintoolkit.org/team
ANALYSIS	
Development of the good practice	Players of the Pain Toolkit Quiz can see what the experts say about the questions before doing the quiz http://quiz.paintoolkit.org/team
Means used to overcome or remove the obstacles	Do a second job (a cleaning job) to pay for the development of the Pain Toolkit Quiz
Factors enabling the process	Interactive between patients and healthcare teams
EVALUATION	

How your **good practice** meets the criteria below:	
Reproducibility:	The Pain Toolkit Quiz can be changed and updated with new questions at any time and with financial help, can be translated into many other languages.
Innovativeness:	All the experts who took part were: Physiotherapist, GP, Occupational Therapist and two patients.
Added value:	This process showed how patients and healthcare professionals can work together.
Appropriateness:	yes
NEXT STEPS	
Key Takeaways:	Keep pain self-management: Simple/ interesting Fun
Next Steps:	How patients and healthcare professionals can work together to provide a simple way to make pain self-management inter sting and effective

Good Practice Number 16

CONTACT PERSON	
Name:	Judy
Surname:	Birch
Organisation:	Pelvic Pain Support Network (PPSN)
Position:	CoFounder
Country:	UK
Email:	info@pelvicpain.org.uk
Short description of the person submitting this project	Judy Birch is the Co-Founder of the Pelvic Pain Support Network and a qualified teacher. She is the coordinator of this project and has planned and delivered the content in collaboration with the School of Healthcare at the University of Leeds and the University of Southampton. Her role is voluntary.
DESCRIPTION	
Title of the good practice:	Patients as Teachers in Health Professional Education
Category:	Empowerment Innovation Clinical practices Professional education
Who are the stakeholders involved in the Good Practice?	
Civic Organisation(s):	Pelvic Pain Support Network

Heasaylthcare Organisation(s) :	School of Healthcare: University of Leeds University of Southampton Medical School
Health Professionals:	Sharon Wood: Pain Curriculum Lead, School of Healthcare, University of Leeds Prof Ying Cheong: Senior Lecturer, Obstetrics and Gynaecology Curriculum lead, University of Southampton
University:	University of Leeds and University of Southampton
Location:	Leeds and Southampton
Start Date:	11/2009
End Date:	12/2016
Objectives:	The British Medical Journal (BMJ) and others have published articles over many years that emphasise the need for and the importance of patient involvement in medical education. Surveys and feedback from health professionals regarding input on chronic pain into the curriculum have highlighted the general lack of such content. Of all health professional groups, physiotherapists appear to have the most input on chronic pain into their training. The objective of this work is to give trainee health professionals – both nurses and doctors the opportunity to hear firsthand, as part of the taught curriculum, about the personal experience of people with long term pain regarding their encounters with health professionals. These sessions are delivered by patients who are also experienced teachers, and are thus taught

	from a firsthand “Patient Experience“ perspective rather than as abstract “Case Studies”. This method of delivery gives students the opportunity to ask questions, to delve deeper and to clarify the whole picture from the patient perspective. These ‘Patient Teacher’ sessions were introduced in the School of Healthcare (SHC), University of Leeds (UoL), BSc(H) Nursing (adult) Programme in 2009 and in 2016 for Medical Students at the UoL and the University of Southampton (UoS).
Outcomes Impact on participants:	For the BSc(H) Nursing (adult) programme, qualitative feedback via the module evaluation process has been collated since 2009. This data is reviewed via the SHC Programme Leader, Director of Education and Head of School and made available to the wider University and all SHC staff. In addition, the PPSN ‘Patient Teachers’ have obtained and evaluated qualitative and quantitative feedback on a short rating questionnaires from all of the ‘Patient Teacher’ sessions since 2009. It is clear that the students highly value this input. Students say that they have no input on ‘Patient pain experience’ anywhere else in the curriculum nor do they have any input on chronic pelvic pain. They report that the impact it makes will benefit them in their subsequent roles as practitioners. Since the introduction of the SHC ‘Patient Teachers’ sessions, at least one student elects to focus their assessment on Chronic Pelvic Pain. This raises the

	individual students awareness of chronic pelvic pain issues and management strategies and ultimately may contribute to clinical practice chronic pain awareness and discussions. The sessions for doctors in their 4th year of training started at Leeds and Southampton in 2016. The groups so far have responded positively with observations such as “Why is not there a multidisciplinary approach to chronic pain as there is for cancer and other conditions ?“ and “it is so important to have the patient perspective alongside the "medical model".
Resources:	Supportive lecturers who have a role in planning the curriculum and are committed to including the patient perspective as an integral part of the educational process alongside the theoretical, nursing and medical input. Patients who are willing, able and experienced in talking about/discussing the impact of long term pain on their life and personal health matters with students Lecture room facilities with white board and audiovisual facilities to allow PowerPoint presentation delivery Virtual Learning Environment (VLE). Guest lecturer login details for the audiovisual equipment PPSN website linked in the VLE Admin/Accounts department to reimburse travel/external speaker fee/donation to charity for time.

ANALYSIS	
Development of the good practice	In 2008, the nursing lecturer and leader of the ‘pain module’ at the UoL held an open event as part of the IASP Annual Pain Awareness Campaign. PPSN and other pain support groups were invited. This led to a trial by UoL and PPSN of a “Patient Expert Experience “ session on chronic pelvic pain for 3rd year undergraduate nurses on the BSc(H) Nursing (adult) degree programme. Four group sessions of 20 students on the noncompulsory component of the programme were included. The one hour sessions included the “Patient story”, survey data on diagnosis, treatments and effectiveness, the role of the charity and questions and discussion. The session was supported with PPSN leaflets and a PowerPoint presentation which was made available to students to access via the VLE. These sessions were by one person from PPSN who had experience of treatment both in and outside of the UK. The feedback from the student nurses was extremely positive with a few requesting more information about treatments. The sessions were repeated the following year; the feedback and evaluation was overwhelmingly positive. In subsequent years an increase in the number of students to 150/180, and the change of the pain module from an optional to a compulsory component, led to parallel sessions taught in groups of 30, requiring two patient speakers, both with

	experience of treatment outside the UK. The ‘Patient Teachers’ are consistently evaluated as invaluable contributors to the module, with feedback “inspiring”; “brought everything we were learning into context”; “helped to understand issues around pain” and “thought provoking”. In 2016/17 the Patient Teacher experience input was extended to the trainee 4th year doctor curriculum at UoL and introduced at UoS. The doctors’ content is taught in half hour sessions: in Leeds to 250 students in 5 groups of 50; in Southampton to 80 students in 4 groups of 20. About half the students will become GP’s and others will specialize in a range of disciplines.
Means used to overcome or remove the obstacles	An initial discussion with the SHC, Director of Student Education and Service User and Carer Lead Lecturer, led to the development of a proposal for funding to support the ‘Patient Teacher” sessions. The success of the proposal enabled access to room, audiovisual and VLE resources. Regarding the session that was cancelled, students were exceedingly supportive of the ‘Patient Teacher’ and did not negatively evaluate this event. The team of this project has discussed how to prevent the potential of a cancelled session in the future due to unforeseen circumstances. The idea is to either use an existing PPSN video or develop either a live recording of a session or a prerecorded session, this would be then made available to students via the VLE. As there are limited

	PPSN 'Patient Teachers' to deliver the sessions to 6 consecutive groups of 30 nursing students, the team also discussed how this could be managed. For a number of years the PPSN 'Patient Teachers' delivered two, one-hour sessions back to back. This 2-hour delivery however, was found to be too intense and physically demanding, and so for 2016 the module timetable was restructured to allow the one-hour sessions to be delivered across a number of weeks rather than two weeks. The PPSN 'Patient Teachers' found this approach much more positive and so this will be applied for future years. Travel cost reimbursements and speakers' time will be an important factor in future discussions with University staff/curriculum developers.
Factors enabling the process	PPSN has been fortunate to meet some lecturers/academic staff who are committed to the value of patient input and involvement in the delivery of the curriculum for chronic pain and who are willing to engage with patients who may have had difficult and negative experiences of services in order to prompt questioning amongst students about the way they may approach their future relationship with their own patients in clinical practice. Lecturers have given PPSN free reign to deliver the information without constraint and by doing so have demonstrated their trust in PPSN and in its ability to make what is taught really meaningful and powerful. This has led to a

	unique experience for the student nurses and has (in their own feedback afterwards) made it very memorable. The supporting structures within the SHC facilitated the proposal and implementation of these sessions and involvement in module and curriculum development. The Nursing and Midwifery Council (UK) identifies the importance of Service Users and Carers involvement in curriculum planning. This requirement has facilitated the encouragement of the SHC for PPSN 'Patient Teachers' to work collaboratively in the development of 'pain content' in the new curriculum for 2018.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	The principles and format of the sessions transferred successfully from Leeds to Southampton. This practice should be reproducible in any trainee health professional educational setting/undergraduate course, in any country.
Innovativeness:	To PPSN's knowledge this is the first time in any country that patients have been involved as teachers in nursing and medical education in the field of chronic pain. The latter has been neglected in medical education generally; greater attention to the subject in collaboration with patients is encouraging. The UoL nursing session evaluations contributed to the development of a more

	interactive approach which has gained positive feedback. This approach has benefited from the confidence, knowledge and experience that the PPSN Patient Teachers have gained through delivery of the sessions over the past 7 years. The Patient Teachers bring in different pieces of equipment that use in their personal management of chronic pain. This raises students awareness regarding the complexities and individualised nature of chronic pain management. Through this approach students gain knowledge and insight into non-standardised approaches to self-management, which is more real than a theoretical classroom discussion or lecture. A recent innovation from one of the Patient Teachers was the involvement of her husband in the sessions. This encourages the students to think not only of the impact of chronic pain on the psychological, spiritual and physical (for example) aspects of the 'Patient Teacher's' chronic pain but to begin to understand the wider impact this has on family and friends. Informal feedback from students includes the following comments: 'that was so brave' and 'this was so powerful'.
Added value:	Students want their training to be relevant and they want contact with "real life" patients. Those with chronic pain are particularly challenging. Students highly value the opportunity to hear from and to speak to these patients. To date many say

	that it will have a positive effect on how they view and approach those with long term pain in practice. Nursing students regularly feedback that the sessions contributed to the theoretical and practical aspects of the module being brought together and making sense for everyday clinical practice. Students comment that the sessions made the theoretical content real and that it all fitted together in the PPSN 'Patient Teacher' sessions. These sessions are also frequently evaluated as 'one of the best parts of the module' highlighting the value that students assign to these sessions. In 2015, two of the local 'Patient Teachers' became members of the 'pain module team' and the 'pain component curriculum development team'. Thereby patient experiences and expertise are now directly influencing the development and delivery of undergraduate adult nursing pain education. The PPSN 'Patient Teachers' were also involved with a UoL Nursing Student Pain Interest Group 'IASP Neuropathic Pain, Awareness Campaign' in 2015. This was led by students for students within the SHC and was positively attended and evaluated.
Appropriateness:	There is often a requirement to include "Patient Experience" within the curriculum. This lends itself to involving patients with personal experience of chronic pain who have come through a possibly tortuous path with a sense of humour intact! The PPSN 'Patient Teachers' are always greeted by a member of the module team whom they are familiar

	with and taken to their room and assisted with audiovisual aids. The module team lecturer stays throughout the session as indicated by the PPSN 'Patient Teacher'. The rooms are requested, where possible, on the ground floor to facilitate easy accessibility. Student needs are met through interactive question and answer sessions. A number of students are sensitive to the PPSN 'Patient Teacher' personal circumstances and have reported that they try not to ask too many questions even though they have a lot to ask. The PPSN 'Patient Teachers' always invites students to contact them after sessions with any additional questions or queries.
NEXT STEPS	
Lessons Learned:	A first initial step is to seek evidence from organisations regarding the positive effect that User and Carer sessions with 'Patient Teachers' can have on undergraduate education: British Medical association (BMA), Nursing and Midwifery Council (NMC), International Association for the Study of Pain (IASP) etc. It is imperative that the organisation implementing the session develops a partnership with the User and Carer organisation so that the goals and expectations and future plans are clear. A good communication strategy and working relationship between the two partners makes a huge difference to the development and success of the session. This information can then be implemented into a proposal for the

	organisation hosting the sessions, which may or may not require funding. A timely agreement for session delivery dates and funding (if required) contribute to successful planning, development and implementation of the session. Sharing ideas for the session content and providing a context for previous and future theoretical and practical sessions help to make the content relevant, at the right level and without repetition. Involvement of the 'Patient Teachers' with module and curriculum planning brings a new perspective and suggestions of resources to their development.
Key Takeaways:	1. The involvement of 'Patient Teachers' in undergraduate nursing and medical curriculum contextualises the theoretical components of pain education and raises students awareness of the complexity of individuals pain experiences. Students consistently evaluate the sessions as the best part of their pain module with the following comments often repeated; 'inspiring, necessary and insightful'. 2. Building a relationship between the educational organisation and User and Carer organisation where there are shared goals and involvement in learning and teaching strategies is imperative for successful implementation of sessions for students. Through these future adaptations, developments and innovations can be initiated that contribute to raising chronic pain awareness in undergraduate students.

Next Steps:	To develop or adopt a video of a ‘Patient Teacher’ to add to the VLE. To develop a new nursing undergraduate curriculum and the existing partnership will contribute to the pain content within this. Some blended learning initiatives are being developed in partnership to direct some of the chronic pain content. Feedbacks from the trainee doctors in Leeds and Southampton will be evaluated and future sessions discussed/amended in due course.

Good Practice Number 17

CONTACT PERSON

Name:	Gemma
Surname:	Fernandez Bosch
Organisation:	Asociación Sine Dolore
Country:	Spain
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Short description of the person submitting this project	She is the president of the Sine Dolore association, which struggles every day to make "visible the invisible: pain".

DESCRIPTION

Title of the good practice:	Christmas party
Category:	Empowerment

Who are the stakeholders involved in the Good Practice?

Civic Organization(s):	Asociación Sine dolore
Health Professionals:	Everyone
Location:	Menorca
Start Date:	12/2016
End Date:	12/2016

Objectives:	The Christmas appetizer is an event which brings together patients with their families and medical staff. There is a festive atmosphere, which let patients forget their troubles for a moment. This is also another way to make visible the invisible, as governments authorities participate too and so they indirectly endorsing the fight against pain.
Outcomes **Impact on participants:**	The Christmas appetizer involves also patients' families and local/national authorities so that they can really see that the pain affects people regardless of age, social classes, etc. Pain is between us every day. A very important step for the association is to involve also patients' families as most of the time patients feel lonely and their pain misunderstood. Our mission is to fight patients' loneliness and facilitate their quality of life and well-being.

Resources:	The real human cost is incalculable. This activity is possible thanks to the intervention of all our volunteers and partners. Everyone contributes and the association covers the economic aspect. The initiative is basically a happy hour with the participation of a chorus which sings Christmas songs and does it for free. Sine Dolore also draws lots and with the money raised the association covers the costs of the event.
ANALYSIS	
Development of the good practice	The good practice is to make patients see and feel that they are not alone, that among all Sine Dolore association works for a decent quality of life, without pain. This initiative makes all participants equal and standing together. Sometimes it is difficult to get the full support of the loved ones; for this reason Sine Dolore fights day by day to let the patient have a better quality of life. It is very important that the whole society understands and helps Sine Dolore to fight with the invisible evil, which is not seen and cannot be measured: pain.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	It would be good that all associations or entities that fight against pain could organise a similar initiative, since usually at Christmas time people are more receptive, more

	sensitised in any cause and is a great time to make this work visible.
Innovativeness:	The visible solution is that patients' relatives begin to understand and see how many people are in the same situation. It is a moment to share opinions, solutions, information.
Added value:	The visible solution is that patients' relatives begin to understand and see how many people are in the same situation. It is a moment to share opinions, solutions, information.
Appropriateness:	The Christmas party of course covers many needs, because it makes patients feel not alone, it unites people affected by chronic pain with others, and it also helps establish ties of friendship and support between patients and their families.
NEXT STEPS	
Lessons Learned:	It is fundamental to do it with sympathy, to believe in what you do and above all do it for those who suffer every day.
Key Takeaways:	Treating pain, alleviating suffering and improving patients' quality of life.
Next Steps:	Treating pain, alleviating suffering and improving patients' quality of life.

Good Practice Number 18

CONTACT PERSON	
Name:	Gemma
Surname:	Fernandez Bosch
Organisation:	Asociación Sine Dolore
Country:	Spain
Email:	gemmafernandez@sinedolorefoundation.org
Short description of the person submitting this project	She is the president of the association whose mission is to fight against pain.
DESCRIPTION	
Title of the good practice:	Gala Sine Dolore
Category:	Empowerment
Who are the stakeholders involved in the Good Practice?	
Civic Organisation(s):	Sine Dolore
Location:	Menorca
Start Date:	05/2016
End Date:	05/2016
Objectives:	The Gala Sine Dolore is an activity open to

	everybody. Through music we want to make the invisible visible: through culture and the musical notes people are made aware of chronic pain and at the same time they join the fight against pain.
Outcomes Impact on participants:	The Gala is celebrated in the Main Theater of Mahon. It is an emblematic place as it is one of the oldest buildings in Europe. It can accommodate about 800 people, therefore message conveyed by the Gala reaches 800 people. Artists who perform for free delight the public with high-level musical performances. The message is clear: they all fight against pain, they want to make it visible, raise awareness of this problem as chronic pain
Resources:	Once again, the Minorcan society responds and supports the initiative. With the help of volunteers, Sine Dolore makes this Gala possible. The location is free. Musicians also perform for free and the entry is free to reach a wider audience.
ANALYSIS	
Development of the good practice	This activity starts with presentations delivered by doctors with a simple and clear key message. After that there is musical entertainement and final greetings and notes by a member of the association Sine Dolore. Culture helps spread the message and information about chronic pain. However, during the event there is also the

	possibility for participants to receive information, thanks to memebers of Sine Dolore and also volunteer doctors.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	It is easy to organise a similar event if one gets the institutional support (so that the premises are free) and the support of musicians. However, also if these two things are not free, the initiative is still reproducible but resources to finance it should be found.
Innovativeness:	Music reflects the struggle against pain. It is also important to be constant and persistent in the struggle against pain.
Added value:	The best accomplishment is the joy people attending the event feel. For a moment all people are going in the same direction and fight together against pain to improve patients' quality of life.
NEXT STEPS	
Lessons Learned:	Treat pain relieve suffering and improve patients' quality of life.
Key Takeaways:	Treat pain relieve suffering and improve patients' quality of life.
Next Steps:	Keep fighting against pain and raising awareness.

Good Practice Number 19	
CONTACT PERSON	
Name:	Luca
Surname:	Di Blasio
Organisation:	Department of Medicine and Aging Science "G.d'Annunzio" University of ChietiPescara
Position:	Research fellowship
Country:	Italy
Email:	andiblasio@gmail.com
Short description of the person submitting this project	Andrea Di Blasio is an Italian PhD. working at the “Department of Medicine and Aging Sciences” of the “G. d’Annunzio” University of ChietiPescara. His research activity is about 1. the study of the relationships among physical activity, physical exercise and health, with a special focus on female health and chronic non-communicable diseases; 2. the study of the effects of exercise on female health and chronic non-communicable diseases, with a special focus on its effect on breast cancer treatments and side effects. He attended several specialistic courses to increase his skills in the field of public health, kinanthropometry, physical activity analyses and both physical exercise planning and periodisation in health and diseases. The project presented is a multidisciplinary project merging University and Hospital competences. The leader of the University group is Prof. Giorgio Napolitano, while the leader of the Hospital group is Prof. Ettore Cianchetti.

	Luca Di Blasio is the coordinator of the operative group, i.e. the group providing for participants screening and physical exercise practice.
DESCRIPTION	
Title of the good practice:	Allenarsi per la salute
Category:	Clinical practices
Who are the stakeholders involved in the Good Practice?	
Civic Organisation(s):	Associazione ISA, no profit organization involved in all grades (i.e. primary, secondary, tertiary, quaternary prevention) of cancer prevention.
Healthcare Organisation(s) :	Complex Operative Unit of General Surgery Specialized in Senology of the "G. Bernabeo" Hospital, Ortona, Italy
Health Professionals:	Prof. Ettore Cianchetti senologist; Prof. Giorgio Napolitano endocrinologist; Prof. Ines Bucci endocrinologist; Prof. Sabina Gallina cardiologist; Andrea Di Blasio Ph. D. in human movement sciences; Teresa Morano exercise specialist; Alessandra Cimini psychologist; Roberta Faraone nutritionist; Francesco Di Donato dietician;
University:	Departments of 1. Medicine and Aging Sciences, 2. Oral and Biotechnological Sciences, 3. Neuroscience and Imaging "G. d'Annunzio" University of ChietiPescara, Chieti, Italy

Other:	Case managers of the Complex Operative Unit of General Surgery Specialized in Senology of the "G. Bernabeo" Hospital, Ortona, Italy; Sports Medicine service of the "SS. Annunziata" Hospital, Chieti, Italy
Location:	"G. Bernabeo" Hospital, Ortona, Italy "G. d'Annunzio" University of ChietiPescara, Chieti, Italy
Start Date:	02/2016
End Date:	12/2017
Objectives:	The main objectives of the projects are: 1. to characterise the health status of breast cancer survivors and to study the correlates and determinants of their health status; 2. to prevent/treat the negative side effects of breast cancer treatments (i.e. fatigue, arthralgia, myalgia, shoulder and upper limb functions and ROM impairments, insomnia, anxiety, depression, obesity and cardio-metabolic diseases onset) through both physical exercise practice and nutritional education; 3. to offer individual counseling about the proper lifestyle to adopt to prevent/treat the negative side effects of breast cancer treatments. The objective number 1 is reached through a multidisciplinary evaluation by a senologist, a cardiologist, an endocrinologist, a sports medicine specialist, a psychologist, a nutritionist, a kinanthropometrist and a physical exercise specialist. In order to optimise the objectives number 2 and number 3, the eligible

	participants selected were trained for three months, for 3 hours per week, under the supervision of three physical exercise specialists and then had a personal counseling with both a physical exercise specialist and a nutritionist.
Outcomes Impact on participants:	Basal characterisation of the considered breast cancer survivors (BCS) revealed that they had high daily salivary cortisol, high daily carbohydrates and satured fat intake, and high daily pain. On the contrary, they had low daily salivary DHEAS, low quantity and quality of nocturnal sleeping, low aerobic fitness, low daily fiber intake, and low self-reported health. High daily salivary cortisol has been shown negatively correlated with sleeping quality and quantity and with self-reported health. On the contrary, it has been shown positively correlated with self-reported pain. After three months of supervised physical exercise practice, participants reduced daily salivary cortisol and pain. On the other hand, they increased sleeping quality and quantity, self-reported health, and daily salivary DHEAS that has been shown correlated with the variation of self-reported pain: a greater DHEAS increase was related to a greater pain reduction. Results also indicate the presence of a dose-response relationship: greater physical exercise adherence brought greater positive results.
Resources:	To carry out the project, it is necessary to have the following professional competencies: a senologist, a cardiologist, an endocrinologist, a sports medicine specialist, a case manager, a psychologist, a nutritionist, a kinanthropometrist

	and 3 physical exercise specialists. It is also necessary to have the following facilities: three surgeries; technical instruments for the cardiologist (i.e. echocardiography machine) as well as for the sports medicine specialist (i.e. technical instruments for stress testing), nutritionist (i.e. software for dietary intake analysis), kinanthropometrist (i.e. electrical bioimpedance analyzer, anthropometric tape, segmometer, balance) and fitness testing; two gyms; Nordic walking poles, mats, free weights, elastic bands; office supplies.
ANALYSIS	
Development of the good practice	The main operative steps of this projects are the following ones: 1. the case managers of the Complex Operative Unit of General Surgery Specialised in Senology of the "G. Bernabeo" Hospital (Ortona, Italy) recruited participants according to the established inclusion and exclusion criteria; 2. Luca De Blasio contacted the selected breast cancer survivors in order to complete the recruitment; 3. In a single afternoon, the cardiologist, the psychologist, the kinanthropometrist and the physical exercise specialist visited eight participants in order to verify and collect data about their cardiovascular, psychological, kinanthropometric and fitness characteristics. At the end of the afternoon each participant received a dietary diary (to fill in for 3 consecutive days) and a Sense-wear armband they had to wear for four consecutive days, in order to record and collect data about dietary habits and daily physical activity; 4. after these steps,

<table>
<tr><td></td><td>participants were subjected to a stress test by a Sports Medicine specialist, in order to verify their cardiovascular eligibility to a physical exercise programme; 5. after the evaluation steps explained above, participants were trained for three months for three hours each week. Each session was conducted and supervised by three exercise specialists. Nordic walking, Yoga, Pilates and adapted circuit trainings have been the main disciplines used to train participants; 6. after the 3-month training, the evaluation tests (described in point no. 3) were repeated and each participant received personal advice about his lifestyle. This means that, at the end of the training period, participants were properly educated to proper physical exercise practice and to A healthy lifestyle, according to their condition, in order to improve positive psychophysical results and to maintain them in the long run. 7. every five months, 50 new women started the project.</td></tr>
<tr><td>Means used to overcome or remove the obstacles</td><td>During the point 1 of the process, the psychologist revised the list of the case manager in order to verify the presence, among the selected patients, of his patients with a particular psychological status. This improved the recruitment process and reduced the risk of possible abstentions.</td></tr>
<tr><td>Factors enabling the process</td><td>The most important factors enabling the good practice are: a multidisciplinary approach, a high-specialised team.</td></tr>
<tr><td colspan="2">EVALUATION</td></tr>
<tr><td colspan="2">How your good practice meets the criteria below:</td></tr>
</table>

Reproducibility:	It is possible to reproduce and implement the good practice in other situations and places because it does not need a lot of economic resources. In order to reproduce the good practice the main need is to properly form and train the team. To implement the good practice it is possible to establish a team with more or different professionals according to the specific necessity/ies, or to adopt technical instruments.
Innovativeness:	The innovative solution of this good practice is the prevention and the use of a multidisciplinary team to make the prevention complete. It takes care of women after the surgery by training those women to a healthy lifestyle, by giving practical tips and rules to prevent/treat the negative side effects of breast cancer treatments which - if not properly treated - may lead to a new pathological condition and to a high drug use.
Added value:	This good practice, including the scientific research, allowed to investigate the impact of walking and Nordic walking on lymphedema and on head, neck and shoulder ROM, as well as to create a special series of exercises for breast cancer survivors, in order to overcome the limits of walking and Nordic walking on lymphedema, head, neck and shoulder ROM. To be more clear, introduction to Nordic walking (i.e. 10 lessons of Nordic walking technique) does not affect lymphedema in breast cancer survivors. This might be because novice Nordic walkers do not adequately

	generate an effective muscular pump through coordination of the alternated bimanual open–close cycle. On the contrary, when there is a proper technique, Nordic walking has been particular useful. The walking training is not able to positively affect lymphedema and the cited ROMs because during walking upper limbs are not actively used. According to our results, the Isa method, i.e. the series of specific exercise, appears to close the gap of both walking and Nordic walking, as better explained in our published manuscripts. http://www.karger.com/Article/Abstract/453599 https://www.jstage.jst.go.jp/article/jpts/28/10/28_JPTS2016375/_article
Appropriateness:	This good practice enabled an efficient management of the needs because it naturally prevents the onset of the psychophysical side effects of breast cancer treatments and it is a natural treatment of them.

NEXT STEPS

Lessons Learned:	The most important operative tip is to create a complete and competent multidisciplinary team assuring a solid base for the intervention. When the work routine is created, the work automatically goes on.
Key Takeaways:	1. Talking about breast cancer, if we really want to take care about women, it is very important to consider the fact that the intervention does not end with surgery and subsequent chemotherapy/ radiation/pharmacological therapies prescription. It

	is very important to accompany each woman toward that behavioural route assuring a successful prevention (i.e. primary, secondary, tertiary and quaternary prevention) against the negative side effects of breast cancer treatments. 2. In order to be really effective, an intervention must have, among their goals, the mission to give all the effective weapons for health leading to an effective disruption of the self-reinforcing negative loop characterising the health status of breast cancer survivors.
Next Steps:	The next steps of this project are to increase the number of women that it is possible to treat every 5 months, and to transform the project in a permanent service.

Good Practice Number 20

CONTACT PERSON	
Name:	Pim
Surname:	Giel
Organisation:	Happy motion
Position:	President
Country:	The Netherlands
Email:	p.giel@happymotion.org
Short description of the person submitting this project	Pim Giel (1959) worked 30 years in health care; nursing, aged care, intensive care, anesthesia, as a teacher and as an independent innovation manager. He knows the problems so from the inside. He decided to combine his experience in the care of his passion for making documentaries. He is now a fulltime director/ producer and he made the last few years dozens of commissioned films about care: two documentaries about dementia (*My Head In Your Hands* and *Ger, my head into his own hands*) and a documentary about chronic pain (*In order to be crazy*). With his own foundation Happy motion he aims to deal with serious topics from a positive angle, challenging manner and with the experience to bring central image and link it to an (educational) event, conference or symposium. He gives throughout the country (often with patients

	and experts from his films) presentations about his vision care. Where his film is a reason for encounter, dialogue and moving discussions in the hall between patients, caregivers and healthcare professionals.
DESCRIPTION	
Title of the good practice:	Pijn Samen (Pain Together)
Category:	Empowerment
Who are the stakeholders involved in the Good Practice?	
Civic Organisation(s):	Chronic Nerve Pain Association Foundation National Network Remedial Chronic Pain Samenwerkingsverband Pijnpatiënten naar één stem (Partnership Pain patients to one vote) Breathworks Mindfulness Book and Support Pain 2 Power Foundation Invisible Ill
Healthcare Organisation(s) :	Pain Platform Netherlands (PPN) National Association for LUPUS, APS, Scleroderma and MCTD Eurocept Adelante Rehabilitationraining Pain Consultant Hogeschool Arnhem and Nijmegen Sophia Children Foundation Batafurai St. Jude Medical Spine & Joint Centre Astellas Heliomare Medinello Health Deal Chronic Pain Home Health Products Symphony
Health Professionals:	Dutch Society of Anaesthesia Employees Pain Nurses (V & VN) Dutch Association for Acupuncture DC Clinics Prague Institute TranseCare, professional treatment of chronic

	pain
Other:	Grünenthal SIP Pain Alliance Europe SchwaMedico Pfizer
Location:	Kalfjeslaan 19 1181BN Amstelveen
Start Date:	09/2016
End Date:	10/2016
Objectives:	Pain Together is an initiative of Happy Motion foundation. The main aim of the project are: acknowledge and recognise chronic pain; promote cooperation between regular and complementary therapists; promote own management by patients. For the achievement of these goals, Pain Together used the most efficient means of communication to attract attention: movies! An essential support of the project Pain Together, among other things, came from the documentary "To be crazy" in which six pain patients are followed for one year and an half. All six are seeking solutions to combat the pain, or - at the very least - to facilitate handling of the pain and thus to improve their quality of life.
Outcomes **Impact on participants:**	Results achieved: seven movies, two conferences, a book published, education trajectory, nationwide campaign Week Pain, country presentations and discussion meetings, (digital) media campaigns.
Resources:	The cost of the project Pain Together and the

	pillars of the campaign the Pain Week are estimated at approximately € 300,000.
ANALYSIS	
Development of the good practice	For each patient a separate portrait with different themes. From these individuals, a variety of educational materials have been developed. At present there are six films and the documentary. The class meetings, usually leading by the filmmaker or another project member comprising: a general view of the care and treatment of chronic pain; display the footage; debriefing with emphasis on solutions to improve care. Duration meeting: about three hours. The meeting were open to everyone. Through the trainer programme: coordination with the receiving party who wants to give training and the choice of an educational film or documentary
Means used to overcome or remove the obstacles	The organization Happy motion is looking for a wide support to finance its plans, consisting of partners subsidy ingredients, funds, trade associations and businesses (Inter alia, insurance companies, employers and pharmaceutical companies). The financing is in full swing. They have also launched a crowdfunding campaign: (http://www.deweekvandepijn.nl/doneer) 'Pain to give a face" to contribute to the creation of the documentary and book publishing and pain patients in order to make the 2nd congress possible and monitor its

	streaming. The target amount is € 40,000. Therefore Happy motion not only approaches its partners and stakeholders, but also raise pain patients and their supporters on to the Pain Week also support.
Factors enabling the process	Involvement of numerous stakeholders form diverse fields and singular citizens using the crowdfunding initiative.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	Yes, using powerful images and videos represent a primary approach to understand the problem. Patients' personal experiences and pictures as well as social media are powerful tools.
Innovativeness:	Pain Together thereby tries to connect to all stakeholders in the pain field and the media. It is of paramount the cooperation with all interested stakeholders in the area of chronic pain.
Added value:	In addition to the patients and professionals, the project Pain Together results important for carers employers, municipalities, insurers, pharmacists, chemists and pharmacists. All project activities were finally combined with the Pain Week, which took place from 26 September to 1 October 2016.
Appropriateness:	The documentary and all the other things

	produced will provide material for teaching and informing patients and professional about pain management.

Good Practice Number 21

CONTACT PERSON	
Name:	Paolo
Surname:	Rossi
Organisation:	Alleanza Cefalalgici Cluster
Position:	Chief
Country:	Italy
Email:	paolo.rossi9079@gmal.com
Short description of the person submitting this project	Paolo Rossi is the Project Leader of the following good practice. He is also Vice President of European Headache Alliance, Chief of Alleanza Cefalalgici Cluster, Chief of the Headache Clinic INI Grottaferrata Research Associate University Centre for Adaptive Disorders and Headache (UCADH), Pavia, Italy. In addition to that, he is Professor of Clinical Neurology at the Nursing School of the Tor Vergata University in Rome, assistant at the Neuro-Rehabilitation Unit, INI Grottaferrata. Main research areas: headache, pain medicine, clinical neurophysiology, integrative and alternative medicine. Other scientific activities: he is member of the Scientific and Editorial Committee and Reviewer for more than 20 international scientific journals, including Frontier in Neurology, BMJopen, BMCneurology, Complementary and

	Alternative medicine, Complementary therapies in medicine. He has written more than 70 Medline articles.
DESCRIPTION	
Title of the good practice:	At lessons from the expert patients (EP) : advices for the physicians to improve their care of cluster headache (CH) patients
Category:	Empowerment Innovation
Who are the stakeholders involved in the Good Practice?	
Civic Organisation(s):	Alleanza Cefalalgici
Healthcare Organisation(s) :	IRCCS C.Mondino, Pavia
Health Professionals:	Paolo Rossi, Cristina Tassorelli
University:	Pavia (Italy)
Other:	INI Gorottaferrata, European Headache Alliance, OuCH UK, OuCH Italy
Location:	Rome, Pavia, Dublin, London; Valencia
Start Date:	04/2016
End Date:	03/2017
Objectives:	Cluster headache (CH) in an excruciating form of primary headache characterised by recurrent unilateral, short lasting attacks of very severe headaches and most commonly appearing in clusters, that is active periods separated by pain-free

	remission periods. Despite the diagnosis of CH is very simple, and rapid and effective treatments for alleviating CH pain induced sufferings are available, data from literature have documented that CH is largely under-recognised, undertreated and underestimated. Barriers to a proper care for CH are strictly connected to its low prevalence. In fact, as for other rare or infrequent disorders CH is not adequately known, apart from few specialists, and - as a consequence - CH patients' needs are largely unmet. As for other rare or infrequent disorders, a precious but untapped resource is represented by the expert patients. The aim of this project was to collect a list of recommendations from CH expert patients (EP) for the physicians engaged in the CH management, with the purpose to improve their ability in taking care of CH patients.
Outcomes Impact on participants:	77% of the EP' advices could be grouped in 7 main recommendations: 1) Prescribe the correct medication at the right dose and in the right quantities; 2) Consider few clinical clues to make the diagnosis: it is very simple! And educate other doctors; 3) Provide good information and be able to correct the misleading ones; 4) Take the patient seriously, listen to him to recognise his suffering and that CH is a valid medical disorder that can have a significant impact on the person, and support him (care, not cure); 5) Be sensitive to the CH

	consequences on the patient's significant ones and provide, if necessary, family and carer's consultations; 6) Suggest patient to not conceal and to be active in patients' support; 7) Allow quick access for ECH patients to headache specialists. These commandments have been used as guidelines to propose pragmatic patient-centred changes in health care services dedicated to CH patients. The following actions were started: to encourage the national and international associations focused on headaches to multiply the initiatives to educate the physicians about this disorder; to call upon the EU parliament and the Member States to remove the barriers to the access to effective treatments and to acknowledge that CH is a highly disabling disorder; to invite the headache specialists to refer to the patient associations their CH patients; to encourage the physicians to create facilitated pathways to allow a quick access to headache specialists.
Resources:	Patient associations providing assistance and support to CH sufferers in six European countries received a letter of invitation to join the study in September 2014. Those CH groups who accepted to participate were requested to provide a list of recommendations and advices for the physicians engaged in the CH management from at least 5 expert patients. EP advices were analysed through content analysis.

ANALYSIS	
Development of the good practice	The idea of collecting expert patients' recommendations was developed during a debate at the General Assembly of the EHA and translated into a project by Dr. Paolo Rossi. This approach could work only if the patients are highly motivated, as the disease is not heterogeneous but patients share the same problems. Cluster headache was identified as the ideal disease which could obtain the major advantages by this approach. Contacts were established with the main patient associations of CH patients in Europe that gave their enthusiastic adherence to the initiative.
Means used to overcome or remove the obstacles	Every participating country was asked to create a small focus group of expert patients having a face-to-face discussion on few general topics. As a result, the adherence to the project's aims significantly improved.
Factors enabling the process	Cluster headache patients live extraordinary sufferings amplified by the ignorance of the physicians about this disease and by the approach that people have towards pain disorders. Thus, patients' are very motivated to collaborate to initiatives that have the objective to improve their quality of life. Furthermore, as it often happens with rare and almost rare disorders, they are very expert about

	their disorders. Finally, Cluster headache patients share the same problems everywhere in Europe. The project made possible for the European CH patients to talk to physicians with a single voice strengthening the feasibility of the expert patients' approach.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	The initiative had been reproduced in three different countries with very consistent findings.
Innovativeness:	Patients' involvement in chronic pain management is usually limited to a tick-box exercise, that is patients are usually asked to answer to questionnaires measuring the impact of pain on their life with a limited attention to their needs, desires and values. This study has proposed an approach achieving the three core elements of the patient-centred care provision: communication, health promotion and partnership.
Added value:	The patients' recommendations may be easily translated into pragmatical solutions. Most of these solutions have been easily activated. In Italy, for instance, it has been possible to improve the access to effective treatments such as oxygen and sumatriptan e.v. by working in partnership

	with scientific societies, regulatory agencies and pharma industries (a generic form of sumatriptan has been introduced and widely distributed in the market; the legislation about the prescription of oxygen has been changed). At the same time, special pathways accelerating the access of CH patients from GPs to selected headache centres have been activated (very positive experiences took place near Rome, where the GPs were informed about the possibility to have a diagnostic suspect of CH with three simple questions and to refer the patient directly to headache centres. This allowed the participating centres to triplicate the number of CH patients visited in the 2016). In Italy, as well as in UK, patients have ranked the headache specialists accordingly to their ability to satisfy the patients' expectations. This allowed patients to be followed by headache specialists actually knowing in detail the problems of CH. Other pragmatically solutions need more complex actions, such as the involvement of the politicians and the implementation of national and international legislations. However, the project represents a short track to listen to the patients' voice for all the ones that are interested in it.
Appropriateness:	The expert patients' suggestions once translated into a change of the patients' care approach will enable a more efficient and effective diagnostic and therapeutic

	management of CH patients which is currently unable to satisfy patients' needs.
NEXT STEPS	
Lessons Learned:	The main lesson learned is that the expert patients' voices are precious for implementing the care pathway of chronic pain patients. A special care is necessary to identify the expert patients and, secondly, to encourage them to work in group. Indeed, the discussion is crucial to translate the personal experience into recommendations that can be valid for everyone.
Key Takeaways:	Expert patients may provide valuable recommendations to improve care of CH and other chronic pain disorders. Expert patients' voices may be easily used to propose pragmatic patient-centred changes in healthcare services dedicated to CH.
Next Steps:	To spread the expert patients' recommendations in every European country, to involve the academic institutions and all the stakeholders to work in partnership to put the EP's recommendations in practice.

Good Practice Number 22

CONTACT PERSON	
Name:	Rosario
Surname:	Rodriguez Gonzalez
Organisation:	National Fibromyalgia and Chronic Pain Confederation
Country:	Spain
Email:	confederacion.fibromialgia@gmail.com
Short description of the person submitting this project	The National Fibromyalgia and Chronic Pain Confederation has conducted a project of addressed to patients with fibromyalgia and their relatives. This group of patients is socially forgotten, because fibromyalgia is not an accepted disease in society. In many cases these patients need information and answers to their doubts. Usually, doctors tell them they suffer from a chronic illness and give then a diagnose, but no other information. Patients get scared by this news. The National Fibromyalgia and Chronic Pain Confederation wants to help patients and offer them a useful, fast and effective service. To serve this purpose, they have established a helpline service so that anyone interested can access, regardless of their place of residence. Patients will always be assisted by a specialised professional. Concrete doubts will be solved. Psychological assistance will be given to patients, since they require it.

	This has been a pioneering project in Spain and has obtained some fantastic results.
DESCRIPTION	
Title of the good practice:	Helpline of care for fibromyalgia patients and their families
Category:	Innovation
Who are the stakeholders involved in the Good Practice?	
Civic Organisation(s):	National Fibromyalgia and Chronic Pain Confederation
Healthcare Organisation(s):	National Fibromyalgia and Chronic Pain Confederation
Health Professionals:	Psychologists, social workers and physiotherapists
University:	Cadiz University
Other:	Association of patients and their families
Location:	Calle Virgo 11, Jerez de la Frontera 11406 (Cádiz)
Start Date:	01/2016
End Date:	12/2016
Objectives:	Fibromyalgia is a chronic rheumatologic disease that affects several systems of the human body and its functions, being represented by innumerable symptoms. Although in recent years the rate of people affected by this disease has been increasing and the visibility of this disease has grown, these patients must face great problems to which, today, is not yet being given a solution. Some of the main

	problems are: it is a chronic disease with great variability in its symptoms; it affects the biological, psychological and social sphere of patients; there are not too many research teams working on it. That is why National Fibromyalgia and Chronic Pain Confederation has set up a helpline for people affected by fibromyalgia and their families. It is the most agile and efficient way of working to meet the existing needs, posing the following objectives: • Provide an information service and specialised help on fibromyalgia, on the existing healthcare resources and patient associations, among others, aimed at people suffering from these diseases or at people who are suspected of suffering from them. • Advise the family members of people with fibromyalgia about the disease, treatment and how to adequately support their relatives. • To create a protocol of psychological first aid, to branch patients affected by fibromyalgia in need of immediate attention to professionals collaborating with associations federated to National Fibromyalgia and Chronic Pain Confederation.
Outcomes Impact on participants:	The results of the project have been satisfactory. Although it is imperative to be aware that it has been a pioneering project throughout the Spanish territory, people have gradually become acquainted with it and with the helpline number, 901 760 997. At first, we have taken into account the calls received, which have been progressively proportioned as the months passed by. This seems very positive since it is a sign of real acceptance. The number of calls is increasing and this means that the service helps a greater number of patients. Another positive result has been the great users'

	satisfaction with regard to the helpline service, which was high regardless of whether they were directly affected by the disease, or the relatives of someone suffering from fibromyalgia.
Resources:	To carry out this project, it is essential to rely on human resources. Different professionals (such as a psychologist and a physiotherapist) have been involved to provide a multidisciplinary, physical and mental vision of the illness. We also had the support of a administrative professional and of the presidents of different member associations of the National Fibromyalgia and Chronic Pain Confederation to launch of the project. The premises of the Confederation can be found in Jerez de la Frontera (Cadiz), Virgo Street, no. 1011. The building no. 10 has 72 m^2 and it usually hosts formative meetings, workshops and meetings for members. There are 50 chairs, a table for the talks and sports material. The establishment number 11 has 70 m^2 and is distributed this way: An office equipped with computers and a printing press, internet connection and a telephone. It used for the activities carried out by the staff, and it is where the stationery is kept. A waiting room which has a library. A room where the physiotherapy is performed. It is equipped with specific and varied technical material. Our premises are adapted for disabled people.
ANALYSIS	
Development of the good practice	This project will be implemented at national level and addressed to people affected by Fibromyalgia, as well as to their

	families. The project also aims to improve the networking among patient associations and federations in Spain. Based on previous analysis, it seems clear that, in Spain, people with Fibromyalgia are currently a group with high levels of social vulnerability and who did not get an adequate response from the Public Health System yet. Patients are usually addressed with negative adjectives which increase the symptoms of their disease. The society is getting more sensitised with the reality of this disease. It is of great importance to continue working and advancing in research. Different mechanisms will be installed to offer these patients the help they need. We consider it a very interesting way to make available to patients and their families a telephone hotline, through which they can receive information about the disease. Information on the services offered in Public Health, the diagnostic process, the process for the recognition of disability and/or incapacity for work, existing treatments, among others. 1. Elaboration of a Catalogue of Services in Fibromyalgia of Spain. 2. Establishment of a "Protocol of first psychological aid" and branching to professionals of entities close to the patient. 3. Startup of a helpline 901 4. Media campaign of the program.

Means used to overcome or remove the obstacles	Some of the solutions adopted by the Confederation was the contract entity to a psychologist maintaining the initial budget.
Factors enabling the process	Factors facilitating the process have been: the fact that the Confederation is a stable entity, and it is able to overcome unexpected events, which inevitably might appear once a planned project kicks off; the support of member entities and their implication in each activity were essential as well. Another relevant factor is that the Confederation is part of the National Confederation of People with physical and/or organic disabilities (COCEMFE), which also gave its unconditional support.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	The implementation of this project in Spain has proven that a helpline is a very useful resource for patients. People greatly value a resource to learn about fibromyalgia and clarify doubts. If this service does not exist in other countries, it will be highly recommended to implement it. Regardless of the country, patients living with Fibromyalgia as well as their families have a number of common characteristics and are facing very similar situations. Due to this, a the establishment of helpline is very helpful and indeed it has generated very positive feedbacks in Spain, helping many

	people. For this reason, and based on the successful Spanish experience, it is to be expected that the same applies also to other countries.
Innovativeness:	The innovative nature of the helpline for Fibromyalgia patients and their families has been based on the previous absence of a similar service for these patients, and on the fact that it allows to reach every patient affected by Fibromyalgia in Spain, regardless of his town of residence. In this way any person living in Spain would have a number to instantly resolve his doubts. The Confederation has been a pioneer in this type of project. Although currently there is a slight increase in the knowledge of chronic pain and Fibromyalgia, it is still unknown socially. The people affected by these pathologies, undergo a long process until they get a diagnosis. Furthermore, they are diagnosed with a painful chronic disease they have to live with for the rest of their lives, and with no information about it. Fibromyalgia is a disease that has no cure yet. However, it is still possible to improve the quality of life of patients affected by this disease. The first thing is to accept the idea of being diagnosed with a chronic disease, which also implies to adopt a series of appropriate behaviours. The Confederation considered essential to offer advice and information to these people. Another important aspect for patients was the possibility to receive help

	and assistance remotely.
Added value:	Unplanned innovative solutions and results have been achieved, thanks to the promotion and collaboration of public and private entities. All hospital departments have been reached, as well as many hospitals and countless outpatient clinics. Indeed, hospitals and clinics are the places where Fibromyalgia patients feel more lost and disoriented, both when they get the diagnosis and when they still do not have it yet. Also networking with health professionals was essential.
Appropriateness:	The main drawback with Fibromyalgia is the lack of social acceptance. Sometimes, some people think that it does not exist. Because of this social situation, patients in many cases feel disoriented, lost and uninformed. There is an enormous need to be heard and understood. Thus, this helpline has managed to meet these patients' needs.
NEXT STEPS	
Lessons Learned:	Implementing this project in other countries would be very positive and easy to do. The main advice steps follow are detailed below: • Have all the information about entities dealing with Fibromyalgia in the country; • Establish a helpline 901; • Carry out an informative campaign in all the health departments of the different

	regions; • An internal informative campaign on the activity to all members within the local fibromyalgia associations; • Networking with the different physical fibromyalgia associations of the country. The objective of this project was to provide a service to the entire population of Spain affected by fibromyalgia and their relatives. This project offers orientation, information and training, and sheds a light to the helpless situation which the patients face. It is a pioneer in Spain.
Key Takeaways:	The involvement and coordination between all the different associations in Spain that are dedicated to Fibromyalgia to know the different services offered in each city. The union between all in the improvement by the conditions in the life of this collective, is a priority. When working in a network, it's all benefits. The next point would be the approach to all the regions of Spain. We have created the care of professionals specialised in this disease to each patient or family member who at a given moment has needed it. The speed of response and guidance in the next steps would be immediate.
Next Steps:	Maintain a continuity of the project, adding improvements. One of the next steps will be a psychological online service through Skype. Future plans also concern a complementary

	telephone assistance offering specific training on self-care for patients in different parts of Spain, and in particular in those cities where the helpline gets more calls.
OTHER INFORMATION	
Notes:	The project was thoroughly disseminated through mass media (radio programmes mostly), as well as in magazines, newspapers, and even on television. • http://eldia.es/agencias/8678036DFIBROMIALGIAlineapacientesfibromialgiagraciascontribuyentes • http://www.tenerifesolidario.org/es/noticias/confederacionfibromialgiafatigacronicaespanadesarrollaproyectoatenciontelefónica • http://www.tenerifesolidario.org/es/noticias/confederacionfibromialgiafatigacronicaespanadesarrollaproyectoatenciontelefónica • http://www.somospacientes.com/noticias/asociaciones/serviciodeatenciontelefonicadeapoyoapacientesconfibromialgia/ • http://fibrofamur.blogspot.com.es/ • https://www.gualchos.org/blog/

	• http://www.cehegin4u.es/en/noticia/3572sanidadimpulsaennuestromunicipiounproyectodelaconfederacindefibromialgiayfatigacrnica • http://www.ponyville.es/serviciodeatenciontelefonicaaenfermsdefibromialgiayfamiliares/ • http://www.laverdad.es/agencias/murcia/201605/11/lineaparapacientesfibromialgia674312.html • http://www.lapanoramica.es/noticia/cehegincontaraconatenciontelefonicaparaenfermosyfamiliaresdefibromialgiayfatigacronica/https://fibropositivas.wordpress.com/2016/11/10/telefonodeatencionafamiliaresypacientesconfibromialgia/#more1691 • http://www.cocemfebarcelona.es/noticia/laconfederacionfibromialgiayfatigacronicaespanadesarrollaunproyectodeatención • http://www.lainformacion.com/salud/enfermedades/CONFEDERACIONFIBROMIALGIADESARROLLATELEFONICAESPECIALIZADA_0_915809173.html

Good Practice Number 23

CONTACT PERSON	
Name:	Santiago
Surname:	Alfonso
Organisation:	Acción Psoriasis (Spanish Psoriasis and Psoriatic Arthritis Patients Association)
Position:	Director
Country:	Spain
Email:	accionpsoriasis4@gmail.com
Short description of the person submitting this project	Santiago Alfonso is director of Acción Psoriasis and the project leader of the following best practice.
DESCRIPTION	
Title of the good practice:	ELearning. Online educational platform for patients with psoriasis and psoriatic arthritis
Category:	Empowerment Innovation
Who are the stakeholders involved in the Good Practice?	
Civic Organisation(s):	Acción Psoriasis
Healthcare Organisation(s):	Spanish Academy of Dermatology and Venereology

Other:	It is planned to involve other public institutions such as the Spanish Society of Rheumatology, the Official College of Physicians, Nurses and Pharmacists and other private institutions that support the project.
Location:	Internet, so its sphere of action is global, it operates worldwide.
Start Date:	Start in May 2014
End Date:	It has no end date
Objectives:	It has been found that the management of the disease depends on several factors, such as knowledge of the disease, adherence to treatment, doctor-patient relationship, personal characteristics, emotional state and attitude of patients, among others. For this reasons, it is important to give people affected by psoriasis tools to improve the management and evolution of the disease. In the same way, it is of vital importance that patients have an adequate knowledge of their therapeutic options. Indeed, the empowered patient coexists better with his illness. For these reasons, Acción Psoriais launched the Online ELearning course. Training patients and increasing their knowledge about their disease leads to an improvement in the control and management of the disease itself. Furthermore, empowerment of patients provides resources and tools to live better with the pathology and improves their quality of life.

	Primary objective: to establish a network of expert psoriasis and psoriatic arthritis patients. Secondary objectives: 1. To test the level of knowledge about the disease at baseline. 2. an e-earning platform for psoriasis and psoriatic arthritis patients and their relatives. 3. Assess the level of benefit for each subject of the training.
Outcomes Impact on participants:	For patients: the psoriasis and psoriatic arthritis patient who becomes aware and takes an active role with the pathology learns and educates, improving at the same time the health outcomes and adherence. He also helps other patients by providing information and support. 2. For healthcare providers: the expert and informed patient manages the disease in a better way, has a better health, takes the treatment better and makes easier the communication and relationship with the health care provider saving time and efforts. 3. For public institutions: the expert patient saves money of his public health system as he does not waste resources; at the same time, he optimises the management of his disease by using less medications and fewer visits to healthcare providers which joined the online platform. 4. For civic organisations: Psoriasis Action aims to improve the lives of patients with psoriasis and psoriatic arthritis. This activity improves quality of life of these patients working both directly with the patient and his family and also to improve the patient's condition in the health system and society in general.

	The online educational platform is within the Psoriasis Action website so the patient and family can easily find other resources of the association offered on this website.
Resources:	The online training course of expert patients in psoriasis and psoriatic arthritis has been devised by the patient organisation Action Psoriasis. It has especially involved the Communication Department, composed of four people, who have managed and reviewed the course content. The association has trained a person responsible for contacts with patients and management of online activity. The course has been also tested by different patients' profiles. The project has been developed by a company expert in developing projects in the health area, who has created the online platform and project communication plan. Financial resources were provided by the association and by various sponsors which contributed to the support of Acción Psoriasis activities.
ANALYSIS	
Development of the good practice	The patient performing this activity may: know what this disease is and how it works; learn what tests or checks to be held; report on the best treatment for each patient and what is its purpose, clarify doubts about basic daily issues related with the disease. Acción Psoriasis consists of three phases: 1. Initial evaluation; 2. Patient and family's training 3.

	Evaluation of the effectiveness and usefulness of the course. Patients and/or their relatives attend this course, patients become experts in psoriasis and psoriatic arthritis and receive a certificate of expert patient. Patients can attend classes anytime and anywhere , as they are always available online.
Factors enabling the process	Two main factors: 1. the patient's need to better understand his disease, treatment options available, and tools to live better with this chronic disease. 2. Innovation, as there was no training for psoriasis patients online.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	We can reproduce this activity in different languages and also about different diseases.
Innovativeness:	There was no online courses for psoriasis patients.
Added value:	Acción Psoriasis develops numerous awareness activities and trainings for patients, health providers and society in general, but the online course complements patient education and aims to create a network of experts to be integrated in the volunteer association network. In addition to that, through the online platform access to patient education is provided also for patients unable to move to our training meetings in different cities or countries.
Appropriateness:	There is an ongoing evaluation of the data

	provided by the online platform: number of participants, course status, online patients.This evaluation helps understand if patients' needs are actually met or if certain areas demand more information.
NEXT STEPS	
Lessons Learned:	Results obtained tell us that 90% of course users are satisfied with classes attended. Users also affirm to have improved their psoriasis control. In addition, they would recommend the course to their relatives.
Key Takeaways:	The person who becomes aware and assumes an active role with his pathology, learns and trains, improves health outcomes, and adherence to therapies. He also helps other patients by giving them information and support.
Next Steps:	Acción Psoriasis wants to launch a new online course exclusively for psoriatic arthritis.
OTHER INFORMATION	
Notes:	The lack of knowledge about a pathology leads to fear and often to breakdowns, as well as to the inability to seek solutions or tools that can reduce pain and help coexist better with the disease. An active and expert patient will be more involved in his treatment, will have strategies and tools to combat that pain and, in conclusion, will be in control of

	his own pathology and will have the ability to make decisions regarding his psoriasis, along with a dermatologist.

Good Practice Number 24

CONTACT PERSON	
Name:	Gustavo
Surname:	Norte
Organisation:	Chronic Pain Unit, Anesthesiology Department, Centro Hospitalar e Universitário de Coimbra
Position:	Anesthesiology resident
Country:	Portugal
Email:	gustavo.norte@gmail.com
Short description of the person submitting this project	Gustavo Norte is an anesthesiology resident, now finishing his second year of training. His special interest in chronic pain has led him to perform chronic pain rotations which consists in clinical activities and research work. He is the main researcher of this project.
DESCRIPTION	
Title of the good practice:	Compressive therapy in patients with chronic pain related to leg ulcer
Category:	Empowerment Innovation Clinical practices Professional education
Who are the stakeholders involved in the Good Practice?	

Helthcare Organisation(s) :	Chronic Pain Unit, Anesthesiology Department, Centro Hospitalar e Universitário de Coimbra
Health Professionals:	Gustavo Norte Anesthesiology resident Marta Moreira Anesthesiology resident Ana Valentim – Anesthesiology consultant Elsa Santos – Registered nurse Juliana Paciência– Registered nurse Manuela Sampaio – Nurse consultant
Location:	Coimbra
Start Date:	05/2011
End Date:	12/2018
Objectives:	Main objective: implementation of compressive therapy in patients with chronic pain related to leg ulcer. Specific objectives: specific training for the implementation of compressive therapy by nurses of the chronic pain unit; elaboration of a procedure protocol for the use of compressive therapy in selected patients of the chronic pain unit; reduction of pain using compressive therapy as an adjuvant technique in patients with leg ulcer without significant arterial pathology; promotion of leg ulcer healing and prevention of its recurrence using compressive therapy. The success of compressive therapy is reliant on the patients' self-care at home. During their consultation with the nurses, patients are provided with essential information (oral and written) in, ligature care, alarm signs of ischemia, daily registry of pain and pharmacologic management, specific

	footwear, promotion of physical exercise and specific feeding habits. All patients are also provided with a pack of four ligatures, two of them are applied during the consultation as they need specific management, while the other two are stored at the patient's home. They need to be washed, dried and packed properly according to nurses' indication. Ischemia of lower leg is a possible complication of compressive therapy. Patients are informed of ischemia signs and how to proceed in that case. Patients are encouraged to fill out a daily registry of pain using a numerical scale to better evaluate pain in different situations and thus optimising pain control with systemic analgesics, which are prescribed in a specific range by the medical doctor. This pain registry also helps the medical doctor to understand the patient's pain range and adapt the prescription to his needs. Daily physical exercise (specially walking and mobilisation of tibiotarsal joint) and regular intake of proteins, iron, vitamins and other nutrients are encouraged to improve and fasten ulcer healing. A guide about how to exercise and which foods to eat is provided through a flyer and also during the consultation with the nurse.
Outcomes Impact on participants:	Between May 2011 and April 2014, 52 patients with leg ulcer were referred to the chronic pain unit, 12 of whom were excluded by significant arterial pathology. Of the 40 remaining patients, 11 were undergoing

	compressive therapy in another hospital, and 10 had no criteria to perform the treatment or refused. We found that 90% of 19 patients submitted to treatment, presented pain reduction by 50% during the 4th week of treatment and 80% of patients were pain-free after 8 weeks of treatment. The systemic analgesics consumption was reduced in 20% of patients. Ulcer healing was achieved during the 12th week in 45% of patients while this occurred in 32% patients in the 24th week. The remaining patients were admitted to treatment before the 12-week time and the average time to ulcer healing was 16 weeks. With regard to the follow-up after ulcer healing, all patients were observed after 15 days, a month, three months, six months, and annually after treatment discharge. Ulcer relapse occurred in 59% of patients, and it was associated with incorrect use of compression socks, wider ulcer and issues such us venous thromboembolism.
Resources:	Educational resources: professional training program in leg ulcers treatment of venous or mixed aetiology using compressive therapy (35h) in a specialised unit in leg ulcer treatment; additional training in evaluation of ABPI (10h), assessment of leg ulcers and updates in congresses and workshops in this subject. Physical and Human resources: the activity was conducted in a chronic pain unit, where proper space (treatment room and consultation office) was available, two nurses with training and availability to perform

	treatment (4h/week); medical evaluation every four weeks (doctor experienced in chronic pain), a vascular surgeon available for occasional evaluation; portable Dopplers with 8mgHz probe; shower in the treatment room with hot/cold water; electric stretcher; manual sphygmomanometer; spring type oximeter; sterile clawless tweezers; consumables sterile scalpel blades and gauze; nonsterile latex examination gloves; adhesive and cling film; clothes suitable for the healing phases (pressed cotton bandages, polyamide bandages, Jersey stocking, short traction bandages and compressive therapy kits); information and evaluation resources; leaflet to inform the patient about self-control of pain; management of analgesics and ulcer care; ulcer care and pain assessment scales (Numeric Scale of PainNSP, Brief Pain InventoryBPI, Specific Questionnaire for Neuropathic Pain Screening–DN4, Pressure Ulcer Scale for HealingPUSH, Hospital Anxiety and Depression Scale–HAD, Quality of Life scaleQoL).
ANALYSIS	
Development of the good practice	Evaluation • Patients' clinical evaluation is done by the doctor and nurses during the consultations and also when there is stagnation or worsening of ulcer healing. • The evaluation and pain control is done by the doctor and nurses during the consultations and in case of uncontrolled pain (by the doctor). • Ulcer

	evaluation is done during the consultations with the nurses. • Vascular evaluation is performed during the consultations with the nurses and after six months of treatment (evaluation of ankle brachial pressure index ABPI) or when pain patterns seems to be associated to arterial pathology. • Compressive therapy takes place in patients: with ABPI >0.8 and ≤1.3 and with ABPI >0.5 and ≤0.8, after vascular surgeon assessment, conscious and oriented, not institutionalised and with consistent family support. Able to maintain preventive care for recurrent ulcer No oncological pathology in progress. Procedure • Ulcer local approach: cleaning of the ulcer's lower limb with running water and Offenbach soap or similar at body temperature; pain monitoring; ulcer debriding; suitable clothes for the ulcer's healing phase; • Compressive therapy: signature of informed consent for the procedure; evaluation of peripheral O2 saturation in the ulcerated limb before compression; application of Jersey bandage if skin irritation is present; a cushion in the lower limb from the fingers to the popliteal region with cotton bandages; suitable compressive material according to standard technique; assessment of peripheral O2 saturation in the ulcerated limb after compression, information to the patient about signs of arterial compromise, ligature care and contact if any complications arise;

	• Prevention of ulcer relapses: application of fit elastic stockings to prevent relapses; regular medical and nursing consultations after healing (15 days; 1, 3 and 6 months; annually) to adjust analgesic schedule if necessary; • Maintain records throughout the process.
Means used to overcome or remove the obstacles	Dedicated time for compressive therapy within the working hours. Results were shown to the vascular surgery department. Creation and protected storage of a paper database. Use of a basin to do the leg lavage, as an alternative to the shower. Sharing of the post-anaesthetic care with Doppler probes when compressive therapy was performed.
Factors enabling the process	Sharing of the positive outcomes in several hospital departments so the referral of patients would be more effective. Unit management support in the acquisition of specific resources and divergence of professionals' schedule for the procedure. Positive returns in terms of patients and their families' satisfaction and quality of life.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	Training of nurses and physicians in the procedure and pain control is of little cost for the outcomes achieved. Learning curve to achieve procedural expertise is small. This therapy needs only basic physical resources

	that are available in most medical units. The evaluation resources are simple to use with standard criteria to select patients. Doubts in patients' evaluation or treatment can be clarified by intercommunication with other units or medical specialties.
Innovativeness:	Implementation of leg ulcer compressive therapy protocol in a public chronic pain unit, enhancing and facilitating pain control in patients of greater complexity. Only a few units perform this treatment in Portugal. Decrease in drug consumption and its adverse effects, in emergency and hospital admissions, as well as in prescription of antibiotic therapy for infected ulcers and fasten chronic pain unit discharge.
Added value:	The nurses involved in this project are also trainers in several workshops on the topic, promoting the implementation of this treatment in medical units throughout Portugal. This nonpharmacological technique decreases drug consumption for pain management and its adverse effects. It is proved to improve ulcer healing, decrease number of emergency and hospital admissions as well as consultations in chronic pain units. It has decreased prescriptions of antibiotic therapy for infected ulcers reducing medical costs. At the same time, it has improved patients and their families' satisfaction and quality of life. Two (2) nurses working full time in the Chronic Pain Unit (35h/week) dedicated 5h/ week to

	Compressive Therapy. Seven (7) anesthesiologists partially rotating to perform the 25h/week consultations (in two consultation offices at same time). All doctors had been trained to evaluate patients and refer to Compressive Therapy if the admission criteria are met."
Appropriateness:	Among the lower limbs ulcers, venous aetiology is the one with the highest prevalence, corresponding to approximately 85% of the ulcers found in this location, being chronic venous insufficiency the main cause of its onset. Chronic pain related to the presence of leg ulcer is usually difficult to control, since in most cases patients experience mixed pain: e.g. nociceptive and neuropathic pain resulting from the chronification of an ulcer. An individualised analgesic regimen based on the WHO analgesic ladder is often insufficient due to the non-healing of ulcers and pain characteristics that lead to strong opioids prescriptions, so other strategies need to be considered. Compressive therapy is one of the first line strategies for the treatment of ulcers of venous aetiology, with proven gains both in the favourable wound evolution and in the treatment of associated pain. A consensus document produced by the European Wound Management Association corroborates the previous idea and further adds the reduction in costs with nursing care. This technique consists on the application of compression to the lower limb using specific bandages,

	compressive stockings or other inelastic systems, triggering several complex physiological and biochemical effects that affect the venous, arterial and lymphatic system, improving venous return and reducing oedema.
NEXT STEPS	
Lessons Learned:	Patients’ ability to perform proper ulcer care during and after healing is essential for treatment success. Lack of analgesic drug support during early phases of treatment may lead to failure to apply compression due to patients’ pain.
Key Takeaways:	Compressive therapy is internationally recognised as a first line strategy in the treatment of venous and mixed leg ulcers with proven gains in healing, pain control and quality of life. It represents an inexpensive and effective measure, easy to implement and without significant side effects. The establishment of this program in central hospital units can play a key role in the training of other health professionals, especially those on primary care. Strict pain management in several phases of the treatment are essential for ulcer healing and compressive therapy success’.
Next Steps:	Relocation of chronic pain unit facilities with optimal utilities. Increase the number of qualified nurses to perform this treatment. Acquisition of resources (Doppler probes and manual sphygmomanometer with different

	bracer sizes). Training of family nurses at primary health care on ulcer care and screening of its signs to refer if necessary. Refer patients with controlled pain and no healing abilities of the ulcer to trained family nurses at primary health care. Create a functional multidisciplinary wound treatment unit within our hospital. Create a protected online database.
OTHER INFORMATION	
Notes:	Links: Granick, Mark S., Teot, Luc; Surgical Wound Healing and Management 2nd edt, 2012; CRC Press, ISBN: 9781841849270 Harding K, et al. Simplifying venous leg ulcer management. Consensus recommendations. Wounds International 2015. Available to download from: http://www.woundsinternational.com Price P, Gottrup F, Abel M. Ewma Study Recommendations: For Clinical Investigations in Leg Ulcers and Wound Care. J Wound Care. 2014 May;23 Suppl 5:S1S36. European Wound Management Association (EWMA). Position Document: Hardtoheal wounds: a holistic approach. London: MEP Ltd,2008. Gottrup, F., Apelqvist, J., Price, P. Outcomes in controlled and comparative studies on nonhealing wounds: recommendations to improve the quality of evidence in wound management. J Wound Care 2010;19:6,23768. Who executes: Nurse and medical doctor

	Evaluation • Patients’ clinical evaluation: First medical and nurse consultations When there is stagnation or worsening of ulcer healing • The evaluation and control of pain is done: First medical and every nurse consultations Whenever uncontrolled pain (by the doctor) • Ulcer evaluation is performed: Every nurse consultation • Vascular evaluation is performed: First nurse consultation and after 6 months of treatment (evaluate anklebrachial pressure index ABPI) When pain pattern presents characteristics of associated arterial pathology. • Application of compressive therapy takes place in patients: With BPI >0.8 and ≤ 1.3 and with ABPI >0.5 and ≤ 0.

Good Practice Number 25

CONTACT PERSON	
Name:	Lars
Surname:	Bye Møller
Organisation:	FAKS The Association For Chronic Pain Patients
Position:	Vice president
Country:	Denmark
Email:	larsbyemoeller@gmail.com
Short description of the person submitting this project	Lars Bye Møller is vice president of The Association For Chronic Pain Patients (FAKS) which is a Danish nondiagnosis specific patient organisation. After the SIP 2012 in Copenhagen he also took part in the foundation of a Danish interest organisation "SmerteDanmark" (Pain Denmark) where he was vice president for four years. Together the two organisations founded the telephone helpline SmerteLinjen (The pain line). Today, he is member of the steering committee managing the telephone helpline "SmerteLinjen". Besides taking part in lot of the organisational tasks, and political work, he is also an eager photographer and videographer. This comes in handy when trying to portray and make chronic pain visible and the work of the organisation through social media. Last but not least important, he himself lives with chronic pain due to fibromyalgia. After several years spent

	learning how to navigate the healthcare system and by coincidence being referred to an interdisciplinary pain clinic, he finally saw some improvement. He now uses his position to undertake various patient empowerment initiatives and increase the awareness of chronic pain and put it on the political agenda.
DESCRIPTION	
Title of the good practice:	SmerteLinjen (The pain line)
Category:	Empowerment Innovation
Who are the stakeholders involved in the Good Practice?	
Civic Organization(s):	SmerteDanmark (Eng, Pain Denmark)
Helthcare Organisation(s):	SmerteDanmark (Eng, Pain Denmark)
Location:	Denmark, Copenhagen. 2500 Valby Urtehaven 76, Kld
Start Date:	03/2017
End Date:	Ongoing
Objectives:	One of the initial reasons for starting a telephone helpline was to take some of the pressure off from people calling and asking FAKS for personal help in the patient organisation. Also the idea was to pursue a more professional and organised approach to

	guide people living with chronic pain and their relatives. Main goals: providing free information and support to people suffering from chronic pain and their relatives; recognition of the pain people experience and helping them to navigate the healthcare system, the social system and their own lives; guiding people towards the right treatment as soon as possible and empowering people to take responsibility for their own lives. Secondary goal: in addition to offer guidance, FAKS also hoped for the telephone helpline to help spread and increase the awareness of chronic pain among citizens and professionals.
Outcomes Impact on participants:	Statistics and data: first of all being able to track the call rate is important not only to see if our effort is effective, but also in order to provide leverage for future fundraising. Second, FAKS tried to know more about our callers in order to adapt our advice with the right content and knowledge (sex, age, residency, marital status, income basis, caller group patient, relative, health professional, other, subject, where did you hear about the pain line).
Resources:	Human resources: first of all you need people truly committed, especially when you lack the financial resources this is even more key. It became evident to us how crucial it is to have a good network. Working with health professionals provided contacts that became important in recruiting volunteer advisers

	such as pain nurses and social advisers. Facebook helped to get contacts when looking for people to be part of the exhibition. Facebook has played a vital part and not only to recruit volunteer phone advisors but also to call attention and raise awareness about the helpline. Financial resources: 150.000 euros from the Ministry of Health received for the project. These funds covered board meetings, training and supervision of volunteers. 2. 216.000 euros from private funding, raised from Trygfonden for an awareness campaign.
ANALYSIS	
Development of the good practice	Recruitment of volunteer advisors: volunteers were recruited through an existing network via Facebook and locally, while the professionals were recruited through a professional network, that is the University Hospital. Education and supervision of advisors: supervision of the counselors advice is four times a year. Awareness campaign: FAKS and PainDenmark raised €200,000 of private funding for an awareness campaign to promote the helpline and chronic pain "The face of pain". Part of the money were used to develop an exhibition with photos and stories of 10 people living with chronic pain. Among these, four are famous Danish people. The exhibition then travelled around the country in different hospitals. Every time the exhibition toured in a new hospital, press and different politicians such as the officials of the region of healthcare were invited.

Means used to overcome or remove the obstacles	To cut a long story short, a budget based upon a similar initiative was used. Some but not all the money were granted, so some items were rearranged. Altogether this process took half a year. Pairing up Skype meetings was also helpful.
Factors enabling the process	Paving the way for public founding. Starting out a lot of projects with health professionals and political groundwork. Altogether this helped the organisation gain reliability and put chronic pain high on the political agenda. This eventually led to a meeting with the former Minister of Health in 2014 were the idea of a helpline was first presented.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	Due to the various issues chronic pain often cause, FAKS aimed at providing interdisciplinary bio/psycho/social counseling. Because of this, four different types of advisory were identified: pain patient, pain nurses, social workers and psychology students.
Innovativeness:	Considering the awareness campaign, using the pictures of known people played a big role in getting the attention on national TV and media coverage. Moreover, the media paid interest to the other characters as well.
Added value:	Create a social network for chronic pain patients and their relatives, allowing room for the individual no matter what the diagnosis

	was.
OTHER INFORMATION	
Notes:	When looking at demographics and the epidemiology of chronic pain in the different European countries, it is important to consider the vast differences in the numbers of the populations. Keeping this in mind, here are some info on the Danish population. Denmark is a relatively small country on $42.99m^2$ and a population of 5.6 million citizens. Taking into account that approximately every one in five persons have experienced chronic pain this translates into around 850,000 adult people living with chronic pain.

Good Practice Number 26

CONTACT PERSON

Name:	Anna
Surname:	Giss
Organisation:	Suomen Kipu ry
Position:	Board member, advocate
Country:	Finland
Email:	anna.giss@suomenkipu.fi
Short description of the person submitting this project	She is a 28 year old student from Finland. She has studied German language and culture, teaching, nursing and social services, but most important: she has learned from my personal experiences in life. She has gone through a short training programme after which She has worked as an "experience advocate". In the near future she has to retire because of her four chronic pain conditions, but she is not giving up on volunteer work. Pain is her everyday life, involving Thoracic Outlet Syndrome, Complex Regional Pain Syndrome, chronic complex migraine and bulging disc with radiculopathy. She is very outspoken and have done advocacy in the media, and through her own ways.

DESCRIPTION

Title of the good practice:	Experience advocate

Category:	Empowerment Innovation Clinical practices Professional education
Who are the stakeholders involved in the Good Practice?	
Civic Organisation(s):	Suomen Kipu ry
Healthcare Organisation(s) :	Suomen Kipu ry
University:	Tampedei d
Other:	GIIS
Location:	Tampere and all of Finland, plus the whole worldí
Start Date:	11/2014
End Date:	09/2026
Objectives:	Teaching from personal experiences, that is it. Anna Giss holds advocacy speeches in nursing schools, and whereever people happen to reach her out from. She tells people what it is like to live her life, how does pain affect her, what difficulties she has come across with, how could the nursing staff help her, what is there to think about when they have a patient like her. During these lessons, she always let people ask her any questions. By asking questions they really want to know, they will get the answers they are looking for. Her main goal with these advocacy speeches is that other pain patients

	could benefit from these lessons. If a nursing student attends her lectures and then comes across with a patient with similar kind of conditions, he or she might remember how to act, what to ask, and what not to do, based on her lecture. She also posts photographs on Instagram that reflects her battles with her health condition, but also her everyday life. The account name is: @lusikoitakiitos. With over 800 followers she has lots of people from the spoonie community (chronically ill people who identify as an spoonie, the name coming from the spoon theory). Photos really say more than words: some of her photos are cruel, some poetic. She also has her own pain and health related blog: http://www.lily.fi/blogit/lusikoitakiitos She also writes some advices and information to people, who are in similar situations. These all together makes her a great pain advocate.
Outcomes Impact on participants:	The teachers who have asked her to give speeches, have told many times how innovative the students where after they had had the chance to ask Anna Gill things. Now the students have a piece in their memory on how to act, if a person suffering from pain comes for their patient. She has also been contacted after my appearances in the media. People told her how they have found power in theirselves, but some other people have also studied her conditions a bit more and have offered some help. The impact might also be that a chronic pain patient who has stayed in the bed under the covers way too

	long, can read the blog or see her on TV or in a magazine, and think: "oh the hell with it. If that young girl does it, so do I."When she gives her advocacy speeches, there are usually roughly 35 nursing students plus two or three teachers. She goes to the University of applied sciences of Tampere about ten times a year, that means she has educated about 350 nursing students every year for a couple of years now. In the last month there have been at least 1,4k individual visitors on her blog.
Resources:	As for now she does not take any charge when she goes and gives these advocacy speeches. If she travels far, then she asks to get the transport to be paid. Her blog and Instagram, those are also free of charge. Sometimes she does some collaborations, meaning she has had some discounts from products and she has written about them. But she has done that rarely.
ANALYSIS	
Development of the good practice	In the future she will be able to tell more people about these advocacy speeches. They could be held for example at big companies, trying to spread awareness and understanding, as there are always people living with chronic pain in nearly every company. With advertising she could get some benefits for the blog, but she wants to keep it health-related and only writes about things she really stands behind herself.

Means used to overcome or remove the obstacles	Advocacy. Advertisement. Those are the main things that need to be done. She does that in her blog every now and then, but also sends e-mails to different nursing schools etc. to inform them about her activities. She has also shared her experience with media to reach a wider audience.
Factors enabling the process	Media appearances helped to get the message around about people willing to share their experience living with chronic pain to nurses, doctors and everyone. When her blog got the "recommended" stamp she gained new readers, which means some more people ready to try to understand others. In 2016 Anna Gill gave an interview about her advocacy work that was published in four or five newspapers, so hopefully more than 400.000 people read that. In December 2016, one of the most popular talk shows broadcasted an interview too. That TV show is usually seen by about 500.000 people when it airs, and it is now to be seen worldwide online for a year. There are 189 entries on Anna Gill's blog; at the end of 2016 the blog achieved the "recommended" label from the hosting website. This means that there are some blogs on the site that have been voted to be recommended both by the readers and the portal. The site is run by one of the biggest magazine companies in Finland.

EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	It is really possible to spread this work all around the world! Being a public speaker is not always easy, you have to know people might ask very personal questions, and it is not that easy to tell about your life over and over again. Therefore it is really important to take part in training programs or at least talk to people who do this already. Everyone can start a blog or just make an Instagram account and start using hashtags.
Innovativeness:	Yes, involving real patients with future nurses.
Added value:	Not only does the audience benefit from these speeches, but more importantly they affect their future patients. The health-related blog is hosted on a bigger blog site, and just recently it was voted as one of the "recommended" blogs of the site. So a larger audience can read it. Feedbacks received from ordinary people who report they now understand better obstacles people can go through and things to keep in mind when meeting people with chronic pain.
NEXT STEPS	
Lessons Learned:	Do it, but first learn from others. It might seem easy to go talk about your life and pains, and write and photograph them, but there is so much more... She would be happy

	to travel around the world giving advocacy speeches, and also teach future advocates. The main lesson learned is to be active. It really made the difference when she first wrote an email to a TV production and to a magazine. In both cases, the producers contacted her right away telling they were interested in her story.
Key Takeaways:	Each and everyone of us in an individual, every patient should be met as a unique human being. There is no need for stereotypes, but there is always space for kindness and that little spark in the eye.
Next Steps:	Tell the whole world about her story, so that others would benefit from her experience. She feels ready to tell the bad and the good things.
OTHER INFORMATION	
Notes:	Anna Giss defines herself the Mary Poppins of chronic pain. But without the umbrella, as she sits in a wheelchair, she can't travel where the wind blows. As there are people who do not have the opportunity to attend her public speaking gigs, that is why she has the blog and why she does things with the media: to reach out for a larger group of people. Blog: www.lily.fi

Good Practice Number 27

CONTACT PERSON	
Name:	Gemma
Surname:	Fernandez Bosch
Organisation:	Asociacion Sinedolore
Position:	President
Country:	Spain
Email:	gemmafernandezbosch@gmail.com
Short description of the person submitting this project	The association Sine Dolore is an entity that fights against pain, to make visible this evil that is neither seen nor can be measured. They are volunteers and with the few resources they have they always try to benefit society at the maximum.
DESCRIPTION	
Title of the good practice:	Sinedolore World Park
Category:	Empowerment Professional education
Location:	Menorca
Start Date:	05/2016
End Date:	01/2017
Objectives:	Menorca is the least known island of the Balearic Islands, which since the beginnings of mankind has been related to pain. In its

	history, apart from the great amount of talaiotic wealth, there is the Hospital of the Island of the King, a place where the pain was visible during the wars, as thousands of soldiers of different nationalities were brought here. Also, there is the Island of Lazareto, where Leprosy patients used to be isolated. The history of Menorca day by day was involved in advancing to improve the quality of life, alleviate suffering, that is why Sinedolore is born: to fight against pain and make it visible. The main objective of this event is to make visible the invisible, that is pain. 20% of population suffers from this invisible evil. Sinedolore's mission is to raise awareness about this great problem. This is why the island of Menorca for four days becomes celebrates the struggle against pain. Menorca is a place that in itself has a great quality of life, its tranquility and its environment is ideal for this project.
Outcomes Impact on participants:	The greatest result is that anyone who is on the island, has been able to understand the problem of pain. During these days, many doctors from different parts of the world give informative, explanatory talks about how to alleviate suffering, how to understand the patient, what possible treatments there are, latest research etc. The biggest impact is that people who come to Menorca from other places find an island totally dedicated to the fight against pain.
Resources:	First of all, what is essential is the help of all

	the Menorcan entities. This initiative is possible thanks to the collaboration of the municipalities of the island, private companies and employers, associations, hotels and restaurants, including the support of the military and the church. Being all involved is much easier and cheaper. Using free public spaces it is possible to hold conferences for anyone who wants to participate. Sports activities are also done in sporting clubs. During these days, also military museums and diocesan museums are free. We also have the collaboration of the press, which facilitates the activities that take place during the days of the park, as well as programmes spread in hotels and shops on the island.
ANALYSIS	
Development of the good practice	This initiative is done in the month of May. On its third edition, which will be from 4 to 7 May 2017, the park will have hundreds of activities in the whole island. In each town there are different initiatives, craft markets, exhibitions, football matches, conferences, etc. All activities are meant to raise awareness about pain. During these days, a scientific activity takes place too: it is a congress against pain where doctors from all over the world meet and share the latest techniques and scientific advances against pain. It should be noted that in each city hall conferences held are addressed to patients and their relatives and are given by pain

	specialists. During the lectures, attendees learn, understand and even ask their doubts about pain. The island is decorated with banners to create more atmosphere. SineDolore World Park is advertised everywhere in the island, such as in the airport, on taxis, buses, in shops etc. As said before, all this is possible because of the great civic collaboration.
Means used to overcome or remove the obstacles	As said before, the only thing was meeting with many people, and investing many hours to explain things over and over again to make people understand the importance of fighting against pain.
Factors enabling the process	The biggest factor that makes this initiative possible is the human factor. Thanks to this, thanks to all the people who believe in Sine Dolore association, this event has been possible so far.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	Without support it is not possible to do it. It has taken 12 years to get support from all levels: the church, the politicians (with changes of parties) military and above all the society.
Innovativeness:	This practice produces awareness and understanding. It helps patients feeling misunderstood by their relatives about their pain.

Added value:	It is important to raise awareness about the problem. The best reward is that everybody contributes to fighting pain.
Appropriateness:	The greatest benefit after 12 years of struggle, is the union of society to fight against pain and to improve patients’ quality of life.
NEXT STEPS	
Lessons Learned:	The advice is to have a lot of patience, this is not a question of money, it is a question of solidarity, social involvement, hard work and above all of common belief in the fight against pain.
Key Takeaways:	The advice is to have a lot of patience, this is not a question of money, it is a question of solidarity, social involvement, hard work and above all of common belief in the fight against pain.
Next Steps:	To alleviate suffering, to fight against pain and to improve patients’ quality of life. We just want a world without pain.

Good Practice Number 28

CONTACT PERSON	
Name:	Rosario
Surname:	Rodriguez Gonzalez
Organisation:	Alba Andalucia
Position:	President
Country:	Spain
Email:	federacionandaluzafmysfc@gmail.com
Short description of the person submitting this project	The ALBA Andalucia Federation was born in 2007 as an associative entity for Fibromialgya, Chronic Pain and Multiple Chemical Sensitivity patients, as these pathologies are considered barely known as chronic illnesses that have an important repercussion. Nowadays, the presence of this entity in Andalucia has a growing trend, with a total of 66 member associations, representing a collective of 13,000 patients. There has currently been a slight advancement in the field of knowledge of chronic pain and fibromyalgia, but it can be said that it is still widely unknown in society. Although unfortunately it lacks a cure, the life of patients can still be improved, through the own acceptance that they have a chronic illness and that as a consequence they have to follow a series of steps. That is why, the challenge posed by this project was to create an informative guide aimed at patients

	diagnosed with fibromyalgia. So far, there is not a guide, manual or publication by a public or private institution directed towards patients to shed light to the helpless situation which they face.
DESCRIPTION	
Title of the good practice:	Informative guide for fibromyalgia patients
Category:	Empowerment
Who are the stakeholders involved in the Good Practice?	
Civic Organisation(s):	Colegio Oficial de Farmaceúticos de Andalucía
Healthcare Organisation(s) :	Consejeria de Salud de la Junta de Andalucía
Health Professionals:	Gonzalo Gragera Gallardo, Psicólogo Alberto de la Orden Torres, Fisioterapeuta Neikel Moreno Gomez, Psicologa
University:	Granada University
Other:	AFIJE, Asociación de Fibromialgia Jerezana
Location:	Jerez de la Frontera, Cádiz, Andalucia, Spain
Start Date:	01/2016
End Date:	05/2016 ongoing
Objectives:	The general aim was to offer patients affected by fibromyalgia a total knowledge of the different aspects of the illness, ways to face it and ways of taking care of themselves. The

	specific goal was to provide with knowledge about the existent techniques and resources to fight the illness in order to improve the quality of their lives. A better treatment of the pain caused by fibromyalgia involves raising awareness among patients of their joint responsibility about their state of health and having to overcome the stereotypes which label patients as passive receptor of care. Indeed, it was necessary to switch to a model where the patient is key to reach a good state of health. For that purpose, empowering the patient and motivating him was fundamental too.
Outcomes Impact on participants:	Patients have been provided with knowledge about the illness in more than 55% cases, and also with a set of specific strategies and skills to learn how to have and maintain a positive attitude about their health. The guidebook has changed into a tool that supplies information for the family and people around the patient, improving the understanding about the illness and inducing to a better acceptance of it. The guidebook works as a tool addressed to the medical personnel to be well informed about the illness and be able to provide patients with a better service. The handbook has been well received by different Spanish organisations. Thanks to the dissemination of the guidebook, the illness was made visible to more people, and society was provided with general information in a more accessible format.

Resources:	To carry out this project, it is essential to rely on human resources. The project has implied collaboration of different professionals (such as a psychologist and a physiotherapist) to provide a multidisciplinary, physical and mental vision of the illness. It also had the help of a professional administrative and the presidents of different member associations of the Federation for the kick-off of the project. Premises of Alba Andalucia can be found in Jerez de la Frontera (Cadiz), Virgo Street, number 1011. The establishment number 10 has 72 m^2 and it is meant to hold different activities and meetings, such as formative meetings, workshops and meetings for members. There are 50 chairs, a table for the talks and sports material. The establishment number 11 has 70 m^2 and it is equipped with computers and a printing machine, internet connection and a telephone. It used for the activities carried out by the staff, and it is where the stationery is kept. There is also a waiting room, which has a library, and a room for physiotherapy, equipped with specific and varied technical material. The premises are accessible for disabled people.
ANALYSIS	
Development of the good practice	Alba Andalucia federation considers essential that patients have a transversal knowledge in the different areas of the illness that affect their physical and psychological wellbeing. This why they intended to create a guide in

	which the basic aspects of fibromyalgia, possible treatments that could ease patient's quality of life, encouragement to have a healthy lifestyle, education regarding health, available resources, etc. were explained in a simple and understandable way. The main activities in chronological order were: 1. Meeting of the ALBA Andalucia board to debate the aspects and topics to be dealt with in the guide and to establish guidelines for its dissemination according to the number of patients in each province. 2. Dissemination of the guide "Aspects and Cares of Fibromyalgia", which was divided into three levels: regional, provincial and local. In addition to that, it was spread through social networks, posters, television and newspapers. 3. Clarification of the guide's content: the theoretical contents of the guide were written by the Andalucian Federation's experts team, who were in contact with the different professionals from the member entities to determine the issues to be addressed, the structure, the separation of contents depending on their specialty, etc. 4. Project assessment once the guide was distributed. The evaluation was performed through a pretest and posttest method, making use of surveys about different points found in the guides.
Means used to overcome or remove the obstacles	The main obstacle was to raise funds in order to obtain the necessary extra money. Getting the necessary money was not easy as the Alba Andalucia federation had to do internal

	activities in order to get funding from private entities.
Factors enabling the process	The main positive factors of the process have been: the fact that Federation is a stable entity, and it is able to overcome unexpected events, which inevitably appear once the project planned comes across. The support of member entities and their implication in each activity were essential as well. Another relevant factor is that the Federation is part of the National Fibromyalgia and Chronic Pain Confederation (Spain), so the project got their unconditional support too.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	Not only it is possible to reproduce the project, but it is also highly recommended to carry out good practices in other regions of Spain. When a practice surpass the expected outcomes and has such a positive impact on its target, it becomes a good example to be followed in other places. For those regions which do not have a guide or publication specifically aimed for the education and counseling of fibromyalgia patients, as it was in Andalucia, it has an even more positive effect. If any entity was willing to start a similar project, they could count on the collaboration of Alba Andalucia Federation and cooperation for the development of the good practice in another region, although it is important to have in consideration the

	necessary differences about the attention and information for the patients depending on the specific site.
Innovativeness:	The innovative nature of the Informative Guide about Aspects and Cares of Fibromyalgia lies on the previous absence of any publication or handbook targeted to the population, considering essential the information and education about the aspects for the better understanding and facing of the illness for patients. Therefore, the ALBA Andalucia Federation is a pioneer in this type of project. Although nowadays there is a slight progress on the field of knowledge of chronic pain and fibromyalgia, it is still widely unknown in society.
Added value:	The project has had an influence on parallel aspects, such as the awareness and increase of sensitivity of different professionals. It should be pointed out that this project (the organsation of the project, the work performed by the professionals involved, its results, etc.) has been positively valued by the people who have got a guide, member and not member associations of ALBA Andalucia Federation, medical and pharmacist personnel and the Regional Ministry of Health, who has even posted the guide in its own web page as a good resource for population in general. The Ministry of Health also distributed the guide among the medical personnel of the Andalucian Health Service. For these reasons, the impact

	initially expected when this project was planned has been exceeded.
Appropriateness:	The principal needs that this illness has is the lack of information for patients, the population in general and even part of the medical society. The aim of this project has been to provide an answer for this need. Indeed, it has improved the education of the three collectives, the fibromyalgia patients from Andalucia (as it has been verified in the evaluation), the population in general (which shows a raise of awareness and interest), and also within the health personnel. This experience has been a challenge for Alba Andalucia Federation.
NEXT STEPS	
Lessons Learned:	Implementing this project in other countries would be very positive and it could be carried out in a simple way following some steps. The main advice for them to follow are detailed below: creation of an informative guide by experts and professionals, written in an understandable register so that everyone (patient or not patient) can easily learn more about fibromyalgia; a correct dissemination of the project that is going to be done in all the health service offices in the different regions; an internal dissemination among all the local fibromyalgia associations who are members of the entity. This project offers orientation, information and training to population affected by fibromyalgia in regions where

	handbooks were never published, regardless of the city or country where the project is carried out, and sheds a light to the helpless situation which the patients face.
Key Takeaways:	Thanks to the informative guide created by the Federation patients' transversal education regarding different aspects and basic care about this illness have increased. Patients have also been encouraged to accept the diagnosis of a chronic illness, and made aware of the steps they should follow in order to have a life as normal as possible. This project has also contributed to increase involvement and interest of health personnel from different fields (psychology, medicine, physiotherapy, nursing, pharmacology, etc.) in our collective.
Next Steps:	Thanks to the informative guide created by the Federation patients' transversal education regarding different aspects and basic care about this illness have increased. Patients have also been encouraged to accept the diagnosis of a chronic illness, and made aware of the steps they should follow in order to have a life as normal as possible. This project has also contributed to increase involvement and interest of health personnel from different fields (psychology, medicine, physiotherapy, nursing, pharmacology, etc.) in our collective.

OTHER INFORMATION	
Notes:	A part from reaching all the goals considered before launching the project, this work has had more repercussions than it was expected. Indeed, this guide has raised awareness among the Andalusian population in general, as since we started handing out the guides, phone calls from people interested in knowing more about fibromyalgia increased.

Good Practice Number 29

CONTACT PERSON	
Name:	Alexey
Surname:	Danilov
Organisation:	Russia Headache Society
Position:	Head of the centre
Country:	Russia
Email:	danilov@intermeda.ru
Short description of the person submitting this project	Alexey Danilov (Moscow, Russia) project leader and professor at the Department of Neurology of the I.M. Sechenov First Moscow State Medical University. He is also executive director of the Interdisciplinary Medicine Association (Moscow, Russia), head of an awareness raising project "Brain ecology", coordinator of an Internet portal for doctors and patients "PAIN", co-organiser of two international education schools: «Brain and pain: biopsychosocial approach to pain management» and «Brain ecology». A.B. Danilov is a member of Russian and International Association on pain studies.

DESCRIPTION	
Title of the good practice:	Patient education for headache management
Category:	Empowerment

	Professional education
Who are the stakeholders involved in the Good Practice?	
Healthcare Organisation(s) :	World Alliance of Headache; the International Headache Society; the European Federation of headaches
Health Professionals:	Prischepa Anastasia V. Roman Ilyasov Ravilevich
University:	First Moscow State Medical University
Location:	Moscow, Butyrskaya Street, Building 4, Building 2.
Start Date:	01/2014
End Date:	01/2017
Objectives:	Russia Headache Society, in collaboration with the department of Neurology, I.M. Sechenov First Moscow State Medical University, has developed an educational project for doctors, patients and citizens in general, based on the European recommendations for headache management. According to the International Headache Society, the effectiveness of proper headache treatment can be up to 95%. However, more than 70% of patients are not satisfied with their treatment(s), due to the lack of awareness about the causes and mechanisms underlying the headache, and misconceptions about the treatment. The aims of the school are the dissemination of knowledge about headache and learning

	techniques of pain self-management.
Outcomes **Impact on participants:**	The screening tool ID Migraine; Algorithm of diagnostics Migraine triggers; Algorithm of migraine treatment; website PAININFO.RU; headache schools for patients, brochures for patients; clinical study on efficacy of patient education; educational seminars for doctors.
Resources:	The project was possible thanks to the support of the Centre for patients 'pain management'. Clinic professor Kalinchenko in conjunction with the Department of Nervous Diseases IPO First Moscow State Medical University and with the support of the World Alliance and the European Headache Federation pain.
ANALYSIS	
Development of the good practice	The aim of the course is to enable participants to gain knowledge, skills, and understanding in the area of primary and secondary headache as well as in headache self-care. This will also contribute to participants' personal and professional development. By the end of the course, they should have enhanced their clinical skills, including their capacity to interact appropriately with affected individuals. Ideally, this should translate into an enhanced quality of life for headache sufferers. The key aim is that the knowledge gained from the course can be applied in the participants' various professional fields. The teaching course must be specifically designed

	to help participants to: recognise the various clinical presentations of headache; to become familiar with the “red flags” and “comfort signs” approaches to diagnose secondary headache; to understand the latest findings in headache pathophysiology; to prepare treatment plans according to patients’ needs; to develop a headache management “toolbox” for patients, incorporating acute and preventive treatment approaches; to devise strategies in order to help patients understand headache treatment strategies and improve patient therapeutic compliance; to provide strategies and action plans for national organisations dealing with headache care.
Means used to overcome or remove the obstacles	Patients were asked to keep a diary about their condition to help doctors not only to make an effective diagnosis, but also a treatment plan accordingly. In the diary were reported frequency, duration and intensity of headache attacks, along with all the symptoms in detail. Patients were also asked to tell about their dietary habits, drugs used, alcohol and cigarettes consumption so that doctors have a wider understanding of their general health status. Events at home or at work that might affect headache are also reported. As for women instead, any changes during their period were reported. All these information are relevant to identify triggers of headache.
Factors enabling	The website PAININFO.RU is an informative

the process	portal reporting about all the main types of pain. Information is addressed to both patients and health professionals. It is divided into thematic sections and easy to access. Portal developed by leading experts on the problem of pain to get in touch with patient more directly.
EVALUATION	
How your **good practice** meets the criteria below:	
Reproducibility:	The Headache school is a widespread project in Europe. The main aim is to investigate how patient education can improve the headache management and increase patient's satisfaction.
Innovativeness:	The screening tool ID Migraine is a way to recognise how chronic you migraine is. You need to answer three key questions regarding your headache during the last three months. Migraine diagnosis algorithm: migraine is diagnosed solely; questions and answers are helpful to diagnose migraine.
NEXT STEPS	
Key Takeaways:	Migraine is a widespread, disabling disorder. Ordinary analgesics are not effective enough: many patients become drug abusers because of are uninformed about migraine management. Patient education can improve headache management and increase patient's satisfaction.

	Education of doctors, patients and people in general is the most effective way to learn headache management.

Good Practice Number 30

CONTACT PERSON	
Name:	Simon
Surname:	Evans
Organisation:	Migraine Action UK
Position:	Chief Executive
Country:	UK
Email:	info@migraine.org.uk
Short description of the person submitting this project	Simon Evans, the Chief Executive of Migraine Action, speak to a migraine sufferer from North Wales, who has suffered migraines for many years.
DESCRIPTION	
Title of the good practice:	The Needs of Migraine Sufferers Across Wales
Category:	Empowerment
Who are the stakeholders involved in the Good Practice?	
Location:	27 East Street Leicester LE1 6NB
Start Date:	03/2015
End Date:	01/2017
Objectives:	The treatment and management of headache disorders is poor across the UK. Anecdotally,

	we had heard it was worse in Wales with patients expected to travel significant distances to access services, and with NICE guidance not being followed in Cardiff (the major population centre). Goals: Undertake research to ascertain the facts, and compare services across the UK; develop a simple plan to influence politicians at the Welsh Assembly Change policy.
Outcomes Impact on participants:	Secured funding through a partnership with Allergan Engaged a political consultancy; undertook research with people with migraine. Undertook research proving services in Wales were worse than in England, and that one health board was ignoring NICE guidance; ran an event at the Welsh Assembly, presenting findings and securing the attendance of politicians from four main political parties; secured change in policy at Cardiff and Vale University Health Board; received an invitation to speak at the Cross Party Neurological Conditions Group at the Welsh Assembly, and developed long-term relationships. Due to the enormous success of the event, the Vale Health Board have agreed to introduce Botox for migraine.
Resources:	Advisory support (whether by phone, on line or in person); information (through booklets, website and the support of a nurse specialist on the dedicated helplines); research (collaborating with academic institutions in order to understand the causes of, and reduce the impact of migraine) and as a Link

	between medical professionals and those who are affected by migraine.
ANALYSIS	
Development of the good practice	Back in March 2015 Migraine Action brought Migraine Insight to Cardiff to help as many of the estimated 430,000 migraine sufferers in Wales receive the right information and take control of their migraine. With leading experts, Dr. Andrew Dowson, Dr. Peter Brooks and Dr. Mohammed Hassan, the event was a huge success! Many attendees learnt of new treatments and how to manage this debilitating neurological condition.
Means used to overcome or remove the obstacles	The Migraine Action team along with patients with migraine met with Assembly Members and Special Advisors of the Senedd. Patients were given the opportunity to speak of the difficulties they have experienced in accessing effective treatments in Wales.
Factors enabling the process	Studies conducted by Migraine Action identifying that 58% of respondents in England had been to see a doctor privately compared to an enormous 72% in Wales. Respondents reported that they had been "referred to a neurologist on NHS but she was less than understanding/interested".
NEXT STEPS	
Key Takeaways:	Have a strong evidence; take more stuff/ volunteers than you will need; get professional help.

CHAPTER 4 - Conclusions

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

In Europe, actors such as patients' associations and other organisations are already committed to fighting unnecessary cancer and not cancer-related pain. In addition, European Institutions and policy makers have understood the size of the problem. It is clear that chronic pain requires a better legal and political support at national and European level.

Despite many improvements occurred in the last few years, too many patients suffering from chronic pain are not entitled to receive the necessary assistances. What is affirmed in theory, it is very often denied in practice. Improvements and concrete actions against unnecessary pain are certainly needed everywhere.

For Active Citizenship Network, it is crucial to gather and share good practices, identify priorities and recommendations, to get the commitment of the patient associations, professionals and healthcare institutions. At the same time, it is also fundamental to promote concrete activities involving all the stakeholders to transfer what we have achieved from the European agenda into the European culture: that is, 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 by ensuring that the right to avoid unnecessary suffering is guaranteed everywhere and to everyone.

With this aim, and - in general - to contribute to value all the contacts and experiences gathered during this First European Prize on Chronic Pain and in these years through the different collections of good practices, Active Citizenship Network has decided to promote the first civic Hub-incubator of best practices against pain across Europe: the "Pain Euro-Mediterranean Coalition".

This Coalition is co-promoted together with “Sine Dolore”[5], the Spanish patient association organising every year in Menorca Island the “SINE DOLORE WORLD PARK” [6]., the first and only global event intended to involve all the society on the issue on pain: the whole island is transformed into a theme park against pain to promote a better quality of life.

The idea of the Coalition came out on June 2016 during the event realised at the EU Parliament “Pain therapy and the degree of patient’s pain in the age of cross-border healthcare”[7], which was supported by the MEPs Interest Group “European Patients’ Rights and Cross-border Healthcare”.

After the collection of good practices of this European Prize on Chronic Pain, the idea of an agora of operators of good practices on pain has become more effective to ensure longer life to the good practices themselves and to identify conditions to replicate or implement them in other contexts.

There is the willing of Active Citizenship Network and Sine Dolore to cooperate for the development of concrete efforts against unnecessary pain. This Coalition aims to be:

- The network of operators of good practices on pain, encouraging the exchange of experiences among health professionals, healthcare providers, Institutions, civic associations and Patient Advocacy Groups (PAGs);
- An open multi-stakeholder platform mainly addressed to the constituency dealing with pain relief at local and national level across Europe rather than to EU umbrella organisations;
- The fusion of experiences coming from pain and patients’ rights constituencies;

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[5] https://sinedolore.org/

[6] http://sinedolore.org/sine-dolore-world-park/

[7] http://www.interestgroup.activecitizenship.net/115-june-21st2016-pain-therapy-and-the-degree-of-patient-s-pain-in-the-age-of-cross-border-healthcare.html

- The missing piece necessary to integrate the scientific research on pain with the “civic information” approach on the topic;
- A bridge on pain built in the Mediterranean area but intended to overcome EU borders and reach non-EU countries as well;
- A facilitator for advocacy and policy actions on chronic pain at local, national and European level.

The Coalition has been officially presented in May 2017 in Menorca (Spain), in the framework of the third edition of the “Sine Dolore World Park”, followed by the Euroepan presentation during the SIP-Societal Impact of Pain[8] in Malta in June 2017.

The diversity of members within the Coalition will strengthen collaborations among all the relevant stakeholders. At the same time, the different perspectives shared will enrich European and national experiences, expertise, data and benchmarking on chronic pain.

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[8] www.sip-platform.eu

Back cover

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Besides the good practices, we have also gathered suggestions to improve this initiative, so thanks to all the people who provided us with precious insights, they will be very useful for the second edition of the European Civic Prize on Chronic Pain.

About Active Citizenship Network (ACN)

ACN 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 organisations, which are involved as partners in its projects addressed to encourage active participation of citizens in European policy-making.

ACN mirrors Cittadinanzattiva's Italian policies, such as healthcare, consumer protection, corporate social responsibility, education and training at global level. ACN's 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.

First edition

Collecting Good Practices

European Civic Prize on Chronic Pain

ACTIVE CITIZENSHIP NETWORK

The Jury of the Prize was composed by the following project partners

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