

COMMUNICATION  
CORPORATE SOCIAL  
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ADVOCACY  
TIVISM  
RIGHTS  
FEDERALISM  
PUBLIC  
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CITIZENS  
CONSUMERISM



# Chronic pain: making the invisible visible.

European collection  
of good practices



## **Index**

Foreword.....	2
CHAPTER 1 – Humanization and good practices from a civic point of view.....	3
CHAPTER 2 – Project for the collection of good practices on chronic pain.....	8
CHAPTER 3 – Apps for chronic pain management.....	11
CHAPTER 4 – Good practices .....	22
CHAPTER 5 – Good practices from Italian Alesini Award.....	117
CHAPTER 6 – Conclusions .....	118

# **Chronic pain: making the invisible visible European collection of good practices (Edition 2014)**

## **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<sup>1</sup>. The topic was confirmed in the final document: “Europa Un Nuovo Inizio - Programma della Presidenza Italiana del Consiglio dell’Unione Europea”<sup>2</sup>.

This means that in 2014, for the first time at European level, the issue of chronic pain is being put on the agenda by the EU institutions: it is of paramount importance that the public feels empowered to voice its support.

Cittadinanzattiva Onlus and its European branch Active Citizenship Network (ACN) are both deeply involved in the European and national debate on patients' rights against unnecessary pain, and welcome the Italian Presidency of the Council of the European Union intention to tackle the issue of pain therapy and palliative care, and would be delighted to contribute to the agenda and its content.

Placing pain therapy and palliative care on the European agenda allows the Italian Presidency of the Council of the European Union to position Italy as a pioneer in this field and share its own experience with other member states, especially with regard to the “best practice law 38/2010 on palliative care and pain therapy”.

Above all, it allows the promotion of a higher level of awareness on the issue of chronic pain therapy among European citizens, European and national policy and decision-makers and, over the longer term, reduce the negative impact of chronic pain on European society as a whole.

This would not only ensure a lasting legacy of the Italian Presidency of the Council of the European Union, but also pave the way to a better future for patients in Europe suffering from chronic pain.

Based on the observation of activities undertaken by previous Presidencies in the area of healthcare, the initiative outlined in this Report (solely or combined with an integrated approach) could be considered by both the Italian Presidency of the Council of the European Union and the stakeholders as a way to promote the debate on palliative care and pain therapy during its term.

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<sup>1</sup> [www.politicheeuropee.it/attivita/18796/relazione-programmatica-2014-al-parlamento](http://www.politicheeuropee.it/attivita/18796/relazione-programmatica-2014-al-parlamento)

<sup>2</sup> [http://italia2014.eu/media/1350/programma\\_ita\\_def.pdf](http://italia2014.eu/media/1350/programma_ita_def.pdf)

## CHAPTER 1 – Humanization and good practices from a civic point of view

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### 1. The role of patients' organizations in compassionate care

The guidelines set by the World Health Organization on the treatment of pain and its support date back to the 1990s and indicate that “Freedom from pain is a right of every patient suffering from cancer, and access to the relevant therapy is a means to respect such right”.

Since then much has been done - also regarding treatments unrelated to cancer – mainly thanks to the role of patients' associations.

As with any other issue, also in the case of pain we can act in terms of fighting both its intensity and its frequency and, ultimately, the effects it causes. It is with this objective that for many years a series of associations of citizens and patients in different countries have been organizing awareness-raising and information campaigns, field surveys, *ad hoc* discussions on the theme and the proclamation of the Charter of Rights. In this way they show how close they are to patients, taking care of them, protecting their rights and demanding the respect of human dignity. It is no coincidence that they are always in the frontline when it comes to compassionate care, which includes all that makes a patient feel better even if it is not healing related.

Obviously, the theme of compassionate care is inextricably linked with that of pain, not so much in the sense that one (pain) is the reflection of the lack of the other (i.e. a lack of compassion in the therapeutic process), but rather in the sense that greater compassionate care should deal as much as possible with counteracting pain, whether acute, chronic or severe and, in general, unnecessary pain deriving from lack of specific treatment or when this is overlooked.

Unfortunately, there are many situations in which the right to compassionate care is not met. In particular, the over thirty years' experience in Italy of Cittadinanzattiva-Tribunal for Patients' Rights allowed us to single out the following negative traits:

- **carelessness towards patients:** patients not washed or changed with the correct frequency and with the necessary care, not helped to get up or go to the bathroom, left in bed too long without being moved in order to avoid bedsores.
- **behaviour of doctors and nurses:** inappropriate communication with citizens; little time spent with patients, rude behaviour, lack of patience.
- **ill-treatment:** uncalled for restraints, conditions of severe neglect (dirty and unfed patients, lack of continued assistance, etc.). Violating the dignity of the patient (profanities, verbal abuse).
- **psychological ill-treatment.**
- **violation of privacy:** confidential information related in front of strangers, lack of appropriate places and timing reserved for interviews with physicians, lack of privacy during medical examination.
- **“Unnecessary pain”:** lack of information on pain therapy, pain therapy clinics closed during the summer season or insufficient (long waits), inability to obtain opiates (morphine or similar).

## **2. Definition of Good Practice**

Generally we tend to consider the protection of rights as an action aimed at highlighting the gap between the expectations of citizens and the state of the services and therefore the violation of rights which need to be protected. In fact, when dealing with protection it is easier to pick up bad news than encounter well-known best practices. However, in reality, due to the constructive nature of the actions of citizens, the collection and dissemination of good practices has a key role in the protection of rights since it allows 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” stigmatizing, 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 programs aimed at this purpose. Among the most useful and most effective 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.

A good practice is defined as such when it also meets the following five requirements:

- Measurability (possibility to quantify the impact of the initiative);
- Innovation (ability to produce new and creative solutions in order to improve the quality of services and the protection of citizens' rights);
- Sustainability (ability to rely on existing resources or ability to generate new resources);
- Reproducibility (possibility of its transfer and application in places and situations other than those in which it was developed);
- Added value (positive and tangible impact on users' rights and the promotion of civic participation).

## **3. Good practice: the policy of Cittadinanzattiva at National and European level**

The commitment of Cittadinanzattiva - and its European branch Active Citizenship Network - to promote and provide incentives for service improvement, innovative experiences and community oriented policies has deep roots going back to 1988 and to the journey of the “Minibus rights” when operators were rewarded (in this case within the healthcare services) for having favoured the protection of citizens' rights. These improvements in the services lead to the sharing of experiences among policymakers, patient organizations, and, most importantly, to the improvement of the lives of those suffering from chronic pain.

Over the years we have refined assessment tools, and have found a proper definition of good practices, identified their key features and instituted awards dedicated to their public

acknowledgement as well as real databases; in the meantime, the Good Practices have begun to have a real impact on many and varied contexts, with the consequent increase in the number of awards and recognitions.

The questions are, therefore, is the contribution given by Cittadinanzattiva on this front a positive factor, and have the expected results been achieved? The answer, of course, cannot be negative, because to seek, encourage, reward and promote good practices answers, now more than ever, to 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 centre 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 will bring about a change “from below” in the relationship between citizens and Public Healthcare providers in a framework 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 goal and the tools used to pursue it are in common: press, network, databases, juries of experts to evaluate the projects reported on the basis of the above five criteria.

At European Level, Active Citizenship Network and Pain Alliance Europe drafted in 2012-2013 a report highlighting a collection of Good Practices to avoid unnecessary suffering and pain<sup>3</sup> and in the previous years these organisations promoted an informal community of “good operators” in the field of:

- Active Ageing: “Best practices on Active Ageing citizens in health policies”<sup>4</sup>
- Chronic disease “Best practices on Chronic Patients and Organizations’ Empowerment”<sup>5</sup>

Active Citizenship Network is currently working to strengthen a community in pain management and the involvement of patients.

#### **4. Chronic pain: the commitment of Cittadinanzattiva at national and European level**

Cittadinanzattiva has more than 30 years’ experience in the fight to protect citizens’ rights in the healthcare sector, which began at national level with the “Tribunal for Patients’ Rights” (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 together with Active Citizenship Network (ACN) it began promoting also at European level civic participation and protection of rights, unifying almost 100 civic and patients associations all over Europe.

Over the last 15 years, Cittadinanzattiva has been increasing its actions towards the promotion and protection of citizens’ rights against unnecessary pain by supporting:

- Protection against violations of the right of individual citizens
- Promotion of awareness raising campaigns

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<sup>3</sup> [www.activecitizenship.net/patients-rights/109-pain-report-on-respect-of-patients-rights-among-the-europe.html](http://www.activecitizenship.net/patients-rights/109-pain-report-on-respect-of-patients-rights-among-the-europe.html)

<sup>4</sup> [www.activecitizenship.net/patients-rights/projects/65-6th-european-patients-rights-day.html](http://www.activecitizenship.net/patients-rights/projects/65-6th-european-patients-rights-day.html)

<sup>5</sup> [www.activecitizenship.net/patients-rights/141-best-practices-on-chronic-patients-and-organizations-empowerment.html](http://www.activecitizenship.net/patients-rights/141-best-practices-on-chronic-patients-and-organizations-empowerment.html)

- Actions designed to promote cultural changes
- Institutional mediation
- Civic research and production of citizens' information
- Civic Recommendations
- Proclamation of the Charter of Rights not to suffer
- Collection and dissemination of good practices

The last two paragraphs will deal with the last two above mentioned activities. For further information about our engagement in the fight against unnecessary pain, please visit our website: [www.activecitizenship.net/patients-rights/projects/83-the-engagement-of-cittadinanzattiva-in-the-fight-against-useless-pain.html](http://www.activecitizenship.net/patients-rights/projects/83-the-engagement-of-cittadinanzattiva-in-the-fight-against-useless-pain.html).

## **5. The issue of pain in the Charter of Rights**

The objective of the Charters of Rights regarding healthcare is the proclamation of a “set of rights” which integrate and specify the more general right to health.

Widely used in healthcare, the citizens' Charter of Rights is a tool to understand and interpret the more general constitutional rights regarding health.

The European Charter of Patients' Rights stands out as a milestone since it covers a wide spectrum of rights according to a geographical point of view, and was drafted and proclaimed in a European context, representing the result of a joint effort between the Tribunal for Patients' Rights and 15 civic organizations partners in the European Network of Cittadinanzattiva, Active Citizenship Network.

Drawn up in 2002, it is based on the experience of the Tribunal for Patients' Rights and in particular on previous national, regional and local Italian Charters for Patients' Rights and on the Charter of Fundamental Rights of the European Union.

The European Charter brings together the inalienable rights of the patient which each EU country should protect and guarantee.

All of the following rights under the Charter of Fundamental Rights of the European Union are central to European citizens and health services, now at risk, among other things, due to the global financial crisis of national welfare systems.

Art.11 of the European Charter of Patients' Rights clearly establishes the Right to Avoid Unnecessary Suffering and Pain: “Each individual has the right to avoid as much suffering and pain as possible, in each phase of his/her illness”.

Other Charters, however, although of a National and non-European nature, stand out because they focus solely on the issue of the fight against unnecessary pain. For this reason they can also be considered an example of good practice. These papers are very important since surveys and the identification of the factors of analysis are the two starting points for the promotion of healthcare.

They were drawn up in Canada<sup>6</sup>, Italy<sup>7</sup> and Ireland<sup>8</sup>, written, developed and promoted by patients' associations and citizens.

<sup>6</sup> [www.canadianpaincoalition.ca/index.php/en/about-us/the-charter](http://www.canadianpaincoalition.ca/index.php/en/about-us/the-charter)

<sup>7</sup> [www.cittadinanzattiva.it/corporate/salute/5014-italy-charter-of-rights-against-unnecessary-pain.html](http://www.cittadinanzattiva.it/corporate/salute/5014-italy-charter-of-rights-against-unnecessary-pain.html)

<sup>8</sup> [www.chronicpain.ie/about-us/charter-rights](http://www.chronicpain.ie/about-us/charter-rights)



The fact that they were conceived in different continents stresses how the issue of fight against pain has neither limits nor boundaries. On the contrary, it should as far as possible, foster meetings among the many actors concerned with the issue of easing the suffering of patients.

## **6. Award and Prizes promoted by civic and patients organizations**

In the healthcare sector<sup>9</sup>, in non-cancer chronic pain, good practices are an important part of the policy objectives pursued by Cittadinanzattiva at national and European level. As previously mentioned, the fight against unnecessary pain is part of our wider activity, concerning the humanization of medical practices and attention on pain. The aim is to supply structures and diagnostic/therapeutic programs more patient oriented, viewing individuals as single physical, social and moral entities.

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<sup>10</sup>;
- the “National Prize on Chronic Pain Nottola - Mario Luzi” (since 1997)<sup>11</sup> organized by Cittadinanzattiva-Tuscany.

Considerations about the award for the humanization of care. First of all, over the years there has been an improvement in the quality of candidate projects, a sign this that over time the real meaning of citizens' involvement and guidance to users has been better perceived (in the early years most of the projects were just service charters).

Secondly, the fact that most of the reports come from citizens shows a more positive attitude towards this issue as it is in sharp contrast with the belief that there is a disaffection towards policies (in its broadest sense) and civic activism on the part of citizens.

Finally, the participation of winners of previous editions in the juries: this is an incentive to create a stable network of operators sensitive to the issue of good practices, thus transforming one single experience into a system.

Obviously, there are several rewards in many countries which valorise good practices<sup>12</sup>. What is maybe missing is a European award able to foster the recognition and the sharing of ongoing excellences.

The hope, therefore, is that the initiative "Chronic pain: making the invisible visible. European collection of good practices " promoted by Active Citizenship Network will become a regular feature, a proper award for good practices at European level for the fight against pain.

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<sup>9</sup> For further information at: [www.cittadinanzattiva.it/approfondimenti/attivismo-civico/cittadinanza-dimpresa/4972-good-practice-the-policy-of-cittadinanzattiva.html](http://www.cittadinanzattiva.it/approfondimenti/attivismo-civico/cittadinanza-dimpresa/4972-good-practice-the-policy-of-cittadinanzattiva.html)

<sup>10</sup> [www.cittadinanzattiva.it/progetti-e-campagne/salute/altro/6028-buone-pratiche-in-sanita-2014.html](http://www.cittadinanzattiva.it/progetti-e-campagne/salute/altro/6028-buone-pratiche-in-sanita-2014.html)

<sup>11</sup> <http://cittadinanzattivatoscana.it/premio-nazionale-nottola-mario-luzi>

<sup>12</sup> For example, in Italy other awards related to pain are: Journalist Award “38 VOLTE BASTA!” promoted by Antea Onlus; Premio Giornalistico “Vivere senza dolore” promoted by the patient association “Vivere senza dolore”; 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 per (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.



## CHAPTER 2 – Project for the collection of good practices on chronic pain

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As already stated in the foreword, 2014 represents an important political opportunity: for the first time at European level the issue of chronic pain is being included in the agenda by the European Institutions, also thanks to the active work of a number of civic associations from all over Europe.

In this context, Active Citizenship Network decided to start a civic research-project at European level with the aim to highlight the existing good practices in several European countries regarding the fight against pain.

The aim of the “European civic research: collection of good practices on chronic pain” is to help raise the level of awareness, increase the evidence of known positive experiences and successes, and strengthen commitment in this issue.

In particular, the research allows us to give continuity to the investigation on good practices in the fight against pain started by Active Citizenship Network - in cooperation with Pain Alliance Europe - in 2012-2013.

### **1. The project’s objectives**

- Keep the focus on chronic pain as a health priority locally, nationally, and at the European level;
- Encourage the exchange of experiences between professionals and patients' associations;
- Raise awareness among institutions about the need to identify chronic pain as a priority in health policies and programs at European and national level;
- Create a body of evidence which can be used to support the expansion of programs specifically directed to the care and treatment of patients with chronic pain;
- Raise awareness about the technological advances and their impact on healthcare and treatment of chronic pain – and how these improve the lives of chronic pain patients.
- Present collected good practices experiences on chronic pain in a public event during the Italian Presidency of the Council of the European Union.

### **2. Active Citizenship Network - objectives:**

- Recognition as one of the most active civic actors in the field of chronic pain in Europe;
- Help to create a European network of operators of good practices linked to Active Citizenship Network;
- Transfer at European level good practices and awards already promoted by Cittadinanzattiva at national level.

The collection of good practices is not a new award, but only the recognition of ongoing excellences, but could at the same time be the basis for a European award for the fight against pain and a regular feature in the European Agenda as an opportunity to meet for national award organisations who reward the commitment of operators, associations and stakeholders involved in the fight against pain and in making the invisible visible. For this reason we have decided to call the European meeting “Chronic pain: making the invisible

visible. European collection of good practices” and to present the event as a First Edition, with the hope that it may be regarded in the years to come.

### 3. The topics and the draft for the collection of good practices

- **Policies** - (patient empowerment, civic participation, awareness raising, etc.) with a particular attention to campaigns and educational initiatives;
- **Innovation** - apps & tools for chronic pain management (devices for patients, care givers and healthcare professionals), focusing the attention on the real added value they produce;
- **Age** - solutions for the young, the elderly, etc.

In order to collect information, it was necessary to write a form, divided into the following four parts:

- **description of the good practice:** title, fields (empowerment<sup>13</sup>, civic participation, etc.), actors involved (public institutions, civic organizations, etc.); 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 carrying 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:** reproducibility (is it possible to reproduce and implement the good practice in other situations and places?), innovation (did the good practice produce any innovative solutions?), added value (was the use of the good practice more helpful than the approach through solutions previously used?), appropriateness (did the good practice produce an efficient problem management?);
- **contact details** (name and surname, organization, country, email and phone number) with a short description of the organization and the option to add any other relevant information not mentioned on the form (i.e. links to web pages, etc.).

### 4. Sources

The collection of good practices involved several sources of information:

- database of good practice collected in Italy by Cittadinanzattiva over the years, thanks to the above mentioned awards;
- the European community on “good operators” in the field of active ageing and chronic disease promoted at European level by Active Citizenship Network;

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<sup>13</sup> information, support and capacity-building of individual patients with chronic pain, as well as their relatives, who usually play a key role in helping them to deal with their conditions, including social, psychological, and other impacts. This includes partnerships between patients’ organisations and other stakeholders, i.e. health professionals, public institutions, the media, healthcare industry, etc.

- networks and contacts of civic and patients organizations linked at European level with Active Citizenship Network on the issue of chronic pain (i.e., all the associations who signed *Civic Recommendation on chronic pain*<sup>14</sup> drafted in 2013);
- the organizers of principal Awards on Pain, and the promoters of national awards and competitions on the fight against pain;
- professional network, institutes and stakeholders in several countries linked to chronic pain;
- Ministries of Health;
- the media (specialized magazines/journals and newsletters, articles, websites, etc.).

## **5. How the good practices were selected**

The original idea was to select the good practices after an evaluation by a “Jury” of expert members representatives of patients organizations, civic associations, professionals and experts on e-health for the section related to the apps.

The work of the jury was not to draw up a list of the best good practices, but only to select those more interesting to be presented publicly in a European meeting and more likely to bring about further improvements for chronic pain patients in Europe.

Unfortunately, the summer period made it impossible to actively involve the experts, therefore the selection was carried out entirely by Active Citizenship Network.

Obviously, this is an aspect which will need further improvement in future.

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<sup>14</sup> [www.activecitizenship.net/files/develop-eu-pain-patient-pathways-recommendations-pamphlet.pdf](http://www.activecitizenship.net/files/develop-eu-pain-patient-pathways-recommendations-pamphlet.pdf)

## CHAPTER 3 – Apps for chronic pain management

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Patients and HCPs currently face a dizzying array of healthcare apps which can be used as part of their wellness, prevention or treatment regimens.

Active Citizenship Network and experts have selected the top ones which stand out in terms of innovation and enhanced patient care.



**Title:** CFSMapp

**Main topic:** CHRONIC FATIGUE SYNDROME (diagnosis, treatment and care, coping with daily living, self-monitoring)

**Summary:** This app about coping with chronic fatigue syndrome (CFS) was launched in July 2014 together with a specialist group from the Griffith University Clinic in Australia.

**Reviews:** “This app is a sleep tracker, a symptoms tracker, a medications tracker, and an alarm system. It is also a journal, in which the user can log the severity of the pain, the location of the pain, the type of the pain. The app has charting, a report-writing facility, and allows printout and email. 1%-5% of our members have used a test version of the app”. Fibromyalgia UK (Source: PatientView survey, July-August 2012)

**Developer:** BodyMapps (UK-based social-enterprise health-app developer set up in 2012 by Fibromyalgia UK)

**More information:** “European Directory of Health Apps 2012-2013”, PatientView 2012



**Title:** Diabetes UK Tracker (FREE APP)

**Main topic:** DIABETES (DIAGNOSIS, TREATMENT AND CARE, NUTRITION AND DIET, SELF-MONITORING)

**Summary:** Logs blood glucose, blood-fat and blood pressure levels, calories, carbohydrates, HbA1c, insulin, ketones, and weight. Graphs visualise results across days and weeks. Photos of meals, or other reminders of the day, can be added. Specific records can be saved as 'talking points' to help in the recognition of patterns. Allows graphs and notes to be emailed to healthcare professionals and others, or shared on Facebook or Twitter.

**Reviews:** "The app is aimed at helping people with type-1 and type-2 diabetes to better manage their condition, and is an example of how technology can help people with diabetes minimise the risk of complications. It is designed to be quick and simple to use, taking the daily chore out of logging levels such as blood glucose, carbohydrates and calories. The app was designed by a team that included user experience professionals, clinical specialists and people with diabetes, to help you manage your condition. Although there are a number of diabetes tracker apps available, the Diabetes UK app has some unique features to give it the edge. It is the first diabetes app that allows you to track how you are feeling, and see whether this affects your levels. Save specific records as 'talking points', to help you recognize patterns, and use them as reminders in healthcare appointments. This unique feature will help you get the most out of appointments by setting an agenda of your concerns." Diabetes UK (Source: <http://bit.ly/pmjmZB>)

**Reviews:** "The main benefits of the app are being able to keep track of blood sugar results, and seeing trends in your readings. You can store medical information, and doctors' details. 1%-5% of the patients with whom we are familiar use this app". Local patient group specialising in diabetes, UK (Source: PatientView survey, July-August 2012)

**Reviews:** "I wouldn't give it quite as many stars as four out of five. It seems to only like weight being entered in stones and pounds, which is a pain for us metric types. But, more importantly, it lacks an export, backup, restore function— I would consider that a little vital. If I do exercise, I have to add the fact as a note (but that's OK). A body-mass indicator (BMI) calculator when entering weight would be useful, too". Blogger on diabetessupport, UK (Source: <http://bit.ly/RPImLc>)

**Developer:** Diabetes UK (UK-based patient group specialising in diabetes)

**More information:** "European Directory of Health Apps 2012-2013", PatientView 2012



**Title:** FibroMapp

**Main topic:** FIBROMYALGIA (diagnosis, treatment and care, coping with daily living, self-monitoring)

**Summary:** This app about coping with fibromyalgia (FM) was launched date in November 2013.

**Reviews:** "This app is a sleep tracker, a symptoms tracker, a medications tracker, and an alarm system. It is also a journal, in which the user can log the severity of the pain, the location of the pain, the type of the pain. The app has charting, a report-writing facility, and allows printout and email. 1%-5% of our members have used a test version of the app". Fibromyalgia UK (Source: PatientView survey, July-August 2012).



**Title:** iheadache

**Main topic:** HEADACHE/PAIN (diagnosis, treatment and care, coping with daily living, self-monitoring)

**Summary:** A headache diary that allows the number of headaches, their duration and severity, the degree of disability and impact, medication and usage, symptoms, and triggers to all be tracked. Classifies headaches according to International Headache Society criteria as a migraine, probable migraine, tension headache or unclassified headache. Information can be broken down by seven, 28 or 30 day slots. Can generate reports to share with a doctor (the information and analysis units have been designed to help the user's doctor design a treatment plan). Free 'Lite' version only retains data for 2 weeks, and also contains advertisements.

**Reviews:** Recommended by the National Headache Foundation (NHF), USA (Source: <http://bit.ly/c4WbkF>)

"Headache diaries are one of the best tools to support patients and healthcare providers in staying on top of the headache disorder. But for many people, keeping track of the incredible panoply of triggers that can set off a headache is a big stressor (and yet another headache trigger). If you need a way to keep a detailed history of your headache patterns and treatments, look no farther than your mobile phone. It's easier than ever to maintain your essential headache information and generate detailed reports for health care providers. Pros of 'iheadache': Allows you to track the amount of time you were disabled, or partially disabled. Gives you a migraine disability assessment (MIDAS) score. Cons of 'iheadache': Can't customise triggers. Somewhat basic features. Pop-up ads in the free version". Head Wise, National Headache Foundation (NHF), USA (Source: <http://bit.ly/rozBtN>).

**Developer:** BetterQOL.com (USA-based designer of online medical tools)

**More information:** "European Directory of Health Apps 2012-2013", PatientView 2012



**Title:** MEApp

**Main topic:** MYALGIC ENCEPHALOMYELITIS (diagnosis, treatment and care, coping with daily living, self-monitoring)

**Summary:** This app about coping with myalgic encephalomyelitis (ME) has a scheduled launch date of October 2012.

**Reviews:** "This app is a sleep tracker, a symptoms tracker, a medications tracker, and an alarm system. It is also a journal, in which the user can log the severity of the pain, the location of the pain, the type of the pain. The app has charting, a report-writing facility, and allows printout and email. 1%-5% of our members have used a test version of the app". Fibromyalgia UK (Source: PatientView survey, July-August 2012).

**Developer:** BodyMapps (UK-based social-enterprise health-app developer set up in 2012 by Fibromyalgia UK)

**More information:** "European Directory of Health Apps 2012-2013", PatientView 2012



**Title:** My Pain Diary: Chronic Pain Management

**Main topic:** PAIN (diagnosis, treatment and care, coping with daily living, self-monitoring)

**Summary:** For people with allergies, back pain, chronic fatigue syndrome (CFS), depression, fibromyalgia, headaches or migraine. A pain diary that allows multiple chronic conditions to be tracked. Intensity of pain, its locations, the types, the triggers, and treatments can be documented. A text note, and up to three photos, can be added to each entry (perhaps showing discoloration, swelling, rashes, etc). Interactive graphs help in finding correlations between factors and the weather. Reminders to keep entries consistent can be issued. Password protected. Data can be backed up by 'Dropbox'.

**Reviews:** MPD is an iPhone app that empowers patients of chronic pain and illness to document, track, report, and manage their condition. Recommended by the World Pain Foundation (WPF) (Source: <http://bit.ly/Mh7yd7>)

**Developer:** Damon Lynn (app developer)

**More information:** "European Directory of Health Apps 2012-2013", PatientView 2012





**Title:** myIBD (FREE APP)

**Main topic:** INFLAMMATORY BOWEL DISEASE (diagnosis, treatment and care, nutrition and diet, self-monitoring)

**Summary:** Aims to provide the user with new perspectives on the task of managing inflammatory bowel disease (IBD). Allows the recording of important personal healthcare information, including appetite, mood, pain, and visits to the lavatory. Entries can be viewed as a graph, or as text. The app also contains information about IBD.

**Reviews:** Recommended by the National Headache Foundation (NHF), USA (Source: <http://bit.ly/c4WbkF>)

**Reviews:** Recommended by Crohn's and Colitis Australia (Source: PatientView survey, July-August 2012).

**Reviews:** "Track your pain, food, frequency of bathroom visits, and get access to educational tools to help you manage your symptoms. The 'myIBD' app helps teens and parents living with Crohn's disease and ulcerative colitis manage their disease and get help more quickly. This app was developed by the staff at Toronto's Hospital for Sick Children". Collaborative Chronic Care Network (C3N), USA (Source: <http://bit.ly/QZikGo>).

**Reviews:** "It's great to have mobile software for IBD health tracking. I give major props to the Hospital for Sick Children in Toronto for funding this project. The basics of this app (like logging stools and pain) are intuitive. Logging more nuanced symptoms (appetite, fatigue, general wellbeing, pain after eating, and stress) are made difficult by an unintuitive information architecture (finding your way to the right screen is confusing). And, lastly, the 'Payoff' graph (the whole reason you'd be logging in the first place) was not given enough design or development attention. As a result, the app doesn't do much to motivate the patient to track. So I'll leave you with one call to action for designers and developers working on health-tracking apps: for a patient to track their health on a daily basis, they must have both motivation and ability. Give them the ability through easy and intuitive interfaces, but don't forget to motivate them through a great payoff, insights, and rewards (helpful graphs and views of the data that make the tracking well worth the time given)". Crohnology Blog, USA (Source: <http://bit.ly/MWA7d7>)

**Developer:** Hospital for Sick Children (Canada-based hospital)

**More information:** "European Directory of Health Apps 2012-2013", PatientView 2012



**Title:** Pain Care (FREE APP)

**Main topic:** PAIN (diagnosis, treatment and care, coping with daily living, self-monitoring)

**Summary:** A tool to help patients manage chronic pain or sports injuries. Allows the user to track medications, side effects, symptoms of pain, and triggers. After the journal has been kept for some time, the app will estimate the cause of the pain, and consider the efficacy of treatment/medication options. Provides an automatic natural-language summary of the patient history, with analytic charts designed to fit into pain specialists' decision-making workflow (making personalised treatment options easier for doctors to create). Data can be shared with a doctor securely via the Internet.

**Reviews:** "Offers a comprehensive, visual pain scale, ideal for people who have difficulty keeping an electronic diary. No cost. Doctors find the app useful. The tech skill level required to operate the app is easy to moderate". Family Caregiver Alliance (FCA), USA (Source: <http://bit.ly/QKJmwJ>).

**Reviews:** "The 'Pain Care' app has won the 'Project HealthDesign' developer challenge 2010, sponsored by the Robert Wood Johnson Foundation (RWJF) and the California HealthCare Foundation (CHCF)". Louise H. Batz Patient Safety Foundation, USA (Source: <http://bit.ly/TcxDKD>).

**Developer:** Ringful LLC (USA-based app developer)

**More information:** "European Directory of Health Apps 2012-2013", PatientView 2012



**Title:** Pause Boogie from the Rheumatism Association (Pauseboogie fra Gigtforeningen) (FREE APP)

**Main topic:** ARTHRITIS/PAIN (coping with daily living, support for symptoms or disabilities)

**Summary:** Demonstrates how to perform a series of exercises intended to ease and prevent pain and discomfort in muscles and joints. Lists exercises for the back, feet, hips, knees, neck, and shoulders. For people with arthritis or osteoarthritis.

**Reviews:** "Pauseboogie' is a fun and easy way to get more exercise into your daily programme. It is a set of simple, but effective, exercises for each of the typical areas where people often have pain. The app can be personalised, so that everyone can put together their own unique 'Pauseboogie'". Gigtforeningen (Rheumatism Association), Denmark (Source: PatientView survey, July-August 2012)

**Reviews:** "The Gigtforeningen has launched a new movement app, 'Pauseboogie', with simple exercises to get us to spend the day with small breaks to strengthen the body. It's fun, easy, and free, and you can do the exercises anywhere. The app's exercises are presented by a Pilates instructor and a choreographer/dancer. The Association is leading the fight against the sedentary life. Download the free app, so that you always have exercises at your fingertips". Gigtforeningen (Rheumatism Association), Denmark (Source: <http://bit.ly/peh4Sw>)

**Developer:** Gigtforeningen (Denmark-based patient group specialising in arthritis) - Plant (Denmark-based advertising agency)

**More information:** "European Directory of Health Apps 2012-2013", PatientView 2012



**Title:** Phrase Board (FREE APP)

**Main topic:** COMMUNICATION DISABILITY/PAIN (coping with daily living, diagnosis, treatment and care, improving communication)

**Summary:** A means of allowing people who cannot speak to display some basic concepts to other people. Large 'Yes' and 'No' buttons allow for simple expression. Scrollable lists of 'Having', 'Feeling', and 'Want' statements provide for quick communication. Custom messages and frequently-employed phrases can be input and saved. A message bar allows statements to be highlighted. A 'Pain' page allows pain to be expressed. A slider displays pain on a one-to-ten scale; the duration, frequency, location and type of pain can all be expressed. Simple pictures can be drawn for further emphasis. Not a 'speaking' app.

**Reviews:** "The advantages: the app aims to allow an individual with a communication impairment to communicate their location, level and frequency of pain, to answer basic questions, and to make basic comments and requests. The person can also save custom comments that are more relevant to their own situation. The disadvantages: the app does not allow for voice output, so that any medical professional in attendance would need to be watching what the person is touching on the screen". Patient group specialising in communication disability, Australia (Source: PatientView survey, July-August 2012)

**Reviews:** "This app is designed for patients with speech difficulties. Users can indicate where and how much they hurt with scrollable lists, and with a chart of the human body. It also lets users type custom messages, or even draw messages. The app is text-only. Reviews have been favourable, especially since the app is free. One user said it "has all of the basic functions needed for a patient's communication needs, when speaking is not an option". The main downside is the lack of speech functions. But, as one user noted, "what makes it worth looking at is the free hand-'draw' feature that lets you draw with your finger if you don't know a word". Central Coast Children's Foundation, USA (Source: <http://bit.ly/MX4p1l>)

**Developer:** Eamonn and Ian Ilc (USA-based app developer)

**More information:** "European Directory of Health Apps 2012-2013", PatientView 2012



**Title:** RheumaTrack (FREE APP)

**Main topic:** ARTHRITIS/PAIN (diagnosis, treatment and care, self-monitoring)

**Summary:** Helps people with rheumatism monitor their condition. Problems (for example, inability to work, morning stiffness, times of infection, etc) can be recorded and tracked. Allows the development of the condition to be tested with a functional-ability assessment questionnaire of symptoms ('Funktionsfragebogen Hannover', FFbH). Pain levels can be logged in a 'Pain diary' (pain scale based on the 'Visual Analogue Scale', VAS). Represents rheumatism by means of a tracing development, lists, or calendars. Notes can be taken. Issues reminders of due dates to collect replacement medications.

**Reviews:** Recommended by Dr. Peer Malte Aries, at the London 2011 European League Against Rheumatism (EULARS) Conference Rheuma-Online (Source: <http://bit.ly/MPesrk>)

**Developer:** Nicole Derouaux [USA-based app designer] - Mutterelbe (Germany-based design company)  
**More information:** "European Directory of Health Apps 2012-2013", PatientView 2012.



**Title:** SmallTalk Intensive Care (FREE APP)

**Main topic:** COMMUNICATION DISABILITY (diagnosis, treatment and care, improving communication)

**Summary:** Provides a list of phrases and images with which patients can communicate to medical professionals some of their needs and feelings (such as “I have chest pain”, or “I need a doctor”). Intended for patients and

people who have difficulty speaking (perhaps due, for instance, to a language impairment, or not knowing enough English), and for those who cannot speak at all (perhaps due, for instance, to being intubated, or on a tracheotomy tube). Phrases chosen are spoken in a natural human voice, and accompanying pictures emphasise meaning.

**Reviews:** “An app to help patients with speaking difficulties (whether because of an impairment, or because of an operation) express their needs to medical-care providers in the intensive care unit (ICU). Users choose from picture-based vocabulary to ‘speak’ phrases like, “I am in pain,” or “I want to be comforted.” The pictures that match the words make this app useful for non-English speakers as well. Reviewers found the app useful for the ICU, though one user said that the interface “was not great.” The pictures are self-explanatory, and make the app a convenient tool for non-native-English speakers”. Central Coast Children’s Foundation, USA (Source: <http://bit.ly/MX4p1l>)

**Reviews:** Recommended by the Aphasia Hope Foundation (AHF), USA (Source: <http://bit.ly/OV0nby>)

**Developer:** Lingraphica (USA-based manufacturer of products for people with aphasia and apraxia)

**More information:** “European Directory of Health Apps 2012-2013”, PatientView 2012



**Title:** SmallTalk Pain Scale (FREE APP)

**Main topic:** COMMUNICATION DISABILITY/PAIN (diagnosis, treatment and care, coping with daily living, improving communication)

**Summary:** A means of allowing people who cannot speak (particularly people with aphasia, apraxia, or dysarthria) to communicate the amount and

the type of pain they are feeling to other people (including caregivers, family members, and healthcare professionals). Provides a vocabulary of pictures that talk in a natural human voice. The app’s pain scale is based on images and descriptions of pain from the ‘Wong-Baker Faces Pain Scale’.

**Reviews:** “Advantages: the app offers the user a pain scale with words and faces for them to select their pain level. It has voice output, allowing the user to speak this aloud, as well as a selection of words to describe the pain. The disadvantages: the vocabulary in the app is not customisable at all, and is quite limiting”. Patient group specialising in communication disability, Australia (Source: PatientView survey, July-August 2012)

**Reviews:** “This app contains a series of images and pain descriptions that let the user communicate the type and level of pain. Some reviews mentioned that this app does not allow for sentence construction, or any editing. However, it does allow for a great deal of specificity by offering vocabulary for body parts, positional words, and pain related adjectives (such as aching, dull, radiating, sharp, etc)”. Central Coast Children’s Foundation, USA (Source: <http://bit.ly/MX4p1l>)

**Developer:** Lingraphicare Inc (USA-based hospital equipment manufacturer)

**More information:** “European Directory of Health Apps 2012-2013”, PatientView 2012.



**Title:** Tip Share (FREE APP)

**Main topic:** ARTHRITIS/PAIN (diagnosis, treatment and care, coping with daily living, support for symptoms or disabilities)

**Summary:** Helps the user to manage joint pain from arthritis by reading advice and 'tips' from other people who are living with the same condition.

The user can share personal tips about managing arthritis pain, rate other people's tips, and view tips supplied by the Arthritis Foundation.

**Reviews:** "People can use the app as a tool to network with others about the disease, and share ways they have found to manage their signs and symptoms. It's great. You can find out how to manage your arthritis joint pain from people like you. In this peer-to-peer arthritis community, the app gives you the opportunity to share your own arthritis tips about managing arthritis pain, rate other people's tips, and view tips from the Arthritis Foundation. It's a community of support, and a way to keep track of your health. 11%-20% of the patients with whom we are familiar use the app". Arthritis Foundation, USA (Source: PatientView survey, July-August 2012)

**Reviews:** Recommended by the Community Health Charities of the National Capital Area (CHCNCA), USA (Source: <http://bit.ly/P5UFOz>)

**Developer:** ConRadical LLC (USA-based app developer)

**More information:** "European Directory of Health Apps 2012-2013", PatientView 2012



**Title:** Minosse

**Main topic:** Low back pain (Patient Track Manager, diagnosis, treatment and care)

**Summary:** The aim is to supply objective criteria of priority, accessible to any GP and scientifically valid. The GP registers on the website and in a few minutes answers a series of questions on the intensity of the pain symptoms, the degree of disability that the pain generates, the possible presence of a neuropathy or a fracture. Through an algorithm, the system elaborates data, indicating whom to address the patient and with which priority, or suggests to review the therapy, by prescribing for at least 15 days an opioid analgesic, if not yet given.

**Reviews:** It allows GPs to collect the fundamental information about the intensity and lasting of patients' pain and undertake the best management course. This permits the GP to address the patient to the more suitable specialist and to assess the real level of priority of medical examination, in case pain lasts more than twice a week and does not answer to an analgesic therapy correctly set up.

**Developer:** ASS n°5 "Bassa Friulana"

**More information:** [www.aisd.it/news.php?item.118.5](http://www.aisd.it/news.php?item.118.5)



## PAINlab

**Title:** PAINlab APP

**Main topic:** Free application for GPs for pain assessment helping in the detection of pain in both collaborative and non collaborative patients. The GP can directly access the list of all the available scales, or define the profile of the patient through a specific form and check the scales selected based on the information entered.

Once identified the pain scale of interest, the GP can perform the examination of the patient. Results can be saved or sent via mail.

The 1.0 version of PAINlab provides the health professional a total of 4 scales for pain assessment, the FLACC scale, the Wong-Baker scale, the NO PAIN scale and the FLACC scale.

**Summary:** In March 2010, the Italian Parliament approved a pain care law (N.38/2010) that guarantees the right of patients to pain therapy. However, implementation has been sluggish due in part to the lack of tools for pain assessment. PAINlab app addresses this need by providing a tool that is easy-to-use and available in all situations for both GPs and specialists. This APP was presented as good practice during the Eyeforpharma Award in March 2014.

**Reviews:** The physician enters a unique medical credential key after downloading the app. PAINlab provides several scales for the physician to assess the patient's pain intensity. The complete patient assessment can be downloaded as a pdf available via email. Additional scales are expected to be added in 2014, as well as feedback channels to support further development.

**Developer:** EDRA LSWR

**More information:** <http://social.eyeforpharma.com/digital/6-top-apps-or-initiatives-enhanced-healthcare#sthash.hJ3RWtks.dpuf>



**Title:** FibroMapp

**Main topic:** Pain management app designed specifically for Fibromyalgia and CFS / ME.

**Summary:** It is a combination of 8 apps in 1 to help you track:

- PAIN SEVERITY, LOCATION OF PAIN, TYPE OF PAIN - personalised to your needs/activities that have helped relieve or cause pain
- SLEEP AND SLEEP DEBT - simply tap the screen to start recording when you are awake/going to sleep
- FLARE-UP BUTTON -for when you quickly want to record a flare and its severity
- MEDS TRACKER - personalise your meds, dosage and even set an alarm to ensure you aren't over or under medicating
- MOOD TRACKER – JOURNAL - FATIGUE TRACKER - OTHER SYMPTOMS/CONDITIONS TRACKER
- Follow up section to review what has helped and what has made symptoms worse

All of which you personalise to your needs so that you are only filling in the areas that pertain specifically to you. FibroMapp helps you to gain more control by giving you the tools to track what is possibly causing pain, fatigue, sleep issues, mood and flare-ups and much more.

**Reviews:** Increase in patients becoming confident in managing their pain and improved communication between health professionals and patients. Maximize use of limited resources and reduced waste.

**Developer:** Bodymap

**More information:** it is listed on the UK NHS list of approved apps



**Title:** Manage my Pain

**Main topic:** Pain management app.

**Summary:** Manage My Pain helps you and others better understand what you are going through. It has helped thousands of people with conditions like fibromyalgia, migraines, arthritis, or back pain better understand their symptoms and provide evidence of their pain for their doctors, insurance companies, or government agencies. Manage My Pain creates reports designed by doctors for doctors - ones that your doctor will actually read!

- Track your pain using a simple, quick, yet powerfully customizable entry screen
- Get insight to your condition through statistics, charts, graphs, and calendar views
- Sync with the cloud to safe-keep your records and keep all your devices up to date
- Share what you're going through by creating evidence-based reports for diagnosis, treatment, and claims
- Personalize your account by recording your medical and personal characteristics
- Get support from a responsive team and detailed user guides

**Reviews:** Increase in patients becoming confident in managing their pain and improved communication between health professionals and patients. Maximize use of limited resources and reduced waste.

**Developer:** ManagingLife.com

**More information:** It is listed on the UK NHS list of approved apps. [www.managinglife.com](http://www.managinglife.com)



## CHAPTER 4 – Good practices

<b>Number</b>	1
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Penka Georgieva
<b>Organization</b>	Patients Organizations With you
<b>Country</b>	Bulgaria
<b>Email</b>	pgeorgieva@dir.bg
<b>Short description of the organization/public institution</b>	
<p>The partners of the Patients' Organizations "With you" are: the Association of Reproductive Health, Pregnancy and Childcare "Smile"; Alliance of Transplanted and Operated patients ATO "Future for All"; the Association of Patients with Cardiovascular Diseases. The entity is registered as a Non-Governmental Organization working for society as a whole with the following purposes:</p> <p>1-promote civic participation in public debates with the institutions in order to foster the involvement of citizens in the management and control of the healthcare system.</p> <p>2-introduce and consolidate the principle of equal partnership among the institutions, the medical professionals and patients' organizations in the development and adoption of strategies, criteria, standards, policies and practices in the healthcare system.</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Diabetic neuropathy. Information is a health promoter! Questionnaires to help identify symptoms and early diagnostics. Better management of diabetes.</i>
<b>Field</b>	<p>Empowerment: The practice helps to empower the public at large in health prevention. It also helps identify and screen diabetes symptoms.</p> <p>Civic participation: It promotes civic participation and strengthens partnerships between the civil society and businesses in the field of healthcare. A publishing company was involved in a health promotion campaign and provided awards in the form of books for the participants.</p> <p>Awareness raising: The practice helped raise citizens' awareness about the symptoms of diabetic neuropathy through a survey questionnaire. It reached out to a larger audience by presenting the findings of the survey in a press conference.</p>
<b>Actors</b>	<p><b>Civic Organization(s)</b></p> <ul style="list-style-type: none"> <li>Many patient organizations as well as parents' organizations</li> </ul> <p><b>Other Subjects involved</b></p> <ul style="list-style-type: none"> <li>Internet sites for health promotion</li> <li>Publishing companies</li> </ul>
<b>Location</b>	Bulgaria
<b>Term</b>	From January 1 to March 31, 2014
<b>Objectives</b>	The project focused on the development of questionnaires highlighting the symptoms of diabetic peripheral neuropathy and on the conducting of a survey to assess awareness and promote knowledge and information on the management of symptoms.

	The uniqueness of the project lies in the fact that the questionnaires were disseminated through social networks. People were encouraged to fill in the questionnaires and for this received a new book for free following a contest. The objective was to motivate citizens to check the sugar level in their blood and identify specific symptoms. It was an interactive approach in the form of a game.
<b>Outcomes Impact on participants</b>	In the case of diabetic neuropathy patients do not realize immediately that they may be hyperglycaemic. They often see their doctor with complaints such as weak limbs, tingling, numbness, burning, etc. The practice educated the participants and made them realise they should take better care of themselves.

## ANALYSIS

<b>Development</b>	The project was launched by the Patients' Organization "With you" Suitable Partners were identified: businesses and social networks. The project focused on the circulation of questionnaires through social networks. Participants were motivated to participate in the survey by filling in the questionnaires as a condition to participate in a drawing of awards in the form of new books which were given for free by the publishing company. At the end of the project the results were presented at a special press conference.
<b>Age</b>	Please specify the main age group of the patients involved: <ul style="list-style-type: none"> <li>• 0-20</li> <li>• 20-50</li> <li>• 50-70</li> </ul>
<b>Disease / Pathology</b>	Diabetic peripheral neuropathy
<b>Obstacles</b>	The obstacles were technological: the specificity of the social networks and how to motivate the participants to fill in the questionnaires. These obstacles were overcome with small technical modifications.
<b>Factors enabling the process</b>	The awards in this project were new books. In the course of time we realized which books people were most interested in and therefore selected suitable ones. This motivated the participants to fill in the questionnaires and in return supplied information and fostered awareness about diabetes.

## EVALUATION

<b>Reproducibility</b>	Reproducible also for the prevention of other diseases
<b>Innovativeness</b>	The use of social networks to motivate citizens to check their sugar levels is an innovative approach to health prevention since people often do not undergo prophylactic examinations.
<b>Added value</b>	Promoting public and private partnerships
<b>Appropriateness</b>	Helps motivate people to undergo prophylactic examinations

NEXT STEPS	
<b>Lessons Learned</b>	Our practice can be transferred to any country. Our only advice is to select the award according to where the project will be implemented. The award should be attractive in order to motivate people to participate. It does not necessarily have to be expensive.
<b>Keys takeaways</b>	<ol style="list-style-type: none"> <li>1. Well-developed questionnaires. Clear, precise and intriguing questions.</li> <li>2. Selection of the awards according to the country in order to raise greater interest.</li> </ol>
<b>Next Steps</b>	Collection of the results of the survey. Analysis of citizens' responsibility towards prophylactic examinations. Disseminating the findings through social networks in order to increase more public awareness regarding this disease.

<b>Number</b>	2
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Gavrilov Silvi
<b>Organization</b>	National Patients' Organization
<b>Country</b>	Bulgaria
<b>Email</b>	stgavrilov@mail.bg
<b>Short description of the organization/public institution</b>	
<p>The National Patients' Organization, established in 2009, is the largest umbrella patients' organization in Bulgaria. Its membership includes more than 64 patients' organizations covering oncology, diabetes, hepatitis, asthma, people with special needs, Parkinson's and other diseases. The NGO is recognized by the Bulgarian Ministry of Health as a national patients' organization and as such is empowered to contribute with its expertise in the work of the Ministry of Health at various levels, as well as at the Healthcare Committee of the National Assembly. Its role is to advocate before the Government and to defend the interests of patients. In addition, the NPO gives opinions on legislations, as well as on administrative acts, related to healthcare concerns. The NPO presents views and ensures their publication in the documents of the health administration public bodies.</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Better access for patients to opioid anaesthetics. The Bulgarian case.</i>
<b>Field</b>	Awareness raising.
<b>Actors</b>	<ul style="list-style-type: none"> <li>• Public Institution</li> <li>• Civic Organization</li> </ul>
<b>Location</b>	Bulgaria
<b>Term</b>	04.2010 - 12. 2012
<b>Objectives</b>	To promote the reimbursement of pain medications for oncological patients for home treatment.
<b>Outcomes Impact on participants</b>	The result of the joint efforts of all, following the initiative by the NPO, was the adoption of legislative amendments to Ordinance 40, art. 6 Annex 10, in the section on prescription of opioid painkillers. The amendments to the Regulation entered into force on 13 <sup>th</sup> April 2013. As from this date opioid painkillers are 100% reimbursed by the NHIF for in-home treatment of cancer pain for all patients. For the first time since its creation in 2000 NHIF declared that it will reimburse the treatment of pain relief.

<b>ANALYSIS</b>	
<b>Development</b>	<p>The case is related to the reimbursement of painkillers and better access for Bulgarian patients to these drugs following their inclusion in the reimbursement list of the National Health Insurance Fund (NHIF). Between 2010 and 2012 the National Patients' Organization received, on a regular basis, complaints from patients and patients' organizations in regard to the reimbursement of painkillers for treatment of cancer patients by NHIF.</p> <p>What was the situation? Treatment of the pain was provided for</p>

	<p>under the – then -current legislation, only after a patient is admitted to a medical facility. There was no statutory provision which obliged NHIF to reimburse painkillers for treatment administered at home by the patients. There was no normative act whatsoever that could oblige any institution to reimburse home treatment of cancer patients. The hospitals did not have available funding to provide home treatment of patients' pain. Due to lack of funds directors of cancer hospitals limited the number of patients undergoing medical treatment for pain.</p> <p>The legal department of the National Patients' Organization discussed the case and decided that it was necessary to modify the legislation so that patients could be reimbursed for their in-home treatment of pain. As a consequence, the need to seek synergy with all stakeholders arose, so to find the best suitable solution, given the chronic shortage of funds in the National Healthcare Insurance Fund for treatment with medicines. In our opinion, the legal certification of the existing clinical pathway and inclusion of painkillers in the reimbursement mechanisms was the solution of the case. The next step included the adoption of legally binding mechanism for access of cancer patients to painkillers for in-home treatment.</p> <p>Therefore, the National Patients' Organization launched consultations with all stakeholders: the Ministry of Health, pharmaceutical manufacturers, the National Healthcare Insurance Fund, and with healthcare professionals. A Working Group was established, formed upon the initiative of the NPO, in order to discuss the necessary legislative changes. The regular meetings of the Working Group began in August 2012.</p>
<b>Disease /Pathology</b>	Cancer
<b>Factors enabling the process</b>	We received excellent support by the healthcare professionals and from the pharmaceutical industry.

NEXT STEPS	
<b>Lessons Learned</b>	<p>This brief example illustrates the role that patients' organizations can play in improving communication among stakeholders in the healthcare system where patients need to voice their concerns. We received excellent support by the healthcare professionals and from the pharmaceutical industry. We realized that together we can solve many complex problems related to access for patients to effective drugs, even where normative and legislative amendments were necessary.</p>

<b>Number</b>	3
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Christel Lombaerts
<b>Organization</b>	Centrum voor Klassieke Homeopathie
<b>Country</b>	Belgium - Flanders
<b>Email</b>	christellombaerts@gmail.com; christellombaerts@ckh.be
<b>Short description of the organization/public institution</b>	
The aim of the Centre for Classical Homoeopathy is to spread the philosophy of classical homoeopathy and to bring its findings into practice. To accomplish this CKH organizes lectures and seminars. It participates in remedy trials and provides training in classical homoeopathy. CKH supports administratively and logistically initiatives and projects founded by students and former students who promote homoeopathy among healthcare operators such as psychologists, osteopaths, midwives, etc.	

DESCRIPTION			
Title	Research/Practice of Homeopathy for pain relief in chronic pain		
Fields	Awareness raising: Brochures and lectures for the general public		
	Education, research: Training and research		
Actors	Public Institution(s) <ul style="list-style-type: none"><li>Universities, hospitals</li></ul>		
	Other Subjects involved <ul style="list-style-type: none"><li>Individual practitioners</li></ul>		
Location	Germany, Switzerland, Iran, UK, etc.		
Term	See overview of the research projects: 1991-2012		
Objectives	Research to reveal the effects of homeopathy for pain relief		
Outcomes Impact on participants	Homeopathy is a popular treatment in patients with chronic pain. Results vary according to several factors. Statistic of positive research (details in document):		
	Date publication	N. participants	Ailment
	2012	248	chronic low back pain
	2002	43	chronic low back pain
	2007	15	neuralgia
	2009	47	fibromyalgia
	2004	62	fibromyalgia
	1986	24	fibrositis
	1998	65	pain with osteoarthritis
	2000	68	migraine
	1997	63	migraine
	1991	60	migraine
Resources	Identify inherent indispensable resources to carrying-out the initiative (human and financial resources, logistic facilities, information,		

	experiences etc.)
ANALYSIS	
<b>Development</b>	Set up a research project for the study of the characteristics of homeopathic treatment: individualisation, holistic approach, measuring well-being and symptom relief.
<b>Age</b>	Please specify the main age group of the patients involved: <ul style="list-style-type: none"> <li>• 0-20</li> <li>• 20-50</li> <li>• 50-70</li> <li>• 70-90</li> </ul>
<b>Disease / Pathology</b>	Good results already have been demonstrated in chronic low back pain, migraine, osteoarthritis and fibromyalgia.
<b>Obstacles</b>	Homeopathy is a controversial subject since its mechanisms cannot be yet adequately explained. One of the problems faced by scientists is that of “boosted” products (different from diluted ones). In recent years however, several hypotheses have been formulated to explain both boosting and homeopathic mechanisms which are currently the subject of further research. Furthermore, there is substantial solid research showing that there is indeed an effect. At the same time a research model should be designed to fit the uniqueness of homeopathy. Research is further complicated by the characteristics of homeopathy and the variety of methodologies applied.
<b>Factors enabling the process</b>	Cooperation with regular medical institutions (hospitals, universities) which can provide the premises for clinical trials.

EVALUATION	
<b>Reproducibility</b>	Homeopathy is a highly individualized method. Reproducibility is one of the main difficulties.
<b>Innovativeness</b>	Homeopathy starts from the experience of the patient, not from measurable parameters, therefore it can be applied even when the diagnosis is not clear.
<b>Added value</b>	No adverse effects were registered.
<b>Appropriateness</b>	Homeopathy can be applied whenever there is experience of pain, regardless of the diagnosis or other (regular) medication or therapies.

NEXT STEPS	
<b>Lessons Learned</b>	Thorough review of all the existing research and learn from the shortcomings: low number of participants, avoid self-reporting, use a standardized measurement (MyMop), control with other therapies, avoid using placebos.
<b>Keys To Grasp</b>	What are the two key to grasp about your Good Practice that you want to convey? <ol style="list-style-type: none"> <li>1. Easy access to treatment/products</li> <li>2. Follow-up should be frequent and thorough</li> </ol>



<b>Next Steps</b>	Meet with public organisations operating in the field to encourage them to investigate homeopathy as a treatment for chronic pain.
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#### OTHER INFORMATION

- [www.homeoinst.org/database](http://www.homeoinst.org/database)
- <http://hpathy.com/scientific-research/>
- [www.homeopathyeuropa.org/Research](http://www.homeopathyeuropa.org/Research)
- [www.homeopathy-ecch.org/content/view/50/69/](http://www.homeopathy-ecch.org/content/view/50/69/)
- [www.homeopathy-soh.org/research](http://www.homeopathy-soh.org/research)
- [www.facultyofhomeopathy.org/research](http://www.facultyofhomeopathy.org/research)

<b>Number</b>	4
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Maryvonne De Backer
<b>Organization</b>	Douleurs Sans Frontieres - Dsf
<b>Country</b>	France
<b>Country Region</b>	Europe
<b>Email</b>	maryvonnedebacker@yahoo.fr
<b>Short description of the organization/public institution</b>	
<p>Douleurs Sans Frontières –DSF (Pain without borders) is a French and international solidarity and non-profit organization operating specifically in the field of pain, suffering and terminal disease symptoms. Founded in 1996 by physicians working in hospitals and in pain centres in order to share their experiences. DSF is an association recognized since 2003 as a public utility organization. The mission of DSF is project planning and development both in France and abroad jointly with partners such as patients' associations, and its aim is to promote, foster and develop citizens' awareness as well as the prevention and training of personnel to deal with pain, suffering and terminal disease symptoms. The founding member is president Alain Serrie who is also the chief of the department of medicine for the fight against pain, palliative care and urgent care for headaches at the hospital Lariboisière in Paris; he is also member of several scientific societies. The director general and the members of the Board are pharmacists, doctors, surgeons, children psychiatrists, psychologists and nurses. The organisation's headquarters is located at the Hospital Lariboisière in Paris.</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Increase citizen's awareness through forum theatre for better prevention and dealing with chronic pain (Title of the play : Aïe plus jamais ça – No, never again)</i>
<b>Field</b>	Empowerment: of citizens and of public and private partners involved in each play. Activities for empowerment involve also a number of healthcare and social service operators who will attend the performances and answers questions posed by citizens/patients.
	Civic participation: Endeavouring to involve in all the performances both patients' associations and healthcare operators as partners gives force to the project and strengthens the joint responsibility in the fields of education, prevention and dealing with chronic pain.
	<p>Awareness raising: Raising citizens' awareness during the performances as well as before and after the event. The aim of all this is to inspire a change of attitude towards pain and make patients become actors in the prevention and dealing with chronic pain.</p> <ul style="list-style-type: none"> <li>• The perceptions and beliefs regarding pain in France are today still an obstacle to dealing with this issue: «Don't complain, if you are a man!», « There are other people who are suffering more than you are! », « Being ill is normal at our age», « I mustn't talk about my pain», « I dare not speak to my doctor about this pain which does not go away, he has patients whose ailments are more serious», «Nothing can be done to lessen my pain», «If I fight my pain I become stronger»,</li> </ul>

	<p>«Pain is inevitable!»...</p> <ul style="list-style-type: none"> <li>• Many people misunderstand the consequences of insufficient or non-existent dealing with pain. Yet, pain can be so invalidating as to limit one's autonomy and make socialisation impossible. It becomes a further reason for exclusion and a factor of social inequality both for patients and their families.</li> </ul>
Actors	<p><b>Public Institution(s)</b>  Raise strong support from the actors for each performance by inviting:</p> <ul style="list-style-type: none"> <li>• Healthcare institutions such as hospitals, centres and networks for the fight against pain</li> <li>• Territorial communities and other public actors such as municipalities which have set up a city healthcare group, a municipal centre for social action, a regional healthcare agency, a regional council, a general council etc.</li> </ul> <p>The performances which took place 2011, 2012, 2013 and in the first half of 2014 were attended by: 23 public partners involved in the awareness raising events, 8 centres/networks for the fight against pain, 12 municipalities with a city healthcare centre each, 3 regional authorities.</p> <p><i>An example of attendance at the 1<sup>st</sup> performance in Lyon:</i></p> <ul style="list-style-type: none"> <li>• Managers and operators of pain centres of the Rhône Alpes region: the team of the pain centres of CHU de Saint-Etienne, of Basses Barolles and of the St Luc Hospital (Lyon), the Palliative Care mobile unit, the HCL Groupement Hospitalier Nord - Hôpital de la Croix-Rousse (Lyon)</li> <li>• Municipalities: the municipality of the 1er Arrondissement of Lyon (withc les 2 councilors responsible for Healthcare and Culture ) and the main municipality of Lyon</li> </ul> <p><i>Further examples of the attendance at the 12<sup>th</sup> performance Hérouville St Clair (14, Calvados)</i></p> <ul style="list-style-type: none"> <li>• The participating partners were: the local Administration of d'Hérouville Saint Clair, The Regional Healthcare Agency of the Basse Normandie, the Regional Administration of the Basse Normandie, The healthcare network «Réseau de services pour une vie autonome» (Independent life service network), the regional network for the fight against pain of the Basse-Normandie, the Consom'Boutique of the community centre for social action of Hérouville Saint Clair</li> </ul> <p><b>Civic Organization(s)</b>  The following associations were involved both before and after the performances:</p> <ul style="list-style-type: none"> <li>• Healthcare patients and users' associations</li> <li>• General practitioners, healthcare professionals and social workers' associations</li> </ul> <p>Total number of associations attending the event in 2011, 2012, 2013 and in the first half of 2014: 142.</p>

	<p>The strong involvement of the Association Francophone pour Vaincre les Douleurs (AFVD) – French speaking association for the fight against pain – must be mentioned. This association is strongly committed in the project, particularly within the steering committee. The alliance between an association of healthcare professionals (DSF), and one of pain patients (AFVD) has strengthened the purpose of the project.</p> <p><i>An example of the attendance to the first performance in Lyon:</i></p> <ul style="list-style-type: none"> <li>• 5 civic associations : the Healthcare Inter-associative Convention, the CISS Rhône Alpes formed by 88 associations, the AFVD, the Algodistrophic patients' association, the disabled children association of Lyon with its day-nursery "Une Souris verte" and the community centre Louis Braille of St Priest with its group of elderly people.</li> </ul> <p><i>A further example of the attendance at the 12th performance at Hérouville St Clair (14, Calvados). Attending partners :</i></p> <p>AFVD, the Local Administration of Hérouville Saint Clair, the Healthcare Regional Agency of the Basse Normandie, the Regional Administration of the Région de Basse Normandie, the Healthcare network «Réseau de services pour une vie autonome» (Independent Life Service Network), the Regional Network for the fight against pain of the Basse-Normandie, the Consom'Boutique of the community centre for local action CCAS of Hérouville Saint Clair and the Handi' Cap citoyen (federation of handicapped patients' associations for support, guidance, information, counselling and social assistance of handicapped people).</p> <p><b>Other Subjects involved</b></p> <p>The media are considered partners since their involvement is essential to raise the public's interest around the theatre events.</p> <p>Three types of communication:</p> <ul style="list-style-type: none"> <li>• Through specialised and generalist media such as monthly magazines (local, regional and national), weekly publications, daily newspapers (local and regional), radio and TV (national, regional and local).</li> <li>• Ample diffusion of the event and the awareness raising message through the partners' communication network.</li> <li>• Through websites</li> <li>• An example of how the <u>first performance</u> in Lyon was reported: a 6 minute programme by Santé de France 5 on April 5, 2011. (Available at <a href="http://www.douleurs.org">www.douleurs.org</a>)</li> </ul>
<b>Location</b>	Lyon (69 – Rhône), Hérouville St Clair (14, Calvados), Poitiers (86 - Vienne) - St Priest (69 – Rhône), Tarbes (65 - Hautes-Pyrénées ), Paris (4 événements), Bron (69 – Rhône), Cannes (06 -Alpes Maritimes), Compiègne-Noyon (60 - Oise).
<b>Term</b>	Start date: March 2011 and ongoing with expected further development for the years 2015, 2016 et 2017
<b>Objectives</b>	Citizens' awareness raising through forum theatre events in order to:

	<ul style="list-style-type: none"> <li>• Inspire a change of attitude towards pain, inviting the public to question their beliefs, urging them to speak about their pain and informing them about prevention of chronic pain and its consequences in terms of loss of independence.</li> <li>• Contribute to make citizens become active in the prevention of chronic pain and in research, cure and assistance giving them a better knowledge about pain and the techniques for pain relief and on the networks of pain management centres.</li> </ul>
<b>Outcomes Impact on participants</b>	<p><i>For patients and the general public</i></p> <p>Citizens who have attended the performance have changed their beliefs and consider now pain less and less inevitable; they are no longer shy about speaking about their pain and feel less lonely; they are also more aware of the consequences of insufficient or non-existent pain management and are better informed on their rights and on the existence of diversified methods of dealing with pain as well as the location of the nearest pain centre.</p> <p>The following are comments made by spectators after a performance: «Now I understand that I should no longer be afraid of speaking about my chronic pain because even if not everybody believes me, somebody will. I feel less lonely and am encouraged to look for someone who can help me. I have listened to a woman who said that it took her 15 years before understanding that she would have to contact a pain centre. I did it after two years of suffering thanks to this event.» Another comment: «People who suffer from pain are given the means to become actors in dealing with it.» This awareness raising activity through forum theatre is also part of the dynamics aiming at strengthening users' co-responsibility in dealing with pain, in openly speaking about it and being proactive in finding relief. It should be pointed out that many of the people attending the events have become «bearers of the awareness raising message». Moreover, the attention of a great number of people has been indirectly raised by the media (articles and interviews about the events).</p> <p><i>About the associations and the associations' conventions</i></p> <p>The associations have begun to reinforce their role on education about pain by informing citizens about the theatre events and their members disseminate the awareness message on chronic pain. Furthermore, they promote patients' rights and encourage citizens' participation to healthcare policies as regards prevention and dealing with pain. For instance, on the occasion of the theatre performance in Lyon, the inter-associative health convention of the Rhône Alpes region, comprising 88 associations, has reinforced its role in the issue of chronic pain.</p> <p><i>Public institutions</i></p> <p>Some public institutions, through the activity of their social action community centres, have raised the issue of chronic pain during the theatre events in order to prompt a debate among professionals of liberal leanings to reinforce the consciousness in disadvantaged citizens. Pain</p>

	<p>has often become a priority in both their programs and activities. How were these benefits/impacts identified/evaluated?</p> <p><i>Patients and the general public</i></p> <p>The DSF's coordinator, together with the main partner, has carried out a quantity and quality survey on each event, collecting the following data:</p> <ul style="list-style-type: none"> <li>• Number of spectators</li> <li>• Type of audience</li> <li>• Participation to the <i>forum theatre</i> debate (an average of 90% of the audience joined in the debate)</li> <li>• A paper has been produced starting from the analysis of the audience's contribution</li> <li>• Stories of people suffering from «chronic pain» who have changed their perception as well as their way of dealing with pain; the performance is based on quality criteria.</li> </ul> <p><i>Public institutions</i></p> <ul style="list-style-type: none"> <li>• Number and type of actors involved; type and quality of their commitment</li> <li>• Number of cities, regions and local authorities involved in the project</li> <li>• Strengthening of cooperation ties among patients' associations, networks, centres and professional healthcare services.</li> </ul> <p><i>Involvement of media:</i></p> <ul style="list-style-type: none"> <li>• Number of articles published and radio programmes</li> <li>• Quality of messages.</li> </ul>
<p><b>Resources</b></p>	<p>Identify inherent indispensable resources to carrying-out the initiative (human and financial resources, logistic facilities, information, experiences etc.)</p> <p><i>Essential human resources</i></p> <ul style="list-style-type: none"> <li>• DSF is enacting this good practice with the main cooperation of the <i>forum theatre</i> coordinator.</li> <li>• The TENFOR company based near Lyon (scene director and two actors) was chosen by DSF since it is specialised in <i>forum theatre</i> performances and is experienced in healthcare issues. Supported by the AFVD and other patients' associations in the region where the performance takes place.</li> </ul> <p><i>Logistics</i></p> <ul style="list-style-type: none"> <li>• Accessible venues</li> </ul> <p><i>Financial resources</i></p> <ul style="list-style-type: none"> <li>• Resources for the payment of: <ul style="list-style-type: none"> <li>◦ Coordination (promotion, communication and partners involvement)</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ Theatre company</li> <li>○ Communication</li> <li>○ General expenses (rental of venues, travel, hotel accommodation etc.)</li> </ul> <p><i>Information</i></p> <ul style="list-style-type: none"> <li>● Use of generalist and specialized media</li> </ul>
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ANALYSIS	
Development	<p>Brief description of the main activities:  <i>1st step:</i> creation of an original play on chronic pain together with TENFOR,</p> <ul style="list-style-type: none"> <li>● In order to familiarize with the problems given by chronic pain TENFOR has organized a number of meetings with professionals and patients with the support of DSF. The message will be better understood by a wider public since it is devised with several different partners.</li> <li>● TENFOR has also developed the scenario, dialogues and script. DSF has contributed with its experience to improve it and has given its approval supported by AFVD which is a member of the steering committee.  (Please see Attachment 2: presentation of the forum theatre and the company)</li> </ul> <p><i>2<sup>nd</sup> step:</i> public preview</p> <p><i>3<sup>rd</sup> step:</i> improvement of the scenario  The DSF and TENFOR experts have introduced further improvements to better harmonise the scenario according to the topic.</p> <p><i>4<sup>th</sup> step:</i> the DSF coordinator identifies and mobilizes key public and private partners in order to involve:</p> <ul style="list-style-type: none"> <li>● Local communities</li> <li>● Doctors trained in the fight against pain</li> <li>● Patients and users' associations</li> <li>● Healthcare and social service professional associations</li> </ul> <p><i>5<sup>th</sup> step:</i> fundraising and finding the venues</p> <p><i>6<sup>th</sup> step:</i> organization of a valid communication network to achieve visibility before and after the event</p> <ul style="list-style-type: none"> <li>● Posters, fliers and invitations</li> <li>● Media targeting</li> <li>● Drafting and printing of the press release</li> <li>● Organisation of the press conference</li> <li>● Targeted dissemination and articles/mentions/interviews</li> </ul>



	<p>according to the media involved</p> <ul style="list-style-type: none"> <li>• Invitations to journalists to attend the forum theatre</li> </ul> <p>7<sup>th</sup> step: Invitation to a diversified audience and logistic organization of the event</p> <p>8<sup>th</sup> step: evaluation of the performance and company This will allow to:</p> <ul style="list-style-type: none"> <li>• Assess the scenario in order to carry out changes, if needed, after the performance</li> <li>• Summarize the public debate</li> <li>• Improve the method to mobilise the partners</li> </ul>
<b>Age</b>	<p>Please specify the main age group of the patients involved</p> <ul style="list-style-type: none"> <li>• 0-20</li> <li>• 20-50</li> <li>• 50-70</li> <li>• 70-90</li> </ul>
<b>Disease / Pathology</b>	<p>Chronic back ache, migraine, neuropathic pain in general, shingles in elderly people, algodystrophic syndrome, fibromyalgia, cancer, rheumatoid polyarthritis, diabetes, and all other pathologies mentioned by the public during the performances.</p>
<b>Obstacles</b>	<p>At what stage and which kind of obstacles you met during the project (cultural or operational obstacles).</p> <ul style="list-style-type: none"> <li>• The main obstacle is the level of funding</li> <li>• The second is to make people accept to wait as long as it is necessary to prepare and assess each performance in order to involve the partners and «make do»</li> </ul> <p>Means used to overcome or remove the obstacles.</p> <ul style="list-style-type: none"> <li>• Fundraising</li> </ul> <p>In view of the difficulties in obtaining subsidies for several performances funds were raised during each event. This has also allowed to involve a number of lenders/donators and public actors at local and regional level.</p> <p>For example, the event of Noyon/Compiègne was supported by the (60 -Oise):</p> <p>Noyon's local authority, the Culture and Communication Centre of the General Council of the Oise Region and the Caisse d'Epargne de Picardie.</p> <ul style="list-style-type: none"> <li>• Have time to establish alliances and to carry out awareness raising campaigns on the issue of pain by some of the partners involved.</li> </ul> <p>The preparation of a theatre performance well in advance, at least 3 months, will help to achieve a strong commitment by the partners and the right mix of healthcare professionals and patients as well as reciprocal consciousness raising.</p>
<b>Factors enabling the</b>	<p>According to experience, it seemed difficult to immediately raise the</p>

<b>process</b>	<p>interest of non-sufferers in meetings dealing with pain. Moreover, certain people would not attend conferences anyway. This issue is often scary and behaviours to avoid the topic have been noted.</p> <p>This practice touches all citizens directly whether or not suffering from pain. Therefore, the choice of a forum theatre is a positive factor since it is an ideal cultural vehicle to surprise without raising alarm and a place where to question beliefs and attitudes.</p> <p>This type of debate is aimed at the public at large and also at those people who are little or not at all used to this kind of culture since one of the strong points of the forum theatre is its adaptability to all circumstances.</p>
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<b>EVALUATION</b>	
<b>Reproducibility</b>	<p>This good practice is enacted and growing stronger in France. Among the organisations involved, the social action of Groupe REUNICA is committed to support financially DSF for 9 performances in various cities. In fact, this action is well in line with the social action of the Groupe Réunionica operating on the prevention of chronic pain and the consequent loss of autonomy.</p> <p>On the other hand, the positive achievements in awareness raising in citizens and public and private actors regarding chronic pain by the forum theatre allows DSF to produce these performances at international level thus giving an answer to the demand for a project on medical education on pain in infants in the Maghreb.</p>
<b>Innovativeness</b>	<p>The premise to this good practice helps to look at pain in France as a social issue, a right rather than only a healthcare problem. Are not, in fact, perception and beliefs today still an obstacle in dealing with pain?</p> <p>Moreover, this premise encourages the quest for involvement of the public in Healthcare and Culture actors.</p> <p>Also, this good practice in awareness raising aims at drawing the attention of many citizens through the forum theatre. Free entrance to these performances is a priority since it would be a facilitating factor ; also, people who live in situations which make access to information difficult could be more easily reached.</p>
<b>Added value</b>	<p>All written reports produced by the forum, starting with the analysis of the debates with the audience will be included in a “white book” and sent to the French government with the view to convene a national conference of the civic society on pain.</p>
<b>Appropriateness</b>	<p>The use of theatre to deal with this issue is pertinent and appropriate.</p> <p>This type of theatre is appreciated by people who are not or are little familiar with this kind of culture since one of the strong points of the forum theatre is its adaptability to all places and to everybody since the people who are interested in this topic are both young and old, belong to all walks of life including citizens living in difficult</p>

	<p>areas.</p> <p>The play “Aïe plus Jamais ça” can be performed in workplaces, parks, community centres, university lecture theatres, town halls and, of course, proper theatres.</p>
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### NEXT STEPS

<b>Lessons Learned</b>	<ul style="list-style-type: none"> <li>• Find a theatre company already experienced in healthcare issues and in <i>forum theatre</i></li> <li>• Pay attention to the cultural setting of the story (scenario adapted to the context and to local culture)</li> <li>• Keep the issue always in sight, since there is the risk to say too much</li> <li>• Know that this good practice aims both at raising questions and awareness and at establishing a bonds among the participants</li> <li>• Ensure the attendance of public and private actors and that of the media and local activists</li> <li>• Do not be afraid to adapt the approach to improve the consensus and the response from the public</li> </ul>
<b>Key Takeaways</b>	<ol style="list-style-type: none"> <li>1. Associate patients, healthcare and social service professional organisations</li> <li>2. Involve public actors in the fields of Healthcare and Culture</li> </ol>
<b>Next Steps</b>	<p>If applicable, what are your organization’s next steps for your Good Practice?</p> <p>There is an ongoing effort to implement this good practice in other countries and to adapt this experience to the issue of pain in children.</p>

### OTHER INFORMATION

<p>A 6 minute documentary was broadcast on Santé de France 5 on April, 5 2011. (Available at <a href="http://www.douleurs.org">www.douleurs.org</a>)</p>
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<b>Number</b>	5
<b>CONTACT DETAILS</b>	
<b>Organization</b>	Centre Hospitalier de Clermont-Ferrand Fondation APICIL
<b>Country</b>	France
<b>Short description of the organization/public institution</b>	
It is a hospital regional centre divided into 15 departments representing all specialisations. Each department is under the authority of a Director and each service is run by a Service Manager. The departments include a number of services and their managers are appointed by the Director General in joint proposal with the President of the Medical Commission and the Doyen de l'UFR de Médecine.	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Ecrire pour soulager la douleur (Writing to ease the pain)</i>
<b>Field</b>	Empowerment: Providing support and capacity building of individual patients with fibromyalgia, including social, psychological, and other impacts. The main objectives are to bring together people who are suffering from this debilitating condition, within a 'safe' environment enabling them to share concerns and ideas, build friendships and obtain up-to-date information about managing their pain.
	Civic participation: Patients play a fundamental role in this activity. Their active participation and will to react represent the keystone of this good practice.
	Awareness raising: Writing activities aim at easing pain by firstly raising awareness in patients. Free expression entails the necessity to face their chronic disease (with a particular attention to campaigns and education initiatives).
<b>Actors</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>Centre Hospitalier de Clermont-Ferrand</li> </ul> <b>Other Subjects involved</b> <ul style="list-style-type: none"> <li>Fondation APICIL.</li> </ul>
<b>Location</b>	Clermont-Ferrand, Auvergne
<b>Objectives</b>	Patients suffering from chronic diseases should discuss their problems with the doctors and this relationship should help them to re-acquire self-confidence and independence since this "return to life" can be only reached through recovered autonomy.
<b>Outcomes Impact on participants</b>	Writing can be a means to master one's illness through confiding to others one's own intimate feelings about pain.
<b>Resources</b>	Human resources: Professional facilitator.

<b>ANALYSIS</b>	
<b>Development</b>	The writing workgroup is a place for exchange and confrontation. Activities are coordinated by a professional facilitator and the meetings are held on a weekly basis according to the timetable set by the doctors.

<b>Disease / Pathology</b>	Fibromyalgia
<b>Obstacles</b>	The main obstacle is acquiring awareness of the problem and trust in the other participants. The presence of a professional facilitator and of other people with a similar issue encourage experience sharing among the patients.

<b>EVALUATION</b>	
<b>Reproducibility</b>	Yes
<b>Innovativeness</b>	A number of mediation techniques can be used for art-therapy. Painting and music are those more widely used. Nevertheless, new methods like writing and dancing are being developed.
<b>Added value</b>	Using the Good Practice was it helpful instead of having approached needs in any already experienced way?
<b>Appropriateness</b>	It allows people to express their pain when simple words are not sufficient.

<b>OTHER INFORMATION</b>	
<a href="http://www.chu-clermontferrand.fr">www.chu-clermontferrand.fr</a>	<a href="http://www.fondation-apicil.org">www.fondation-apicil.org</a>

<b>Number</b>	6
<b>CONTACT DETAILS</b>	
<b>Organization</b>	Fondation APICIL and Hospital Emile Roux in Puy-en-Velay
<b>Country</b>	France
<b>Short description of the organization/public institution</b>	
The hospital Emile Roux in Puy-en-Velay is a public human organization composed of doctors, nurses, administrative clerks, logistics and technicians to guarantee the best welcome conditions for both patients and visitors.	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Une Prise En Charge Multimodale Du Syndrome Fibromyalgique (Multimodal taking in charge of the fibromyalgia syndrome)</i>
<b>Field</b>	Empowerment: Providing support and capacity building of individual patients with fibromyalgia, including social, psychological, and other impacts.
<b>Actors</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>• Consultation douleur du Centre Hospitalier du Puy-en-Velay</li> </ul> <b>Other Subjects involved</b> <ul style="list-style-type: none"> <li>• Fondation APICIL</li> </ul>
<b>Location</b>	Auvergne, Puy-en-Velay
<b>Term</b>	2011-2014
<b>Objectives</b>	<p>Fibromyalgia syndrome (FMS) is a debilitating condition of almost unknown aetiology and pathogenesis characterized by widespread musculoskeletal pain and tenderness, as well as secondary symptoms like fatigue, depression, irritable bowel syndrome and sleep disturbances. A standard therapy regimen is lacking and the condition causes high direct and indirect costs (for example, health care use and sick leave).</p> <p>Balneotherapy is an effective alternative in treating fibromyalgia syndrome (FMS) for patients who have difficulties in their everyday life and suffer from pain and anxiety. It is an efficient approach to reduce the effects of pain, not only physical but also psychological. The final objective is to reduce the impact of pain on daily life. This approach completes a diversified program of complementary approaches in groups, developed around pain. Balneotherapy seems to be a very efficient approach to help persons suffering from fibromyalgia.</p>
<b>Outcomes Impact on participants</b>	Patients complain less about their pain, anxiety, and difficulties in the daily activities. A number of scientific researchers has also assessed the chemical effects on the human body by monitoring oxytocin, brain-derived neurotrophic factor (BDNF), ATP and serotonin transporter.
<b>Resources</b>	Occupational therapist (Psychomotor specialist), Structure (Pool), physiotherapists

<b>ANALYSIS</b>	
<b>Development</b>	This project began in 2002 and two groups of patients suffering of fibromyalgia have already drawn benefits from it while another group is beginning its activity. This multi-modal way of dealing

	<p>with pain conforms with the last recommendation from the High Health Authority of July 2010. It is carried out in 10 half-day sessions of hospitalization.</p> <p>Each lesson is made up of:</p> <p>One lesson of balneotherapy at the hospital's pool with two physiotherapists involved in the project</p> <p>One lesson of therapeutic education, which concerns one aspect of the disease (pain, sleep, managing of the activity, relaxing)</p> <p>Each half-day ends with relaxation techniques related to the topic of the day.</p> <p>Groups of 8 or 10 people were involved. Patients are examined again after three and six months to assess the quality of their lives.</p>
<b>Disease / Pathology</b>	Fibromyalgia
<b>Factors enabling the process</b>	Structure (Pool), physiotherapists and Occupational therapist (Psychomotor specialist)

<b>EVALUATION</b>	
<b>Reproducibility</b>	Yes
<b>Innovativeness</b>	Considering the Canadian Recommendations of 2003, those of the US of 2005 and of EULAR (European League Against Rheumatism) of 2007 the Centre Hospitalier du Puy-en-Velay decided to adopt a multimodal taking in charge of this polymyalgia syndrome.
<b>Added value</b>	Balneotherapy (BT) and hydrotherapy (HT) offer interesting treatment alternatives and are commonly used as additional interventions in the management of FMS, despite an ongoing debate about their efficacy. Researches (an Internet survey of 2,596 people with FMS) found that around 26% of individuals suffering from FMS use pool therapy and 74% heat modalities (warm water, hot packs). The interventions perceived to be most effective (effectiveness rating $\geq 6.0$ ) on a scale of 0 to 10, with 10 being most effective, were rest, ( $6.3 \pm 2.5$ ) (mean $\pm$ SD), heat modalities ( $6.3 \pm 2.3$ ), pain medication ( $6.3 \pm 2.4$ ), sleep medication ( $6.5 \pm 2.7$ ) and pool therapy ( $6.0 \pm 3.0$ )

<b>OTHER INFORMATION</b>	
<a href="http://www.ch-lepuy.fr">www.ch-lepuy.fr</a>	<a href="http://www.fondation-apicil.org">www.fondation-apicil.org</a>



<b>Number</b>	7
CONTACT DETAILS	
<b>Name and Surname</b>	Gerard Mick
<b>Organization</b>	Centre for Pain Evaluation and Treatment Neurological Hospital
<b>Country</b>	France

DESCRIPTION	
<b>Title</b>	<i>Localized Neuropathic Pain (LNP) Screening Tool for chronic pain patients</i>
<b>Actors</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>Centre for Pain Evaluation and Treatment Neurological Hospital</li> </ul>
<b>Objectives</b>	Neuropathic pain (NP) is a common type of chronic pain in which 60% of patients present with localized symptoms. Early diagnosis of NP is often a challenge in primary care. Moreover, so far no standard diagnostic procedure for localized NP (LNP) is available. To help general practitioners, a screening tool was developed and evaluated.
<b>Outcomes Impact on participants</b>	<p>General practitioners rated usefulness, simplicity, and time requirements of the tool. Diagnostic accuracy was expressed by sensitivity, specificity, and positive and negative predictive values.</p> <p>Results:</p> <p>General practitioners consecutively screened 2079 chronic pain patients (mean age 60.7 11.1 years, 69.9% female). Using the tool, 394 patients were diagnosed with LNP. Screening including sensory examination took 7 min (median). General practitioners rated the tool as useful (24/31; 77.4%) or very useful (7/31; 22.6%) for diagnosing LNP and facilitating clinical practice (30/31; 96.8%). Under daily practice conditions, sensitivity and specificity of the tool for detecting LNP was 46.7% and 86.6%, respectively.</p> <p>The proposed screening tool was shown to be easy and useful for detecting NP and LNP in chronic pain patients as a fast first assessment tool in primary care, thus facilitating the choice of a topical treatment.</p>
<b>Resources</b>	The study was supported by Grunenthal GmbH, Aachen, Germany.

ANALYSIS	
<b>Development</b>	<p>The screening tool for the identification of probable LNP in patients presenting with chronic pain in general clinical practice was developed based on the grading system principles for NP proposed by the Neuropathic Pain Special Interest Group of the International Association for the Study of Pain expert committee with the main focus turned towards medical history and distribution of painful symptoms and sensory signs. It was stipulated that the tool should be easy to understand and easy to use, and that it should not be time-consuming. The tool, in the format of a pocket card (9 cm 14 cm), consists of four screening questions lead to the diagnosis</p>

	<ol style="list-style-type: none"> <li>1. History</li> <li>2. Anatomy</li> <li>3. Sensory examination</li> <li>4. Size of the painful area</li> </ol> <p>If the answer for the first three questions is “Yes” neuropathic pain is probable; four times “Yes” indicates a high probability of the indication Localized Neuropathic Pain (LNP).</p> <p>The LNP screening tool was evaluated in clinical practice (Spanish trial) Conclusion of the evaluation: LNP is a frequent type of NP and is often underdiagnosed. The LNP Screening Tool supports early diagnosis of LNP and supports early targeted treatment according to guidelines</p>
<b>Age</b>	<p>Please specify the main age group of the patients involved</p> <ul style="list-style-type: none"> <li>• 20-50</li> <li>• 50-70</li> <li>• 70-90</li> </ul>
<b>Disease / Pathology</b>	Localized Neuropathic Pain (LNP)
<b>Obstacles</b>	The drop-out rate was high but was accounted for by using correction factors in the diagnostic accuracy calculations. A strength is the unselected chronic patient population: spectrum of disease correctly reflects day-to-day clinical practice and is not biased.
<b>Factors enabling the process</b>	Diagnostic accuracy of the tool therefore appears to be realistic.

<b>Number</b>	8
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Martine Chauvin
<b>Organization</b>	AFVD Association Francophone pour Vaincre les Douleurs (French association for the fight against pain) - <a href="http://www.association-afvd.com">www.association-afvd.com</a>
<b>Country</b>	France - Poitou-Charentes
<b>Email</b>	<a href="mailto:association-afvd@neuf.fr">association-afvd@neuf.fr</a>
<b>Short description of the organization/public institution</b>	
<p>AFVD is a patient organization for people suffering from chronic pain, of the type foreseen by the 1901 law, established by Martine Chauvin at Pompaire in Deux-Sèvres in December 2006.</p> <p>Martine recounts the circumstances which led her to this decision in her book « Jeu, Set, et Match » (Game, Set, and Match).</p> <p>The association has about 150 members, patients, relatives and friends throughout the country.</p> <p>AFVD was recognized as an organization of public interest in June 2008.</p> <p>It is also a founding member of the Pain Network Alliance Europe, PAE established by decree dated July 6, 2012.</p> <p>The association has received the National Approval to represent users in dealing with hospitals and healthcare authorities (Official Gazette of 18 July 2012) and is also a member of the CISS (Interassociative Healthcare Committee) at regional level.</p> <p>The Code of Practice Charter and all documents related to the governance of the Association are downloadable or can be sent on request.</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Permanence d'accompagnement</i>
<b>Field</b>	Empowerment: The proposed actions will take place initially in Poitou-Charentes selected by AFVD as a pilot region. They will concern pain out-patients treated within the framework of a collective project as well as those patients treated by local structures. Patients will request assistance in the centers on a voluntary basis, the final objective being the improvement of the patients' quality (with a particular attention to campaigns and education initiatives)
<b>Actors</b>	<p><b>Public Institution(s)</b></p> <ul style="list-style-type: none"> <li>• CHU Centre d'Etude et de Traitement de la Douleur Poitiers (86)</li> </ul> <p><b>Civic Organization(s)</b></p> <ul style="list-style-type: none"> <li>• Association Francophone pour Vaincre les Douleurs (French association for the fight against pain)</li> </ul>
<b>Location</b>	Ville; Poitiers Région; Poitou-Charentes
<b>Term</b>	1er semestre 2014

<b>Objectives</b>	Centres located in healthcare structures and association centres The centres will monitor, share and assist chronic pain patients. They are free and open to everybody in France. The service is supplied by voluntary experts trained in therapeutic education by AFVD and are set up in partnership with healthcare professionals who consider them an indispensable tool to complete their taking charge of patients.
<b>Outcomes Impact on participants</b>	Since its onset the purpose of AFVD has been to work hand in hand with healthcare operators in order to offer complementary actions and synergies. Medical experience is fundamental but the patient's life is a wealth to take advantage of since patients know better. Therapeutic education is a priority: experts are new partners, desirable if not essential, for out and in patients as well as for their families in order not to feel alone with their pain and lost when not seeing their doctor. Experts always make their presence felt during visits or when waiting is perhaps too long and above all before the very first meeting. Together with the professionals they help patients to reach an acceptable level of life as soon as possible.
<b>Resources</b>	In order to successfully run this project, it is necessary to establish a close partnership with the healthcare professionals. Participating patients will have to attend a 40-hour training course in therapeutic education or hold a university degree. Then host structure should offer suitable premises and we must also foresee a yearly budget in the Poitou-Charentes of € 5.000 for the centres for assistance and of € 7.000 for expert training courses.

<b>ANALYSIS</b>	
<b>Development</b>	In order to develop this part of the project AFVD is strengthening its commitment through the «Vivre Mieux Avec» (To live better with) <sup>15</sup> .the objectives to be reached are the following: assist the patients to improve their independence and decision taking all along the course of the project; improve patients' knowledge about the complexity of chronic pain; organize structures destined to improve the patients' physical and psychological well being; teach the patients how to re-invest the knowledge acquired in their daily life; take into account the psychological aspects when helping patients to better co-exist with their illness; improve the psychological assistance of both patients and their families; foster mutual understanding among patients, careers and families; learn to manage emotions. The objective is to help patients to recover the ability to live with their illness so that they can find new strength and self confidence, thus re-acquiring their independence over pain.
<b>Age</b>	Please specify the main age group of the patients involved <ul style="list-style-type: none"> <li>• 0-20</li> <li>• 20-50</li> </ul>

<sup>15</sup> Rrdbn Réseau Régional Douleur de Basse-Normandie [www.douleur-rrdbn.org](http://www.douleur-rrdbn.org) with AFVD supporting the project.

	<ul style="list-style-type: none"> <li>• 50-70</li> <li>• 70-90</li> </ul>
<b>Disease / Pathology</b>	AFVD is the only patients' association in France for people suffering from chronic pain or pain deriving from any type of pathology (headache, cancer, rheumatism, diabetes, multiple sclerosis, post-surgery pain etc.)
<b>Obstacles</b>	The only obstacle is funding.

<b>EVALUATION</b>	
<b>Reproducibility</b>	Our good practice has been developed only in the Poitou-Charentes region but can be repeated in all regions where there are voluntary workers prepared to train as patients' experts and medical teams prepared to work with us on a voluntary basis.
<b>Innovativeness</b>	We are now developing a therapeutic education programme for the fight against pain together with healthcare professionals in those structures where our centres of assistance are already operational.
<b>Added value</b>	Thanks to its implementation, this good practice is producing an added value in terms of doctors taking charge of patients and for its personalised approach. This is a way of sharing knowledge in the interest of the sufferers. The team, carers, patients and families explore together the best solutions for the patients' wellbeing by inspiring confidence through empathy, ability to listen, talk and communication. Patience and a positive attitude to motivate help and encourage patients to become actors in their illness and learn how to deal with pain.
<b>Appropriateness</b>	Out of 150 patients met during the first half of 2014 in the Poitou-Charentes region, 145 completed our satisfaction questionnaire and wished that the association further develop its activities and were satisfied with how they had been listened to, the reception and the sharing of opinions. 100% of the patients felt that they had been helped to get back on to the right track. The 5 patients who did not return the questionnaire had shown difficulties in communicating.

<b>NEXT STEPS</b>	
<b>Lessons Learned</b>	Our good practice is available for those countries which are interested in implementing it. We would be happy to share with others all that we have learnt.
<b>Keys Takeaways</b>	<ol style="list-style-type: none"> <li>1. our work complements that of the healthcare professionals</li> <li>2. experience sharing is fundamental for a better management of chronic pain</li> </ol>
<b>Next Steps</b>	<p>The next step will be to develop our «Vivre Mieux Avec» programme together with the healthcare professionals. The programme will include 6 meetings and will be implemented by small multi-purpose groups of chronic pain sufferers (max 10 participants) with different pathologies.</p> <p>Each meeting will be held once every fortnight from 2 pm to 5 pm. It</p>

	<p>is important that AFVD experts meet the participants 15 minutes before the meeting and stay with them 15 minutes after its end. The meetings will be chaired by an ETP doctor who will join the discussion when necessary. It is also important to ensure the regularity and continuity of the programme. The expert will contact the group member a few days before each meeting.</p> <p>A shared educational assessment paper (Bilan Educatif Partagé pratiqué) will be drawn up together by a carer and an expert.</p> <p>Each meeting is divided into several steps:</p> <ul style="list-style-type: none"> <li>• 1: listening time (2 pm-3 pm). Each participant has 5 minutes to explain the reason for being there and what he/she expects from the meeting. In this way each person will have something to offer the others and receive something in return</li> </ul> <p>2: Respiration and Movement (3 pm-3.30 pm). Patients will discover or re-discover psychomotor mobility and the will to active. Participants will repeat these exercises at home gradually</p> <p>1. 3:Break (3.30 pm -3.45 pm)</p> <ul style="list-style-type: none"> <li>• 4: speaking about what patients know or believe about their illness (3.45 pm – 4.15 pm). Start from what patients know and encourage interaction: knowledge will increase through these exchanges (treat with respect beliefs and perceptions expressed by everyone if these do not represent a risk for the patient)</li> </ul> <p>2. 5: this step will be developed according to the issues treated. Medical and non medical therapeutic approach, knowledge of medication, psycho corporeal techniques (4.15 pm – 5 pm). This step will develop differently in each meeting and will be an occasion to invite a guest (a doctor specialized in psycho corporeal techniques, a physiotherapist, a medical consultant, a pharmacist, an MDPH doctor, occupational doctor, a nurse etc). patients can use the information acquired for their daily life (support CDs and videos, support written information)</p> <p>3. 6: opinion sharing and summary of the meeting</p> <p>Steps 4 and 5 will depend on the issues debated. During each meeting we shall go over what took place in between our encounters.</p>
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<b>Number</b>	9
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Harry Kletzko
<b>Organization</b>	German Pain League and Integrative Managed Care GmbH
<b>Country</b>	Germany - Hessen (Mid-West-Germany)
<b>Email</b>	Harry.Kletzko@schmerzliga.de; Harry.Kletzko@imc-de.de
<b>Short description of the organization/public institution</b>	
<p><b>German Pain League</b>  The German Pain League (Deutsche Schmerzliga), founded in 1990, is the largest chronic pain patient organization in Germany. It is a non-profit and non-governmental organization with more than 5,000 members and runs more than 100 regional self-help groups. The German Pain League is also a member of the International Alliance of Patients' Organizations (IAPO).  The mission of the "Deutsche Schmerzliga" is to improve the situation and life of patients suffering from pain. Above all, this means improving the general framework of healthcare policies and opening up therapeutic channels for patients suffering from chronic pain.</p> <p><b>Integrative Managed Care GmbH</b>  Integrative Managed Care GmbH (IMC) is a company managed by physicians specialized in pain therapy. We are developing integrative therapy concepts which we implement together with health insurance companies and specialist pain centres all over Germany.</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Integrative Therapy Concept for Back-Pain</i>
<b>Field</b>	Empowerment
<b>Actors</b>	<p><b>Public Institution(s)</b></p> <ul style="list-style-type: none"> <li>Several German Health Insurance Companies, such as Techniker Krankenkasse.</li> </ul> <p><b>Other Subjects involved</b></p> <ul style="list-style-type: none"> <li>36 specialist pain centres nationwide. Therapy areas: Psychotherapy</li> </ul>
<b>Location</b>	All over Germany.
<b>Term</b>	The program started with 5 pain centres in 2005 and today we have 36 pain centres and several health insurance companies involved.
<b>Objectives</b>	<p>The main objective is to prevent back pain from becoming chronic.</p> <p>The program also reduces costs by decreasing the time patients are absent from work due to pain to the spine and the back.</p>
<b>Outcomes Impact on participants</b>	<p>This multimodal program is very successful. Before starting it patients were suffering from back pain for 4 weeks or longer, but after 4 weeks of multimodal treatment (Psychotherapy, Physiotherapy and Pain Therapy – 3 times a week) 55% of the patients were fit for work again.</p> <p>Some patients needed a treatment longer than 4 weeks, but after a maximum of 8 weeks, 85 % of the patients in the program were fit for work again.</p> <p>Most importantly, the program is sustainable: patients stay fit for work because they have started changing their life styles (they relax more,</p>



	<p>practice more sports etc.); 90 % are still fit for work 6 months after the end of the program.</p> <p>Therefore, the program improves the quality of life of each single patient. It reduces therapy costs for health insurance companies as patients recover after a short period of time.</p> <p>It helps national economy by preventing people from being unable to work because of severe back pain problems.</p> <p>Both pain centres and patients are asked to keep detailed records of the therapy they are undergoing. Results are then evaluated by a scientific institute.</p>
<b>Resources</b>	<p>Health laws should promote new multimodal treatment programs.</p> <p>Physicians should welcome working together with other health professionals (psychotherapists and physiotherapists).</p> <p>Health insurance companies should be willing to finance new treatment programs.</p> <p>Patients should be open-minded towards possible new treatments.</p>

<b>ANALYSIS</b>	
<b>Development</b>	<p>Patients come to the pain centre for a medical screening (multimodal: Psychotherapy, Physiotherapy and Pain Therapy).</p> <p>When the medical team decides that the program is suitable for the patient, a multimodal therapy (3 times a week) for a maximum of 8 weeks will start. The intensity of the treatment depends on the individual needs of the patient. Elements of the treatment are: educational, relaxation techniques, behavioural therapy, strength-, cardio- and coordination-training along with individual medical therapy.</p>
<b>Age</b>	<p>Please specify the main age group of the patients involved</p> <ul style="list-style-type: none"> <li>• 20-50</li> </ul>
<b>Disease / Pathology</b>	Back Pain
<b>Obstacles</b>	<p>This is a new concept, therefore it needs a new way of thinking and the willingness to establish new structures. For this reason, some health insurance companies do not risk financing a concept not knowing the possible outcome. Some patients for example do not want psychotherapy treatment in case they are stigmatized as “crazy”. Some physicians are afraid of losing “their” patients to the pain centre etc.</p> <p>The best means to overcome such obstacles is being successful, so that people start trusting the idea.</p>

<b>EVALUATION</b>	
<b>Reproducibility</b>	Yes, in every country where health laws allow this new concept and where stakeholders are willing to try something new and set up new multimodal structures.
<b>Innovativeness</b>	Yes, the program is sustainable, it can prevent back pain from

	becoming chronic.
<b>Added value</b>	Yes, please see the above section Outcomes /Impact on participants
<b>Appropriateness</b>	Yes, please see the above section Outcomes /Impact on participants.

<b>NEXT STEPS</b>	
<b>Lessons Learned</b>	Finding an open-minded health insurance company and start the program with them. Start with only few pain centres to see if the concept works or if changes should be required.
<b>Key Takeaways</b>	1. Be open-minded, try to think and do something new 2. Find stakeholders with the same mindset and cooperate with them
<b>Next Steps</b>	We would like to involve in the future more health insurance companies and extend treatment to other diseases.

<b>Number</b>	10
CONTACT DETAILS	
<b>Name and Surname</b>	Frans Copers
<b>Organization</b>	EUROPEAN SHIATSU FEDERATION
<b>Country</b>	Greece - Attica
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DESCRIPTION	
<b>Title</b>	<i>A Study of the Effects of Shiatsu on Pain Management at the Pain Management Clinic of the University Hospital Aretaieion Athens Greece.</i>
<b>Field</b>	Empowerment: It increases patients' self-confidence helping them understand that they can control pain and mitigate it.
	Civic participation: The holistic approach went beyond merely addressing the origin of their chronic pain. The interaction with the patients was aimed at enhancing their understanding of the nature/aetiology of their pain.
	Awareness raising: Enhancing the capacity to understand the aetiology and nature of pain.
<b>Actors</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>Pain Management Clinic of the University Hospital Aretaieion Athens Greece</li> </ul> <b>Civic Organization(s)</b> <ul style="list-style-type: none"> <li>Hellenic Shiatsu Society.</li> </ul>
<b>Location</b>	Athens
<b>Term</b>	March 2008- October 2011
<b>Objectives</b>	To assess the effects of Shiatsu, psychotherapy, acupuncture and reflexology on patients suffering from chronic pain
<b>Outcomes Impact on participants</b>	Improvement in: level, frequency, duration of pain, quality of life (stress levels, parallel complaints/illnesses, functioning, mood, satisfaction. Almost every patient expressed feelings of relaxation and relief. All commented on the unique experience of being treated as individuals with a particular health issue, and not just as an impersonal "medical statistic".
<b>Resources</b>	Human resources, information, experiences etc.

ANALYSIS	
<b>Development</b>	<p>The team included two shiatsu practitioners, a founding member and current President of the Hellenic Shiatsu Society (HSS) and an HSS member both working together with and supervised by three chief anaesthesiologists who also teach at the University of Athens Medical School.</p> <p>The number of patients was 68 with an age range 30-85 and were referred for shiatsu treatment by the doctors and ourselves. Each member of the team treated: 25 patients (about 300 sessions), 38 (about 240 sessions), 13 (about 257 sessions) respectively, for a total of 797 sessions, with each patient receiving approximately 12 sessions. Psychotherapy, acupuncture and reflexology are also</p>

	integrated at the pain clinic but were not measured in this study. Patients expressed their appreciation for the advice they received from us about regular exercise (breathing, walking, yoga, stretching, etc.) and nutrition. Relief from secondary problems (intestinal disorders, stress, hormonal imbalances, allergies, and insomnia) was related mainly to shiatsu. Therefore, our holistic approach went beyond merely addressing the origin of their chronic pain.
<b>Age</b>	Please specify the main age group of the patients involved <ul style="list-style-type: none"> <li>• 20-50</li> <li>• 50-70</li> <li>• 70-90</li> </ul>
<b>Disease / Pathology</b>	Myoskeletal problems (fibromyalgia, athletic injuries, deformities, osteoporosis, etc). Auto-immune diseases (Multiple Sclerosis, Rheumatoid Arthritis, etc). Neurological diseases (Migraines, post-herpes neuralgia, trigeminal neuralgia, etc). Complex Regional Pain Syndrome (CRPS).
<b>Obstacles</b>	Older patients tended to be more pessimistic and linked their health problems to their limited life expectancy. They tended to get disappointed and to give up more easily. Additional complications compounding their pain included psychosocial issues such as addictions, family problems, financial stress, and mental stress.
<b>Factors enabling the process</b>	Positive thinking and optimism of patients.

## EVALUATION

<b>Reproducibility</b>	Yes
<b>Added value</b>	Patients praised our support after their doctors had run out of options for pain management.
<b>Appropriateness</b>	Yes

## NEXT STEPS

<b>Lessons Learned</b>	Age was not a definite parameter to the decrease of pain. PTSD, grief, and psychological factors played a frequent role in their pain profiles.
<b>Key takeaways</b>	1. Compliant patients experienced faster and better long term results 2. Positive thinking, optimism and self-confidence

<b>Number</b>	11
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Agron Bytyqi
<b>Organization</b>	Professional Health Association – Pain Section, Kosovo
<b>Country</b>	Kosovo - Prizren
<b>Email</b>	agron_bytyqi@hotmail.com
<b>Short description of the organization/public institution</b>	
<p>The Professional Health Association (PHA) is one of the largest professional and multidisciplinary associations for pain treatment in Kosovo. Operators working at the PHA are health professionals of various specialties actively involved in the diagnosis and treatment of pain and the number of memberships is increasing every year. PHA was registered at the Ministry of Public Service of the Republic of Kosovo January 20, 2009. It is made up of: anaesthesiologists, neurologists, oncologists, physiatrists, family physicians, orthopaedists, surgeons, internal specialists and nurses who deal with the diagnosis and treatment of pain.</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>International conferences for pain treatment</i>
<b>Field</b>	Civic participation
	Awareness raising
<b>Actors</b>	<p><b>Public Institution(s)</b></p> <ul style="list-style-type: none"> <li>Ministry of Health in Kosovo,</li> <li>Faculty of Medicine, UCCK, Clinic of Anaesthesiology – Pristina,</li> <li>Regional Hospital “ Prim. Dr. Daut Mustafa” Prizren.</li> </ul> <p><b>Civic Organization(s)</b></p> <ul style="list-style-type: none"> <li>IASP, EFIC, Patients’ Rights Association in Kosovo (PRAK)</li> </ul>
<b>Location</b>	Prizren
<b>Term</b>	9-12 October 2009 cont. (annual)
<b>Objectives</b>	<ul style="list-style-type: none"> <li>Promotion of the latest achievements on pain management</li> <li>Inclusion of pain management in medical school curricula</li> <li>Awareness raising of healthcare operators</li> <li>Awareness raising of policy makers</li> <li>Set up a team to implement the treatment of pain in the Albanian Healthcare System, as an example for all countries with limited resources</li> <li>Patient education for pain management</li> </ul>
<b>Outcomes Impact on participants</b>	<p>Professionals are trained to improve pain treatment.</p> <p>Institutions are encouraged to send doctors and nurses to training courses in pain management</p> <p>Patients do not have to contact private clinics asking for help in their fight against chronic pain but can use dedicated structures</p>
<b>Resources</b>	<p>Financial resources: MoH –Prishtina, Participants and pharmaceutical companies</p> <p>Professional human resources: Professional Health Association, Pain Section (PHA)</p> <p>Logistic facilities and organization: PHA and PRAK</p>

### ANALYSIS

<b>Development</b>	<p>The Professional Health Association in collaboration with the Ministry of Health of Kosovo, the International Association for the study of Pain (IASP), the European Federation of IASP Chapters (EFIC), Patients' Rights Associations in Kosovo (PRAK), the Clinic of anesthesiology in Pristine, the Regional Hospital "Prim.Dr. Daut Mustafa" Prizren, and pharmaceutical companies have organized a series of International Conferences on Pain Treatment which have been held every year since 2009.</p> <p>These conferences targeted the implementation of pain therapy in Kosovo through encouraging methods and modern scientific research, education and training of people to enhance the quality of pain treatment standards. There are usually also workshops with health professionals demonstrating various procedures for pain management. Each conference is attended by around 400 participants from different fields and places and by well-known international and national experts from the US, Italy, Switzerland, Turkey, Macedonia, Albania, Austria, Germany, Croatia, Kosovo etc. The topics covered at the conferences are: acute postoperative pain, chronic pain, pain treatment of cancer diseases, headaches, pain treatment with ozone, pain management education for health professionals etc.</p>
<b>Disease / Pathology</b>	Pain management
<b>Obstacles</b>	Implementation of the recommendations made at the conferences.
<b>Factors enabling the process</b>	<ul style="list-style-type: none"> <li>• New approach to pain treatment</li> <li>• New approach to pain evaluation</li> </ul>

### EVALUATION

<b>Reproducibility</b>	There is no need to since all those interested who are living in the region can attend.
<b>Innovativeness</b>	Yes, by using pain evaluators, prescribing opioids and innovative techniques in pain management.

### NEXT STEPS

<b>Lessons Learned</b>	Organise more workshops during the conference.
<b>Key Takeaways</b>	<ol style="list-style-type: none"> <li>1. Training of healthcare staff</li> <li>2. Exchange of best practices</li> </ol>
<b>Next Steps</b>	Continuation and widen these activities, making them more attractive and beneficial for both health professionals and patients.

<b>Number</b>	12
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Agron Bytyqi
<b>Organization</b>	Professional Health Association – Pain Section, Kosovo
<b>Country</b>	Kosovo - Prizren
<b>Email</b>	agron_bytyqi@hotmail.com
<b>Short description of the organization/public institution</b>	
<p>The Professional Health Association (PHA) is one of the largest professional and multidisciplinary associations for pain treatment in Kosovo.</p> <p>Operators working at the PHA are health professionals of various specialties actively involved in the diagnosis and treatment of pain and the number of memberships is increasing every year -</p> <p>PHA was registered at the Ministry of Public Service of the Republic of Kosovo January 20, 2009. It is made up of: anaesthesiologists, neurologists, oncologists, physiatrists, family physicians, orthopaedists, surgeons, internal specialists and nurses who deal with the diagnosis and treatment of pain.</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Courses: Cancer and neuropathic pain treatment in Kosovo</i>
<b>Field</b>	Awareness raising
<b>Actors</b>	<p><b>Public Institution(s)</b></p> <ul style="list-style-type: none"> <li>Ministry of Health in Kosovo.</li> </ul> <p><b>Civic Organization(s)</b></p> <ul style="list-style-type: none"> <li>Patients' Rights Association in Kosovo (PRAK), IASP and EFIC.</li> </ul>
<b>Location</b>	Prizren and Prishtina
<b>Term</b>	25 March – 25 October 2013
<b>Objectives</b>	<p>To help people suffering from pain to a better quality of life and to full reintegration into society with the help of trained doctors.</p> <p>Training of primary health care medical staff through courses on Pain. Management (Cancer and neuropathic pain) in the Republic of Kosovo.</p> <p>To offer quality pain treatment both in Primary health care and at home.</p> <p>Help patients suffering from pain (guaranteeing the respect of human rights according to the EFIC Declaration of pain).</p> <p>Help both families and the community as a whole.</p>
<b>Outcomes Impact on participants</b>	<p>Introduction to new achievements related to the diagnosis and treatment of pain (neuropathic and cancer).</p> <p>Exchange of experiences related to pain management.</p> <p>Successful dealing with patients suffering from pain, use of opiates and monitoring of side effects.</p> <p>Professional qualifications - used for licensing and re-licensing of professionals.</p>
<b>Resources</b>	<p>Financial resources: EFIC, IASP and MoH-Prishtina</p> <p>Professional human resources: Professional Health Association,</p>



	Pain Section (PHA) Logistic facilities and organization: PHA and PRAK Information: PHA and PRAK
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ANALYSIS	
<b>Development</b>	<p><i>Description of the courses</i>  Courses for general training were held in English with the support from Grunenthal and presented in multimedia format. Educational concepts were based on theoretical knowledge, practical advice and interactive teaching in multimedia format. Adapted for both medical and law backgrounds and supported by international counselling by pain therapy experts from Switzerland, France, Portugal, Austria, the US, Spain, Italy. Final documentation was checked by national and international associations (EFIC, WIP).</p> <p><i>Courses were based on</i>  A workshop including short lessons, interactive questions and discussions about study cases.  Lecturers.  Courses covered important areas regarding pain management such as:</p> <ul style="list-style-type: none"> <li>• physiological principles</li> <li>• pharmacological principles</li> <li>• intervention procedures</li> <li>• non pharmacological therapy</li> <li>• cancer pain therapy</li> <li>• opioid therapy for non-cancer pain</li> <li>• pain therapy in specific pain syndromes</li> <li>• workshop including short lessons, interactive questions and discussions about study cases</li> <li>• Short lessons based on international pain courses giving theoretical background in physiology, pharmacology and principles of general treatment</li> </ul> <p><i>Questions</i>  Interactive questions were used to involve participants in the topic and using the knowledge acquired during the workshop on pain management in clinical practice.</p>
<b>Disease / Pathology</b>	Pain treatment (cancer and neuropathic pain)
<b>Obstacles</b>	We have encountered no obstacles during the organisation of the course but we are aware that other cities in Kosovo experienced some institutional obstacles.
<b>Factors enabling the process</b>	<ul style="list-style-type: none"> <li>• Strong commitment by family doctors</li> <li>• New approach in pain treatment</li> <li>• New approach in pain evaluation</li> </ul>

EVALUATION	
<b>Reproducibility</b>	Yes, it would be beneficial to implement it in other cities

<b>Innovativeness</b>	Using pain evaluators and prescribing opioids
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<b>NEXT STEPS</b>	
<b>Lessons Learned</b>	<ul style="list-style-type: none"> <li>• Such courses should be held continuously</li> <li>• Include programs for patients with chronic pain</li> </ul>
<b>Key Takeaways</b>	<ol style="list-style-type: none"> <li>1. Training of healthcare staff</li> <li>2. Training of patients (due to lack of financial support we could not organise such courses)</li> </ol>
<b>Next Steps</b>	Continuing and improving these activities

<b>Number</b>	13
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Roberti Anna
<b>Organization</b>	Healthcare District 18 ASL RM E
<b>Country</b>	Italy - Lazio
<b>Email</b>	anna.roberti@asl-rme.it

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Hospital - territory integrated care network in ASL Rome E- for access to palliative care and pain therapy</i>
<b>Actors</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>Healthcare District 18 ASL RM E</li> </ul> <b>Civic Organization(s)</b> <ul style="list-style-type: none"> <li>Cittadinanzattiva</li> <li>AVO – Associazione Volontari Ospedalieri (Association of Hospital Voluntary workers)</li> </ul>
<b>Location</b>	Rome
<b>Term</b>	02 May 2012 - 26 Nov 2013
<b>Objectives</b>	To establish a network of professionals able to communicate among themselves and handle the problem in a shared approach to respond appropriately to the health needs of citizens. Internal and external structures and human resources involved: the structures and resources involved were the district managers and the spokes in the area, i.e. the Presidio S.Spirito under direct management, the Policlinico Gemelli, the S. Filippo Neri, the Cristo Re, IDI-San Carlo di Nancy, the S. Andrea Hospital, and FBF S. Pietro, all pain professional pain therapists, the hub of reference (Policlinico Tor Vergata), the person responsible, the Hospices, Primary healthcare doctors and A.V.O.
<b>Outcomes Impact on participants</b>	Establishment of the network of pain surgeries; training Primary healthcare doctors on the type of pain, on the correct treatment and the correct admission to pain clinics; the creation of a tool (brochure) to inform about the structures in the territory and how to contact them; help citizens to know their rights through the distribution of the brochure at the PUA (Punto Unico di Accesso – Information Points) and at the information office in the Santo Spirito Hospital as well as its publication on the website in the section “citizens area”.

<b>ANALYSIS</b>	
<b>Development</b>	The organizational process can be summarized as: the establishment of the Committee for Hospital-Territory without pain; meetings organized by the person responsible of the project with the actors of the network i.e. Primary healthcare doctors, spokes, hub reference and hospices; establishment of a joint workgroup to debate on the issue of shared tools and research for the setting up of a network; development and implementation of training programmes for Primary healthcare doctors; drawing up a paper-based document to make

	communication effective between Primary healthcare doctors and spokes (attached); meeting open to all actors in the network and associations of voluntary workers to present the results; communication to citizens of the setting up of the network and dissemination of a brochure through the district Information Points for citizens and through the information point at the S. Spirito hospital, as well as the publication on the hospital's website in the section "citizens area". Law Reference: Law 38/10, Decrees of the Commissioner <i>ad acta</i> of the Lazio Region 83/10, 84/10, 115/2010, 117/2011, 15/2013, State-Regions Agreement of 28 October 2010.
<b>Disease /Pathology</b>	Patient suffering from chronic disease

#### NEXT STEPS

<b>Next Steps</b>	Further training for Primary healthcare doctors is currently being organised in order to increase the prescription of opiates, an indirect indicator of the implementation of Law 38/10 (prescription monitoring)
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<b>Number</b>	14
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Dr Francesca Busa
<b>Organization</b>	Healthcare Service ILSS 3 Bassano del Grappa - Centre for Cognitive Decline
<b>Country</b>	Italy - Veneto
<b>Email</b>	neuropsicologia@aslbasano.it

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Dementia: patient-centred treatment</i>
<b>Actors</b>	<p><b>Public Institution(s)</b></p> <ul style="list-style-type: none"> <li>Healthcare Service ILSS 3 Bassano del Grappa - Centre for Cognitive Decline</li> </ul> <p><b>Civic Organization(s)</b></p> <ul style="list-style-type: none"> <li>Cittadinanzattiva</li> <li>Associazione Volontariato Parenti malati di Alzheimer e altre Demenze (AMAd) - Association of Voluntary Relatives of Alzheimer patients and other types of dementia</li> </ul> <p><b>Other Subjects involved</b></p> <ul style="list-style-type: none"> <li>Family, informal and professional caregivers (in-home nurses)</li> </ul>
<b>Location</b>	Italy, Veneto Region
<b>Term</b>	02 Nov 2009 - 31 Dec 2013
<b>Objectives</b>	<p>Delay the development of the disease, alleviate problems related to behavioural disorders, reduce social stigma, postpone institutionalization in nursing homes and encourage living in their own environment, also processing the experiences related to early onset AD (see psychotherapy). In the context of non-pharmacological therapy, such as formal and informal cognitive stimulation, family members improve their relationship skills and deal better with the situation (psycho-educational courses, information sessions), know what the welfare system offers (care allowances, prosthetics, disability benefits), find moments for debate (self help groups) and are able to alleviate any feelings of loneliness and burn out.</p>
<b>Outcomes Impact on participants</b>	<p>The results were: an enlargement of the range of users (which affects all users sent by the Primary healthcare doctors); waiting lists for the first visit within 45 days; about 1,000 patients assisted every year (between the two hospital clinics and territorial activities); quarterly psycho-educational courses; periodic courses for cognitive stimulation and prosthetic assistance; collaboration with the Association of users and relatives AMAd; weekly Mutual Help Group meetings; case conferences (UVMD) with drawing up of customized plans; 150-200 assessments for care allowances; positive monitoring indicators thanks to the questionnaires of perceived quality of the territorial activities (questionnaires collected during the courses and psycho-cognitive stimulation cycles); agreements with a Leisure Centre to set up a MEETING CENTRE where psychosocial activities can be carried out in order to overcome barriers and stigma.</p>

ANALYSIS	
<b>Development</b>	Each person with suspected dementia (about 800 ut./year, of which about 350 new) has guaranteed access to a medical specialist diagnosis (communicated to the Primary Healthcare doctor) within a short time (45 days max.) with the support of a neuropsychological assessment and counselling and with prescription drug therapies indicated by the Guidelines. A subsequent medical examination (geriatric and neuropsychological) is provided depending on the diagnosis, according to indications also from the Primary Healthcare doctor. Doctors therefore try to find a balance, which allows the patient to receive a diagnosis as early as possible without inappropriate diagnostic testing and not justified by a subsequent gain in health. At the same time, activities and opportunities are offered to both the patient and caregiver, free of charge, for the purpose of non-pharmacological treatment and prevention: cycles of cognitive stimulation for people with slight or mild AD; house visits for prosthetic therapy when the environment has to be modified and adapted to the patient with dementia in order to minimize hindrances; cycles of individual and family psychotherapy for people with Early Onset Alzheimer's Disease. Individual therapy is aimed at supporting coping skills and development of residual abilities such as sense of humour; cycles of group therapy for patients with mild cognitive impairment or early onset of initial dementia; psycho-educational classes for relatives, caregivers and in-home nurses; information and training for relatives and professionals (run by AMAd - Association of Alzheimer's Disease and other dementias); Mutual Help Groups (run by AMAd); financial help for family members who support a patient with dementia and behavioural disorders thus delaying institutionalization; personalized assistance plans for special cases through the UVMD (District Multidimensional Assessment Unit); consulting and weekly information on welfare, aids and diagnostic care pathways, as well as actions to promote the rights of the person with Alzheimer against discrimination and healthcare ageism (see September 21 initiatives) in collaboration with AMAd.
<b>Age</b>	Please specify the main age group of the patients involved <ul style="list-style-type: none"> <li>• 70-90</li> </ul>
<b>Disease /Pathology</b>	Chronic diseases (Dementia, Alzheimer's disease or vascular dementia, Lewy bodies etc.,)

EVALUATION	
<b>Reproducibility</b>	Further informal indicators report that the diagnostic approach could be widespread in Italy with a significant number of cases of integration (e.g. in Treviso).

<b>Number</b>	15
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Franca Benini
<b>Organization</b>	PIPER Study Group
<b>Country</b>	Italy
<b>Short description of the organization/public institution</b>	
<p>Members of PIPER (Pain In Pediatric Emergency Room) group: T. Zangardi, F. Benini (Azienda Ospedaliera Universitaria, Padova); A. Nocerino, G. Crichiutti (Azienda Ospedaliera Universitaria, Udine); G. Messi, E. Barbi (Istituto Materno Infantile Burlo Garofolo, Trieste); C. Ghizzi, M. Benedetti (Azienda Ospedaliera Universitaria Integrata, Verona); A. Arrighini (Azienda Ospedaliera Spedali Civili P.O. dei Bambini, Brescia); A.F. Podestà, C. Scalfaro (Azienda Ospedaliera S. Carlo Borromeo, Milano); C. Stringhi, S. Rotta, I.R. Di Salvo (I.C.P. P.O. Buzzi, Milano); E. Fossali (Ospedale Policlinico Cà Granda De Marchi, Milano); A. Urbino, M. Taglietto (Azienda Ospedaliera Infantile Regina Margherita Sant'Anna, Torino); C. Marciano (Azienda Ospedaliera S.S. Antonio e Biagio e C. Arrigo, Alessandria); E. Piccotti, L. Manfredini (Istituto Giannina Gaslini, IRCCS, Genova); F. Mannelli, A. Messeri (Azienda Ospedaliera Universitaria Meyer, Firenze); G. Cardoni, G.M. Piattellini (Azienda Ospedaliera Universitaria Salesi, Ancona); C. Tomasello, N. Pirozzi (Ospedale Pediatrico Bambino Gesù, Roma); F. Midulla (Policlinico Umberto I, Roma); A. Chiaretti (Policlinico Agostino Gemelli, Roma); A. Campa, F. Borrometi (Azienda Ospedaliera Santobono Pausilipon, Napoli); P. Maremonti, Rita Grandolfo (Ospedale Pediatrico Giovanni XXIII, Bari); F. Fucà, R. Parrino (Bari A.R.N.A.S., Palermo).</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>PROGETTO P.I.P.E.R. (Pain In Paediatric Emergency Room)</i>
<b>Actors</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>Supported by the Ministry of Health</li> </ul>
<b>Location</b>	Italy
<b>Term</b>	From 2010 to 2013
<b>Objectives</b>	The Study Group PIPER (Pain in the Paediatric Emergency Room) with the support of the Ministry of Health and the contribution of Angelini produced and distributed to all Italian First Aid departments the video "Pain? No Thanks!" to show doctors, nurses, and especially young patients and their parents, that assessing and treating pain is essential, because not to suffer is a right. The highest goal of the group PIPER is to facilitate the drawing up of recommendations for the management of all types of pain in paediatric emergency departments and to develop a legally valid strategy for the use of drug and non-drug therapies to fight pain.
<b>Outcomes Impact on participants</b>	The expected results are better training and information. The video, "Pain? No Thanks! " embeds the idea shared with the group that training doctors and nurses on the correct application of law 38 is not sufficient since it must convey also to the public the importance of the assessment and treatment of pain so that everybody is aware that pain is not only harmful and useless, but often also avoidable.
<b>Resources</b>	The data from the PIPER group were obtained by collecting the experience of 19 paediatric emergency departments from 2010 to 2013 with the goal of



	<p>improving pain management in emergency. It is important that everyone understands that any level of pain can and must be defeated: doctors, nurses, but also children and their parents should know that suffering should not be endured without seeking relief.</p> <p>This project was supported by an unrestricted grant from Angelini S.p.A. Angelini had no role in the design of the survey, development of the questionnaire, data analysis, preparation of the manuscript, and decisions about submission.</p>
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ANALYSIS	
<b>Development</b>	In order to understand the importance of proper management of pain, after the distribution in 2013 of 10,000 copies of the poster on the treatment of pain, the PIPER group made the video "Pain? No thanks!". It is a short film - starring the actress Paola Minaccioni - delivered to all healthcare facilities and screened in waiting areas, to raise awareness among parents and make them understand that suffering is not an inevitable situation and it is possible to reduce it through its assessment and appropriate action.
<b>Age</b>	Please specify the main age group of the patients involved <ul style="list-style-type: none"> <li>• 0-20</li> </ul>
<b>Disease /Pathology</b>	Pain experienced by children in emergency departments

<b>Number</b>	16
<b>CONTACT DETAILS</b>	
<b>Organization</b>	Ospedale S.Croce e Carle
<b>Country</b>	Italy - Piemonte
<b>Email</b>	urp@ospedale.cuneo.it
<b>Short description of the organization/public institution</b>	
The Hospital (ASO) S. Croce e Carle Cuneo has always been considered one of the institutes of reference of the Local Healthcare Service Cuneo 1 (ASLCN1). It is an institution of national importance and high specialization. The Hospital provides in and out – patient services for diagnosis, treatment and rehabilitation paid by the National Health Service and is also available to private patients.	

<b>DESCRIPTION</b>	
<b>Title</b>	Therapy for patients with fibromyalgia
<b>Actors</b>	<p><b>Public Institution(s)</b></p> <ul style="list-style-type: none"> <li>Azienda Ospedaliera (ASO) S. Croce e Carle Cuneo</li> </ul> <p><b>Civic Organization(s)</b></p> <ul style="list-style-type: none"> <li>Associazione Cuneese malati reumatici (Cuneo Association of Rheumatic Patients)</li> </ul>
<b>Location</b>	Piedmont, Italy
<b>Term</b>	Since March, 7 2014 (ongoing)
<b>Objectives</b>	The project was started by the S. Croce and ACUMAR (Cuneo Association of Rheumatic Patients); its objective is to work with a cognitive-behavioral approach alongside any drug treatment and through physical activity and relaxation techniques to fight fibromyalgia.
<b>Outcomes Impact on participants</b>	This project is a breakthrough since it provides people not only with a pharmacological care pathway but also with a cognitive-behavioral approach.
<b>Resources</b>	A trained Occupational Therapist is of paramount importance to providing information and during training, with the use of relaxation techniques and physical exercise as a therapy to reduce pain, weakness and insomnia.

<b>ANALYSIS</b>	
<b>Development</b>	The project includes weekly group activities supervised by an occupational Therapist expert in rheumatic diseases, and a monthly outing in the area to encourage socialization and physical activity.
<b>Age</b>	<p>Please specify the main age group of the patients involved</p> <ul style="list-style-type: none"> <li>20-50</li> <li>50-70</li> </ul>
<b>Disease / Pathology</b>	Fibromyalgia

<b>Number</b>	17
<b>CONTACT DETAILS</b>	
<b>Organization</b>	FI.DA.PA. (FEDERAZIONE ITALIANA DONNE ARTI PROFESSIONI AFFARI) - ITALIAN FEDERATION OF WOMEN IN ARTS PROFESSIONS BUSINESS
<b>Country</b>	Italy - Piemonte
<b>Email</b>	fidapa@tin.it
<b>Short description of the organization/public institution</b>	
<p>FIDAPA is an association which aims to promote, coordinate and support the efforts of women working in the field of Arts, Professions and Business, independently or with other organizations, associations and other subjects; enhance the skills and preparation of its members, directing them towards social and cultural activities which can promote the improvement of life, including employment; encourage women to an ongoing commitment as well as a conscious participation in social, administrative and political life, endeavouring to remove the still existing obstacles; be the voice of women working in the field of Arts, Professions and Business, organizations and institutions at national, European and international level; work on removing all forms of discrimination against women, both within the family and in the workplace, in full compliance with existing laws relating to equal opportunities; promote friendly relationships, mutual understanding and cooperation among people from all over the world.</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Together to fight pain</i>
<b>Field</b>	Awareness raising
<b>Actors</b>	<p><b>Public Institution(s)</b></p> <ul style="list-style-type: none"> <li>Department of Health Protection and Healthcare of the Piedmont Region, the Faculty of Medicine and Surgery University of Turin, the Order of Medicine Surgeons Province of Turin and with the relevant Commission</li> </ul> <p><b>Other Subjects involved</b></p> <ul style="list-style-type: none"> <li>Regional Unions FIMMG e FIMP</li> </ul>
<b>Location</b>	Piedmont, Italy
<b>Objectives</b>	The project aims to disseminate knowledge and the use of Pain Management and Palliative Care among people and healthcare professionals, making drug prescriptions easier to obtain, setting up regional master courses, introducing a specialization course in the treatment of pain in all universities, turning the project FIDAPA Turin into a national project.
<b>Outcomes Impact on participants</b>	The implementation of this proposal has a positive economic impact since it contributes to reduce the time of hospitalization: an adequate pain therapy accelerates recovery and cuts down follow-up costs when patients are under control after the acute phase of the illness and therefore tend to avoid unnecessary visits since they think they are feeling better.
<b>Resources</b>	According to FI. DA. PA acute, chronic and terminal pain must be fought and cared for both in hospital and in the territory. To achieve this objective, the teaching of pain management must be practiced in

	universities for all healthcare professionals - doctors, psychologists, pharmacists, nurses - and should continue with annual compulsory refresher courses. Everybody can help our project by forwarding their thoughts to our blog. We do not ask for major innovations or financial investments, but simply that the existing network of healthcare organizations (the Region, the University, the Order of Physicians and Pharmacists, the Doctors main Unions) provide better services.
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ANALYSIS	
<b>Development</b>	The project's objective is that Pain Management and Palliative Care become compulsory courses all over the country: for students in the 6th year of Medicine and Surgery studies, specific three-year post-graduate training for general practitioners, the setting up of a Commission for Palliative Care and Pain Management by the Association of Surgeons and the Province of Turin, training courses for family paediatricians and GPs, the adoption of painless childbirth with epidural anesthesia in Italian hospitals, dissemination of the project "Together to fight pain" at national level in FIDAPA, the thesis award on "Chronic pain in Europe." The teaching of pain management must be practiced starting from universities for all healthcare professionals - doctors, psychologists, pharmacists, nurses - and should continue with yearly refresher training courses.
<b>Age</b>	Please specify the main age group of the patients involved <ul style="list-style-type: none"> <li>• 20-50</li> <li>• 50-70</li> </ul>
<b>Disease / Pathology</b>	Chronic pain

<b>Number</b>	18
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Dr. Paolo Notaro
<b>Organization</b>	NO PAIN ONLUS (associazione italiana per la cura della malattia dolore) - Italian Association for the treatment of pain
<b>Country</b>	Italy - Lombardy
<b>Email</b>	info@nopain.it
<b>Short description of the organization/public institution</b>	
NOPAIN is a non-profit organization founded in Milan December 28, 2007 which promotes the treatment of pain in Italy. Its objective is to provide support to patients suffering from chronic pain and their families both in terms of legislation (people's needs) and logistics (where to go for the treatment of pain, care centres), and to disseminate the relevant information (latest press releases on the subject of pain, cultural insights).	

DESCRIPTION	
<b>Title</b>	<i>White Book</i>
<b>Field</b>	Awareness raising
<b>Actors</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>• Lombardy region</li> <li>• Direzione Generale Famiglia e Solidarietà Sociale - Department for Family and Social Solidarity.</li> </ul>
<b>Location</b>	Milan, Lombardy
<b>Term</b>	Since 2009
<b>Objectives</b>	A book outlining the complex situation and problems regarding several diseases and medical conditions which can cause chronic pain syndromes and affect many people. The goal is to show that there are few dedicated resources, uneven organizational models, cultural confusion about end of life palliative treatments and disorientation among patients. The aim of the survey is to inform public opinion about these issues, to raise awareness among professionals and institutions for an analysis of the problem and of the economic and social benefits which could result from a coordinated treatment of chronic pain.
<b>Outcomes Impact on participants</b>	The results contained in the White Book were achieved through data collection certified by SPC Srl in Milan and showed a markedly uneven number of services offered to patients, both in terms of organizational characteristics, services and resources available, and for the names adopted by these structures. Pain therapy is applied to 43 structures, pain relief to 29 structures, palliative care to 19 structures, pain medicine to 8 structures, algology to 3 structures and wellness medicine to 2 structures.
<b>Resources</b>	The operators involved contacted, as ordinary citizens seeking information and clarification, all public and private hospital structures part of the National Health Service which have a department for pain therapy.

ANALYSIS	
<b>Development</b>	This was the first study carried out in our country on Pain Therapy structures for non-neoplastic chronic pain. A descriptive survey

	carried out in accordance with international quality standards and legislation for the classification according to the level of care in Italian structures called Pain Therapy and/or similar, which involved 158 public and private structures (the latter supplying public healthcare services the cost of which is covered by the regions) operating in Italy, of which 133 were able to treat all pain syndromes and 25 only one or more benign pain syndromes. 26 facilities which treat cancer pain have not been considered.
<b>Disease / Pathology</b>	Chronic pain

<b>Number</b>	19
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Alfonso Papa
<b>Organization</b>	A.O.R.N. Azienda Ospedaliera V. Monaldi (Department of Pain Therapy)
<b>Country</b>	Italy - Campania
<b>Short description of the organization/public institution</b>	
The Department of pain therapy at the Monaldi Hospital in Naples is managed by Dr. Alfonso Papa. The UOSD is a branch of the Hospital Critical Area Department which carries out Pain Therapy through drug treatment, analgesia and local anaesthesia, surgery, physical therapy, electrical stimulation, medullary neuromodulation and ozone therapy.	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Pain therapy: spinal cord stimulation</i>
<b>Location</b>	Naples, Campania
<b>Term</b>	2014 ongoing
<b>Objectives</b>	Implant of a new cutting-edge system for the treatment of chronic neuropathic pain i.e. a spinal cord stimulator.
<b>Outcomes Impact on participants</b>	This treatment offers several benefits: it decreases side effects and complications, and consequently the need for additional surgery; power consumption is very low and patients do not have to constantly adjust their equipment. 14 implants have already been carried out by Dr. Papa where each patient had a little stimulator implanted which sends electrical impulses to an anatomical structure within the spinal cord called the dorsal root ganglion.
<b>Resources</b>	Funding came from the Department of pain therapy at the Monaldi Hospital in Naples.

<b>ANALYSIS</b>	
<b>Development</b>	The neurostimulator is the only system in the world approved for stimulation of the ganglion called Axium SCS (Spinal Cord Stimulation). The electrical impulses interfere with the ganglion which is basically a 'centre' that processes the nerve signals to the brain and, thanks to this innovative electrical stimulation, pain is re-modulated and effectively blocked.
<b>Age</b>	Please specify the main age group of the patients involved <ul style="list-style-type: none"> <li>• 20-50</li> <li>• 50-70</li> <li>• 70-90</li> </ul>
<b>Disease / Pathology</b>	Chronic neuropathic pain



<b>Number</b>	20
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Dr Claudio Reverberi, Giovanni Frigerio and Rodolfo Bucci
<b>Organization</b>	Barolat – Neuromodulation Institute
<b>Country</b>	Italy - Lombardy
<b>Short description of the organization/public institution</b>	
The Barolat Neuromodulation Institute is based at the Nursing Home "Le Betulle" in Appiano Gentile where professionals are able to deal with several health problems, both in day hospital and in surgery, with or without hospitalization, and has the most modern and advanced diagnostic technologies and surgical support.	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Wireless neurostimulator</i>
<b>Location</b>	Como, Lombardy
<b>Term</b>	Since 2014 ongoing
<b>Objectives</b>	The wireless neurostimulator is the first medullary wireless neurostimulator for treating chronic pain.
<b>Outcomes Impact on participants</b>	Its innovation consists in switching to a wireless system to power the stimulator, with considerable benefits for the patient: the new device is implanted in the spinal cord into the epidural area. One of its advantages is that it can be used in MRI exams, which were not previously allowed. It connects via radio frequency through electrodes. The procedure takes only half an hour and is painless for the patient.
<b>Resources</b>	The implant was built by the team composed of doctors Claudio Reverberi, Giovanni Frigerio and Rodolfo Bucci and carried out on three patients, a 60 year old man and two women of 71 and 72 years of age respectively.

<b>ANALYSIS</b>	
<b>Development</b>	It is a technique with no side effects: there are no age restrictions or contraindications. It consists in implanting an electrode in the area where the pain originates which transmits electrical impulses blocking pain. The pulse generator, equipped with a very small battery, is no longer placed under the skin but in a comfortable and easy to wear belt. The procedure is carried out under sedation in day hospital, followed by periodic checks once or twice a year. It is important that neurostimulation is carried out by experts, otherwise it may not give the desired results.
<b>Age</b>	All ages
<b>Disease / Pathology</b>	Chronic disease, back pain

<b>Number</b>	21
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Marta Gentili
<b>Organization</b>	Living without pain Onlus
<b>Country</b>	Italy - Lombardy
<b>Email</b>	info@viveresenzadolore.it
<b>Short description of the organization/public institution</b>	
<p>Living without pain is non-profit organization dedicated to the dissemination of knowledge on the subject of unnecessary pain. Our goal is to stimulate a serious and constructive reflection on the possibilities of improving pain management: a useless torture which demeans the dignity of a person. Humanity means ending unnecessary pain. Taking care of a person is learning to control the illness which disrupts a personality and interferes with the will to live and to endure certain therapies. Increasing the level of awareness on this issue is the first step towards obtaining a better quality of life.</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>"Link Up"</i>
<b>Field</b>	Civic participation
	Awareness raising
<b>Actors</b>	<p><b>Public Institution(s)</b></p> <ul style="list-style-type: none"> <li>Supported by the Ministry of Health</li> </ul> <p><b>Civic Organization(s)</b></p> <ul style="list-style-type: none"> <li>Patients' associations: Living without pain, Società Italiana di Medicina Generale (SIMG) - Italian Society of General Medicine</li> </ul>
<b>Location</b>	Italy
<b>Term</b>	From March 2013 to May 2013
<b>Objectives</b>	The objective of the project is to understand what care pathways patients suffering from pain can access at Primary healthcare centres and other centres specialized in analgesic therapy, but also to outline the training needs of GPs, identifying potential areas of intervention for a real continuity of care within the local healthcare network.
<b>Outcomes Impact on participants</b>	<p>The results of the project show that 46% of patients independently call on centres for pain therapy without prior screening by a family doctor, and in 23% of cases without even having an ongoing therapy. NSAIDs are still the drugs most used by the general practitioner and the specialised clinicians and are also used for prolonged treatments of more than 4 months.</p> <p>Communication between the community and hospitals to ensure continuity of care advocated by Law 38 is still poor, therefore a real support network should be created as soon as possible.</p> <p>Almost 1 out of 2 patients refer directly to specialist pain therapy centres. They suffer on average from severe pain associated with low back pain or sciatica, but they are treated with a therapy - prescribed by a general practitioner (83%) - based on NSAIDs (in 35.2% of cases) for a period of approx. 3 months.</p>
<b>Resources</b>	Clinicians and patients have met through the 'Link up' initiative, both in

	the surgeries of family doctors and in specialist centres for pain therapy, to better understand what is the procedure followed by citizens, where they go for a first visit and why.
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ANALYSIS	
<b>Development</b>	The LINK UP project involved 15 hospitals' pain therapy centres and 60 SIMG (Italian Society of General Medicine) family physicians. The initiative involved the compilation by both hospital clinicians and GPs of a series of questionnaires in order to figure out how patients with chronic pain looked for the right treatment for their illness. The survey aimed to verify how and by whom patients were treated for pain therapy and what relationship existed between GPs and hospital specialists in the framework of hospital care on the territory. A total of 1,379 questionnaires were collected, 855 from specialist centres and 524 from SIMG physicians.
<b>Age</b>	Please specify the main age group of the patients involved <ul style="list-style-type: none"> <li>• 20-50</li> <li>• 50-70</li> <li>• 70-90</li> </ul>
<b>Disease / Pathology</b>	Chronic pain

<b>Number</b>	22
<b>CONTACT DETAILS</b>	
<b>Organization</b>	Univeristy of Turin
<b>Country</b>	Italy - Piedmont
<b>Email</b>	borse.studenti@unito.it
<b>Short description of the organization/public institution</b>	
The University of Turin is one of the oldest Italian universities. It offers a wide range of first-level and specialist graduate programs (over 190), first and second level master courses, and several other educational and training activities.	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Award for the promotion and dissemination of a culture on healthcare assistance/complementary care and the fight against pain</i>
<b>Actors</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>University of Turin</li> </ul> <b>Civic Organization(s)</b> <ul style="list-style-type: none"> <li>Associazione FI.DA.PA. – Studio Gilardi</li> </ul>
<b>Location</b>	Turin, Italy
<b>Term</b>	From 2009 to 2010
<b>Objectives</b>	The competition aimed to reward the Graduates from the Faculty of Medicine and Surgery of the University of Turin who had written a thesis on the following topic: "The fight against chronic pain in Europe".
<b>Resources</b>	The prize of the award was € 2.000

<b>ANALYSIS</b>	
<b>Development</b>	Candidates submitted their applications to the Dean of the University of Turin.
<b>Age</b>	Please specify the main age group of the patients involved University students
<b>Disease / Pathology</b>	Chronic pain

<b>Number</b>	23
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Stefano Negrini
<b>Organization</b>	ISICO (Istituto Scientifico Italiano Colonna Vertebrale) – Italian Scientific Institute for the study of the Spinal Column)
<b>Country</b>	Italy
<b>Email</b>	isico@isico.it
<b>Short description of the organization/public institution</b>	
The Italian Scientific Institute for the study of the Spinal Column (ISICO) promotes and develops an innovative approach in non-surgical rehabilitation treatments of diseases affecting the back, both for children and elderly patients.	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Research Award: "A physical and educational program to reduce cephalgia and pain in the neck and shoulders in the workplace: a randomized clinical trial "</i>
<b>Actors</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>• University</li> </ul>
<b>Location</b>	Italy
<b>Term</b>	2014
<b>Objectives</b>	ISICO grants a scholarship to the best research work in the field of rehabilitation treatment of diseases of the spinal column, published by Italian authors in indexed journals. The ISICO Award reflects the importance the Institute gives to research considering it a fundamental tool for the development of therapies based on scientific evidence.

<b>ANALYSIS</b>	
<b>Development</b>	The research conducted by the group (University of Turin, Città della Salute e della Scienza di Torino) took into consideration the neuromuscular factor in triggering or increasing headaches, cervical and shoulder pain. The researchers then developed a cognitive behavioural program which helps patients to understand when their muscles are too tight and teaching them simple exercises to relax them.
<b>Age</b>	Please specify the main age group of the patients involved <ul style="list-style-type: none"> <li>• 70-90</li> </ul>
<b>Disease / Pathology</b>	Cephalgia and pain to the neck and shoulders

<b>Number</b>	24
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Dr. Rym Bednarova, Dr. Luca Miceli
<b>Organization</b>	Asl Palmanova (Udine)
<b>Country</b>	Italy – Friuli Venezia Giulia
<b>Email</b>	Fabulle69@libero.it
<b>Short description of the organization/public institution</b>	
<p>The Local Health Service (ASL) of Palmanova is a local government service of the Friuli-Venezia Giulia Region. Its objectives are: health, performance and structures provided by the national and regional planning and in particular by regional health plans, ensuring the level of service and interventions on prevention, diagnosis, therapies, rehabilitation and other educational initiatives, carrying minimum risks to patients and supplying satisfactory services for users in terms of assistance, relations with healthcare operators and outcomes. These services and benefits may be supplied directly by the Local Health Service through its facilities (health districts, departments, authorities, hospitals) or provided by other accredited private structures through specific agreements.</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Priority criteria for low back pain</i>
<b>Field</b>	Empowerment
	Civic participation
	Awareness raising
<b>Actors</b>	<p><b>Public Institution(s)</b></p> <ul style="list-style-type: none"> <li>ASL Palmanova</li> </ul> <p><b>Civic Organization(s)</b></p> <ul style="list-style-type: none"> <li>Cittadinanzattiva Onlus and Associazione Italiana Studio del Dolore (AISD)</li> </ul>
<b>Location</b>	Palmanova ( Udine) - Novara, Friuli-Venezia Giulia –Piemonte
<b>Term</b>	From June 02, 2014 to June 02, 2015
<b>Objectives</b>	<p>The project has defined both a specific approach that links the general practitioner to the specialist in the field of low back pain (LBP) in order to guarantee that the latter has a clear vision of the patient's problem and continuity of care among professionals, providing the person firstly the correct medication, and then, if necessary, access to professionals within a reasonable time (priority). The innovative part of this project was to find a decisional algorithm, carried out on the patient by the Primary healthcare doctor, able to give a numerically measurable, transparent, comparable and repeatable score, on which were drawn up a series of priority criteria to send the patient with LBP to a specialist. Specifically, an indication for the Primary Healthcare doctor to route the patient suffering from LBP to the specific specialist is the need to use opioids for more than two weeks (after a trial of 2-3 weeks with NSAID) if suffering from moderate-to-severe pain (assessed through the NRS numeric scales rate), with a preference for the neurologist or pain therapist in the presence of neuropathic symptoms (assessed by the scale douleur neuropathique 4), for the physiatrist in case of serious disability (assessed by the ADL activity daily life scale) to the</p>

	Emergency Room doctor in case of suspicion of red flag situations (e.g., fractures, cauda equina syndrome). All these parameters were related to the Priority Criteria (CdP), U (urgent), B (short), D (deferrable), P (programmed), which already exist in Friuli Venezia Giulia for other kinds of diseases, in a fair and transparent approach, and calculated automatically by reading the document produced by the group of experts mentioned above. we decided to include our shared considerations in a software, available for free on our website and on an APP for mobile devices (tablets and smartphones). This project is open and available on the web at <a href="http://www.minosse.biz">www.minosse.biz</a> , on Apple store (APP Minos) and Google store (APP Minos).
<b>Outcomes Impact on participants</b>	Through the project "Minosse" we expect an increase of appropriateness both in prescription of pain medication (favouring opioids) and in the governance of patients with LBP, with a decline of specialist visits inappropriate for both professionals and waiting lists, with a consequent reduction in private (ticket) and public spending by the Regional Health Services (SSR). The primary interest remains, however, the patient, who, in a perspective of empowerment which in 2014 cannot be ignored, is entitled to a clear, shared, fair and transparent path (PDTA), and, through our information technology products be actor and controller of the decision-making process concerning him/her. A second objective is to involve institutional stakeholders in m-health (mobile health) as an innovative, replicable, measurable, sustainable and possible added value for the Italian Health system.
<b>Resources</b>	The project was the subject of a thesis presented at the School of Business Administration at the Bocconi and also a thesis in Medicine at the University of Udine, accepted for publication by the journal Pain Practice ("Development of an APP helpful to manage patients with low back pain, in press), with an Impact Factor of 2.605. Thanks to the dedication of professionals and a liberal donation for the development of the software, we should point out that this is a self-financing project.

ANALYSIS	
<b>Development</b>	The project was carried out by teamwork made up of the ASS 5 Bassa Friulana dr. Rym Bednárová, dr. Ugo Colonna, dr. Khalid Kussini, dr. Paduano Romano, dr. Marsilio Saccavini, dr. Franco Cominotto, dr. Otello Regeni, the University Hospital of Udine (dr. Luca Miceli), the Friuli Venezia Giulia Central Directorate for Health (dr. Marco Scarbolo), the Italian Association for the Study of Pain (AISD) and the Bocconi in Milan who have created a task force of professionals involved in the delicate theme of LBP (pain specialist, physician experienced in priority criteria and PDTA, orthopaedist, physiatrist, Primary healthcare doctors, First Aid doctor);
<b>Age</b>	All ages
<b>Disease / Pathology</b>	Patient with chronic disease: in particular low back pain



<b>Number</b>	25
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Dr. Roberto Casale
<b>Organization</b>	Montescano Pain School
<b>Country</b>	Italy
<b>Short description of the organization/public institution</b>	
<p>The Montescano school, for Clinical and Instrumental Diagnostic Processes in Pain Medicine, was founded in 2009 through the joint initiative of the then President of EFIC, Professor Giustino Varrassi, and the Italian Councillor of EFIC, Dr. Roberto Casale. During the EFIC Councillors' meetings and the many friendly discussions among the Councillors, some hot points always remained on the table as unsolved basic issues that in some way preceded the pivotal and final goal of pain medicine i.e. how to treat patients with chronic pains.</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Pain Simulator</i>
<b>Field</b>	Empowerment: Supplying the tools to allow patients to manage their pain. Providing information, support and capacity building of individual patients with chronic diseases and chronic pain.
	Civic participation: Through the questionnaire, people can actively participate in their treatment by identifying the characteristics of their pain and committing to managing it.
	Awareness raising: The questionnaire arises the awareness of patients concerning the causes of their pain. In so doing it also contributes to make them react and increase self-confidence. The box allows doctors and other people to understand patients' pain, therefore contributing to arise the public awareness on the issue of chronic pain.
<b>Actors</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>Montescano Pain School</li> </ul> <b>Civic Organization(s)</b> <ul style="list-style-type: none"> <li>Pain Alliance Europe</li> </ul> <b>Other Subjects involved</b> <ul style="list-style-type: none"> <li>Grunenthal</li> </ul>
<b>Location</b>	Widespread campaign
<b>Term</b>	2013
<b>Objectives</b>	The estimated healthcare costs and loss in productivity associated with chronic pain equal 3-10% of European economic growth. Low awareness of chronic pain as a healthcare problem and the consequences for sufferers and society at large undermine efforts to find solutions. The campaign aims to raise awareness about the burden felt by patients suffering from localized neuropathic pain, to support patients in their need for information about their unbearable pain, to improve communication between patients and physicians and to avoid misdiagnosis and improve the trial and error treatment approach.
<b>Outcomes Impact on</b>	This practice helps to raise general awareness, through empathy with patients suffering from this disease and from their difficulty to express

<b>participants</b>	what they feel. The presentation of the box during an event in Brussels allowed to raise awareness among European Parliamentarians, a multi-stakeholder platform of patient organizations, academia and industry.
<b>Resources</b>	Financial resources (Grunenthal), logistic facilities, information, experiences.

<b>ANALYSIS</b>	
<b>Development</b>	<p>The good practice consists of two parts: a box reproducing the effects of pain and a questionnaire.</p> <p>The box was developed to demonstrate how localized neuropathic pain feels like and discuss the burden felt by patients suffering from this disease and their difficulty to express what they feel. The “My pain feels like...” box can reproduce the same sensations experienced by patients, through electrodes placed on the nerve tracts and mimic the neuropathic pain stimulus.</p> <p>On the campaign website you will find a questionnaire entitled “My pain questionnaire” which encourages patients to use their own words to describe their pain. This will increase healthcare professionals’ understanding of the words related to localized neuropathic pain. It also inquires about how pain affects the life of the patient and invites to point out the areas of the body where pain is mostly felt.</p>
<b>Disease / Pathology</b>	Chronic pain
<b>Factors enabling the process</b>	Visibility of the box and translation of the on-line questionnaire in different languages.

<b>EVALUATION</b>	
<b>Reproducibility</b>	Yes
<b>Innovativeness</b>	Yes, the research project concerning the “My pain feels like...” box represents a real innovation in this field.
<b>Added value</b>	It allows the raising of public empathy with people suffering from chronic pain.
<b>Appropriateness</b>	Stresses the need to raise awareness and attention on this social problem.

<b>Number</b>	26
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Anna Roberti
<b>Organization</b>	Asl Roma
<b>Country</b>	Italy - Lazio
<b>Email</b>	anna.roberti@asl-rme.it
<b>Short description of the organization/public institution</b>	
The Local Health Service (ASL) Roma is a local government service of the Lazio Region, its mission being to supply citizens local healthcare services regarding: prevention, basic medicine, hospital support, residential care to people who are not self-sufficient and long-term care information, protection and participation.	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>The integrated care network Hospital in ASL Rome-E for access to palliative care and pain therapy</i>
<b>Actors</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>Asl Roma</li> </ul> <b>Civic Organization(s)</b> <ul style="list-style-type: none"> <li>Cittadinanzattiva onlus, AVO (Hospital Volunteer Association).</li> </ul>
<b>Location</b>	Rome, Lazio
<b>Term</b>	From May 02, 2012 to November 26, 2013
<b>Objectives</b>	To build up an integrated healthcare network for pain management and provide general practitioners with adequate tools to respond to citizens' needs and route them, when necessary, to the most appropriate care centre depending on the complexity of their disease.
<b>Outcomes Impact on participants</b>	Guarantee citizens the right not to suffer through: knowledge of their rights; informing the Primary healthcare doctors about healthcare facilities available in the territory, hospices and pain clinics, and the way to access them; uploading on the web the list of all pain surgeries in the area; training courses for Primary healthcare doctors for the appropriate treatment of pain; appropriate routing of patients by Primary healthcare doctors to pain surgeries, according to the type of pain to be treated.
<b>Resources</b>	Internal and external structures and human resources involved: district managers and the spokes in the area, i.e. the Presidio S.Spirito under direct management, the Policlinico Gemelli, the S. Filippo Neri, the Cristo Re, IDI-San Carlo di Nancy, the S. Andrea Hospital, and FBF S. Pietro, all professional pain therapists, the hub of reference (Policlinico Tor Vergata), the person responsible, the Hospices, Primary healthcare doctors and A.V.O.

<b>ANALYSIS</b>	
<b>Development</b>	The organizational process can be summarized as: the establishment of the Committee for Hospital-Territory without pain; meetings organized by the person responsible of the project with the actors of the network i.e. Primary healthcare doctors, spokes, hub reference and hospices; establishment of a joint workgroup to debate on the

	<p>issue of shared tools and research for the setting up of a network; development and implementation of training programmes for Primary healthcare doctors; drawing up a paper-based document to make communication effective between Primary healthcare doctors and spokes (attached); meeting open to all actors in the network and associations of voluntary workers to present the results; communication to citizens of the setting up of the network and dissemination of a brochure through the district Information Points for citizens and through the information point at the S. Spirito hospital, as well as the publication on the hospital's website in the section "citizens area".</p>
<b>Age</b>	<p>Please specify the main age group of the patients involved</p> <ul style="list-style-type: none"> <li>• 20-50</li> <li>• 50-70</li> <li>• 70-90</li> </ul>
<b>Disease /Pathology</b>	Chronic pain

<b>Number</b>	27
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Dr. Mario Marin
<b>Organization</b>	A.S.L. Bassano del Grappa (Vicenza)
<b>Country</b>	Italy - Veneto
<b>Email</b>	mario.marin@aslbassano.it
<b>Short description of the organization/public institution</b>	
<p>The local Health Service (ASL) Bassano del Grappa is a local government service of the Veneto Region, its mission is to ensure citizens the provision of basic levels and uniform assistance set up by the National Health Plan and fulfil, in its own territory, the objectives of the Regional Health Service through an efficient, effective and economical use of the resources allocated to healthcare assistance. The values inspiring the service are the promotion and protection of health as a common good and an individual and fair access to health and social services for citizens. The objective is also to create a widespread system focused on continuous improvement of quality of care, to meet the increasingly complex needs of citizens, make use of innovations in technology and competences.</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Management of chronic pain in elderly people carried out in Healthcare centres</i>
<b>Field</b>	Empowerment
<b>Actors</b>	<b>Civic Organization(s)</b> <ul style="list-style-type: none"> <li>• Associazione Amad and Cittadinanzattiva Onlus</li> </ul>
<b>Location</b>	Bassano del Grappa (Vicenza), Veneto
<b>Term</b>	from July 1, 2014 to December 31, 2014
<b>Objectives</b>	<p>Objective: managing pain in elderly patients in local nursing homes through a correct detection with the use of the above mentioned scale and treatment following the SIAARTI Guidelines on cancer chronic pain. In order to ensure a constant detection of pain it was necessary to define precisely the organization of the treatment of elderly patients in the centres assigning to each professional involved a certain number and type of patients to be monitored. Social and Health Operators constantly giving basic assistance to elderly patients had to take care of specific non communicative patients and detect the presence or absence of pain with the NOPPAIN scale. Nurses instead had to detect pain in communicative patients through the NRS scale and checking out the number and pain level of non-communicative patients referred by the OSS. Primary healthcare doctors then considered the nurses' reports and measurement of pain and evaluated the possible pain treatment to prescribe. Out of 17 service centres part of the ULSS 3, 15 took part in the project. The innovation was to constantly measure pain in all elderly patients at least once a week and include a tool for the detection of pain also in elderly patients suffering from dementia which in these cases is difficult to assess (dementia cases are 53% of the total).</p>
<b>Outcomes Impact on</b>	The expected results were: - to promote in operators of the Service Centres an approach to the reduction of unnecessary pain, especially

<b>participants</b>	when elderly patients suffering from dementia are involved and pain is therefore considered a natural occurrence; training all 'pain' operators and develop scientific tools for its detection having in mind that pain is a symptom and not a signal; carry out a survey on the level of pain in all the structures; divide into two separate lists non communicative patients from communicative ones through the MMSE test; define among professionals communication tools regarding pain; define uniform recommendations for the detection and treatment of pain; check that pain detection is guaranteed in every structure; monitor performance of the main categories of drugs.
<b>Resources</b>	Identify indispensable resources to carry out the initiative (human and financial resources, logistics, information, experiences etc.) The trained staff was composed of: 20 coordinators, 122 nurses and 488 OSS, 20 Primary Healthcare doctors, 15 Psychologists + 5 physiotherapists + 1 social worker. In 15 structures involved, pain detection in communicative and not communicative elderly patients was carried out according to the criteria and tools defined by the project. There is an increase in the use of pain-relieving drugs and a decrease in that of anti-inflammatory drugs; the most widely used drug is Paracetamol. Regular pain detection on 585 communicative patients through the NRS scale. Regular pain detection on 678 non communicative patients through the NOPPAIN scale. Regular detection of pain levels before the beginning of the project (January 2013) and after (May 2013). Implementation of guidelines for the management of pain by Primary healthcare doctors working in the Service Centres.

<b>ANALYSIS</b>	
<b>Development</b>	The following steps have been defined to implement the measurement of pain: list of patients with no diagnosis of dementia on the basis of the MMSE test, drawn up by the psychologist in order to separate non communicative patients from communicative ones; separate lists of non communicative and communicative patients; scheme for assigning patients to specific individual operators (non communicative patients to the OSS, communicative patients to nurses); table listing both OSS and nurses who are treating communicative and non communicative patients; monthly pain chart on which measurements should be entered 10 times per patient per operator; checking the correct use of the Noppain charts filled in by the OSS and by the nurses; checking that the pain level is notified to the nurses and Primary healthcare doctors responsible, through a chart on which the pain level is indicated to the medical staff by the coordinator.
<b>Age</b>	Please specify the main age group of the patients involved <ul style="list-style-type: none"> <li>• 70-90</li> </ul>
<b>Disease /Pathology</b>	Dementia patients

<b>Number</b>	28
<b>CONTACT DETAILS</b>	
<b>Organization</b>	Mater Dei Hospital
<b>Country</b>	Malta – La Valletta
<b>Email</b>	health.pro@gov.mt
<b>Short description of the organization/public institution</b>	
<p>Mater Dei Hospital is a teaching hospital. The Pain Clinic, part of the hospital, is a specialized clinic run by two trained specialists with the help of a multidisciplinary team. This clinic offers pain management for a variety of acute and chronic painful conditions including: Chronic Low Back Pain, Shoulder and Neck Pain, Hip and Knee pain, Post-amputation pain, Post herpetic neuralgia, Diabetic neuropathies, Trigeminal Neuralgia, Complex Regional Pain Syndromes and Cancer Pain</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>The Pain Management Service Mater Dei Hospital</i>
<b>Field</b>	Empowerment: Providing information, support and capacity building of individual patients with chronic diseases and chronic pain, as well as their carers who usually play an essential role in helping them to deal with their condition.
	Civic participation: Support Group. M.D.H. has a support group for patients with chronic pain. The main objectives are to bring together people who are suffering from this debilitating condition within a ‘safe’ environment to be able to share concerns and ideas, build friendships and obtain up-to-date information about handling their pain e.g. relaxation techniques, guided imagery etc.
<b>Actors</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>• The Government of Malta</li> </ul>
<b>Location</b>	La Valletta, Malta
<b>Objectives</b>	The Pain Clinic aims to provide people with the opportunity to go back to work after absence due to intolerable pain and suffering. Some 80% of cases are not related to terminal illnesses while 80% of them are related to back pain. Through the work of the clinic's specialists, these patients could have a second chance to live and work without having to rely on heavy medication to alleviate pain.
<b>Impact on participants</b>	<p>Chronic pain is often accompanied by anxiety; this means people would be out of work or have great social difficulties owing to possible changes in their personalities. These patients will have seen doctors countless times and undergone many forms of treatment (pills or other types of medication). This practice concerns mainly the empowerment of patients. It helps them to decrease pain and reduce the excessive use of painkillers. By so doing, the work of this multidisciplinary team accompanies patients to their reintegration into society.</p> <p>Some 1,200 pain-relieving procedures were carried out at the Mater Dei hospital last year.</p>
<b>Resources</b>	Both competences and the good integration of the multidisciplinary team are of paramount importance. The team is composed of consultants in pain



	management, specialist nurses, physiotherapists, psychotherapists, as well as a radiographer and operating theatre and day-care nurses. Doctors also share their expertise with the staff and in spring will participate in a conference organised with the University of Malta to transfer techniques used in pain management to other doctors working in different fields.
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ANALYSIS	
<b>Development</b>	<p>Brief description of the main activities (Who, How, Main steps)</p> <p>The patient, the pain clinic doctor and the other health professionals, together with the G.P. and the family will work to enable the patient to manage his/her pain and symptoms more effectively and so reduce the impact that pain has on his/her life.</p> <p>Pain could be treated by invasive techniques on patients with spinal and nerve problems or by other therapies such as somatic (holistically orientated) therapies to treat muscle or nerve pain.</p> <p>The therapy is complemented by pain management education, alternative medication to painkillers, transcutaneous electrical nerve stimulations, physiotherapy, psychotherapy, support group to share concerns and ideas, build friendships and obtain up-to-date information about handling pain e.g. relaxation techniques, guided imagery etc.</p> <p>Conferences are organized with the University of Malta to transfer techniques used in pain management to other doctors working in different fields.</p>
<b>Disease /Pathology</b>	Chronic Low Back Pain, Shoulder and Neck Pain, Hip and Knee pain, Post-amputation pain, Post herpetic neuralgia, Diabetic neuropathies, Trigeminal Neuralgia, Complex Regional Pain Syndromes and Cancer Pain

EVALUATION	
<b>Added value</b>	<p>Multidisciplinary team and treatments: Pain Management Education Medication Transcutaneous electrical nerve stimulation (T.E.N.S.) Physiotherapy Psychotherapy Support Group Cancer Pain Visiting Consultant</p>

<b>Number</b>	29
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Mary Vella
<b>Organization</b>	Arthritis and Rheumatism Association (ARAM)
<b>Country</b>	Malta – Mgarr Malta
<b>Email</b>	mary_vella@hotmail.com
<b>Short description of the organization/public institution</b>	
<p>The Arthritis and Rheumatism Association (ARAM) is made up of 300 members and 7 committee members. The committee is made up of people suffering from chronic conditions and run on a voluntary basis. On national level it is officially registered by Malta Council of Voluntary Office Registration No:VO/0425. It is a member of MEUSAC and Malta Health Network. On international level it is a member of the European League of people with Arthritis and Rheumatism in Europe- EULAR, and also member of Agora an organisation which is a platform for the Southern European countries.</p> <ul style="list-style-type: none"> <li>• The main objective is to educate, support and raise awareness about arthritis and rheumatism and any other musculoskeletal diseases.</li> <li>• Improve the quality of life for people suffering from RMDs by organising seminars held by Professionals in the field on various related topics.</li> <li>• Organise Physical activities for the improvement of health, both land-based and pool therapy exercises.</li> <li>• Organize road shows to educate and raise awareness throughout the country.</li> <li>• Work in collaboration with the Health Promotion and Disease Prevention Directorate of the Ministry for Health to establish Self-Management courses run both by patients and Professionals.</li> <li>• Establish an active group for young people suffering from chronic condition.</li> </ul>	

<b>DESCRIPTION</b>	
<b>Title</b>	<b>For a Better life – How to deal with my Condition</b>
<b>Field</b>	<p>Empowerment: Providing information, support and capacity building of individual patients with chronic diseases and chronic pain, as well as to their carers who usually play an essential role in helping them to deal with their condition; including social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry etc.</p> <p>An example of this is the education of patients on the advanced pain management techniques available. Emphasis is made on the safety of these procedures, which in the past was very often one of the reasons why patients did not seek help. Referral pathways are also described.</p> <p>Liaison between pain management specialists and other professionals in order to widen the knowledge of availability of pain management techniques.</p>
	<p>Civic participation</p> <ul style="list-style-type: none"> <li>• People with chronic diseases, carers and family members.</li> <li>• Groups of twelve patients in each course.</li> </ul>
	Awareness raising: during World Arthritis Day Conference, newsletter,

	during seminars and roadshows, website and media.
<b>Actors</b>	<p><b>Public Institution(s)</b></p> <ul style="list-style-type: none"> <li>• Agora, an umbrella organisation for southern European countries.</li> <li>• Health Promotion and Disease Prevention Directorate of the Ministry for Health</li> </ul> <p><b>Civic Organization(s)</b></p> <ul style="list-style-type: none"> <li>• Arthritis and Rheumatism Association Malta</li> </ul> <p><b>Other Subjects involved</b></p> <ul style="list-style-type: none"> <li>• Principles on how to care for oneself, Healthy Diet, physical activity, Circle of influences that affects us, Effective Communication, Doctor and Patient relationship, medicines, solving problems, how to deal with loss.</li> </ul>
<b>Location</b>	Pieta, Malta.
<b>Term</b>	29 April-3 June 2014.
<b>Objectives</b>	Patients were given as much information as possible about topics concerning their disease and chronic condition in order to learn to understand it and learn how to manage it and therefore live an independent healthy life as much as possible.
<b>Outcomes</b>	<p>This practice has empowered the patients to set daily small goals to make progress and achieve better health.</p> <p>As an organisation we established that this course is a must for patients suffering from chronic conditions in order to improve their health. Being in a small group also helped the patients to have their problems addressed individually.</p>
<b>Resources</b>	<p>Registrations of 12 participants.</p> <p>Participation fee of 10 euros each person</p> <p>Medical professional help.</p> <p>Two trained trainers, 2 teacher handbooks.</p> <p>Planning and preparation of 12 lectures, duration two and half hours.</p> <p>Premises for lectures furnished with flipchart and power point.</p> <p>Laptop.</p> <p>Coffee and tea breaks.</p> <p>Printing of hand-outs</p> <p>12 folders for the participants containing a note book, biro, course timetable</p> <p>12 name tags.</p> <p>Other items for brainstorming sessions.</p>

ANALYSIS	
<b>Development</b>	<p>The course was held by two trainers. Two two-day intensive crash courses in Amsterdam for trainers. This was organised through the Agora organisation, an umbrella organisation for the southern countries.</p> <p>Implementation of the course: Announcement of the Course to be organised. Dates, place and time notified. Twelve participants were registered with a participating fee of ten euros each. Meeting with</p>

	<p>Health professional to plan and formulate the 6 lectures of 2.5 hours each. Translation of lectures into national language. Each trainer had to prepare a specified presentation on the topic to be discussed. Preparations of hand-outs, folders and name tags.</p> <p>Attendance sheet recorded and a goal sheet given in each session and recorded for report in the next session.</p> <p>Power point presentations and Flip charts were used during lectures. The participants were encouraged to become actively involved during the sessions. If they felt the need to share their experiences, they could do so.</p> <p>All subjects discussed were to be kept strictly confidential within the group.</p> <p>An evaluation sheet given to the participants at the end of the course.</p> <p>A certificate of attendance given to participants.</p>
<b>Age</b>	<p>Please specify the main age group of the patients involved</p> <ul style="list-style-type: none"> <li>• 50-70</li> </ul>
<b>Disease/Pathology</b>	Arthritis and rheumatoid, Osteoarthritis and Fibromyalgia
<b>Obstacles</b>	<p>As such we did not meet with many obstacles. One member did not turn up for the course due to unforeseen circumstances. Two others had to miss three lectures due to health problems.</p> <p>We had some problems with the delivery of fruit for the coffee break.</p>
<b>Factors enabling the process</b>	We had collaboration and support from everybody involved.

<b>EVALUATION</b>	
<b>Innovativeness</b>	<p>It helped capacity building, the patients learnt how to plan small targets for their health improvements and obtain more information about their chronic condition.</p> <p>This was the first self-management course carried out and produced very positive results both for the participants and the trainers involved.</p>
<b>Added value</b>	In a small group individual attention can be given more easily.
<b>Appropriateness</b>	<p>Did the GP enable an efficient management of the needs?</p> <p>Yes very much.</p>

<b>NEXT STEPS</b>	
<b>Lessons Learned</b>	The trainers must be well prepared for all sort of questions and if they cannot answer they should not be afraid to tell the participants to seek professional advice.
<b>Key Takeaways</b>	<ol style="list-style-type: none"> <li>1. Empowerment through education and information</li> <li>2. Collaboration with different groups can be very beneficial.</li> </ol>
<b>Next Steps</b>	<p>Organize some sort of follow up to see if the patients are implementing what they have learnt.</p> <p>Audit referral patterns</p>

<b>Number</b>	30
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Ivone Machado Coutinho
<b>Organization</b>	Diabetic Association of São Miguel and St Maria Islands
<b>Country</b>	Portugal - Azores
<b>Email</b>	ivone.machado@gmail.com
<b>Short description of the organization/public institution</b>	
<p>The Diabetic Association of São Miguel and St Maria Islands is an association of people suffering from diabetes living in two of the islands in the Azores: St Michael (137,699 inhabitants and St Maria 5,547 inhabitants). It was created with the aim to protect and educate people with diabetes, helping them to better accept their condition, treatment and improving their quality of life.</p> <p>Further priorities are:</p> <ul style="list-style-type: none"> <li>• Social and community integration of people suffering from diabetes and the protection of their rights;</li> <li>• The protection of diabetic patients living in a manifest and recognised situation of economic difficulty;</li> <li>• The Association will encourage and promote education, prevention and scientific research in the field of diabetes. To increase awareness in diabetic patients about Chronic Pain.</li> </ul>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Organization of a network of Chronic Disease Patients Associations</i>
<b>Field</b>	<p>Empowerment: Information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as that of their relatives who usually play an essential role in helping them to deal with their condition, including their social, psychological, and other kind of impacts. This is obtained through partnerships among patients' organisations and other stakeholders, health professionals, public institutions, media, healthcare industry, etc.</p>
	<p>Civic participation: To create national and EU networks to transfer competences and tools, help create partnerships, identify common objectives, etc., so as to have an effective impact on policy-making in the field of healthcare, e.g. courses in self-management, integration of hospital/community services, involvement of chronic patients' associations in the organization of services, etc.</p>
<b>Actors</b>	<p><b>Public Institution(s)</b></p> <ul style="list-style-type: none"> <li>• Divino Espírito Santo Hospital, EPE Ponta Delgada</li> <li>• Local Health Public Centres</li> </ul> <p><b>Civic Organization(s)</b></p> <ul style="list-style-type: none"> <li>• 4 Chronic Patients Associations:</li> <li>• Diabetic Association of São Miguel and St Maria Islands</li> <li>• Senior Association of São Miguel</li> <li>• Azorean Association of Children with Disabilities</li> <li>• Machado Joseph Association</li> </ul> <p><b>Other Subjects involved</b></p>

	<ul style="list-style-type: none"> <li>• Regional Plan for Pain Control</li> <li>• Regional Health Department</li> <li>• Patients and their relatives</li> </ul>
<b>Location</b>	Azores Islands, beginning at St Michael and St Maria islands
<b>Term</b>	After the network associations have been established, maintaining continuous activities
<b>Objectives</b>	Identify people with chronic pain, the impact on their lives, supplying treatment Manage pain and metabolic control impact Identify and signal pain risk factors in diabetic patients Explain measures and strategies (with or without drugs ) for pain control Explain measures to improve the quality of life for patients with chronic pain “Teach” how to live with chronic diseases and chronic pain Policy involvement Show that the treatment of pain is a human right
<b>Outcomes Impact on participants</b>	Epidemiologic studies Pain Treatment Healthy life styles Life Quality Improvement Improvement acceptance of one’s condition Improve control and management of diabetes and other chronic diseases Improve eating habits
<b>Resources</b>	Health Professionals participation in different areas Civic organizations Financial resources from local institutions and stakeholders

<b>ANALYSIS</b>	
<b>Development</b>	Health Professionals from each of the involved areas Community activities Screening programs Promote commemorative days of each association
<b>Age</b>	Please specify the main age group of the patients involved <ul style="list-style-type: none"> <li>• 20-50</li> <li>• 50-70</li> </ul>
<b>Disease /Pathology</b>	Diabetes, Machado-Joseph Disease, Chronic disabilities
<b>Obstacles</b>	Finding people who are not coping with their chronic disease Lack of human recourses Community obstacles in understanding the aim of protecting the rights of chronic pain patients Personal contact with patients and healthcare professionals Personal contact with administrations of healthcare institutions.
<b>Factors enabling the process</b>	Factors which positively affected the Good Practice: Commemorative days of each association and related institutions; information; access to local media.

EVALUATION	
<b>Reproducibility</b>	Networking allows the cohesion of people, the circulation of ideas and dissemination of information among the general public.
<b>Innovativeness</b>	Yes, with screenings, it is possible to implement low cost initiatives and find volunteer workers among students.
<b>Added value</b>	Yes, improving the dissemination of chronic disease control.
<b>Appropriateness</b>	Patients are aware of the need of treatment and of the prevention of risk factors.

NEXT STEPS	
<b>Lessons Learned</b>	<p>The first step is to create a well-motivated team, and believe in the idea;</p> <p>Select carefully the partners; they do not participate directly, but can motivate others to help.</p>
<b>Key Takeaways</b>	<ol style="list-style-type: none"> <li>1. Together we can treat better</li> <li>2. Right to be treated</li> </ol>
<b>Next Steps</b>	<p>Join the Project “100 cities Against Pain”, supported by the municipal council of the cities in the main island:</p> <ul style="list-style-type: none"> <li>• involving the highest number of people possible from all different areas, institutions, associations, social groups, governmental institutions:</li> <li>• involving the media, local TV, the press, radios</li> </ul>



<b>Number</b>	31
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Maria Teresa Flor de Lima
<b>Organization</b>	Regional Plan for Pain Control
<b>Country</b>	Portugal - Azores
<b>Email</b>	mtflordelima@gmail.com
<b>Short description of the organization/public institution</b>	
<p>The Regional Health Directorate has launched a 3 year Health Program involving 9 islands for a total of 246,102 inhabitants. Since 2009 we had a Regional Plan for Pain Control applying national and international guidelines (Montreal Summit, SIP) on pain evaluation, as fifth vital sign, for pain clinics and treatment. The Plan is designed for Acute Pain, Chronic Pain and Delivery Pain. The Regional Plan for Pain Control is managed by a Coordinator. One of our priorities was the training of professionals and the supply of information to the public. We defined strategies, marketing slogans and campaigns, partnerships, plans for each island. We tried to involve the citizens, specially members of Associations of patients suffering from pain. In 2013 the Plan was selected as a Good Practice in a national competition (first in the first group of eleven programs out of a total of 75).</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Regional Plan for Pain Control</i>
<b>Field</b>	Empowerment: Training of all nurses and physicians in small groups in the work place, totalling 362 physicians in three hospitals, 151 family doctors, 899 hospital nurses and 501 in community centres. Organization of Courses, Conferences, Congresses.
	Civic participation: Involvement of Chronic Diseases Patient Associations
	Awareness raising: Continuous information about Pain and Palliative Care in local media in the occasion of National and International Day celebrations.
<b>Actors</b>	<p><b>Public Institution(s)</b></p> <ul style="list-style-type: none"> <li>• Regional Health Directorate</li> <li>• Divino Espírito Santo Hospital, EPE Ponta Delgada</li> <li>• Hospital Santo Espírito da Ilha Terceira EPE</li> <li>• Hospital da Horta</li> <li>• 17 Community Health Centres</li> </ul> <p><b>Civic Organization(s)</b></p> <ul style="list-style-type: none"> <li>• 4 Chronic Patients Diseases Associations:</li> <li>• Diabetic Association of São Miguel and St Maria Islands</li> <li>• Seniors Association of São Miguel</li> <li>• Azorean Association of Children with Disabilities</li> <li>• Machado-Joseph Association</li> </ul> <p><b>Other Subjects involved</b></p> <ul style="list-style-type: none"> <li>• Other healthcare institutions, administrations, sponsors, pharmaceutical industries, partnerships.</li> </ul>
<b>Location</b>	Nine Islands, Azores
<b>Term</b>	We are running the following activities on: epidemiologic studies, evaluation in hospitals and screenings in the community.

<b>Objectives</b>	<p>A certification of quality programs in three hospitals: three pain policy programs.</p> <p>Healthcare Centres: evaluation and systematic registration of the 5th Vital Sign as an indicator of Quality.</p> <p>Routine use of scales to evaluate pain: hospital admissions, emergency services, consultations, home visits.</p> <p>Improvement of the treatment of pain and quality of life of citizens.</p> <p>Prevention of suffering and response to the need for Palliative Care.</p> <p>Multidisciplinary Teams.</p> <p>Different techniques in Chronic Pain Units.</p> <p>Participation in national researches.</p> <p>Establishment of a research group with the University of the Azores in the areas of Pain, Quality of Life and Ageing.</p> <p>Collaboration with patient Associations.</p> <p>“Teaching” how to live with chronic diseases and chronic pain.</p> <p>Policy involvement.</p> <p>Discuss clinical topics during meetings, conferences etc.</p> <p>Show that the treatment of pain is a human right.</p>
<b>Outcomes Impact on participants</b>	<p>Professionals now know about pain evaluation and treatment, pain impact, drugs and technical aspects.</p> <p>They refer more patients to Pain Units.</p> <p>Healthy life styles and Quality of live Improvement in citizens.</p> <p>Public is now aware of the impact of Chronic Pain</p>
<b>Resources</b>	<p>Regional government allocated specific resources.</p> <p>Civic organizations.</p> <p>Financial resources from local institutions and stakeholders.</p>

ANALYSIS	
<b>Development</b>	<p>Community activities.</p> <p>Screening programs.</p> <p>National and international celebration days.</p>
<b>Age</b>	<p>Please specify the main age group of the patients involved</p> <ul style="list-style-type: none"> <li>• 20-50</li> <li>• 50-70</li> </ul>
<b>Disease /Pathology</b>	Acute and Chronic Pain
<b>Obstacles</b>	<p>Geographic.</p> <p>Economic.</p> <p>Human (too few professionals in some fields)</p>
<b>Factors enabling the process</b>	<p>Factors positively which affected the Good Practice: Local and national media, Social networking, Commemorative days, Campaigns.</p>

EVALUATION	
<b>Reproducibility</b>	<p>Networking and media allow the cohesion of people, the circulation of ideas and dissemination of information among the general public</p>
<b>Innovativeness</b>	<p>Did the Good Practice produce any innovative solutions?</p>

	Yes. Through screenings it is possible to implement low cost initiatives, find volunteer workers among students and organize campaigns.
<b>Added value</b>	Was the use of the GP more helpful than having approached the patient's needs in any other already experienced way? Yes. Improving the dissemination of chronic disease control; both professionals and public know better what Chronic Pain is, its consequences and how to minimize its impact.
<b>Appropriateness</b>	Did the Good Practice enable an efficient management of the needs? Patients are aware of the need of treatment, risk prevention factors and early treatment.

### NEXT STEPS

<b>Lessons Learned</b>	To have a well-motivated team, and believe in the idea. To move the implementation of the GP down from national to regional and local level involving interested stakeholders. Careful selection of partners. To get support from politicians and institutions; To be tenacious and persevering.
<b>Key Takeaways</b>	1. It is important that a support is obtained from local leaders to see regional and national laws implemented. 2. Treatment of pain and Palliative Care are human rights
<b>Next Steps</b>	If applicable, what are your organization's next steps for your Good Practice? Join the Project "100 cities Against Pain", supported by the municipal council of the cities in the main island: <ul style="list-style-type: none"> <li>- involving the highest number of people possible from all different areas, institutions, associations, social groups, governmental institutions:</li> <li>- involving the media, local TV, the press, radios</li> </ul> To go carry on the fight for Community Palliative Care

### OTHER INFORMATION

[www.azores.gov.pt/NR/rdonlyres/58E1085F-3CBD-45C7-9A79-061B97D27317/417978/ProgramaRegionaldeControlodaDor.pdf](http://www.azores.gov.pt/NR/rdonlyres/58E1085F-3CBD-45C7-9A79-061B97D27317/417978/ProgramaRegionaldeControlodaDor.pdf)  
 Coordinator of the Regional Nucleus of the Palliative Care Portuguese Association:  
[www.apcp.com.pt/nucleosregionais/acores.html](http://www.apcp.com.pt/nucleosregionais/acores.html)  
[www.apcp.com.pt/noticias/eleicoes-do-corpos-gerentes-do-nucleo-regional-dos-acores-da-apcp.html](http://www.apcp.com.pt/noticias/eleicoes-do-corpos-gerentes-do-nucleo-regional-dos-acores-da-apcp.html)  
 The Regional Plan for Pain Control supports the EFIC Platform SIP: [www.sip-platform.eu](http://www.sip-platform.eu)  
 National Program against Pain: [www.dgs.pt/paginas-de-sistema/saude-de-a-a-z/programa-nacional-de-controlo-da-dor.aspx](http://www.dgs.pt/paginas-de-sistema/saude-de-a-a-z/programa-nacional-de-controlo-da-dor.aspx)  
[www.iasppain.org/files/Content/NavigationMenu/Advocacy/InternationalPainSummit/PortugalPainStrategy.pdf](http://www.iasppain.org/files/Content/NavigationMenu/Advocacy/InternationalPainSummit/PortugalPainStrategy.pdf)  
[www.dgs.pt/outros-programas-e-projetos/paginas-de-sistema/saude-de-a-a-z/plano-estrategico-nacional-de-prevencao-e-controlo-da-dor-penpcdor.aspx](http://www.dgs.pt/outros-programas-e-projetos/paginas-de-sistema/saude-de-a-a-z/plano-estrategico-nacional-de-prevencao-e-controlo-da-dor-penpcdor.aspx)  
 NEW: Soon the Senior Citizens Association of São Miguel (Associação Seniores de São

Miguel - Civic Association) will organize a Palliative Care Volunteers Network and set up a Centre to help palliative care patients and families with social needs.

<b>Number</b>	32
<b>CONTACT DETAILS</b>	
<b>Organization</b>	Hospital de Cabueñes
<b>Country</b>	Spain - Asturie
<b>Short description of the organization/public institution</b>	
<p>The Hospital of Cabueñes is the medical centre of reference SESPA Asturias Health District V, which includes the municipalities of Gijón and Villaviciosa Carreño. The Hospital Cabueñes offers postgraduate medical teaching MIR since 1979, in the following specialties: Pathology, General Surgery, Orthopedic Surgery and Traumatology, hematology hospital pharmacy, Gynecology and Obstetrics, Intensive Care, Internal Medicine, Ophthalmology, Pediatrics, Radiology, Urology. The Hospital also works in the training of specialists in Family and Community Medicine, Occupational Medicine, Psychiatry and Mental Health.</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Live music</i>
<b>Field:</b>	Civic participation
<b>Actors</b>	<b>Civic Organization(s)</b> <ul style="list-style-type: none"> <li>• Sinedolore</li> </ul>
<b>Location</b>	Spain- Gijón
<b>Objectives</b>	The main objective of this study is to see if listening to live music can be a variation toward decreasing medication. The others objectives of this investigation are: determine whether hearing influences the perception of pain; if to listen to live music can influence self-control techniques being employed by the patient unconsciously, and if that same live music can change the anxiety that affects some patients with chronic pain.
<b>Outcomes Impact on participants</b>	Although the study is still being analysed, it is based on highly complex statistical revisions, and it is possible to see patient satisfaction from their comments – that is, that they forgot about their pain.
<b>Resources</b>	The programme included listening to masterpieces of world renown composers but also bagpipes, Asturian folk music, jazz, bolero and even tango. The main resources were: the teachers and the students of the Conservatory of Music in Gijón and Oviedo Conservatory who played every Saturday in the Hospital; Some patients , doctors and medical staff of V area are conducting a study on the outcomes of the programme.

<b>ANALYSIS</b>	
<b>Development</b>	In Cabueñes hospital every Saturday morning for the months of May and June live music was performed. The music according to some specialist can help decreased the request of medication from patients.
<b>Age</b>	All ages
<b>Disease /Pathology</b>	Chronic pain
<b>Reproducibility</b>	Yes everywhere

<b>Number</b>	33
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Dr. Jordi Moya Riera
<b>Organization</b>	Sine dolore
<b>Country</b>	Spain
<b>Email</b>	jmoia@pdi.efhre.edu.es
<b>Short description of the organization/public institution</b>	
<p><i>Sine dolore</i> is a non-profit organization, whose main purpose is to inform and advise the public in general and specifically patients who suffer from pain and their families; encourage and promote research on mechanisms and pain syndromes, as well as help to improve treatment of patients with acute and chronic pain, involving scientists, physicians and other health professionals from various disciplines and areas of common interest in the pain research and treatment. All this in collaboration with the government (health, political, educational, cultural bodies etc ...)</p>	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>International school day “without pain”, for patients suffering from pain and their families</i>
<b>Field</b>	Civic participation
	Awareness raising
<b>Actors</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>Island Council of Menorca Official College of Physicians of the islands</li> <li>professional association of pharmaceutical of the Balearic Islands</li> </ul>
	<b>Other Subjects involved Scientific</b> <ul style="list-style-type: none"> <li>European Foundation for Health Research and Education (EFHRE)</li> <li>University International Efhre (UIE)</li> <li>Cátedra de Urgencias, Emergencias, Catástrofes y Cardioseguridad de la Universidad Católica San Antonio.</li> <li>Unidad del Dolor. Hospital General Mateu Orfila. Ib-Salut</li> </ul>
<b>Location</b>	Menorca, Balearic Island, Spain
<b>Term</b>	October 19, 2013
<b>Objectives</b>	The International school day “without pain” for patients suffering from pain and their families, was celebrated in Maó (Menorca). The objective was to improve the quality of life of patients who suffer of chronic pain and the treatment of the pain.
<b>Outcomes Impact on participants</b>	Meeting participants could learn more information about chronic pain.
<b>Resources</b>	The participation of specialists from pain clinics centres which came from around the Country, summoned by the European Foundation for Health Research and Education.

<b>ANALYSIS</b>	
<b>Development</b>	During the meeting, the concept of pain was discussed, different population characteristics and different treatments that are being

	implemented- the types of acute and chronic pain, epidemiology of chronic pain in Europe, the role of anti-inflammatory drugs, opioids, adjuvant drugs and blockages in the treatment of pain.
<b>Disease /Pathology</b>	Chronic pain



<b>Number</b>	34
<b>CONTACT DETAILS</b>	
<b>Organization</b>	Coordinadora Nacional de Artritis (ConArtritis)
<b>Country</b>	Spain
<b>Email</b>	conartritis@conartritis.org
<b>Short description of the organization/public institution</b>	
The National Coordinator of Arthritis, “ConArtritis” is a non-profit organization that brings together 18 associations of patients with rheumatoid arthritis in Spain. Its mission is to integrate and represent the Associations of Patients with Rheumatoid Arthritis to the authorities and health managers to promote public and legislative initiatives for employment and social integration and improving the quality of life of patients.	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>From patient to patient in the day hospital</i>
<b>Actors</b>	<b>Other Subjects involved</b> <ul style="list-style-type: none"> <li>Asociación Granadina de Artritis Reumatoide (AGAR)</li> </ul>
<b>Location</b>	Granada
<b>Term</b>	From 2011 to ongoing
<b>Objectives</b>	Support and assist the patients with Rheumatoid Arthritis. The project support program for patients with rheumatoid arthritis receiving treatment with biological treatment in Day Hospital
<b>Outcomes Impact on participants</b>	Volunteer operators learn about the disease and what the patient is going through.
<b>Resources</b>	A trained volunteer operator is the right person to provide emotional support as well as advice and help in accepting the disease, increase self-esteem of patients and, ultimately, contribute to improving the quality of life of people suffering from Rheumatoid Arthritis.

<b>ANALYSIS</b>	
<b>Development</b>	The project consists of meetings or talks from "patient to patient" that provide effective support and assistance to patients and their families, especially those who find themselves for the first time in these centre.
<b>Disease /Pathology</b>	Chronic pain, Rheumatoid Arthritis.

<b>Number</b>	35
<b>CONTACT DETAILS</b>	
<b>Organization</b>	Junta de Andalucía
<b>Country</b>	Spain - Andalucía
<b>Short description of the organization/public institution</b>	
The Council of Equality and Social Welfare and Social Policies in the public administration responsible for the design and development of equality policies, health and social welfare in Andalusia and the agencies responsible for the management and delivery of health services and social welfare.	

<b>DESCRIPTION</b>	
<b>Title</b>	Patients education/school: The Fibromyalgia classroom
<b>Field</b>	Civic participation
	Awareness raising
<b>Actors</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>Escuela Andaluza de Salud Pública</li> </ul>
<b>Location</b>	Andalucía
<b>Term</b>	From 2008 to ongoing
<b>Objectives</b>	Patient School developed the idea of improving health and quality of life of people who suffer from an illness, especially for people with chronic diseases, particularly in the case of Fibromyalgia. For this reason the fibromyalgia courses are addressed to all patients suffering from pain and their families, professionals and citizens. The purpose is to improve the quality of life of patients, their families and careers.
<b>Outcomes Impact on participants</b>	The initiative is very important because it provides patients information about fibromyalgia and gives them an opportunity to take part in specific activities which help them deal with their condition.
<b>Resources</b>	The fibromyalgia courses include videos, information guides, activities, library, information about the associations, patient communities, the possibility to access virtual classrooms.

<b>ANALYSIS</b>	
<b>Development</b>	The project helps people who suffer from chronic pain, in particular from fibromyalgia.
<b>Disease /Pathology</b>	Fibromyalgia

<b>Number</b>	36
CONTACT DETAILS	
<b>Name and Surname</b>	Judy Birch
<b>Organization</b>	Pelvic Pain Support Network
<b>Country</b>	UK
<b>Email</b>	info@pelvicpain.org.uk
Short description of the organization/public institution	
<p>Our first aim is to provide support, information and national advocacy for those with pelvic pain, their families and careers. The aim of the support we offer is to empower patients to take greater control over their condition and to help them in making informed decisions about their care. The information we provide is certified by the Information Standard and is evidence based. We advocate nationally on behalf of pelvic pain patients at the Department of Health and in parliament. Our second aim is to raise awareness amongst the medical profession and the public in all matters relating to the diagnosis of pelvic pain and its treatments. This involves communicating with medical trainees, clinicians and researchers about the issues for pelvic pain patients. Our third aim is to encourage research by appropriate institutions in order to gain a better understanding of the impact of pelvic pain on patients' quality of life. All of these activities take place on a regular basis.</p>	

DESCRIPTION	
<b>Title</b>	Developing a national population-based system for pelvic pain
<b>Field</b>	Empowerment
	Civic participation
	Awareness raising
<b>Actors</b>	<p><b>Public Institution(s)</b></p> <ul style="list-style-type: none"> <li>NHS, Public Health England</li> </ul> <p><b>Civic Organization(s)</b></p> <ul style="list-style-type: none"> <li>Pelvic Pain Support Network</li> </ul> <p><b>Other Subjects involved</b></p> <ul style="list-style-type: none"> <li>Better Value Healthcare</li> </ul>
<b>Location</b>	Great Britain (England and Scotland )
<b>Term</b>	Start date: November 2012, End date 2017
<b>Objectives</b>	To use a Population Healthcare approach to design a population based system of care which focuses on the outcomes that should be delivered to patients with chronic pelvic pain (CPP). To overall aim is to increase the value of healthcare services provided to patients with CPP.
<b>Outcomes Impact on participants</b>	<p>A direct outcome of our work was to create a population-based system specification for improving care for patients with CPP. This can be viewed here: <a href="http://www.chronicpelvicpainsystems.yolasite.com/cpp-systems.php">www.chronicpelvicpainsystems.yolasite.com/cpp-systems.php</a></p> <p>We have also been able to engage with our partners to produce annual reports based on the system specification above, which can be viewed here: <a href="http://www.chronicpelvicpainsystems.yolasite.com/annual-reports.php">www.chronicpelvicpainsystems.yolasite.com/annual-reports.php</a></p> <p>This is a very important step because it will allow our partners:</p> <ul style="list-style-type: none"> <li>- To see how they are doing year on year and see whether they are meeting their targets;</li> <li>- To identify network and pathways issues;</li> </ul>

	<ul style="list-style-type: none"> <li>- To constructively compare themselves to other populations with similar socio-demographics and learn from them and improve their services in an evidence-based way.</li> </ul> <p>An indirect outcomes were:</p> <ul style="list-style-type: none"> <li>- increased collaboration across disciplines with a focus on the patient;</li> <li>- greater patient involvement in their care</li> <li>- increased success in research funding applications</li> </ul>
<b>Resources</b>	<ul style="list-style-type: none"> <li>- The support of an overall lead to drive the initiative , in this case a senior person with long experience of working in the NHS.</li> <li>- Health professional time, motivation and expertise in an area where time and expertise are in short supply.</li> <li>- The assistance of a project manager to help with day to day organizational matters.</li> <li>- Admin time for maintaining the momentum, contacting participants. This requires familiarity with the subject from the patient perspective and an established relationship with health professionals in the field.</li> </ul>

## ANALYSIS

<b>Development</b>	<p><u>The Problem</u></p> <p>Because of the high prevalence of CPP, care planning should be on the basis of all the practices being supported by a general pain service, these general pain and related services (gynaecology, gastroenterology, etc.) in turn need support from a super specialist service covering a larger population (approx. 2 million). This type of care planning will enable the improvement of quality of life of people with CPP with timely, integrated care in the form of pain relief, patient centred appropriate intervention and self care as close to the person's home as possible.</p> <p>It is essential that management of people with CPP should involve a multidisciplinary and integrated approach. The team should include physicians with a special interest in pain management and people's health (generally pain consultants are a good example), gynaecologist, psychologist and physiotherapist working in collaboration to ensure that a patient is successfully adapted to their pain. The level of staffing and skill will vary depending on the complexity of treatment(s) required in the context of the local population. However, access to diagnostic skills, medical management of pain, complementary, psychological and physical therapies are essential, as is support of people through the journey to adaptation.</p> <p><u>The Solution</u></p> <p>The solution we pursued to solve the issues described above was to create a Population Based System of Care. The principles of system design are that in designing a system it is necessary to:</p> <ul style="list-style-type: none"> <li>• Define the scope of the system.</li> </ul>
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- Define the population to be served.
- Reach agreement on the aim and objectives of the service
- For each objective to find one or more criteria
- For each of the criteria identify levels of performance that can be used as quality standards
- Identify all the resources used in the system, thus creating a system budget
- Define all the partners so that they need to be engaged in a Clinical Network
- Agree the principal pathways that need to be made explicit
- Produce a system specification
- Prepare a plan to build the system

The principles are put into practice by a design *group* and a design *network*:

- The responsibility of the design group is to coordinate and lead the design of the system and produce a written specification.
- The responsibility of the design network is to ensure that the design of the system is informed by the contribution of all interested partners including patients and carers.

#### Our Approach

I spoke to Sir Muir Gray about the lack of services/provision for those with persistent pelvic pain in July 2012. He requested background information about the subject. Lee Priest at Birmingham Clinical Trials Unit and myself wrote a paper summarizing this based on the MEDAL study NIHR HTA funding application. Following this, Sir Muir Gray obtained funding from the England Department of Health to host a series of 3 workshops in 2013. The first was held at the Royal Society for Public Health, London. The second in Southampton and the third at the Royal College of Obstetricians Gynaecologists, London. Sir Muir Gray chaired each of the workshops. Input and comments on annual report criteria were sought from a wide range of health professionals.

Our work has involved knowledge harvesting from the key stakeholders in the CPP care pathway (including GPs, Pain Consultants, Gynaecologists, Nurses, Patients, etc.) and our focus was divided into the following areas:

#### *Treatment pathway:*

- To provide a streamlined, effective and efficient integrated multidisciplinary management pathway for women with CPP focused on:
  - a) timely access to satisfactory explanations of pain
  - b) offer appropriate, high value evidence based interventions
  - c) patient-centred
  - d) A holistic approach to care including quality of life issues in order to promote health of people with CPP

#### *Education*

- To educate professionals, patients and the public about CPP to challenge social norms (bearing in mind the cultural context)

	<p><i>Research</i></p> <ul style="list-style-type: none"> <li>To promote and support services that allow for coordinated research and audit priorities, which are relevant to patients, to be identified for NIHR and to provide a successful platform for future evidence based research to be built on.</li> </ul> <p><i>Resources</i></p> <ul style="list-style-type: none"> <li>To maximise value from the resources available, maximising benefit and minimising harm</li> <li>To ensure there is on-going adequate patient support available including outside services</li> </ul> <p><i>Wider health care context</i></p> <ul style="list-style-type: none"> <li>To engage people both individually and collectively in the design and management of care</li> <li>To produce a freely available and externally validated annual report for the population served to demonstrate health outcomes and value for money.</li> </ul> <p><u>Pilot Projects</u></p> <p>As part of creating a national system for CPP, we are testing out our approach through a series of pilots in eight localities: North London, East London, Bristol, Southampton, Leicester, Middlesbrough, Oxford and Edinburgh. These pilots are currently being set up or are already underway and the outputs will be reported in the third quarter of 2014.</p>
<b>Age</b>	<p>Please specify the main age group of the patients involved</p> <ul style="list-style-type: none"> <li>20-50</li> <li>50-70</li> </ul>
<b>Disease / Pathology</b>	Those with chronic pelvic pain.
<b>Obstacles</b>	<ul style="list-style-type: none"> <li>Contacting health professionals (logistical) – NHS e-mail systems. Enlisted assistance from admin colleagues in commissioning and hospital settings to circulate e-mails about workshop events.</li> <li>Getting involvement from health professionals to produce an annual report. Many do not see this as their role. Difficulties in obtaining data (the latter, in particular, is ongoing). I obtained some Freedom of Information data from the hospital trusts involved and provided it to the health professionals involved as a start.</li> <li>Support and backing of Sir Muir Gray in Chairing workshops and encouraging professionals to gather data was also an important factor in overcoming our obstacles.</li> </ul>
<b>Factors enabling the process</b>	<p>Close involvement of the NHS and Public Health England through Sir Muir Gray.</p> <p>Close involvement of patient representatives in initiating and following through the project, liaising with health professionals and researchers.</p>

## EVALUATION

<b>Reproducibility</b>	This work was kept simple with a focus on patient outcomes. We did not dictate any changes in methods of service provision – we only
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	<p>requested that participating partners produce an annual report so that they could better understand the gaps in their services to patients, which they could then address in an evidence-based way. Because of this approach, our GP is very reproducible in other situations and places.</p>
<b>Innovativeness</b>	<p>The use of Population-based Healthcare Systems is a unique approach to improving care because they allow us to, in a standardised way, collect outcomes data in the form of simple 1-2 sides A4 annual reports on how different services across England are performing, which will help services to directly address their problems because:</p> <ul style="list-style-type: none"> <li>• they can see how they are doing year on year and see whether they are meeting their targets</li> <li>• identify network and pathways issues</li> <li>• they can compare themselves to other populations with similar socio-demographics and learn from them and improve their services in an evidence-based way. For poor performing services the onus is on themselves to take initiative in learning and will be limited by lack of resources, training etc. Can the better performing service take on a more mentoring role?</li> </ul> <p>This programme will help guide commissioners and providers on the critical deficiencies that exist in their services and by having data from other localities readily available, they can derive potential solutions on how to address these issues to better serve their population's needs. Finally, the systems approach would allow us to answer questions such as:</p> <ol style="list-style-type: none"> <li>1. <i>Is the asthma service in Birmingham of higher value than the service in Liverpool?</i></li> <li>2. <i>Who is responsible for liver services in Kent?</i></li> <li>3. <i>How many osteoarthritis services are there in Nottingham and how many should there be?</i></li> <li>4. <i>Which AF service in London provides the best value?</i></li> <li>5. <i>Is the variation in outcome for people with psychosis increasing or decreasing across Cambridgeshire and across categories of race, gender and socioeconomic class?</i></li> <li>6. <i>Who will be responsible for publishing the Annual Report of diabetes services for Devon?</i></li> </ol>
<b>Added value</b>	<p>Most interventions to improve quality and safety of care focus on pathway-specific interventions, which will never be widely applicable or scalable. Furthermore, many of these interventions do not take patient needs into account.</p> <p>The Population-based Systems approach puts the patient at the centre and provides a means to explicitly focus on delivering Triple Value:</p> <ul style="list-style-type: none"> <li>• Personal Value: ensuring we are delivering care that meets patient needs</li> <li>• Technical Value (<i>patient outcomes/cost</i>): ensuring we are improving outcomes and decreasing cost</li> <li>• Allocative Value: ensuring we are allocating resources for the</li> </ul>



	maximal benefit of the population's health
<b>Appropriateness</b>	<p>There are several existing problems in healthcare which we have not been able to solve including:</p> <ul style="list-style-type: none"> <li>• patient harm,</li> <li>• unwarranted variation in outcomes,</li> <li>• inequity,</li> <li>• failure to prevent the preventable,</li> <li>• rising need, demand and expectations</li> <li>• waste of finite resources (financial and human)</li> </ul> <p>These problems are particularly relevant for patients with CPP and our systems approach gives us the means to address these problems in an efficient and evidence-based way.</p>

NEXT STEPS	
<b>Lessons Learned</b>	Keep it simple and persist.
<b>Key Takeaways</b>	<p>1. In the 21<sup>st</sup> century, it will become increasingly necessary for the healthcare profession to focus on Population Healthcare, which can be defined as follows:</p> <p><i>Population healthcare focuses primarily on populations defined by a common need which may be a symptom such as breathlessness, a condition such as arthritis or a common characteristic such as frailty in old age, not on institutions, or specialties or technologies. Its aim is to maximise value and equity for those populations and the individuals within them.</i></p> <p>2. We need to tackle problems in health and social care services in an era when we will not have any new investment, which requires us to shift our focus to Triple Value:</p> <ul style="list-style-type: none"> <li>• Personal Value: ensuring we are delivering care that meets patient needs</li> <li>• Technical Value (<i>patient outcomes/cost</i>): ensuring we are improving outcomes and decreasing cost</li> <li>• Allocative Value: ensuring we are allocating resources for the maximal benefit of the population's health</li> </ul> <p>Population Healthcare is a safe and efficient means to deliver Triple Value.</p>
<b>Next Steps</b>	Each year progress will be reviewed based on the annual reports received from participating populations. Presentations of these will be invited and discussed at an annual workshop sponsored by Public Health England. The annual workshop will also be a venue through which we will aim to recruit more localities to produce annual reports so that we cover larger proportions of England's population and identify best practice and gaps in care provision.

<b>Number</b>	37
CONTACT DETAILS	
<b>Organization</b>	Pain Concern
<b>Country</b>	UK
<b>Email</b>	info@painconcern.org.uk
Short description of the organization/public institution	
<p>From the very beginning Pain Concern has brought together people living with pain and healthcare professionals specialising in this area to provide support and information and to campaign and advocate for better awareness, understanding, treatment and management of pain. The goals of the association are: to produce information on pain using a variety of media platforms; to provide support to people with pain and those who care for them; to campaign to raise awareness about pain and improve the provision of pain management services.</p>	

DESCRIPTION	
<b>Title</b>	Airing pain (radio programme)
<b>Field</b>	Civic participation
	Awareness raising
<b>Term</b>	Since 2009 ongoing
<b>Objectives</b>	Airing Pain brings together people with chronic pain and top specialists to talk about the resources which can help. Each programme features the experiences of those managing their everyday pain, and interviews with top, internationally- recognised experts. Airing pain is the popular digital radio programme for people living with chronic pain. The radio will take a look at very different ways of giving people in pain the knowledge and power to help themselves.
<b>Outcomes Impact on participants</b>	A radio show can bring information and support directly into the homes of people in pain. This is especially important since Chronic pain conditions very often bring with them social isolation and disability. The show also strives to build and strengthen the ‘pain community’ of those living with pain and the families, friends and healthcare professionals who care for them by educating, informing and sharing different perspectives on pain.
<b>Resources</b>	The broadcasting project began in 2009 when Pain Concern won 1st place and £10,000 of start-up funding in the Napp Awards in Chronic Pain.

ANALYSIS	
<b>Development</b>	Airing Pain is produced and presented by Sony Award-winning BBC broadcaster Paul Evans; it is an online radio show <u>also available on CD</u> .
<b>Age</b>	<p>Please specify the main age group of the patients involved</p> <ul style="list-style-type: none"> <li>• 20-50</li> <li>• 50-70</li> <li>• 70-90</li> </ul>
<b>Disease /Pathology</b>	Chronic pain

<b>Number</b>	38
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CONTACT DETAILS	
<b>Name and Surname</b>	Dr. Deborah Padfield and Dr Rajesh Munglani
<b>Organization</b>	University College London (Slade School of Art), West Suffolk Hospital, Bury St Edmunds
<b>Country</b>	UK

DESCRIPTION	
<b>Title</b>	<i>Face2Face</i>
<b>Field</b>	Civic participation
<b>Actors</b>	<b>Civic Organization(s)</b> <ul style="list-style-type: none"> <li>• Pain concern</li> </ul>
<b>Location</b>	UK
<b>Term</b>	Since 2014
<b>Objectives</b>	The project has many strands: art workshops for clinicians and patients to attend together; the co-creation of photographs with facial pain patients reflecting their experience at different stages of their treatment; the creation of an image resource developed as an innovative communication tool for clinical use; and an artist's film focusing on doctor-patient dialogue and the role of narrative. The project is based on the collaboration with people with pain to produce works of art that represent their experiences.
<b>Outcomes Impact on participants</b>	The art work produced not only provides a voice for individuals who may have felt their experiences marginalised by the medical establishment and society at large, but is also part of a study aimed at finding better ways for people to communicate their pain.
<b>Resources</b>	Images created by Deborah Padfield, from a clenched fist to flying sparks – are now being trialled by patients not part of the project as visual prompts in ordinary medical consultations.

ANALYSIS	
<b>Development</b>	Exploring the potential of images to facilitate communication in medical pain consultations. The project has so far recruited 141 participants and shown the images to 14,000 people.
<b>Age</b>	Please specify the main age group of the patients involved <ul style="list-style-type: none"> <li>• 20-50</li> <li>• 50-70</li> </ul>
<b>Disease /Pathology</b>	Chronic pain, facial pain

<b>Number</b>	39
<b>CONTACT DETAILS</b>	
<b>Organization</b>	Fibromyalgia Association Uk
<b>Country</b>	UK
<b>Short description of the organization/public institution</b>	
Fibromyalgia Association UK is a registered charity managed by unpaid volunteers. The majority of volunteers are also fibromyalgia sufferers who work extremely hard, despite their condition, in order to forward the cause of fibromyalgia. FMA UK was established to provide information and support to sufferers and their families. In addition, the Association provides medical information for professionals and operates a national helpline.	

<b>DESCRIPTION</b>	
<b>Title</b>	Fibromap
<b>Field</b>	Awareness raising
	Specific tool
<b>Term</b>	Since 2014 ongoing
<b>Objectives</b>	FibroMapp is the most comprehensive 8-in-1 chronic pain management app which is helping people gain more understanding and control over their condition. It is helping thousands of people with Fibromyalgia, ME/CFS, Lupus, MS, Arthritis, CRPS just to name a few.
<b>Outcomes Impact on participants</b>	Great for the doctor and even backup info for benefits, and more.
<b>Resources</b>	FMAUK FibroMapp is the most comprehensive pain management app currently on the market. It is unique to each person, therefore it can be personalised to one's needs and requirements and takes into account that there are over 100 different conditions and symptoms within FM. FMAUK FibroMapp helps to gain more control by supplying the tools to easily track the possible reasons for pain, fatigue, sleep issues, mood swings, flare-ups and much more.

<b>ANALYSIS</b>	
<b>Development</b>	FibroMapp is the most comprehensive pain management app currently on the market
<b>Age</b>	Please specify the main age group of the patients involved <ul style="list-style-type: none"> <li>• 20-50</li> <li>• 50-70</li> <li>• 70-90</li> </ul>
<b>Disease /Pathology</b>	Fibromyalgia

<b>Number</b>	40
<b>CONTACT DETAILS</b>	
<b>Name and Surname</b>	Hannah Ensor
<b>Organization</b>	Stickman Communications
<b>Country</b>	UK
<b>Email</b>	admin@stickmancommunications.co.uk
<b>Short description of the organization/public institution</b>	
All Stickman Communications products feature the work of Stickman cartoonist Hannah Ensor. Hannah's unique approach to communicating about disability and medical conditions stems from personal experience and the situations she has encountered.	

DESCRIPTION	
<b>Title</b>	<i>The leaflet "Pain: Common misunderstandings between patients and medical staff"</i>
<b>Field</b>	Awareness raising
<b>Actors</b>	<b>Civic Organization(s)</b> <ul style="list-style-type: none"> <li>• Pain Uk</li> </ul>
<b>Objectives</b>	The objective of this leaflet is to avoid misunderstandings in communication about pain between the patient and medical staff. Being aware of the simplest phrases which have many different meanings can help avoid problems misunderstandings can cause.
<b>Outcomes Impact on participants</b>	This document will be a very effective tool to explain the typical misunderstandings between professionals and patients. Communication issues complicate every aspect of daily life since when a person is in pain language barriers tend to increase.
<b>Resources</b>	Produced in association with Pain UK. £0.10 per leaflet sold through the website donated to Pain UK (registered charity in England and Wales, no. 1145561).

ANALYSIS	
<b>Development</b>	This leaflet, entitled "Pain: Common misunderstandings between patients and medical staff" is an excellent tool when communicating about pain. With its light-hearted, plain speaking style, this leaflet sets out some of the common phrases and their range of meanings, giving everyone who reads it a better chance of communicating effectively about pain.
<b>Age</b>	Please specify the main age group of the patients involved <ul style="list-style-type: none"> <li>• 20-50</li> <li>• 50-70</li> <li>• 70-90</li> </ul>
<b>Disease /Pathology</b>	Chronic pain

<b>Number</b>	41
<b>CONTACT DETAILS</b>	
<b>Organization</b>	Fibromyalgia Association Uk
<b>Country</b>	UK
<b>Short description of the organization/public institution</b>	
Fibromyalgia Association UK is a registered charity managed by unpaid volunteers. The majority of volunteers are also fibromyalgia sufferers who work extremely hard, despite their condition, in order to forward the cause of fibromyalgia. FMA UK was established to provide information and support to sufferers and their families. In addition, the Association provides medical information for professionals and operates a national helpline.	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Medical Pack for GPs and other Medical Professionals</i>
<b>Field:</b>	Awareness raising
<b>Location</b>	UK
<b>Term</b>	Since October 2011
<b>Objectives</b>	If Medical Professionals need information on fibromyalgia it is possible to request that an FMA UK Medical Professionals Pack be sent out to them.
<b>Outcomes Impact on participants</b>	Helpful for both general practitioners and patients.
<b>Resources</b>	The medical packs have been produced by our Medical Advisory Board and contain fully referenced information in the level of detail which doctors will appreciate. While this is aimed at doctors with their terminology, there is also a booklet for patients.

<b>ANALYSIS</b>	
<b>Development</b>	Patients can forward the name of the Medical Professional and the address of their practice. After filling in the request form on our website we will then send a pack to their surgery addressed from us to them.
<b>Age</b>	Please specify the main age group of the patients involved <ul style="list-style-type: none"> <li>• 20-50</li> <li>• 50-70</li> <li>• 70-90</li> </ul>
<b>Disease /Pathology</b>	Fibromyalgia

<b>Number</b>	42
<b>CONTACT DETAILS</b>	
<b>Organization</b>	Pain Association, Pain Concern, Scottish Government, NHS Health Improvement Scotland
<b>Country</b>	UK
<b>Country Region</b>	Scotland
<b>Short description of the organization/public institution</b>	
<p>From the very beginning Pain Concern has brought together people living with pain and healthcare professionals specialising in this area to provide support and information and to campaign and advocate for better awareness, understanding, treatment and management of pain. The goals of the association are: to produce information on pain using a variety of media platforms; to provide support to people with pain and those who care for them; to campaign to raise awareness about pain and improve the provision of pain management services.</p>	

DESCRIPTION	
<b>Title</b>	A new public health campaign to help people with chronic pain
<b>Field</b>	Awareness raising
<b>Actors</b>	<b>Other Subjects involved</b> <ul style="list-style-type: none"> <li>The Royal Pharmaceutical Society</li> </ul>
<b>Location</b>	Scotland
<b>Term</b>	From
<b>Objectives</b>	The campaign aims to encourage people with pain to ask for advice from their pharmacist, as well as promoting awareness of information, resources and training available for self-management.
<b>Resources</b>	The new campaign seeks to empower people with chronic pain. It will signpost where information and support can be found.

ANALYSIS	
<b>Development</b>	<p>Every community pharmacy in Scotland will display posters and information leaflets to communicate how patients can manage chronic pain. The campaign encourages them to talk about pain with their local pharmacist and finding information from reliable sources online.</p> <p>The Royal Pharmaceutical Society set up a section of its website to host all the resources produced by this campaign. Members of the RPS will be able to access the resource documents for pharmacists and use them to improve how they help people with chronic pain. Further information, including the poster, SNAPfax information and the leaflet is available from NHS Scotland.</p>
<b>Age</b>	<p>Please specify the main age group of the patients involved</p> <p>All ages</p>
<b>Disease /Pathology</b>	Chronic pain



<b>Number</b>	43
<b>CONTACT DETAILS</b>	
<b>Organization</b>	The British Pain Society
<b>Country</b>	UK
<b>Email</b>	info@britishpainsociety.org
<b>Short description of the organization/public institution</b>	
The British Pain Society is an alliance of professionals advancing the understanding and management of pain for the benefit of patients. The goals are: promoting excellence and awareness for the benefit of people living with pain; promoting partnerships in pain research, education and management; influencing policies relevant to pain, nurturing the next generation of pain researchers and healthcare professionals, encouraging dialogues about pain, contributing to national and international dialogue about pain.	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Pain in elderly people special interest group</i>
<b>Field</b>	Awareness raising
<b>Actors</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>University of Greenwich School of Health &amp; Social Care</li> </ul>
<b>Location</b>	UK
<b>Term</b>	Since 2012 ongoing
<b>Objectives</b>	Clinical Practice, research and education on pain in elderly people
<b>Resources</b>	The British Pain Society has developed a mechanism by which members of the Society who have a specific interest are given a forum to discuss more in depth their interests. The Society actively encourages and supports the development of such Special Interest Groups; Pain in Older People SIG chairman is Prof. Pat Schofield from the University of Greenwich School of Health & Social Care.

<b>ANALYSIS</b>	
<b>Development</b>	Description of Activities and Scientific Focus: increase awareness and promote education about pain in older people to provide a national and interdisciplinary forum for those interested in clinical and research questions on pain in older people; develop best practice guidelines for assessment and management of pain in older people; promote discussion and research on pain in older people, including: senescence, pain perception, multidimensional assessment of pain and its consequences; pharmacological and non-pharmacological management of pain; uniqueness of the pain experience in patients with cognitive impairment to facilitate the development of international collaborative research efforts on pain in older people.
<b>Age</b>	Please specify the main age group of the patients involved <ul style="list-style-type: none"> <li>70-90</li> </ul>
<b>Disease /Pathology</b>	Chronic pain

<b>Number</b>	44
<b>CONTACT DETAILS</b>	
<b>Organization</b>	The British Pain Society
<b>Country</b>	UK
<b>Email</b>	info@britishpainsociety.org
<b>Short description of the organization/public institution</b>	
The British Pain Society is an alliance of professionals advancing the understanding and management of pain for the benefit of patients. The goals are: promoting excellence and awareness for the benefit of people living with pain; promoting partnership in pain research, education and management; influencing policies relevant to pain, nurturing the next generation of pain researchers and healthcare professionals, encouraging dialogues about pain, contributing to national and international dialogue of pain.	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>The leaflet: "Opioids for persistent pain: information for patients"</i>
<b>Field</b>	Awareness raising
<b>Actors</b>	<b>Other Subjects involved</b> <ul style="list-style-type: none"> <li>• The Faculty of Pain Medicine of the Royal College of Anaesthetists</li> <li>• The Royal College of General Practitioners</li> <li>• The Faculty of Addictions of the Royal College of Psychiatrists</li> </ul>
<b>Location</b>	Uk
<b>Term</b>	Since 2010 ongoing
<b>Objectives</b>	Opioids for persistent pain: information leaflet for patients
<b>Resources</b>	Each publication is available to download free of charge, in PDF format.

<b>ANALYSIS</b>	
<b>Development</b>	This information leaflet was created with the collaboration of Dr Cathy Stannard, (The British Pain Society), Dr Gillian Chumbley (The British Pain Society), Dr Douglas Justins Faculty of Pain Medicine, Royal College of Anaesthetists Dr Judy Myles Faculty of Addictions, Royal College of Psychiatrists Dr Richard Potter Royal College of General Practitioners, Dr Karen Simpson The British Pain Society Dr Amanda C de C Williams The British Pain Society
<b>Disease /Pathology</b>	Chronic pain

<b>Number</b>	45
CONTACT DETAILS	
<b>Name and Surname</b>	Pete Moore
<b>Organization</b>	The Pain Toolkit
<b>Country</b>	UK
<b>Email</b>	petemoore2@yahoo.co.uk

DESCRIPTION	
<b>Title</b>	<i>The Pain Toolkit website</i>
<b>Field</b>	Awareness raising
<b>Location</b>	UK
<b>Term</b>	Ongoing
<b>Objectives</b>	The Pain Toolkit website has been developed from the Pain Toolkit, a simple information booklet which provides people with handy tips and skills to support them along the way to managing pain.
<b>Outcomes Impact on participants</b>	The website is useful for people suffering from chronic pain
<b>Resources</b>	In the website there are useful resources, choices, links for further information and support and videos for Health Care Professionals. It is also possible to download the Pain Toolkit(s) in order to help and assist people in their pain management.

ANALYSIS	
<b>Development</b>	Pete Moore, has developed these tools with the help of friends, family and health care professionals - special acknowledgement to Bradford Pain Rehabilitation Programme team & NHS Kirklees PCT.
<b>Disease /Pathology</b>	Chronic pain

<b>Number</b>	46
<b>CONTACT DETAILS</b>	
<b>Organization</b>	The British Pain Society
<b>Country</b>	UK
<b>Email</b>	info@britishpainsociety.org
<b>Short description of the organization/public institution</b>	
The British Pain Society is an alliance of professionals advancing the understanding and management of pain for the benefit of patients. The goals are: promoting excellence and awareness for the benefit of people living with pain; promoting partnership in pain research, education and management; influencing policies relevant to pain, nurturing the next generation of pain researchers and healthcare professionals, encouraging dialogues about pain, contributing to national and international dialogue of pain.	

<b>DESCRIPTION</b>	
<b>Title</b>	<i>Pain Champion Award 2014</i>
<b>Field:</b>	Award
<b>Actors of the Best Practice</b>	<b>Public Institution(s)</b> <ul style="list-style-type: none"> <li>The all Party Parliamentary Group on Chronic Pain</li> </ul> <b>Civic Organization(s)</b> <ul style="list-style-type: none"> <li>Chronic Pain Policy Coalition, Pain Uk</li> </ul>
<b>Location</b>	UK
<b>Term</b>	2014 ongoing
<b>Objectives</b>	The Award aims to recognize the many hours of work that are given in the voluntary sector to support people living with pain.
<b>Outcomes Impact on participants</b>	The annual reception award provided an opportunity to reflect on the progress of the past year in pain policy, it highlights the value of the pain community in working together.

<b>ANALYSIS</b>	
<b>Development of the GP</b>	The reception presented the inaugural Pain UK Pain Champion Award to Jean Gaffin OBE. This new award has been set up to acknowledge and reward individuals who have gone beyond the call of duty to help tackle chronic pain in the UK, to campaign for better policy in chronic pain care and to help those living with this condition.
<b>Disease / Pathology</b>	Chronic pain

## CHAPTER 5 – Good practices from Italian Alesini Award

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As already mentioned in chapter 1 there are several awards which highlight the successful work at National level. We have included only a short list of Italian awards relating to good practices on the fight against pain:

- Pain Management in non-cooperating patients
- Departmental psychological training on pain in paediatrics
- Progetto Giobbe - RSA senza dolore (Nursing home assistance without pain)
- Priority criteria in low back pain
- Ospedale AMICO
- Managing patients suffering from pain
- The need for palliative care for patients with a chronic infectious disease in its terminal stage
- Telemedicine for difficult wounds

More details are available on the online database: [www.cittadinanzattiva.it/progetti-e-campagne/salute/politiche-sanitarie/1949-premio-buone-pratiche-in-sanita.ht](http://www.cittadinanzattiva.it/progetti-e-campagne/salute/politiche-sanitarie/1949-premio-buone-pratiche-in-sanita.ht)

A European award would also be very important to promote these successful activities.

## CHAPTER 6 – Conclusions

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### 1. Geographical impact

The original idea was to carry out the research in 6 countries, but the great interest on the topic required the project staff to enlarge the area of investigation to the following 11 countries: Belgium (1), Bulgaria (2), France (5), Germany (1), Greece (1), Kosovo (2), Italy (15), Malta (2), Portugal (2), Spain (4), United Kingdom (11).

This is a very good reason to expand the research to additional countries in the future.

### 2. Characteristic of the good practices

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

- A first group of good practices relates to specific diseases. There are 6 examples related to patients suffering from fibromyalgia, 3 good practices each for back pain/low back pain and neuropathic pain/localized neuropathic pain (LNP); 2 for those suffering from dementia and 2 for those suffering from rheumatoid Arthritis/Arthritis and rheumatoid arthritis, osteoarthritis. There are also examples of good practice in the field of pelvic pain, facial pain, and cephalalgia, pain in neck and shoulders, Machado-Joseph disease and diabetes.
- A second more substantial group relates to good practices on chronic pain, without entering into detail: in some cases because they involve communication campaigns aiming at increasing public awareness about the phenomenon, and provide reference points and useful information to patients suffering from chronic pain. In other cases, because they are addressed to more than a specific pathology, including those mentioned above. At any rate, even among this second group, we can distinguish:
  - 2 examples of good practice regarding access to palliative care and pain therapy;
  - 2 examples of good practice regarding pain management/treatment;
  - There are also cases in which alternative medicine has been used (homeopathy and shiatsu).
  - One case refers to the attempt to make opioids for cancer patients more economically accessible.

### 3. Who are they addressed to

- Most of the good practices are addressed to adult patients aged 20-70, with no particular age restrictions, to a lesser degree also to senior citizens over 70.
- Only one good practice is addressed exclusively to children: "Pain in the Paediatric Emergency Room", in Italy.
- There are three good practices addressed specifically to elderly patients (70-90 years old): "Program to reduce cephalalgia and pain in the neck and shoulders", "Management of chronic pain in elderly people carried out in Healthcare centres" for dementia patients (both from Italy), "Pain in elderly people special interest group" from the United Kingdom.
- Only a good practice from Malta, "For a Better life: How to deal with my Condition" is exclusively addressed to 50/70 years old patients.
- In four cases the good practices are addressed to all age groups.

#### **4. Who promotes them**

Patients' and civic associations, professional teams and networks, institutions, research centers and universities, most of the time all these organizations work together. The secret of their success lies in the ability to build networks developing partnerships and cooperation among both public and private stakeholders.

#### **5. Final comments**

The fact that the presentation of these good practices at European level has obtained the official patronage of the Italian Presidency of the Council of Ministers during the Italian Presidency of the Council of the European Union as well as that of the Italian Ministry of Health shows the value of the initiative which has clearly raised the attention of both national and EU institutions.

Our hope is that our work can be a valid contribution to obtain concrete actions once and for all by the policy makers on the issue of chronic pain. Our endeavour is also to raise public awareness, add more operators of good practices to the network, disseminate all positive aspects of our activities regarding a phenomenon which has been for too long invisible to the great majority of people.



## **Back cover**

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### **Acknowledgements**

Active Citizenship Network project staff wishes to thank all the civic and patient associations, professionals, good practice operators, network partners, private and public stakeholders for their support in the collection of good practices.

### **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 organizations 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.

The engagement of Cittadinanzattiva-ACN in the fight against unnecessary pain: <http://www.activecitizenship.net/patients-rights/projects/83-the-engagement-of-cittadinanzattiva-in-the-fight-against-useless-pain.html>.

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